The Lived Experiences of Neuroscience Nurses Caring for

Acute Stroke Patients Requiring End-of-Life Care

by

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Abstract

Cerebral vascular accidents (CVAs) rank as the third leading cause of death in Canada with more than 50,000 of these events occurring annually. The evidence base from which to provide end-of- life care to patients dying from a CVA is currently limited, and there is a dearth of research examining the experiences of nurses charged with the responsibility of caring for these patients. In order to begin to address this gap in the literature, a qualitative study, using van Manen's interpretive phenomenology was conducted to examine and describe the lived experiences of nurses working on an acute neurosciences unit in a tertiary hospital. Nine nurses were interviewed initially, and two nurses participated in follow-up interviews to confirm the interpretation of the data. This manuscript will discuss the essence of nurses' lived experience in caring for these patients, as well as implications for education, practice, and future research.

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Chapter 1: Statement of the Problem

Cerebral vascular accidents (CVAs), or strokes, rank as the third leading cause of

death in Canada with more than 50,000 of these events occurring annually (Heart and Stroke

Foundation [HSF], 2008). While they may be thrombolytic or hemorrhagic in nature,

hemorrhagic stroke accounts for approximately 20% of all strokes and can be caused by a

ruptured aneurysm, a ruptured arteriovenous malformation, or the spontaneous rupture of a

cerebral vessel associated with hypertension (Hickey, 2009; HSF, 2008; Stevens, Payne,

Burton, Addington-Hall, & Jones, 2007). In Canada, 75% of patients experiencing a stroke

will be left with some degree of disability, including physical and/or cognitive challenges,

while fifteen percent will succumb to the event (HSF, 2008). It was found that in the acute

phase following a stroke, or within the first 28 days, 20 (Stevens et al., 2007) to fifty-two

percent (Simmons & Parks, 2008) of patients would die of their injury. This is a significant

number of patients who may require palliative care.

At the initial onset of this acute injury, aggressive medical and nursing measures

may be employed with the goal of improving the patient's clinical status and functional

outcomes. When presenting to the hospital with neurological deterioration and a decreased

level of consciousness, patients undergo a detailed clinical assessment, as well as diagnostic

examinations such as magnetic resonance imaging (MRI), computed tomography scan (CT),

lumbar puncture or a cerebral angiogram. The combination of these assessments provides a

diagnosis and allows for the physician to provide some degree of prognostication (Reilly &

Bullock, 2005). The presumed prognosis and anticipated outcome are used in discussions

with families to determine the medical interventions to be implemented.

Discussions with family members, led by the physicians, typically engage the patient's family in conversations about possible treatment approaches. These options may include active intervention, such as surgery or vessel embolization, in situations in which the bleeding is more severe or is the result of an underlying pathology. Clinical observation of the patient may be the chosen approach if the hemorrhage is less severe and the physician believes that the bleeding and pressure may improve on their own in time. One of the challenges in prognostication in stroke patients is related to the unpredictable response that the patient will have to either surgical intervention or observation. Neither clinical improvement nor even survival can be guaranteed (Inagawa, 2010; Reilly & Bullock, 2005). As patients, families and healthcare providers each come to a situation with different values and beliefs about life and death, including end-of-life care, conflict can arise if those involved have significantly different expectations of care. Differences in expectations regarding various interventions in end-of-life care can also result in difficult situations. These conflicts may involve the implementation of hydration and /or nutrition, the appropriateness of surgical interventions, resuscitation status, or even acknowledgement by all persons involved that the patient is dying (Kirsch, 2009).

The focus of the goals of care for those stroke patients who are dying becomes comfort in nature as opposed to curative (Calvin, Kite- Powell & Hickey, 2007). Because of a paucity of designated specialized palliative care units, however, stroke patients who are not expected to recover are frequently cared for within acute care facilities on acute care neuroscience units where palliative care ideology and practice may not exist. In an acute care setting, a curative ethos exists that provides supportive and rehabilitative care with the

purpose of improving clinical function and optimizing an individual's ability to participate in desired activities of daily living (Chahine, Malik & Davis, 2008; Stevens et al., 2007). It is within this curative ethos, however, that nurses are called upon to provide palliative care to acute stroke patients who are not expected to recover.

Historically, palliative care has focused on symptom management in the care of patients living with advanced cancer (Chahine et al., 2008). Many textbooks and journal articles discuss the ideal medical and nursing care to be provided to oncology populations; however, minimal reference is made to the care of those dying from non-malignant causes, such as individuals experiencing the irreversible sequellae of acute intracranial hemorrhage. The limited literature in this area includes retrospective chart reviews seeking to identify the palliative care needs of patients with neurologic or neurosurgical conditions (Chahine et al., 2008); one descriptive paper evaluating the concepts and content related to end-of-life care addressed in neuroscience nursing journals (Neatherlin & Fox, 2006); critical literature reviews aimed at identifying the palliative care needs of stroke patients; clinical papers discussing the care of patients and families when ventilatory support of hemorrhagic stroke patients is withdrawn (Simmons & Parks, 2008) and the use of ethical decision-making models to facilitate patient involvement in care (Krueger, 2008). One qualitative description of neuroscience nurses' experiences in a neurointensive care unit caring for dying patients (Calvin et al., 2006) and one description and evaluation of interventions aimed at helping neurological critical care patients and their families through the dying process (Yeager et al., 2010) were also located.

Collectively, these works speak to the fact that hemorrhagic stroke patients and their families have complex care needs that are not always recognized or well addressed. Despite

the lack of empirical evidence base within the literature to guide them, neuroscience nurses have the responsibility of providing end-of-life care to these patients and their families. In order to support them in their work, research is first needed that examines, describes and interprets the neuroscience nurses' experiences of providing palliative care for stroke patients in an acute care setting. Explicating the essence of what it is like to care for an acute stroke patient who is not expected to recover will contribute to the beginning body of knowledge that will inform the care neuroscience nurses provide to this patient population and their families, and will serve as a foundation from which interventions aimed at improving the overall experience for patients, families and nurses caring for dying stroke patients in an acute clinical setting can be identified and implemented. Such research also has the potential to inform nursing education, practice, and areas for future research.

Purpose of the Study

The purpose of this study was to examine and describe the lived experiences of nurses working in an acute neurosciences unit who have cared for patients who are dying following an acute hemorrhagic cerebral vascular accident (CVA). The following research questions were addressed:

1. What is the meaning or essence of the lived experience of nurses caring for patients post acute CVA who are dying on an in-patient neurosciences unit in a tertiary hospital?

2. What does it feel like to be a nurse caring for patients who are not expected to survive post acute CVA?

Assumptions Underlying the Study

The following assumptions underlie this study:

1. There are patients for whom aggressive curative treatment may become inappropriate.

2. Care of the dying is a multi-disciplinary process, involving the patient, their family and the caregivers. Caregivers may include significant others, nurses, physicians, healthcare aides, physiotherapists, occupational therapists, and other allied health staff.

3. Neuroscience nurses are challenged to provide care to palliative care patients as they find that the care demands of the more acute care patients limit the time they have available to spend with palliative care patients and families.

4. On an acute neuroscience ward, acute care patients are seen as having priority for nurses over palliative patients.

5. Neuroscience nurses believe that they are adept at providing the best physical care possible to dying stroke patients.

6. Despite their confidence in providing physical care to dying stroke patients, neuroscience nurses may not always be comfortable discussing death and dying with families.

7. Due to the sudden change in the patient's health status after an acute stroke, ethical dilemmas may arise between family members or healthcare team members in discussing treatment options.

Definition of Terms

The following terms are defined as they were used in this study:

Acuity. The intensity of care expected to be required to care for a patient. Factors considered include anticipated time and skill required to provide optimal patient care, with

workload, complexity, and nursing care needs being the focus of determining the level of

acuity of patient care (Brennan & Daly, 2009).

Dying. The physiologic process of organ and cell death of a human being; results in

the end-of-life for the individual, often results in suffering for the family (Coyle, 2010).

End-of-life care. The physical and psychosocial support of an individual and their

family in the face of a life-limiting illness or disease during the final stages of living (Quint,

1967); degree of support varies along a continuum and is reflective of the degree of

disability of the individual (Coyle, 2010)

Essence. The true lived meaning of an event, or phenomenon, as described by the

individual participating in the experience of the event (Streubert Speziale & Rinaldi

Carpenter, 2007).

Experience. A knowledge, skill, or practice derived from the direct observation of

an event; or participation in events or in a particular activity (Merriam-Webster Dictionary,

2011).

Family. A group of people who share a past, has experienced some degree of

emotional bonding, and may or may not live together. Members may or may not be related,

and share behaviors that allow them to identity as a group. They share past, present and

future shared experiences (Weigel, 2008).

Goals of care. Consist of the physical and psychosocial patient care outcomes

desired to be seen as a result of an intervention (Kaldjian, Curtis, Shinkunas & Cannon,

2009).

Medical Model of Care. "A process whereby, informed by the best available

evidence, doctors advise on, coordinate or deliver interventions for health improvement"

(Shah & Mountain, 2007, p. 375).

  Neuroscience nurse. A registered nurse or licensed practical nurse who is employed primarily on the acute neuroscience unit.

  Palliative care. "Is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization, 2011).

Significance of the Study

  Limited empirical work exists examining how nurses provide palliative care to patients who have sustained an acute stroke and are not expected to recover, or their experiences in providing such care. Neatherlin and Fox's (2006) review of ten years of content contained in the American Journal of Neuroscience Nursing demonstrated a paucity of publications on the subject of death and dying in neurosciences. The curative orientation of an acute neurosciences unit may make the provision of palliative care problematic for nurses, and may explain the limited quantity of published literature in this field. Explicating the essence of what it is like to care for this patient population will provide preliminary insights about the care that neuroscience nurses provide for palliative patients, the meanings they ascribe to this experience, and the factors that both facilitate and constrain their abilities to deliver care for this patient population. Ultimately, the findings may lead to suggested interventions that will support nurses in providing care to this patient population, and may provide the foundation from which interventions can be identified and implemented which are aimed at improving the overall experience for patients, their

families and nurses caring for dying stroke patients in an acute clinical setting.

Chapter 2: Literature Review

Prior to developing a research proposal, a literature review is conducted in order to understand both what is known about a phenomenon and where gaps in empirical knowledge exist. In phenomenological research, only a cursory review of the literature is conducted at the outset of a study, with a more expansive review being conducted after the data analysis is complete. This approach is essential in order to minimize the exposure of the researcher to explicit knowledge that may bias his/her analysis of the data (Streubert Speziale & Rinaldi Carpenter, 2007). For this study, the student conducted a preliminary literature review by searching PubMed, Medline, ProQuest and CINAHL and pre-CINAHL databases. These databases were more thoroughly searched after data analysis was completed in order to situate the study findings in the context of existing literature. Terms which were searched individually and in conjunction with one another included: "stroke"; "cerebrovascular accident"; intracranial hemorrhage"; "intracranial bleed"; brain hemorrhage"; "palliative care"; "end-of-life care"; "nursing care"; "nurses' perspectives"; "neuroscience nursing"; " nurses' experiences"; "ethical concerns"; "ethical issues"; "culture"; "religion"; "spirituality" and "phenomenology". Search parameters included literature and textbooks published within the last 10 years in English.

The literature review presented in this chapter was identified by the student and her advisor as being salient to the work of nurses who care for patients who are dying as the result of a stroke, as well as the care required supporting their families. Six categories of literature that were salient to the care of patients who are dying after experiencing an acute intracranial hemorrhage were reviewed. They included: i) the epidemiology, etiology, prognostication and risk factors for stroke; ii) treatment of stroke; and iii) challenges in

providing palliative care in an acute care setting; iv) challenges due to limited empirical knowledge about palliative care in neurosciences; v) challenges related to a lack of education on palliative care in neurosciences; and vi) ethical challenges for neuroscience nurses.

Epidemiology, Etiology, Prognostication and Risk Factors

The epidemiology, etiology, prognostication, and related risk factors for hemorrhagic stroke provide context to the experiences of the nurses required to care for patients who are dying as a result of this pathology, and helps to support the basis for the purpose of this study.

Epidemiology. Epidemiology is the study of the distribution and determinants of health-related states or events (World Health Organization, 2011). For this study, it was necessary to be aware of the epidemiology of strokes in order to put the phenomenological event being studied into context. Cerebral vascular accident (CVA), or stroke, is the third leading cause of death in Canada and the United Kingdom (HSF, 2008; Stevens et al., 2007). More than 50,000 strokes occur each year in Canada, with 6.7 of these events occurring in every 100, 000 persons under the age of nineteen years. While 300,000 individuals in Canada are living with the effects of having had a CVA, approximately 14,000 persons succumb to their CVA annually (HSF, 2008).

Hemorrhagic stroke, which is the focus of the phenomenon in this study, accounts for 20% of all CVAs (Chemmanam & Davis, 2009; Hickey, 2009; HSF, 2008; Stevens et al., 2007) and is associated with a mortality rate ranging from thirty-five to fifty-two percent (Chemmanam & Davis, 2009; Simmons & Parks, 2008; Stevens et al., 2007). A prospective study of a convenience sample of patients ($N = 585$) with subarachnoid hemorrhage (SAH)

conducted in Germany by Güresir et al. (2008) reported a mortality rate of 24.4 %. This mortality rate is slightly lower than other mortality rates reported in the literature and may be due to the fact that there was an underlying physiological vascular anomaly that could be treated in the participants in Güresir and colleagues' study. The higher rates of mortality reported by Stevens et al. (2007), Simmons and Parks (2008), and Chemmanam and Davis (2009) included patients with spontaneous hypertensive hemorrhages, which are difficult to treat with surgery alone due to a lack of abnormal pathology that can be surgically repaired (Reilly & Bullock, 2005; Warlow et al; 2008).

While 78-88% of intracranial hemorrhages are the result of a spontaneous hypertensive bleed or trauma, such hemorrhages may also be caused by cerebral vessel anomalies (Chemmanam & Davis, 2009). The incidence of an intracranial aneurysm in the general population is approximately two to three percent (Inagawa, 2010; Rinkel, 2008), with the risk of the anomaly rupturing being from one to four percent annually (Inagawa, 2010). The size, location, and type of aneurysm affect the rate of rupture, as do certain other risk factors which will be discussed later in this chapter (Hickey, 2009; Reilly & Bullock, 2005; Rinkel, 2008). Aneurysm rupture results in a primary diagnosis of subarachnoid hemorrhage, a type of stroke, and leads to tissue damage resulting in cerebral ischemia and edema. Each of these factors contributes to the secondary clinical diagnosis of intracranial hemorrhage in these cases (Reilly & Bullock, 2005; Warlow et al., 2008).

Arteriovenous malformations (AVMs), another type of vessel anomaly, are found less frequently than aneurysms, with their incidence cited as fifteen to nineteen cases per 100, 000 persons (Warlow et al, 2008). While the chance of this anomaly bleeding is reported to be two to three percent annually (Kumar & Friedman, 2011; Stapf, Mohr, Pile-

Spellman, Solomon, Sacco, & Connolly, 2001), it is important to note that this is also an

annual cumulative risk, with the risk increasing over time. The literature indicates that 50%

of individuals with an AVM will develop some form of neurological deterioration at some

point in their lifetime, and that the majority of those who present with an AVM are in their

early adult years (Auon, Bendok & Batjer, 2012).

  Etiology. The etiology of an illness speaks to explaining its underlying cause

(World Health Organization, 2011) and requires examination of the physiology and

pathophysiology of the illness. Within the context of this study, the function of the central

nervous system is crucial to this understanding. The central nervous system consists of the

brain, the spinal cord, cerebral spinal fluid (CSF) and a cerebrovascular network. The

cerebrovascular system of the brain consists of an intricate circuitry of arteries, veins and

capillaries. The arteries of the brain oxygenate the cerebral cortex, and provide essential

nutrients for brain function. The brain tissue contains nerves that control motor and sensory

functions of the body, including autonomic and voluntary actions. The CSF acts as a

cushion for the brain, and circulates around and through the entire system. A change in the

volume of tissue, blood and/or CSF will result in an imbalance in the interactive stability of

function, with the presenting symptoms being reflective of the area of the brain affected

(Auriel, 2009; Hickey, 2009).

  The underlying causes of hemorrhagic stroke may be multi-factorial, with the most

common cause being a thinning or weakening of the blood vessel wall due to hypertension

or atherosclerosis. When the vessel wall is weakened, it may rupture spontaneously in

conjunction with hypertension, or may rupture following some form of trauma to, or within,

the head. Whatever the stimulus, the affected artery or vein will release blood into the brain

tissue or circulating CSF space. The increased volume of blood into the closed, inflexible

space of the skull exerts pressure on brain tissue, causing tissue ischemia and loss of

neurological function (Auriel, 2009; Hickey, 2009; Reilly & Bullock, 2005; Simmons &

Parks, 2008; Warlow et al., 2008). If the hemorrhage is severe enough, a higher volume of

blood is present, and causes increased pressure in the area of the brainstem. If this occurs,

the reticular activating system is affected, and the patient presents with a decreased level of

consciousness (Auriel, 2009; Warlow et al., 2008).

In addition to spontaneous hemorrhages, vascular malformations such as intracranial

aneurysms may result in hemorrhage if they rupture. Aneurysms can develop as a result of

a weakened blood vessel wall, and are most commonly seen in the arteries of the brain. Due

to the high pressure of the blood flowing through the vessels, arteries are at highest risk to

weaken, as with arteries in other parts of the body. Aneurysms are seen as a balloon or

outpouching on the side of a blood vessel and their presence is confirmed with diagnostic

imaging of the brain. The size of the aneurysm at diagnosis fluctuates, and may increase

over time. An aneurysm most often is not diagnosed until the patient presents with

neurological symptoms, which are usually due to a rupture in the wall of the anomaly (Al-

Shahi & Warlow, 2001; Auriel, 2009; Chemmanam & Davis, 2009; Hickey, 2009; Simmons

& Parks, 2008; Warlow et al., 2008).

The presence of an AVM, another type of vascular anomaly, is confirmed with the

use of diagnostic imaging, which is ordered when the patient presents with a neurological

deficit. If there is a slow leak in the AVM, or a spasm of the vessel, the patient may present

with only a mild headache. If a larger anomaly ruptures, then there is a larger volume of

blood in the tissues, and the patient presents with more significant neurological deterioration

(Al-Shahi & Warlow, 2001; Chemmanam & Davis, 2009; Hickey, 2009). If the patient survives the initial hemorrhage, secondary brain injury resulting from cerebral edema, cerebral ischemia, vasospasm or re-bleed also contributes to uncul herniation in the brainstem, and ultimately death (Chemmanam & Davis, 2009; Reilly & Bullock, 2005; Warlow et al., 2008). Whatever the underlying pathology, acute stroke constitutes a medical emergency and timely aggressive treatment is crucial if the best opportunity for maximal recovery is to be realized. In some cases, despite timely medical intervention, recovery is not possible and the patient will succumb to his/her injury (Chemmanam & Davis, 2009; Hickey, 2009; HSF, 2008; Warlow et al., 2008).

For the purpose of this study, the focus will be on the care of patients who have experienced an intracranial hemorrhage (ICH) for any underlying reason, and exclude those who have had a thrombolytic event. In clinical case studies, those who present with a high grade ICH have been found to deteriorate more rapidly, and are more prone to secondary injury such as diffuse cerebral edema, than those who experience a thrombolytic stroke (Chemmanam & Davis, 2009; Chiu et al., 2010). This makes the experience of caring for patients in the ICH population unique.

Prognostication. For patients who have an extensive hemorrhage, added pressure inside the brain, as well as the subsequent ischemia and brain edema, leads to further clinical deterioration. Even in instances when the aneurysm is repaired and the blood volume normalized, persisting cerebral edema is associated with poor perfusion of the cerebral cortex, resulting in poor oxygenation of the brain tissue, and sustained tissue damage. Based on anecdotal clinical evidence, these patients are found to have a lower likelihood of functional improvement, and a lower chance of survival (Hickey, 2009; Reilly

& Bullock, 2005; Warlow et al., 2009).

Many different scales can be used to measure the severity of the hemorrhage, which in turn, can help to inform the patient's prognosis. These scales include the Hunt and Hess Stroke Scale (Hunt & Hess, 1968; Rosen & Macdonald, 2005), the Fisher score (Rosen & Macdonald, 2005), and the newer modified Intracranial Hemorrhage (ICH) score (Bruce et al., 2011). Each of these scales includes an assessment of the patient's functional status, and also may consider the findings of diagnostic imaging. The choice of scale is based on the individual preferences of the clinician and largely depends on its ease of use in the clinical setting. The use of scales to measure hemorrhage severity allows for communication amongst healthcare providers regarding the severity of the patient's clinical status, and assists in framing discussions regarding prognosis and treatment options within the healthcare team and with family members (Bruce et al., 2011; Warlow et al., 2008).

The Hunt and Hess scale, one of the oldest and more commonly used instruments, is solely based on the clinical symptoms of the patient. It is arranged as a scale from grade I to V, with grade I indicating that the patient has a mild headache and possibly nuchal rigidity, but no focal neurological deficits. A patient with an intracranial hemorrhage determined to be a Hunt and Hess grade V, the most serious grade, will be non-responsive and demonstrates decerebrate posturing. Literature indicates that patients who present with symptoms that equate with a grade IV or V hemorrhage have a poorer prognosis, and decreased likelihood of survival in comparison to patients with a less severe and lower grade ICH. Those who do survive typically have poor functional status and quality of life (Güresir et al., 2008; Hunt & Hess, 1968; Salary, Quigley & Wilberger, 2007). A retrospective review of 133 patients with subarachnoid hemorrhage (SAH), a form of ICH,

concluded that the Hunt and Hess scale is a strong predictor of the aforementioned poor clinical outcomes in patients with an ICH (Salary et al., 2007).

The Fisher Scale is often used in conjunction with the Hunt and Hess scale to describe the severity of a subarachnoid hemorrhage (Ko et al., 2011; Lindvall, Runnerstam, Birgander, & Koskinan, 2009). This scale relies exclusively on computed tomography (CT scan) imaging results, and classifies the severity of the SAH using a scale from grades I through IV. Grade IV indicates that there is extensive, diffuse bleeding in the brain, and suggests an increased risk of vasospasm and subsequent cerebral ischemia that may ultimately lead to a poorer prognosis and lower chance of survival (Ko et al., 2011). A retrospective study conducted in Sweden by Lindvall et al. (2009) concluded that the Fisher score, when used in conjunction with the Hunt and Hess score, was a reliable predictor of clinical outcome, but was not reliable when used independently. In contrast the Hunt and Hess scale can be used independently. Reliance on CT images alone, without consideration of the presenting clinical symptoms, has been not been found to be a strong predictor of prognosis (Lindvall et. al., 2009).

The newer Intracranial Hemorrhage Score is a tool that considers multiple dimensions in determining the overall prognosis of the patient including the Glasgow Coma Scale (GCS) score, the volume of the intracranial blood present, the presence or absence of intraventricular blood, the location of the bleed, and the patient's age. In each area, a score of zero or one is assigned, with a possible total score ranging from zero to six. A score of six indicates a poorer prognosis for the patient (Clarke et al., 2004; Hwang et al., 2010; Zahuranec et al., 2010). In a prospective study in the United States ($N = 487$), a comparison of the ICH score and 30 day mortality rates of stroke patients was conducted. A significant

correlation (p < 0.001) was found between high ICH scores and early mortality. The study

authors concluded that this approach to patient assessment was an accurate and practical

outcome indictor of expected 30 day mortality rates, and proposed that the ICH score is a

useful clinical tool.

In the United States, Clarke et al. (2004) conducted a retrospective chart review of

175 patients who were admitted to an acute neuroscience unit with ICH over a two year

period. On comparison of the ICH score on admission and the 30 day mortality rates, it was

found that patients who scored grades 1, 2, 3, 4, and 5 on the scale displayed 30-day

mortality rates of 13%, 39%, 78%, 96%, and 100% respectively. The author concluded that

this highly significant correlation (p < 0.01) is a strong indicator of the validity of this tool

in prognostication, and suggests it be used in the development and standardization of

medical care plans. This tool may be more useful and accurate, when compared to the

previously noted tools, as it incorporates multiple factors and allows for consideration of

variation in the patient's clinical presentation. The results derived by Clarke et al. (2004) in

observing correlations between the ICH scores and related mortality rates are reflective of

the experiences of clinicians in practice as noted in Warlow et al. (2008).

Related risk factors. The risk factors with which patients present affects their risk

of developing an ICH and the subsequent severity of their hemorrhagic CVA. This in turn

ultimately affects their prognosis. The most significant modifiable risk factors include:

hypertension, smoking, hyperlipidemia, atrial fibrillation, and diabetes (Gorelick, 2009;

Kelly & Minty, 2007; Reilly & Bullock, 2005). Non-modifiable risk factors include age,

gender, polycystic kidney disease, ethnicity and family history, and all contribute to an

individual's risk for stroke. The literature speaks to the importance of individuals in the

modifiable risk groups making life changes to minimize their health risks where possible

(Gorelick, 2009). Literature examining all of these risk factors will now be more fully

discussed.

Modifiable risk factors. Modifiable risk factors represent behaviors which, if

changed by the individual, can lessen the risk the person has of developing an aneurysm or

lessen the risk of an existing aneurysm rupturing. Hypertension, smoking, hyperlipidemia,

and atrial fibrillation are all underlying health conditions and behaviors which can be

controlled by individuals with the goal of minimizing their negative effects on health

outcomes.

Hypertension. Hypertension is seen as the most prominent risk factor for the

development and rupture of intracranial aneurysms. With the resulting increased velocity of

blood flow, the blood vessel wall weakens over time, and may ultimately balloon out to

form an aneurysm. With persisting pressure on the developed aneurysm, the risk of

hemorrhage becomes significant (Inagawa, 2010; Reilly & Bullock, 2005; Simmons &

Parks, 2008). In two clinical case studies in the United Kingdom, Singh et al. (2010)

physically removed and examined the structure and physiology of intact intracranial

aneurysms. Although their sample was quite small, the authors have proposed that blood

viscosity and wall shear stress disturb the elastin and collagen fibers of the vessel wall,

leading to aneurysm formation. Hypertension alone can be a significant enough

contributing factor to the formation and rupture of an aneurysm, but its effects are

compounded when present in conjunction with the other risk factors being discussed in this

chapter (Gorelick, 2009).

Smoking. The behavior of smoking was identified in the literature as the second

most significant risk factor in regards to the development of vascular abnormalities and the

rupture of weakened blood vessel walls (Inagawa, 2010). In a retrospective chart review of

323 patients with non-traumatic SAH at John Hopkins Hospital, Qureshi et al. (2001) found

that hypertension and smoking strongly correlated with an increased risk of SAH and ICH.

Of those cases reviewed, 54% had hypertension, 46% were current smokers, and 39% were

ex-smokers. The authors proposed that smoking degraded the elastin in the blood vessel

wall, causing the vessel to be more susceptible to dilation. These effects are believed to last

even after an individual stops smoking, and support the need for abstinence from smoking

entirely, or even early cessation. Gorelick (2009) stated that smoking increased the risk of

stroke by 1.5 to 2 times the normal risk, and attributed the increase to endothelial damage

from increased blood viscosity, raised platelet aggregation, and vasoconstriction, all of

which are physiological responses to smoking. Gorelick (2009) postulated that it will not be

until after 2 years after quitting smoking that an individual's stroke risk begins to decrease,

and that it may take up to 5 years before the increased risk is normalized.

Hyperlipidemia. Hyperlipidemia has been found to contribute to the development

of aneurysms, but the literature suggests that is seen less frequently in patients who present

with ruptured aneurysms. Inagawa (2010) proposed that perhaps dyslipidemia offered some

protective function in aneurysm rupture. Dyslipidemia has also been found to serve a

protective function in terms of vascular rupture as the thickening of the vessel wall with

atherosclerotic plaques is thought to minimize the risk of rupture for individual patients

(Inagawa, 2010). Although hypercholesteremia plays a significant role in thrombolytic

stroke, it is proposed that it does not contribute to intracranial hemorrhage (Gorelick, 2009).

In a case control study conducted in Japan, Inagawa (2010) found that

hyperlipidemia was the third most significant risk factor for stroke in women over the age of

60 years. While there was no clear explanation provided for this, or as to why men were not

equally at risk, Inagawa speculated that women's risk may be associated with increased

post-menopausal metabolic changes. As a result of some of these changes, women were

more likely to have increased serum cholesterol levels after age 60, which would contribute

to hypertension and heart disease, and subsequent possible rupture of existing aneurysms.

This may explain how hyperlipidemia influenced women's risk as they age (Inagawa,

2010), and is an indirect secondary influence on aneurysm rupture.

    Atrial fibrillation. Patients with a medical history of atrial fibrillation (AF) or mitral

valve disease have a risk of 4.5 percent per year of experiencing a thrombolytic event,

including an ischemic stroke (Fuller & Reisman, 2011). Consequently, such patients are

routinely placed on the anticoagulant medication warfarin, with the intention of minimizing

the chance of thrombosis. Unfortunately, warfarin places individuals at increased risk of

bleeding systemically and in the central nervous system. When a patient develops an ICH,

either spontaneously or from trauma to the head, and they are on an anticoagulant such as

warfarin, ICH is even more extensive (Anderson, 2009; Flaherty, 2010; Rymer, 2011).

    In an American randomized prospective trial of a cardiac device for AF, a secondary

measurement was the incidence of hemorrhage for patients on warfarin (Fuller & Reisman,

2011). In comparing patients who received an implanted intravascular cage ($N = 408$) and

patients who were solely receiving warfarin therapy ($N = 241$), researchers evaluated the

effects of anticoagulation therapy. Major systemic bleeding was evident in 3.6% of patients

who were taking warfarin, with an incidence of hemorrhagic CVA of 1.69% in this same

group. Fuller and Reisman (2011) concluded that the increased risk of bleeding associated

with taking warfarin was a serious consideration when deciding whether or not to prescribe the medication, and that thrombus risk might be equally managed with the placement of a venous filter in lieu of warfarin.

Factors that co-exist with AF appear to increase the risk of individuals developing an ICH. One of these factors is age. In a randomized, blinded clinical trial evaluating two different doses of dabigatran versus warfarin in patients with atrial fibrillation (*N* =18 and 113 respectively), Hori, Connolly, Ezekowitz, Reilly, Yusef, and Wallentin (2011) reported that while less than one percent of persons under the age of 60 years had AF, more than six percent of persons over 80 years have this arrhythmia. In addition, Hanley, Silke, and Murphy (2011) examined academic literature, including prospective trials, Cochrane databases, and other review articles and found that one-third of individuals over the age of 65 years of age experience a fall, with ten percent of those falls resulting in serious injury. These falls may have been related to gait disturbances, cognitive changes, medication effects, muscle weakness from decreased mobility, or depression (Hanley et al, 2011). Patients over the age of 65 years who were taking anticoagulant medication and experienced a fall and hit their head were predisposed to developing a bleed and were at risk to present with a larger volume hemorrhage than their counterparts who were not on anticoagulation therapy. Although reversal of the medication effects was possible, timely treatment was key in minimizing the effects of pressure and ischemia on the brain, and ultimately impacting the prognosis for the patient (Flaherty, 2011).

Non-modifiable risk factors. Non-modifiable risk factors such as age, gender, ethnicity, family history and polycystic kidney disease were found to have some influence on the risk of developing an intracranial hemorrhage (HSF, 2008; Xu, Yu, Mei & Li, 2011).

Less direct research has been conducted examining these risk factors, however, and our understanding of their contribution to the development of an ICH comes from secondary data collected as part of symptom management studies.

   Age. Age was found to contribute to the risk of an intracranial hemorrhage (Inagawa, 2010), as the effects of prolonged hypertension and smoking contribute to the weakening of the vasculature over time. The correlation between age and the risk of stroke is expected to plateau in the fifth and sixth decades of life, and then may even start to decrease in later years. This decrease may be due to cerebral atrophy which is a normal developmental process (HSF, 2008; Jamieson & Skliut, 2010; Rymer, 2011; Zacharia et al., 2010).

   Ryttlefors, Enblad, Ronne-Engström, Persson, Ilodigwe, Macdonald and Loch (2010) were members of a Swedish multi-center, double-blind, placebo trial using clazosentan to evaluate the impact of the medication on the prevention of vasospasm in patients (*N*=413) with a type of ICH called subarachnoid hemorrhage. Demographics recorded included age, gender, the grade of the hemorrhage, diagnostic imaging results, and medical history. Although previously noted authors found that age increased the risk of the incidence of ICH, Ryttlefors et al. (2010) found that age was not a factor in the incidence of the side effect of cerebral vasospasm which is believed to affect functional recovery. While age impacts the incidence of ICH, the risks of related side effects such as cerebral vasospasm are not more common in older patient populations. This particular study did not examine the relationship between age and the incidence of ICH.

   Gender. A literature review by Jamieson and Skliut (2010) found that women experienced ICH more often than did men, but at different ratios over the lifespan. From

ages 45-54 years, women's risk was twice as great as men's; from ages 65-74 years, the risk

ratio was 5:1; over 85 years of age, the risk decreased to 3:1. There was a dramatic increase

in hemorrhagic stroke risk in the middle-age group, attributed to hormonal fluctuations and

the use of hormone replacement therapy post-menopause (Jamieson & Skliut, 2010;

Zacharia et al., 2010).

Gender differences were also evident due to lifestyle choices of women. Women

who did not smoke, maintained a healthy weight (Body Mass Index [BMI] < 22), exercised

three or more times a week, drank alcohol moderately (4-10.5 beverages weekly), and ate a

high fiber, low fat diet had a lower risk of stroke than other women and men (Jamieson &

Skliut, 2010). A BMI of more than thirty was seen as an especially high risk factor for

women, but was further influenced by medical co-morbidities such as hypertension,

diabetes, hyperlipidemia and smoking (Jamieson & Skliut, 2010). In response to these types

of findings, the Heart and Stroke Foundation (HSF, 2008) developed and promote

recommendations about these aspects of healthy living with the goal of lessening the risk of

stroke in the general population.

In their review of medical literature, Jamieson and Skliut (2010) also found that

thrombolytic therapies, pregnancy, and contraceptive use also influence the risk of stroke in

women. Low dose aspirin (100 mg every other day) was found to lessen the chance of a

first stroke in women more so than in men, and was thought to be related to the way in

which women metabolize aspirin. There was no evidence that mortality rates were

impacted by aspirin in either men or women (Jamieson & Skliut, 2010). There was also no

direct evidence that contraceptive use increased a women's risk of stroke, but if the

prescribed dose of estrogen in these medications was more than 50 micrograms, the risk of

stroke was considered to be slightly higher. The overall incidence of stroke in women of

child-bearing age who took oral contraceptives was 4.1 per 100,000 (Jamieson & Skliut,

2010), which is lower than the general population incidence of 6.7 per 100,000 (HSF, 2008).

For women who did become pregnant, the risk of a CVA did not increase during pregnancy,

but the risk of a thrombolytic or hemorrhagic event did increase during the post-partum

phase to 8.1 events per 100,000. Eclampsia and preeclampsia were seen as significant

contributing factors in the development of an emboli, and a subsequent CVA, but not ICH

(Jamieson & Skliut, 2010). Overall, women were at higher risk of the development of both

thrombolytic and ICH.

>*Ethnicity.* There has been some examination of ethnicity as a factor in the incidence

of ICH. Kozub (2010) conducted a literature review examining determinants of community

health in the United States (USA) and determined that African Americans had a

significantly greater incidence of ICH than Caucasian individuals. The general incidence of

ICH in Caucasians was 3.6 per 100, 000, compared to 6.6 per 100,000 for African

Americans. Similarly, Zacharia et al. (2010) conducted a literature review in the USA and

determined that in a population of over 27,000 persons, the rate of occurrence of ICH was

higher in African Americans than Caucasians, but was the highest among Asians from the

Pacific Islands. Specific rates of incidence to support this statement were not cited in the

article.

>*Family history.* The Heart and Stroke Foundation of Canada cites that siblings and

children of individuals who experienced cardiovascular disease under the age of 55 years, or

a CVA under the age of 65 years, are at a higher risk of suffering a stroke themselves. This

includes thrombolytic and hemorrhagic events (HSF, 2008; Zacharia et al., 2010). There is

also some emerging evidence that a family history of intracranial vascular anomalies also

predisposes an individual to developing subsequent cerebral aneurysms. Diagnostic

imaging screening has thus been recommended for some families (Rinkel, 2008).

Hart, Cupples, Wiggam, Patterson, and Yarnell (2011) conducted a prospective

case-control study using questionnaires that were mailed out to 3300 randomly selected

adult patients from eleven different medical practices in Northern Ireland. The

questionnaire was a screening tool to assign participants to the appropriate study arm, and

included items about parental history of stroke, demographic information, and consent for

the research team to contact the participants for future interviews. Of the 1061 responses

received, it was found that 31.3% reported having a parental history of stroke. Researchers

compared and matched groups for age, gender and socioeconomic status and grouped them

according those with a family history of CVA and those without. Phone interviews ($N =$

398; or $n = 199$ case-controlled pairs) were then conducted with those interested

respondents regarding symptoms experienced by their parent, personal health conditions,

and personal lifestyle practices such as smoking and alcohol consumption. Regression

analysis demonstrated that the family link for ICH was more likely related to a family

history of hypertension, which in turn contributed to a risk of ICH.

A familial link was identified in the literature regarding intracranial aneurysms and

the resulting SAH as a form of ICH. In a literature review, Hart et al. (2011) found that

there is a strong genetic predisposition for aneurysmal SAH in families with a known

history of SAH. Brown et al. (2008) published the partial results of the Familial Intracranial

Aneurysm (FIA) study, a multi-centre, multi-country examination of the incidence of

familial aneurysms and related known risk factors. Magnetic resonance imaging (MRI)

screening, and medical history review for the first 303 patients included in the study,

demonstrated that 19.1 % of those with a family history of aneurysm were diagnosed with a

single aneurysm; and 17.2 % were diagnosed with multiple aneurysms. Based on their

review of risks for ICH, the authors concluded that a familial history of cranial aneurysms

should be considered as a screening tool, but evaluated in conjunction with a medical

history that includes the other risk factors discussed in this chapter.

Polycystic kidney disease. Polycystic kidney disease is an autosomal-dominant

disease (ADPKD) that is strongly associated with the development of hypertension, hepatic

cysts and intracranial aneurysms (Xu et al., 2011). Xu et al. (2011) conducted a

retrospective study reviewing the charts of 355 patients with ADPKD, and performed an

MRI of the brain on each of the participants free of charge. The researchers discovered that

12.4 % of their participants had undiagnosed saccular aneurysms, which is higher than the

incidence in the general population. The underlying mechanism for the development of

saccular aneurysms is not known, but may possibly be related to the associated hypertension

(Xu et al., 2011).

Treatment

Patients presenting with an acute intracranial hemorrhage need holistic assessment

to determine the goals of care which are specific to each patient. On admission, patients

may present with mild symptoms and then suddenly develop a decrease in their level of

consciousness, or they may present with severe neurological compromise and already be

unconscious. An individual's medical history, clinical symptoms, diagnostic imaging

results and the existence of health care directives all influence decisions surrounding

treatment. The health care team discusses the findings of the assessment and the prognosis

with the family, and decisions are then made regarding what treatment options to consider (Edlow, 2005*;* Reilly & Bullock, 2005). Those options may include surgical treatment, medical management, or clinical observation, and will now be individually discussed.

Surgical Treatment. A craniotomy can sometimes be performed to physically remove intracranial blood, repair any anomaly found, and relieve some of the pressure in the brain. The desired goal of surgical treatment is resolution or improvement of presenting symptoms, including the patient's level of consciousness. If the surgery is not effective, then the patient continues to deteriorate neurologically. Literature suggests that this deterioration is due to a continuation or resumption of the bleeding, or the development of cerebral edema from the surgical manipulation and/or the underlying injury. Surgery does not guarantee clinical improvement (Reilly & Bullock, 2005; Rymer, 2011; Warlow et al., 2008).

Medical Management. Patients on an acute neuroscience unit (the type of unit that nurses in this study practice on) undergo investigation of their symptoms and are carefully monitored for changes in their clinical status. Any signs of clinical deterioration lead to aggressive medical and nursing management with the goal of improving the patient`s functional recovery. Timely intervention is seen as essential in providing optimal acute patient care (Brennan & Daly, 2009; Rymer, 2011). Besides direct physical pressure from the hemorrhage, neurological deterioration may also be the result of metabolic and hemodynamic changes that are secondary to the brain injury. Electrolyte imbalances, such as hyponatremia are common as a result of fluid imbalances and damage to the posterior pituitary gland of the brain. Patients who experience an intracranial hemorrhage are at high risk to develop "syndrome of inappropriate anti-diuretic hormone" secretion (SIADH). It is essential to treat this syndrome with hyperosmolic saline solution and/ or fluid restrictions

of 1200 to 1500 ml per 24 hours in an attempt to improve serum sodium levels and

subsequently clinical symptoms (Reilly & Bullock, 2005; Warlow et al., 2008). Even with

successful surgery, patients with persistent hyponatremia (i.e., Serum sodium <

130mmol/L), may develop lethargy, confusion, and/or seizures.

Other adjuvant treatments may be necessary to provide physiological support for the

patient, whether or not surgery is conducted. Underlying hypertension can be present even

after the blood vessel has ruptured, and requires close monitoring. Healthcare providers aim

to keep the systolic blood pressure low enough to minimize the risk of re-bleed of the

vessel, but high enough to maintain adequate perfusion pressure for optimal oxygenation of

the cerebral tissues. Physicians determine the range of the ideal mean arterial pressure

(MAP) for the individual patient, and nurses monitor the measurements, notifying the

medical team if pressures become too high or too low, as either extreme can negatively

affect tissue perfusion (Hickey, 2009; Rymer, 2011; Warlow et al., 2008).

For patients who have a ruptured aneurysm as their underlying pathology, calcium

channel blockers (i.e., Nimodipine) can be used to help to minimize cerebral ischemia and

maximize tissue oxygenation (Warlow et al., 2008). Without optimal cerebral perfusion

pressure (CPP), tissue ischemia results, and the patient will continue to experience a

decreased level of consciousness (LOC) and neurological dysfunction. Aggressive

management to ensure adequate cerebral perfusion can be instrumental in how a patient will

respond clinically (Bijlenga et al., 2010; Hickey, 2009; Warlow et al., 2008). Neurological

decline resulting from increased intracranial pressure places patients at risk for developing

seizures. With added pressure in the cranial cavity due to increased blood volume, patients

are at risk to experience either focal or generalized seizures which can also affect their loc.

Medical intervention is aimed at preventing or minimizing the effects of epileptic activity in the brain through the use of anticonvulsant therapy, and the management of serum sodium levels, as previously discussed. Interventions which minimize intracranial pressure, but enhance CPP, help to minimize the risk of seizure activity (Hickey, 2009; Rymer, 2011; Warlow et al., 2008).

Surgical and medical interventions are viable options for many patients on their initial presentation to the hospital. However patients with very serious conditions, and those with multiple co-morbidities, may not be suitable candidates for surgery. For these patients, and those for whom surgery was not effective and recovery is not expected, the focus of care becomes palliative in nature (Reilly & Bullock, 2005).

Pain management. Pain management at the end-of-life was discussed in the literature, with one article exploring pain in unconscious patients. Schnakers and Zasler (2007) examined medical literature with the aim of exploring the assessment and management of pain in persons with disorders of consciousness. The authors stated that although patients in a persistent vegetative state might not be able to experience pain as compared to patients in a minimally conscious state, existing evidence does not allow clinicians to be able to differentiate the degree of conscious pain experienced or capacity to suffer in unconscious individuals. Accordingly, these authors stressed the importance of objectively assessing and adequately treating pain in all patients.

Empirical data to support the assessment of pain of unconscious patients was also discussed by Schnakers and Zasler (2007). Nonverbal cues in response to noxious stimuli, such as grimacing, limb localization, diaphoresis, and tachycardia, were considered to be the most reliable indicators of pain (Schnakers & Zasler, 2007). Subsequently, behavioral

scales have most commonly been used in the assessment of pain. In a review of the

literature to identify scales used to assess non-verbal signs of pain, Cade (2008) examined

the Behavior Pain Scale (BPS), Critical Care Pain Observation Tool (CPOT), and Non-

verbal Adult Pain Assessment Scale (NVPS). In their review, Pudas-Tahkä, Axelin, Aantaa,

Lund, and Salanterä (2009) examined these same three scales, as well as the Pain

Assessment and Intervention Notation algorithm (P.A.I.N.) and the Pain Assessment

algorithm. The latter scale included the observations of vital signs, diaphoresis, and

physical restlessness as signs of pain, which are common in the unconscious stroke patient,

but this tool has not been validated for use in practice. The other four tools incorporated

assessments which were applicable to intubated patients only. There was no evidence in the

literature of validated scales for assessment of pain in the unconscious patient who was not

intubated.

Nursing management. Nursing care of patients with an acute intracranial

hemorrhage involves monitoring fluctuations in loc and hemodynamics to detect changes in

a patient's clinical status (Hickey, 2009; Josephson, 2004). Elevating the head of the bed,

administering prescribed medications, and minimizing environmental stimuli are nursing

interventions identified in the literature that aim to minimize intracranial pressure, and

ultimately improve the patient's loc (Hickey, 2009; Josephson, 2004). Nurses are also

responsible for providing education and psychosocial support to the patient's family and

significant others who may have numerous questions regarding the individuals' clinical

status, as well as future prognosis (Hickey, 2009; Reilly & Bullock, 2005). Neuroscience

nursing textbooks contain information to guide the assessments and identification of nursing

diagnoses that may be applicable when providing acute care to this patient population.

However, there is a paucity of research examining the palliative nursing care of hemorrhagic stroke patients. Consequently, neuroscience nurses appear to have little in the way of empirical evidence to inform their care of dying stroke patients. This lack of evidence was troublesome, given that the nurses' knowledge, assessments and interventions have the potential to profoundly impact patients' clinical outcomes, and the quality of care which patients and families receive.

Josephson (2004) published a nursing literature review which discussed the management of intracranial pressure in patients in the critical care unit who had presented with various neurological conditions. The purpose of the literature review was to educate non-neurological critical care nurses in how to care for patients that may be under their charge. Josephson's work discusses the physiology and importance of adequate cerebral perfusion pressure for recovery, as well for as nursing interventions which support the potential clinical improvement in affected patients. Monitoring of intracranial pressure (ICP), CPP, and vital signs were determined to be critical nursing interventions. Ventilation, positioning, seizure prevention with medications and the use of glucocorticosteroids were indicated to lower ICP, which in turn, maximized cerebral perfusion and oxygenation (Josephson, 2004). This critical care article was focused on recovery, however, and did not elaborate on nursing interventions which were appropriate when these interventions were not effective.

Chahine et al. (2008) retrospectively reviewed all charts of patients referred to the palliative medicine service in an acute hospital setting over a three-year period ($N=2015$). Patients referred to the palliative service included those with a cancer diagnosis ($n=1429$), as well as those with non-malignant illnesses ($n=586$). A total of 177 patients with

neurological diseases were referred to palliative medicine, but 48 charts were excluded as patients' charts were either incomplete or the patient's history was complicated by the addition of a recent cancer diagnosis. Ultimately, the charts of 129 patients with neurologic conditions at the end of life were examined to determine at what point in their illness trajectory these patients were referred to a palliative medicine specialist. The researchers found that patients with a thrombolytic stroke were the most common type of patient group referred ($n=33$), and that patients presenting with intracranial hemorrhage accounted for 6.4% of overall referred consults ($n=15/2015$). Fifty-eight per cent of patients in the study presented with some type of symptom which led to the consult to the palliative medicine service. The findings of this chart review indicated that consults to palliative care for patients with intracranial hemorrhage were low when compared to malignant and neuromuscular diseases. This was thought to be due to a lack of perceived symptom concerns in these patients on the part of the professional healthcare providers.

In a qualitative study conducted by Georges, Grypdonck, and De Casterle in the Netherlands (2002), semi-structured interviews were conducted with palliative care nurses ($N = 10$) working on a palliative care unit in an academic hospital with the goal of describing how nurses perceived their role in caring for dying patients in an acute medical setting. The authors found that although nurses worked at developing relationships with their patients, they tended to be more focused on completing tasks in a competent manner. Moreover, it appeared that in communicating with patients about important issues, nurses tended to fall back on the policies of their unit to answer patient questions (i.e., if a patient or family asked for euthanasia, they would respond with an answer stating policy and local law rather than exploring the reason for the patient request). The authors concluded that it

was difficult for nurses to provide true palliative care when their role is affected by their

workplace environment. Although this study was conducted with nurses working in a

tertiary care setting, it was not specific to the neurosciences setting and the experiences of

the nurses who work there. The findings do, however, speak to the importance of exploring

the impact of the work environment when examining the experiences of the nurses in this

study.

In an attempt to identify the care needs of patients who had experienced a stroke and

were nearing the end of life, Stevens et al. (2007) conducted a retrospective review of

internationally published healthcare literature regarding palliative care. The authors found

only seven articles that discussed the needs of stroke patients at the end of life, and

attributed this paucity of literature to the difficulties in prognostication in the first month

after diagnosis. Of the articles reviewed, only one (Rogers & Addington- Hall, 2005)

examined the perspectives of nurses providing care to stroke patients. The authors

conducted a qualitative study in which nurses identified 22 patients with a severe stroke

whom they expected would die within 3 months from their time of admission to an acute

stroke unit on a teaching hospital. Using non-participant observation, the researchers were

able to identify behaviors engaged in by nurses in the course of providing care to patients

dying as the result of a stroke. Meeting patients' physical care needs, communication about

the care plan and care interventions, discussion surrounding hydration and nutrition, and

prognostication were identified as nursing behaviors that were part of the experience of

providing palliative care to stroke patients and families. The authors concluded there is a

need for palliative care in non-cancer populations and that stroke patients should have

access to end-of-life care based on need rather than diagnosis, with symptom management

and psychosocial support being the focus of care. Collaboration with the palliative care

consult service was suggested as an option to facilitate improved psychosocial support of

families, as well as assist in ensuring that the goals of the patient were being met.

Neatherlin and Fox (2006) performed a retrospective descriptive review of 377 peer-

reviewed articles published in the *Journal of Neuroscience Nursing* from 1993 to 2002 in

order to quantitatively describe the concepts regarding end-of-life care. During this time

frame, only forty articles were found containing some data on end-of-life care, with research

articles ($n = 13$) being significantly less common than anecdotal clinical articles ($n = 27$).

The primary areas discussed in the articles included the perspectives of families of dying

neuroscience patients, their coping systems and support strategies. No content was

identified that discussed the perspectives of nurses providing care. The authors observed

that while neuroscience nurses do have experience caring for dying patients, there was no

evidence on which to base their practice specific to the neuroscience discipline. Neatherlin

and Fox's review clearly indicates a gap in the literature regarding the experience of nurses

providing care to patients who have had an ICH, and thus underscores the need for the

proposed study.

An American qualitative descriptive study (Calvin, Kite-Powell, & Hickey, 2007)

used convenience sampling to examine neuroscience nurses' ($N = 12$) perceptions of end-of-

life care in intensive care. The authors interviewed nurses who had cared for dying patients

in a neurointensive care setting. Analysis of the interview data identified three major

themes. The first theme, providing guidance, referred to the role in which nurses placed

themselves as part of their efforts to support and educate families. Nurses felt empowered

to guide families to make decisions, as nurses felt confident in their communication skills.

In some instances, participants described their communication as being a "push" or "shove" in order to elicit a do-not-resuscitate order or to force decisions regarding medical care interventions. While nurses expressed a degree of discomfort in having these conversations, they believed they were necessary to help educate families so that they might better understand the medical situation, and help open lines of communication and connection between the nurses and families. Participants trusted that the family knew the patient and his/her wishes, and believed that they could elicit key thoughts from the family members to advocate on the patient's behalf (Calvin et al., 2007).

The second theme, being positioned in the middle of communication, referred to the role nurses found themselves in when facilitating communication between families and physicians (Calvin et al., 2007). Nurses sought to understand the patients' goals of care, and advocated on behalf of the patients and families in their discussions with the physicians. Participants found that families often were not as open with physicians as they were with nurses in discussing their concerns, leaving nurses with the role of being the primary source of emotional support for families. Consequently, there were instances in which nurses experienced frustration with families who were not accepting of a patient's imminent death, and this was complicated if the families and physicians had differing goals of care. Nurses found themselves always needing to cautiously reinforce the clinical assessment of the patient with families in an effort to prepare them for the death of the patient, but also found it necessary to do the same with physicians when nurses believed that physicians were being more aggressive with interventions than was desired by the family. Participants in Calvin and colleagues' study valued their role in communication, and felt that it was the most essential aspect of end-of-life care. These findings (Calvin et al., 2007) are consistent with

the work conducted by Hamric and Blackhall (2007).

The third theme, feeling emotions, was evident in the experiences of the nurses providing end-of-life care (Calvin et al., 2007). The authors concluded that each nurse had a different perspective and approach in caring for dying patients. While all nurses embraced the challenge, some found it emotionally draining to respond to all of the families' needs, and experienced a sense of powerlessness and helplessness when unable to resolve each family issue that might have presented. The unpredictability of the dying trajectory, the subsequent inability of the nurses to give the families definite answers to questions that arose, as well as the acuity of the neuroscience intensive care unit contributed to the emotions experienced by the nurses. Nurses experienced stress in their attempts to shift from an acute focus to a comfort focus, as well as provide palliative psychosocial support and then move on to caring for their next patient who was not palliative. Although nurses cherished their role in the provision of palliative care, they found managing their related emotions to be a challenge (Calvin et al., 2007).

Challenges of Providing End-of-life Care in an Acute Care Setting

A review of the literature suggests that nurses face several challenges providing palliative care in an acute care setting (Calvin, Kite-Powell, & Hickey, 2007; Levy et al., 2005; Parish, Glaetzer, Grbich, Hammond, Hegarty, & McHugh, 2006; Stevens et al., 2007; Thompson, McClement, & Daeninck, 2006), with one of these challenges being time constraints. Neuroscience nurses are responsible for administering scheduled medications and performing assessments on acute patients who require monitoring for early detection of neurological deterioration (Hickey, 2009). Research suggests that nurses working on busy acute surgery units with their focus on psychomotor skills and tasks, find it difficult to

spend dedicated time offering psychosocial support and providing education to patients'

significant others about the care being provided (Georges et al., 2002; Rogers & Addington-

Hall, 2005). Thus, time constraints have been seen to have an impact on the provision of

palliative care.

A second challenge identified in the literature regards nurses' knowledge deficits

about palliative care in general, with a specific knowledge deficit in the provision of

psychosocial and spiritual care in particular. A retrospective study conducted in Australia,

which included chart reviews and nurse interviews, was conducted in a 250 bed teaching

hospital in order to analyze the quality of end-of-life care administered in an acute non-

neuroscience care setting (Parish et al., 2006). The charts of twenty recently deceased

patients were reviewed. For each of these patients, two nurses who had provided care were

interviewed ($N = 40$) by the researchers. The authors found that nurses frequently neither

recognized interventions of psychological, social or spiritual support as being part of the

care plan for these patients and their families, nor regularly documented such interventions

in patients' charts. In contrast, nurses documented 100% of the time on the physical needs

of the patient. Moreover, the authors' noted that because nurses failed to recognize when

patient death was imminent, they missed the opportunity to communicate with families

about this fact. Interview data revealed nurses were aware of their lack of general palliative

care knowledge, and the need for more educational resources on their unit, but could not

provide details surrounding what these resources might be. Taken as a whole, these study

findings suggest that nurses working in acute care settings who lacked knowledge about

palliative care nursing tend to focus largely on physical symptom management, while

patients' and families' psychosocial and spiritual concerns went largely unaddressed.

Research suggests that challenges in prognostication, system factors, the physician`s predisposition (or lack thereof) toward a palliative approach, and patient age affect the nurse`s experience of providing palliative care in an acute medical setting. In 2006, Thompson et al. published findings of a Canadian grounded theory study that described the process by which nurses working on an acute medical unit ($N = 10$) work to create a safe haven for passage while caring for patients who were transitioning from acute care to palliative care. Concerns included prognostication challenges in patients with non-malignant diagnoses and difficulties determining when to initiate discussions with families about transition from curative to palliative care. System factors identified as impeding the transition from curative to palliative care included the lack of a clear and consistent ward philosophy regarding the role and value of palliative care in patient care. Rather than being an integral part of the care that is provided to terminal patients, the authors identified that the application of a palliative care philosophy to patient care was highly variable, depending on the individual predisposition of the attending physician. Finally, the age of the patient influenced the transition to palliative care. Although nurses were aware of the need for palliative care in younger patient populations, they were psychologically less comfortable in providing care to younger adult patients as it seemed like death was premature and subsequently more difficult to acknowledge. This perception was found to negatively impact the comfort of nurses in caring for younger adult patients as they found conversations surrounding end-of-life care more emotionally challenging.

Challenges due to Limited Empirical Knowledge about Palliative Care in Neurosciences

The findings of the literature review completed for this study demonstrated a

plethora of information on end-of-life care of cancer patients and the perspectives of

patients, families and physicians about this care, but minimal data on end-of-life care from

the perspective of neuroscience nurses. Only five papers were found that focused

specifically on palliative care in neurosciences and intracranial hemorrhage. Those works

will now be reviewed.

Physicians Simmons and Parks (2008) performed a literature review of palliative

care and neurosciences journals and textbooks and identified specific interventions for

patients dying within thirty days of the acute onset of either a hemorrhagic or thrombolytic,

high grade CVA. The authors summarized appropriate clinical interventions for the care of

stroke patients who were now palliative. Interventions viewed as critical for patients and

families included discussing do-not- resuscitate (DNR) orders, withdrawal of ventilator

support, and family meetings to discuss end-of-life specific interventions. The authors

confirmed that prognostication was a challenge in determining the appropriate care

pathway, but emphasized that establishing a no resuscitation approach did not preclude the

implementation of aggressive treatment measures if this is what is desired by the patient or

family. It was proposed by the authors that aggressive medical treatment with the goal of

clinical improvement could be offered in conjunction with "do-not-resuscitate" orders,

depending on the goals of treatment. They did not offer any rationale for the proposal of

these opposing goals of care.

Fields (2007) presented a case study describing medical and nursing interventions

similar to those identified by Simmons and Parks (2005), but concluded that DNR orders do

not mean the end of care, but rather, a shift in appropriate and relevant interventions.

Appropriate interventions, aimed at promoting a comfortable death for the patient and

emotional support for the family, were seen as easily attainable. A need for the

development of clinical protocols to guide patient care during the transition from aggressive

medical interventions to a palliative care approach was identified as a gap in nursing

resources.

In the third article, Chahine et al. (2008) reviewed all acute care inpatient consults

received by the palliative care service over a three year period ($N = 2015$), with the goal of

determining the palliative needs of patients with non-malignant life-limiting disease. Their

review identified that 70.9 % of palliative care admissions were for malignant conditions,

and only 29.1 % were for non-malignant conditions. In the latter group, only 30.2 % of the

non-malignant admissions were for neurological conditions (i.e., overall 177 of 2015

admissions). After excluding cases that lacked complete documentation and cases in which

it was discovered that patient had a concurrent malignancy, only 129 of 177 charts were

included for review. Of these, only 16 charts (0.8 % of 2015 cases) were those of patients

with acute intracranial hemorrhage. Symptom issues including dysphagia, dyspnea, pain,

and need for hospice placement were primary reasons for consultation to the palliative care

service. As many of the patients with intracranial hemorrhage were unconscious at the time

of diagnosis, perhaps these symptoms were not perceived by health care professionals to be

present. Such perceptions may explain, in part, the lower rates of referral to palliative care.

The fourth article specific to end-of-life care in stroke was written by Stevens et al.

(2007). In this paper, the authors performed a literature review to identify the palliative care

needs of patients who had experienced a stroke. In their search seven papers were located,

but these articles focused on the epidemiology of stroke, family care needs, and long-term

symptom management. Only one article in their review was identified as focusing on the

end-of-life care needs of this patient population. That article asserted that stroke patients

should receive palliative care based on their symptom needs rather than their diagnosis

(Rogers & Addington-Hall, 2005).

Rogers and Addington-Hall (2005) conducted a qualitative research study on an

acute surgical unit in Britain to examine the factors that influenced the care of dying stroke

patients on an acute surgical unit. Researchers engaged in non-participant observation of

the care provided to 22 unconscious stroke patients who were not expected to survive more

than three months. They also conducted interviews with patients, families, physicians,

nurses and allied health professionals. The authors concluded that consults to palliative care

for these patients are rare, as the patients are unconscious and symptom management was

not a concern identified by health professionals. Observational and interview data with

nursing staff revealed that even in a busy acute setting, the staff valued the concept of a

"good death", and provided quality care to patients. Nurses also indicated that the provision

of palliative care may be helpful in supporting and educating families, particularly when

difficult decisions regarding care interventions were being discussed. This finding speaks to

the need to educate nursing staff about the contributions a palliative care approach can bring

to the patient's care beyond that of only symptom management.

The general palliative care literature suggests that nurses are in a key position to care

for families by being available to support them through difficult decision-making situations

and experiences, and providing education and information in response to questions that

arise. Duggleby and Berry (2005) published a Canadian case study discussing the health

care experiences of a 46-year-old woman and her family as they faced a life-limiting illness

in hospice. The findings of the case study indicated that patients and families worked

through the transitions to palliative care at their own pace, and that it was optimal that their

wishes and directives remain respected at all times in order for them to have as positive an

experience as possible. Integrating a review of related literature into their discussion, the

authors found that patients and families appreciated receiving honest information as it

helped to clarify their expectations and allowed them to make informed decisions. The

sharing of information also clarified the purpose of palliative care and allowed the patient

and her family to maintain hope in their journey. Rather than hope for a cure, the patient

and her family now hoped for a lack of suffering, hoped for their family to live life to the

fullest, and hoped for a peaceful death (Duggleby & Berry, 2005).

The literature suggests that neuroscience nurses sometimes find it difficult to

provide psychosocial support to families of patients who were going to die. Yeager et al.

(2010) have proposed a multidisciplinary intervention to support nursing and allied health

clinical practice, with the impetus for the development of this intervention coming from the

experiences of nurses on the unit. After experiencing several deaths over a few days, staff

were emotionally overwhelmed and, as a result, felt that they had not provided families with

adequate psychosocial support. A multidisciplinary team, including bedside nurses, a unit

clerk, a case manager, a neurological and palliative care social worker, a nurse practitioner,

a representative from pastoral care, a neurosurgeon, and hospice nurses were all involved in

the development of the intervention that would be supportive of patients and families

receiving end-of-life care. After reflecting on their practice, reviewing the literature, and

analyzing survey data gathered from staff and families regarding their ideals in end-of-life

care, the team developed the "Embrace Hope" algorithm. Interventions proposed included

identifying the patient as being the focus of care, consulting palliative and spiritual care to

ensure individualized physical and spiritual needs were met, providing education about end-of-life care philosophies, and providing the family with practical information about what to expect and do following the death of the patient. It was proposed that by following a specific algorithm at the end-of-life for each patient, that the patient and family would be supported in experiencing what they perceived to be and "good death".

Yeager et al. (2010) considered the patient to have had a "good death" if it occurred in accordance with known wishes of the patient, the patient was free of suffering and the care provided was respectful of the individual's ethical, cultural and spiritual needs. While the authors, who were nurses, spearheaded this study, the interventions developed to support patients and families at the end-of-life, were devised to be implemented by any member of the healthcare team. The authors reported that structuring care plans in accordance with the algorithm was beneficial on numerous levels, as it facilitated ensuring that patient and family focused care was provided, and also supported the health care teams' ability to manage their workflow in the critical care setting.

Yeager and colleagues also conducted a survey in the form of a questionnaire with patients' next of kin prior to the implementation of the intervention ($N = 38$), as well as after the intervention was completed ($N = 36$), in an effort to evaluate the effectiveness of their algorithm. In the pre-intervention and post-intervention surveys, the authors inquired about families' perspectives regarding several aspects of care, including both physical and psychosocial care. Data analysis revealed that families perceived improvements in the emotional support and overall care they received from health care providers ($p < 0.05$), which in turn supported the nurses to feel that they were providing optimal care. In pre- and post- intervention questionnaires given to healthcare providers, improvements were seen in

the following areas: meeting the patient's wishes ($p < .001$); nurses not feeling time

pressures ($p < .001$); symptom management ($p < .001$); comfort with pain management ($p <$

.001); consistent ethical practices ($p < .002$); consistent cultural practices ($p < .003$); and

consistent clinical practices ($p < .002$). Anonymous staff survey results also reflected a

decreased incidence of perceived moral distress regarding the transition of goals of care and

more positive experiences in providing care to palliative patients when using the "Embrace

Hope" algorithm to guide their care (Yeager et al., 2010).

The development of this guideline helped this care unit to feel more confident in

providing end-of-life care as they were able to have a checklist which helped to ensure that

all patients and families had their physical, psychosocial and spiritual needs met. One

limitation of this study was that the before and after intervention comparison did not include

the same respondents. Thus, the evaluation was not a true evaluation of the intervention,

but rather a comparison of the perceptions of care at two different points in time. It cannot

be definitely stated that the intervention was the only factor that led to the improved

perception of care.

Challenges Related to a Lack of Education on Palliative Care in Neurosciences

Nurses in acute neurosciences units are specially trained to provide care that focuses

on optimizing neurological recovery, so the shift to a palliative focus about which they are

not knowledgeable may lead to confusion and feelings of helplessness and inadequacy in

care plan development (Yeager et al., 2010). It has been suggested by Quint (1967) that a

combination of lack of exposure to the care of dying patients, combined with a lack of

education caring for these patients, leads to anxiety surrounding death with associated

negative attitudes. Drawing on her observations and clinical experience, Quint proposed

that without palliative care education and exposure to care of the dying patient, nurses would adopt negative attitudes and behaviors in care of the dying demonstrated by others with whom they worked. Negative attitudes may then result in nurses withdrawing physically and psychologically from the patient and their family. Quint (1967) hypothesized that exposure to dying patients combined with a lack of palliative care education, resulted in death anxiety and negative attitudes, which in turn resulted in a withdrawal in care of the dying.

The impact of palliative care education and clinical experience with palliative patients has been evaluated in the literature and tends to support Quint's hypothesis. A quasi-experimental study conducted by Degner and Gow (1988) demonstrated that a required course in palliative care education with a required clinical component resulted in improvements in students' attitudes towards care of the dying patient and family. A total of 330 students were assigned to three separate cohort groups: third-year nursing students who received formal palliative care training including a clinical component, third-year nursing students who received integrated palliative care education throughout their program excluding a mandatory clinical rotation, and fourth year non-nursing home economics students. Surveys were conducted with members of each group three times over a period of 10-12 months. Data analysis demonstrated that participants who received structured and formal palliative care education reported being more comfortable providing holistic palliative care and focused more comfortably on the psychosocial and spiritual aspects of care than did the other two groups. One of the limitations of this study was the narrow age range of students included (age 18-22); more mature students may have different life experiences with death, and may thus report a different impact as recipients of palliative

care education. As well, less than half of the students who were eligible to participate in the study actually agreed to be part of the study, so the full impact of the course may not have been captured in the results. Those who did not participate in the study may or may not have found the course beneficial to their personal or professional approach to patient care. Thus, selection bias may have had an impact on the interpreted findings of the study.

Content which tests knowledge about palliative care in the neurosciences setting is also lacking in the Canadian Nurses Association (CNA) neuroscience nursing certification exam. Neuroscience nurses who seek to qualify their expertise in providing care to patients in any clinical setting look at the competencies proposed by the CNA to guide their studies. The guideline for certification requires that nurses demonstrate mastery of 18 categories of competencies and 216 subcategories. Palliative care is noted once under the category of brain tumors, and with this, it is mentioned within a grouping of other items under "understanding treatment options and goals of care in patients with brain tumors" (Canadian Nurses Association, 2008). As there are only 165 questions for 216 competencies, and brain tumors account for 5-9 % of all the questions, it is not likely that there will be significant end-of-life care content on the certification exam. This lack of incorporation of neurosciences palliative care within the CNA guidelines strongly supports the curative care approach and focuses of education in neurosciences, and may explain why there is minimal literature by neuroscience nurses to support this aspect of care.

Ethical Challenges for Neurosciences Nurses

An extensive review of this large body of literature is not appropriate given the uses of literature in phenomenological research, and is beyond the scope of this thesis. However, select literature examining ethical issues will be presented here as a sensitizing lens for this

study. That literature examines issues related to hydration and nutrition supplementation from the perspective of healthcare providers and families, as well as the potential development of healthcare providers' moral distress in response to conflicting personal values in the course of providing palliative care. Areas of hydration and nutrition were focused on within the context of ethical practice as these topics were most prominent when examining ethical issues in the palliative care literature. Anecdotal evidence based on the student researcher's own clinical experience also suggests these issues have the potential to be ethically problematic and lead to conflict amongst families and health care providers.

A literature review conducted by Dalal, Del Fabbro and Bruera (2009) discussed the effects of hydration and dehydration at the end of life in the general patient population. Dehydration was defined as depletion of fluid from the intracellular space that can lead to symptoms such as fatigue, nausea, lethargy, confusion and myoclonus (Dalal et al., 2009). While multiple co-morbidities can also contribute to some of these common end-of-life symptoms, the role of parenteral hydration at this stage was identified by the authors as one which must be considered on an individual basis. The potential development of the side-effects of dehydration, however, caused some nurses to question the intervention of whether or not to administer intravenous fluids at the end of life, and was found to contribute to the development of ethical challenges for nursing staff (Dalal et al., 2009). It was concluded that parenteral hydration should definitely be considered if it was believed to potentially be beneficial in reversing specific conditions such as opioid neurotoxicity, delirium, hallucinations or acute renal failure. Dalal et al. (2009) stated that if these symptoms were reversed, the comfort of the patient would be maximized.

It was also noted in the literature review that common concerns such as fluid

overload and respiratory congestion, which were often thought to be side effects of artificial

hydration, were found to develop only when high volumes of parenteral fluid (> 1000 ml

per 24 hours) were initiated (Dalal et al., 2009). Rather than focusing on this potential

negative, the authors proposed that individual cases and goals of care be discussed to

determine the most appropriate approach. As a result of their review, Dalal et al. (2009)

proposed a theoretical model which outlined the effects of fluid deficits in palliative

patients, and at which point parental hydration should be considered as it might minimize

the incidence of ethical challenges. This model has not been validated in clinical practice

(Dalal et al., 2009).

Australian researchers Van der Riet, Good, Higgins, and Sneesby (2008) conducted

a qualitative study on both an urban and a rural palliative care unit to examine the

perceptions of nurses and physicians regarding hydration at the end of life. The impetus to

conduct the study came from the authors' observing that families were seeking hydration

and nutrition more frequently, even though it was more obvious to the healthcare team that

patients were not able to eat or drink on their own and were near the end of life. Two focus

groups were conducted (n =15 each) with the nursing staff and individual interviews were

held with physicians ($n = 4$). Using discourse analysis, the authors derived three main

themes: family distress when hydration was not provided, participants' perception of

suffering when hydration was provided, and differences in views between participants in

urban and rural care settings, including differences in beliefs amongst staff regarding the

ethos of acute care and palliative care.

Within the first theme, health care providers perceived that families experienced

distress when hydration and nutrition were not provided (Van der Riet et al., 2008).

Families were seen to view food and hydration as essential interventions to ensure comfort at the end of life. Many families were found to equate thirst with suffering, and this was subsequently distressing to healthcare providers, who did not want families to be upset. Physicians and nurses also believed that families viewed the continuation of hydration and nutrition as the last hope for the patient's cure or recovery. This belief was consistent with the findings of the study conducted by Thompson et al. (2006) in which they examined nurses' perceptions of palliative care on an acute medical unit. Within Thompson et al.'s findings, families were seen to believe that the provision of food and hydration were essential to the patient care plan as this act of caring supported the families' ongoing hope for the recovery of health. The offering of fluids and nutrition also allowed families an opportunity to be physically involved in the care of their loved one. Families perceived the termination of such interventions to be more of confirmation that death was imminent (Thompson et al., 2006).

The second theme identified in the study by Van der Riet et al. (2008) regarded the belief held by nurses and physicians that patients suffered needlessly if they did receive artificial hydration or nutrition (Van der Riet et al., 2008). This was a perception contrary to that held by families. Healthcare providers viewed dehydration and the gradual loss of oral intake as part of the natural process of dying. Frequent oral care was seen as the best approach to managing a dry mouth rather than fluid replacement, and this was explained by nursing staff to families. Discord developed when families were not in agreement with this approach to care, but how these disagreements were resolved was not discussed (Van der Riet et al., 2008).

The third theme derived in this study was in relation to the differences in beliefs

amongst the healthcare staff regarding the ethos of care between an urban, tertiary palliative care unit and a rural mixed palliative care/ medicine ward. Diverse philosophies of care regarding the management of hydration and nutrition issues at the end-of-life were evident. In the tertiary care setting, interventions were seen to be more medical and curative in nature, while healthcare providers in the rural setting were more comfortable with minimizing symptoms and maximizing the patients' quality of life. Nursing staff in the urban setting reported that physicians had a more difficult time in withdrawing hydration as it was contrary to their usual acute care ethos. Consequently, nurses working in the tertiary care setting viewed the transition from acute to palliative care difficult at times (Van der Riet et al., 2008). Based on these study findings, the authors recommended that communication and knowledge-sharing between the nurses, physicians and families was essential in discussions in the transition to palliative care. Communication initiated by nursing staff towards more recently trained physicians was seen to promote a shared understanding and awareness of the patient and family experience (Van der Riet et al., 2008).

In a systematic literature review, del Rio et al. (2011) examined attitudes and perspectives of palliative patients, families and healthcare providers in regards to hydration and nutrition at the end of life. The authors found that members of this triad were emotionally impacted when patients were no longer able to eat. Patients and families viewed the process of eating as a sign of health, thus patients felt compelled to eat as much as possible, and families were found to strongly encourage oral nutritional intake, even when this activity resulted in nausea or indigestion. It was also perceived by families that if the patients continued to eat, the expected signs of physical decline, and thus death, could be

delayed. Though patient anorexia at the end of life was seen to cause anxiety primarily to families who were having difficulties in coping with the functional decline of the patient, it also elicited a varied response among healthcare professionals. Despite an awareness of literature regarding artificial hydration, physicians struggled to not provide this support, as they viewed hydration as essential to maintain physiological function. Nurses were found to experience anxiety at their lack of involvement in the decision-making process. The lack of a consistent team focus in addressing hydration issues was found to potentially create emotional distress for patients, families and healthcare providers (del Rio et al., 2011).

Within the literature review conducted by del Rio et al. (2011), cultural and religious factors were identified as influencing the goals of care. Specifically some cultural groups expressed a desire for artificial hydration or nutrition. The literature review revealed that if an individual lived in Sweden, Switzerland, Belgium, Holland, Denmark or Italy, they were more likely to be comfortable with not having fluid and/or nutritional support. In contrast, patients and families who were Buddhists from Taiwan were found to strongly support the need for artificial fluids and nutrition, as this intervention was seen not only to provide physical strength to the patient, but spiritual strength as well. Buddhists believed that neglect of hydration and nutritional status at the end of life resulted in the patient dying of physical and spiritual hunger. The authors reported that it is essential to consider cultural and religious beliefs when trying to understand and respect the perspectives of patients and families (del Rio et al., 2011).

Circumstances which were identified as contributing to patients, families and healthcare providers being more comfortable with the withdrawal of fluids and/or hydration support included: being over eighty years of age, having some form of advanced central

nervous system illness, and any form of cognitive incompetence (del Rio et al., 2011). This

literature review situates the perspective of families in facing decisions about the use of

fluids and hydration at the end of life, and consequently provides context in which to frame

the experiences of nurses providing care to patients and families who are in similar

circumstances. Despite this awareness, however, it was recognized that healthcare

providers still might experience difficult situations due to personal beliefs and values that

might conflict with the beliefs of patients and families. In these circumstances, the authors

suggested that open communications and the guidance of a "mental health professional" (del

Rio et al., 2011, p. 8) might minimize the emotional distress.

Moral distress has been documented as being experienced by all healthcare

professionals in all types of care (Austin, Rankle, Kalgan, Bergum & Lammergeyer, 2005;

Nathaniel, 2006; Zuzelo, 2007), but end-of-life care is identified in the literature as a

situation that is especially prone to moral conflicts as decisions regarding treatment must be

made under a great deal of emotional pressure (Hamric & Blackwell, 2007). The transition

from acute to palliative care may involve withdrawing and/or withholding such

interventions as parenteral support, intravenous (IV) fluids, or even respiratory support

(Levy et al., 2005). Such actions may result in nurses experiencing situations which

challenge their personal values and beliefs, and result in the experiences of moral dilemmas

or moral distress.

Moral distress was a concept developed initially by Jameton (1984) and was

described as occurring when an individual felt that he/she could not pursue what he/she

believed was the "right" thing to do, as the result of systemic constraints. These constraints

were found to cause the development of painful emotions such as anger, frustration and

withdrawal from the challenging situations. External sources that were considered to contribute to these feelings were a perceived lack of time, a lack of leadership support, the influence of the role of the physician in providing care, facility policies and procedures and legal constraints. While a moral dilemma was defined as being the presence of the need for a decision that involved opposing approaches, moral distress was found to be present when an individual felt that they could not personally proceed with what they thought was the proper course of action in these situations (Jameton, 1984).

Webster and Baylis (2000) expanded on Jameton's work to develop a more inclusive definition of this psychological response. In addition to the previously noted perceived constraints, these authors believed that internal influences may also contribute to the development of moral distress. Personal values and individual personality traits were believed to play a role in this aspect of providing ethical care. Whether it involved making errors in judgment in a situation, or not being emotionally strong enough to proceed with the known right course of action, the internal character of the individuals contributed to the outcomes of a situation, and possibly moral distress (Webster & Baylis, 2000).

The literature suggests that when healthcare decisions are made that are in conflict with cherished values, a nurse experiences a challenge to his or her moral integrity. This may result in personal suffering in the form of numerous psychological and physical symptoms if the distress goes unresolved (Corley, 2002; Corley, Elswick, Gorman & Clor, 2001; Corley, Minnick, Elswick & Jacobs, 2005; Peter & Liaschenko, 2004; Zuzelo, 2007). The psychological responses identified in the literature vary for each person, but include feelings such as frustration, anger, grief, helplessness, and/or anxiety. Physical symptoms may include nightmares and headaches (Corley, 2002). Webster and Baylis (2000) have

described this unresolved, repetitive moral distress as moral residue, and suggest that it may have long-term implications for the psychological, emotional and physical health for those who experience it. The thoughts and experiences associated with moral residue are considered by these authors to remain part of who we are and affect our response to future experiences (Webster & Baylis, 2000). If repeatedly facing a circumstance in which a nurse believes that he/ she cannot follow his/her moral compass, moral residue contributes to exaggerated moral distress in future situations in which the nurse is faced with psychologically challenging ethical decisions. Ultimately, depression and burnout may develop, and the nurse may physically and emotionally withdraw from patient interactions. Without attention and empathy, patient care will be affected. (Austin et al., 2005; Corley, 2002; Guttierrez, 2005; Laabs, 2007; Nathaniel, 2006; Rice, Rady, Hamrick, Verheijde & Pendergast, 2008). In contrast, when speaking up about a circumstance that nurses perceive as immoral, or contrary to their beliefs, despite the constraints they perceived in their work environment, it is possible that the nurse might develop moral courage, and possibly avoid experiencing moral distress. By advocating for their own personal values, or those of the patient and family, nurses may be able to minimize the effects of moral distress and maintain a sense of moral integrity (Webster & Baylis, 2000).

Using the definitions presented by Jameton (1984) and Webster and Baylis (2000), Corley (2002) proceeded to propose a moral distress theory which links the concepts of sensitivity, autonomy, competency, commitment, sense-making, judgment, conflict and certainty with the action of the nurse and the impact of his/ her decision on how the nurse is or is not able to resolve their moral dilemma. If nurses can resolve their inner conflict, and proceed in a manner which is congruent with their personal values and beliefs, Corley

proposed that nurses would experience moral comfort, indicating they had no inner

psychological conflict. If they were not able to resolve their moral dilemma, and felt that

they could not proceed in a way that they believed was the proper way to act, Corley's

model purported that nurses would develop moral distress and possible moral residue,

resulting in psychological resignation. This, in turn, would lead to a lack of patient

advocacy and withdrawal from the nursing profession (Corley, 2002). This theory has not

yet been validated in a clinical setting.

Hamric and Blackhall (2007) found that in the USA, 20% of patients in intensive

care were not likely to survive their stay in the unit, which led to frequent discussions

surrounding treatment approaches and end-of-life care. As all healthcare providers brought

different experiences and values to the bedside, it was important to evaluate the impact of

these personal values on the care provided and relationships within the health care setting.

Using convenience sampling, Hamric and Blackhall (2007) undertook a quantitative study

to measure the perspectives of registered nurses and medical residents in regards to

collaboration, moral distress and ethical issues. A survey questionnaire was used to explore

the perspectives of registered nurses ($N =196$) and physicians ($N = 29$) caring for patients at

the end of life in fourteen different regional intensive care settings. The settings included a

critical care unit with neurotrauma patients, but not other neurosurgery patients. An adapted

version of Corley's Moral Distress Scale, McDaniel's Ethics Environment Questionnaire

(McDaniel, 1997), and questions developed from a focus group with physicians and nurses

were used. The 19-item, adapted moral distress scale was validated for use in this study

with Cronbach's [alpha] internal consistency reliability of .83 in the physician group and .85

with the nursing group (Hamric & Blackhall, 2007). The outcomes measured included: the

severity of experienced moral distress; perceptions of the degree of support in the work environment to address ethical issues; and perceptions of the effectiveness of communication amongst staff and communications between staff and the family when approaching discussions surrounding end-of-life care.

The authors found that both nurses and physicians experienced moral distress when faced with providing aggressive medical care which they perceived as not beneficial for the patient, although nurses' perceptions of moral distress rated higher than that of physicians. The researchers concluded that registered nurses experienced a higher incidence of self-reported moral distress than physicians in the study, while physicians perceived a higher degree of collaborative practice than did nurses. With a potential composite score ranging from zero (low moral distress) to 304 (high moral distress), a significant difference was seen in self-reporting between physicians and nurses (p < .0001). Groups one and two of the nurses had mean scores of 80.4 and 70.2 respectively, while the mean score of moral distress reported by physicians was 44.6 (Hamric & Blackhall, 2007). To measure perceptions regarding nurse-physician collaboration, the authors adapted a scale which measures attitudes regarding physician- nurse collaboration which was developed by Hojat, Fields, Veloski, Griffiths, Cohen, and Plumb (1999). The revised tool was a 13-item questionnaire with a Cronbach's alpha of .83 (Hamric and Blackhall, 2007). With a potential score of 13 (low collaboration) to 52 (high collaboration), the authors found that physicians perceived a higher degree of collaboration with a score of 44.7. Nurses reported scores of 39.1 and 42.1 (groups one and two respectively), indicating that they did not see the relationship between nurses and physicians to be as collaborative as physicians did (p < .001 between group one nurses and the other two groups) (Hamric & Blackhall, 2007).

Overall, nurses also perceived the work environment and ethical issues more negatively than did the physicians (Hamric & Blackhall, 2007). In attempting to explain why the severity of nurses' moral dilemmas was reported as more significant than that of physicians, the authors suggested that it is perhaps because nurses are the direct caregivers who are physically implementing the proposed intervention, while physicians are able to be away from the bedside for a greater duration of the time. The nurses are seen as having more of an emotional investment in the care provided. It was not clear, however, if participants understood how to gauge or define moral distress as part of the study, and how they determined that they were experiencing moral distress. This lack of clarity is a significant limitation of this study and its results.

Summary

This chapter critically reviewed literature relevant to the proposed study. Six major bodies of literature were presented. These included i) the epidemiology, etiology, prognostication and risk factors for stroke; ii) treatment of stroke; and iii) challenges in providing palliative care in an acute care setting; iv) challenges due to limited empirical knowledge about palliative care in neurosciences; v) challenges related to a lack of education on palliative care in neurosciences; and vi) ethical challenges for nursing staff. It was evident from the literature review that while a large body of literature exists addressing the end-of-life care of patients dying from cancer and their families, comparatively little literature has been published examining this topic specifically as regards the care of patients dying from stroke. Nonetheless, select palliative care literature was reviewed and presented to help sensitize the researcher regarding issues of end-of-life care in general, particularly as regards ethical issues that arise in care of the dying. The next chapter will describe the

methods used to conduct the study.

Chapter 3: Methodology

In this chapter, the methodology of this study will be described. The concept of phenomenology will be discussed, with a rationale provided for its appropriateness for this study. A description of the research design, data collection approach, and data analysis will be presented, along with actions that were undertaken to ensure the rigor of the results.

While phenomenology is well established as a research method, it is also considered to be a philosophical approach. The philosophy of hermeneutic phenomenology as discussed by Max van Manen (1990) was used to guide this phenomenological inquiry, and is "essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word" (Streubert Speziale & Rinaldi Carpenter, 2007, p. 88). In other words, hermeneutic phenomenology examines the true lived meaning of the experience of a participant within the context in which the experience exists. van Manen's approach to hermeneutic phenomenology combines the works and philosophical traditions of Hursserl and Heidegger. Thus, a discussion of the works of these founding theorists is warranted to truly understand van Manen's approach.

Husserl's Transcendental Phenomenology

Transcendental, or descriptive, phenomenology was initially introduced by Edmund Husserl in the early 1900s in an attempt to improve scientific inquiry in the human sciences. Viewed as the "father of phenomenology", Husserl identified that the human experience could not be separated from the individual, and that the exact same external stimuli may elicit different experiences for different individuals (Dowling, 2007; Laverty, 2003). In an attempt to be as true as possible to the objectivity of quantitative science, Husserl proposed that the researcher shed their own prior knowledge of an event from the investigation

process. It was believed that by identifying, or bracketing, all prior knowledge, the perspective of the researcher could remain separate from the analysis of the experience of study participants. Husserl's approach is epistemological in nature as he viewed the described experience as the source of knowledge (Dowling, 2007). In transcendental phenomenology, the outcome of interview analysis leads to a description of the common universal essences of the phenomenon being examined, but does not allow for a deeper understanding of the phenomenon in the context of the environment within which it exists (Laverty, 2003).

Heidegger's Hermeneutic Phenomenology

Hermeneutic, or interpretive, phenomenology was proposed by Martin Heidegger, a student of Husserl (Dowling, 2007; Laverty, 2003). Heidegger sought to understand the meanings of human experience rather than a description of core concepts. Heidegger's rejected notions of bracketing because he believed that one is inseparable from the world of being, and that it is impossible to have interpretive research free from the influence of the researcher. In hermeneutic phenomenology, time and context shape a person's understanding of the phenomenon. The underlying goal of the hermeneutic approach is to extricate the true meaning and examine the human experience within the context in which it exists. This context may include such things as the role of the researchers, current or past relationships, the physical environment, past experiences, or past knowledge. It is believed that internal and external influences are part of the lived experience and affect how the individual perceives events, and cannot be excluded in analyzing the essences of the experience.

Heidegger believed that all of these influences affect the true underlying meaning

for the participant, and influence the researcher to interpret the findings within the setting

being examined (Laverty, 2003; van Manen, 2007). He suggested a hermeneutic circle

"relies on the circular movement from the whole to the parts, incorporating the contributions

of all deconstructing and then reconstructing, resulting in a shared understanding"

(McConnell-Henry, Chapman & Francis, 2009, p. 11). Using Heidegger's approach to

phenomenology, the researcher aims to gain an ontological perspective of the experience of

the participants, allowing them to gain an understanding of the true reality of the

phenomenon from the perspective of the participant.

van Manen's Approach to Hermeneutic Phenomenology

Max van Manen is a Canadian phenomenologist who developed a theory combining

the works of Husserl and Heidegger, to form what is referred to as a "phenomenology of

praxis", or the qualitative study of clinical practice (Thomé, Esbenson, Dykes & Hallberg,

2004; van Manen, 2007). van Manen believes that all descriptive phenomenology is truly

interpretive by nature, being influenced by the environment of the phenomenon at hand (van

Manen, 1990; van Manen, 2002). He proposed that the goal of phenomenology is to

examine the relations between "being" and the actions that result from "being" (van Manen,

2007). Under the assumption that healthcare professionals grasp and understand parts of the

world instinctively it is essential to examine and describe certain dimensions of practice in a

language which is reflective of this knowledge (van Manen, 2007).

Appropriateness of van Manen's method for this study. van Manen's approach

to phenomenology was an appropriate approach for this study for several reasons. Firstly,

the researcher had some prior knowledge of, and experience with, the phenomenon of

interest being examined, as she had previously worked in the care setting from which

participants in the study were recruited. Secondly, since neuroscience nurses' experiences

in caring for dying stroke patients has not been well investigated, further empirical

understanding was warranted. It is crucial to examine the unique experiences of the

individual nurses who are experiencing the same phenomenon in order to interpret their

experience in a meaningful way. Thirdly, van Manen's method has been widely used to

investigate a wide variety of health related topics, resulting in it being a validated

methodology for practice (Barreca & Wilkins, 2008; Blau, Bolus, Carolan, Kramer,

Mahoney, Jette & Beal, 2002; Shepherd & Woodgate, 2011; Wilkins & Woodgate, 2007).

Research Design

The aim of phenomenological research as described by van Manen is to translate the

lived experience into words and meanings to derive the true meaning of the experiences.

The methodology as described by van Manen (1990) was used to address the aims of this

study, and guide data collection and analysis procedures. The following are six activities

that comprise van Manen's methodology in an attempt to research the lived experience (van

Manen, 1990, pp 30-31):

1. "Turning to a phenomenon that seriously interests us and commits us to the
   world;

2. Investigating the experience as we live it rather than as we conceptualize it;

3. Reflecting on the essential themes that characterize the phenomenon;

4. Describing the phenomenon through the act of writing and rewriting;

5. Maintaining a strong and oriented pedagogical relation to the phenomenon;

6. Balancing the research context by considering the parts and the whole."

These steps were applied in this research study, with study development, data

analysis, data interpretation and discussion occurring collaboratively with the thesis advisor in order to ensure rigor of the process, as well as to ensure rigor of the study interpretation and presentation.

Sample and Setting

Sample. Purposive sampling, a type of convenience sampling, was used in this study. Purposive sampling seeks to include those individuals who have knowledge and experience relevant to the specific phenomenon of interest being studied (Streubert Speziale & Rinaldi Carpenter, 2007). Thus, the sample of interest for this study included neuroscience nurses who had experience caring for patients dying from stroke. Inclusion criteria for the sample consisted of: i) being a registered nurse or licensed practical nurse, who worked on the acute neurosciences unit at a tertiary, teaching hospital; ii) having had experience caring for patients who had suffered an acute CVA and were not expected to survive; iii) being able to read and speak English; iv) being willing to provide written informed consent; and v) being willing to participate in a face to face interview, and if desired, a follow-up focus group.

In order to add to the variability and richness of the data, efforts were also made to try and recruit both newly graduated and senior nurses, as well as male and female nurses. A total of nine nurses were recruited into the study. While the goal was to continue to recruit participants until the data were saturated, the researcher was unable to recruit any additional nurses. Efforts utilized to encourage further participation included: a) attending two additional staff meetings on the unit where potential participants were employed and; b) having a presence on the ward to informally remind nurses of the existence of the study and point out the poster on the unit. Despite these efforts, no additional nurses indicated interest

in taking part in the study. Recruitment procedures are described under the section in this chapter entitled, Data Collection Methods.

Setting. The sample was drawn from nurses working on a neuroscience unit in a tertiary hospital. It is a 32-bed unit with 24 semi-private acute beds, as well as an eight bed step-down unit for more critical patients. Nurses provide care to patients who have suffered acute neurological injury or present with symptoms and concerns related to any neurological disease. There is a combination of non-surgical and surgical patients, requiring close monitoring and post-operative care. This unit was defined as an acute care unit as the goals of care are that of recovery in the acute phases of an illness (Brennan & Daly, 2009).

From April 2004 to March 2009, the medical records department recorded a total of 1,896 persons being admitted to this tertiary hospital with the diagnosis of "subarachnoid hemorrhage" or "intracranial bleed/ hemorrhage". Although exact numbers were not recorded for the specific neuroscience unit itself, it is policy of the facility that those with neurological pathologies are admitted to the neurosciences unit when possible. Of this patient population, a total of forty-nine percent ($N = 943$) of these patients suffered a hemorrhagic CVA, and had an average age of 62 years. Of all of the CVA patients admitted to the facility, nineteen percent ($n = 366$) died prior to discharge or transfer from the facility. This indicates that 38.8% of patients admitted with an intracranial hemorrhage to this unit were provided with end-of-life care by acute neurosciences nurses.

Only curtains separate patients in the step-down unit, with the beds in a semi-circle around the room. This set-up is ideal for patient monitoring, but does not allow for any degree of privacy. While the rest of the patient rooms on the unit are semi-private, staff attempts to create a private room on the unit for patients whose deaths are anticipated.

When there is a shortage of beds on the unit, this is not always possible. The facility has extensive resources available to support the staff in providing psychosocial and spiritual care to the families of dying patients. These resources can be accessed directly by nursing, and include a palliative care clinical nurse specialist (CNS), a pastoral care department, an ethics committee, and a psychiatric nurse liaison. All forms of diagnostic imaging, including computed tomography (CT scan), magnetic resonance imaging (MRI scan), positron emission tomography (PET imaging) and angiography are available to support diagnosis. A blood lab and x-ray services are also available. Intensive care units are on site, with the possibility of urgent access to critical care staff for consultation on cases in which aggressive treatment is part of the goals of care. These services confirm that this site is well prepared to diagnose and manage patients who present with symptoms suspicious for an intracranial hemorrhage and the ethos of cure is well supported (Al-Shahi & Warlow, 2001; Edlow, 2005).

Data Collection Methods

Recruitment Procedures. Prior to the onset of data collection, institutional access to the tertiary hospital was secured and ethical approval from the Education Nursing Research Ethics Board (ENREB) at the University of Manitoba was obtained (see Appendix A). The researcher met with the Unit Manager of the neurosciences unit to obtain permission to proceed with the study, and to explain its purpose and the nature of staff involvement in it. Arrangements were then made to meet with nursing staff at unit staff meetings to explain the purpose of the study, answer any questions that they might have, and to invite nurses meeting the eligibility criteria to participate. An information poster describing the purpose of the study, the eligibility criteria, and the nature of participation in

the project was left on the unit (see Appendix B). The poster contained the researcher's

contact number, and nurses were able to call the researcher directly and confidentially if

they had questions about the study or if they wished to be part of the study.

In order to reach nurses working various shifts and increase sample recruitment, two

staff meetings were attended on the day shift, and two on the evening shift as part of the

original recruitment. Five nurses called the researcher after hearing of the study at one of

the staff meetings. All nurses expressing interest in taking part in the study were screened

to ensure that they met inclusion criteria. Four nurses had expressed a verbal interest in

taking part in the study in passing in the hallway and said that they would call the researcher

to schedule an interview, but did not initially call on their own following this interaction. In

response, one follow-up call was placed to each of the individuals by the researcher to

confirm nurses' continued interests in participation, and as appropriate, set up a meeting for

the interview. In response to these phone calls, all four nurses continued to be interested in

participating in the study and arrangements were made for an interview to be conducted.

Data Collection Approaches. Data collection was conducted using face-to face

interviews with the goal of being able to describe and interpret the meanings of the

experience of nurses providing palliative care to patients who are dying after having an

intracranial hemorrhage. Interviews were conducted to collect the initial data, as well as in

follow-up to validate the findings after the initial data analysis.

Individual face-to-face interviews. In interpretive phenomenology, the interview

process is the most common data collection method (Streubert Speziale & Rinaldi

Carpenter, 2007). After written informed consent was obtained from the individual

participant (see Appendix C), a combination of semi-structured and open-ended questions

were used in a face-to- face interview. The interview was conducted to elicit detailed

responses from the individual about the phenomenon of interest for the study (Streubert

Speziale & Rinaldi Carpenter, 2007; Walker, 2007). The questions chosen were based on

the overarching question developed for the study, and the literature review conducted at the

outset of the study (see Appendix E).

    The location of the interview was mutually agreed upon between the researcher and

participant, with all participants preferring to meet during their shift at the hospital. A

familiar setting is important to allow the individual to be relaxed and comfortable, so he/she

is more likely to share actual experiences in greater detail. If the participant is not

comfortable, or is feeling anxious, he/she may find it difficult to trust the researcher and

may not be as open with feelings or experiences (Streubert Speziale & Rinaldi Carpenter,

2007). All participants agreed to meet to be interviewed in a room in the hospital in which

they worked. The particular area was used for treatments two days a week, and was empty

on other days of the week. The area was private and free of interruptions. A sign was

placed on the door indicating that an interview was in process, and requesting persons not to

enter or disturb this process, and this was effective. A blind on the window was closed

during the interviews to protect the identity of the participants.

    Interview questions were elicited initially with a broad overarching question: "Can

you describe the experience of caring for a patient who is dying following an acute stroke?"

The interview schedule was modified as needed based on participants' responses and the

salient literature (see Appendix E for interview guide for individual nurses). Additional

questions were used to follow-up the initial question, with the intention of obtaining a

comprehensive understanding of the experience from the nurses' perspective. Interviews

lasted on average 40 minutes, and ranged from 20 to 65 minutes in length. All interviews

were audio taped and transcribed verbatim by the researcher. Owing to technical issues

with the audio-tape, however, it was not possible to transcribe the interview of participant

nine, as the audiotape recording was inaudible. Field notes were completed immediately

following the ninth interview, noting recalled phrases and notes about what the participant

had shared.

At the end of each interview, the researcher asked the participants if they had

anything more to share to ensure the interview was not ending prematurely. Upon

completion of the interview, the participants were thanked for their time and given a

hospital cafeteria gift card for $25 as a token of appreciation for the time spent participating

in the study. At the end of each interview, participants were also asked if they would be

willing to be contacted to participate in a focus group with other individuals who have been

interviewed for the study to discuss the themes emerging from the data. Telephone numbers

were collected from those nurses willing to be contacted.

Demographic form. Prior to the onset of the interview, demographic information

was collected from all participants in order to be able to describe the characteristics of the

sample (See Appendix G for demographic form). Included in this form were questions

about the participant's age, gender, years of experience in nursing, years of experience in

neuroscience nursing, education experience in palliative care, and highest level of nursing

education attained.

Field notes. The researcher made brief notes as each interview progressed, as well

as immediately following the interview. Field notes included important points stated by the

participant, as well as notes regarding participants' body language and possible

interpretations of statements made. These notes were effective in ensuring that the

researcher recalled the nonverbal details of interview and could incorporate them into

findings and discussion portions of the results in this study.

Follow-up interviews. Depending on the willingness of nurses who were

interviewed individually to participate, a focus group of all consenting participants was

planned wherein participants could hear about and discuss, the findings that emerged from

the analysis of individual interview data (n= 9). As phenomenology is designed to describe

the experience of the individual, it is argued in the literature that focus groups do not allow

the researcher to capture the true essence of the phenomenon. In evaluating this argument,

Bradbury-Jones, Samford and Irvine (2009) concluded that the focus group does not hinder

the underlying premises of qualitative research, as it still allows for individual expression of

the experience. By having participants discussing the experience of caring for patients

dying following a CVA, the role of the researcher may be less prominent, and the focus will

be discussion of the data that has been shared regarding nurses' experiences. Focus groups

allow nurses to share their experiences, and to possibly further recall specific events and

experiences of their individual practice. Discussing the concerns with colleagues who have

shared these experiences may also encourage a more open dialogue with the participants and

add to the richness of the data by stimulating memories and feelings that might not

otherwise be recalled (Bradbury-Jones et al., 2009; Kitzinger, 1995).

While the initial intent was to conduct a focus group to validate the interpretation of

the findings, there was insufficient interest from the initial group of nine participants to form

this group. Though six of nine participants expressed an interest in being contacted for the

focus group at the time of their individual interview, only two nurses committed to follow

up discussion of the study findings. In lieu of a focus group, it was decided that individual

validation interviews would be conducted.

After receiving approval for an amendment to the protocol from ENREB,

participants were contacted to arrange the interviews. The study findings, including the

overarching meaning and sub-themes, were compiled and emailed to the participants in

advance of the interview. This was done to allow the nurses some time to review the

findings, and allow them time to reflect on the findings in anticipation of their interview

(see Appendix F for follow-up interview guide). After obtaining consent for the follow-up

interviews (see Appendix D), a second individual interview occurred, using the semi-

structured questions indicated in the follow-up interview guide which had been devised for

the focus groups (see Appendix F). The goal was to confirm and/or clarify the preliminary

findings with participants.

One interview was conducted in an office on the research floor at the facility where

the participant was employed. The second interview was conducted in a spare office near

the unit as requested by the participant. Both interview areas were private and informed

consent was obtained prior to starting the interview process. Each follow-up interview

lasted 45 minutes, and was audiotaped and transcribed as was done with the initial

interviews. Both participants confirmed that the study findings they had reviewed

accurately represented the ethos of the unit and the experience of providing palliative care to

patients dying from a severe intracranial hemorrhage. The researcher then posed some

additional open-ended questions to invite participants to elaborate on some of the major

emergent themes. For example, one participant had stated in the initial interview that she

did not think it was ideal that the physician was called upon to speak with families who had

questions about the decisions surrounding the transition to palliative care. In the follow-up interview, it was asked what she perhaps saw as a more ideal approach in these circumstances.

Reflexive journal. Throughout the process of recruitment, data collection, data analysis and writing, a reflexive journal was kept. This journal contains a total of 34 pages of hand written notes and was helpful in allowing the researcher to be able to clearly recall details of the interviews and to acknowledge her personal biases. In hermeneutic phenomenology, the identification of the influence that the researcher has on the participants and the experience is part of the data analysis process. The journal was effective in helping to remind the researcher of her role in the study, and increased awareness of how the participants may be responding in the interviews, as well as how that response may have affected the findings. The most beneficial aspect of the journal was that it helped to remind the researcher that the participants may be feeling like they are being evaluated or judged in reference to their practice. The journal thus served as a continual reminder to the researcher to reassure the participants that the interview was not a test, and that their responses were not being judged as right or wrong. The participants were reassured that the purpose of the interview was to gain a better understanding of their experiences in providing care.

Data analysis

Data analysis occurred concurrently with data collection. After a naïve reading of the interview transcripts, thematic statements were isolated using van Manen's (1990) selective highlighting approach (Laverty, 2003; van Manen, 2007). This approach involves selecting and highlighting sentences that stand out as thematic of nurses' lived experiences. Textual data were reduced by asking, "What phrases seemed particularly essential about

nurses' experiences in caring for acute stroke patients requiring end-of-life care?" This analytic activity helped surface essential themes (i.e., the meanings unique to the nurses' experience and without which the experience would lose its fundamental meaning) that constituted nurses' experiences. Themes were then written and rewritten to develop the interpretation. A continued process back and forth from the parts of the text to the whole was conducted throughout the analysis process. The result was a description of the meaning that nurses' ascribe to their experience and the possible interpretation of that experience. The student's thesis advisor worked with her in a collaborative process during the analysis phase of the study. True to interpretive phenomenology, the beliefs and values of the researcher were acknowledged through reflective journaling prior to beginning the interviews, as well as throughout the data collection and data analysis process.

Methodological Rigor. In order for the results of any qualitative study to be trustworthy, researchers must ensure that rigor, as it understood from a qualitative research paradigm, is addressed. The criteria developed by Lincoln and Guba (1985) were used to help ensure the trustworthiness of this study. These criteria include: i) credibility; ii) dependability; iii) confirmability; iv) transferability; and v) authenticity (Lincoln & Guba, 1985; Polit & Beck, 2004). It should be noted that Lincoln and Guba's initial publication in 1985 included only the first four criteria. Authenticity was added in the 1990s in response to Lincoln and Guba's validation of their criteria (Polit & Beck, 2004).

Credibility. Credibility refers to the confidence of the truth being present and believable in the data itself, as well as the interpretation of the data presented (Lincoln & Guba, 1985; Polit & Beck, 2004). Credibility was achieved in this study through the verbatim transcription of the data, in combination with the use of reflective journaling. Both

of these actions helped to identify the experiences of the nurses and thoughts of the researcher, and assisted the researcher in ensuring that the reality of the phenomenon being presented was the reality of the participant, and not the researcher as a co-constructor of this reality (Lincoln & Guba, 1985). Further credibility was achieved by validating the interpretation of the data in follow-up interviews.

Dependability. Dependability is an essential component of credibility, and is demonstrated through the reliability of the data over time in similar conditions with similar participants (Lincoln & Guba, 1985; Polit & Beck, 2004). The criterion of dependability is met once credibility of the findings is determined (Streubert Speziale & Rinaldi Carpenter, 2007). In this study, dependability was achieved by validating the findings with participants.

Confirmability. Confirmability refers to objectivity and is concerned with representing the true findings of the participants without the biases, motives or perspectives of the researcher (Lincoln & Guba, 1985; Polit & Beck, 2004). It is thus essential that the researcher identify and document his/her predetermined knowledge, biases and assumptions in advance of starting the study as well as throughout the data collection process to ensure that he/she is truly reflecting the pure experience of the participant and not his/her own perceived thoughts. Prior to starting this study, the researcher did start a journal and document preconceived beliefs about the phenomenon being examined. Journaling was maintained throughout the study process to support the audit trail to further ensure rigor. By keeping notes and memos of the journaling and analysis processes, and maintaining the audiotapes of the interviews, anyone who wishes to review the analysis process will be able to see how the conclusions and significance of the results were derived (Streubert Speziale

& Rinaldi Carpenter, 2007).

   Transferability.   Transferability or fittingness refers to the degree to which the

findings of the study have meaning to others in similar settings (Lincoln & Guba, 1985).

This is significantly related to credibility and dependability. Transferability does not imply

that another researcher would be able to arrive at exactly the same findings if a similar study

were conducted at a different time and place. Rather it speaks to the notion that another

study would produce similar findings of commonly derived themes in other similar clinical

settings with similar participants. Transferability was attained by comparing the findings of

this study to other studies found in the literature. The preliminary findings of this study

were presented to neuroscience nurses at a national conference, and it was confirmed in

follow-up discussion that the findings resonated with these nurses within the context of their

practice and experience. This further contributes to validating the transferability of the

findings of this study.

   Authenticity.   Authenticity, the final criteria proposed by Guba and Lincoln (1989),

refers to the ability of the researcher to fairly and faithfully share the full range of the results

obtained, and to present them in such a manner that the reader is able to clearly see the true

essence of the phenomenon examined (Polit & Beck, 2004). This is more difficult to

measure as it depends on the response of the consumer of the research findings. For the

purpose of this study, the researcher did share the findings of the data analysis with two

individual participants who had been involved in the initial individual interviews. Verbal

feedback confirming the analysis contributes to ensuring the authenticity, and subsequently

the rigor, of this study.

   In addition to the criteria set by Lincoln and Guba, (1985) rigor was attained in this

study through triangulation of the data. Triangulation is the use of multiple sources (more than two sources) to confirm the trueness of data analysis and of the study results (Lincoln & Guba, 1985). Multiple data sources including notes from the interview process, transcripts from audiotaped interviews, as well as feedback and review by the thesis advisor and the participants themselves confirmed the accuracy of the data collection and data analysis (Streubert Speziale & Rinaldi Carpenter, 2007). Having a variety of data sources provides trustworthiness and authenticity, and ultimately validity of the project (Anderson & Spencer, 2002).

Ethical Issues Related to the Study

An ethically sound study that involves human participants addresses the ethical principles of autonomy, justice, non-maleficence, and beneficence (Streubert Speziale & Rinaldi Carpenter, 2007). The following sections, which were guided by the *Tri-Council Policy Statement* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010), describe the ethical issues that were considered in this study.

Ethical Review. Prior to initiating the study, approval was obtained from the Education Nursing Research Ethics Board (ENREB) at the University of Manitoba (see Appendix A). The ethics of the study was further guided by the Canadian Nurses Association Code of Ethics, which guides the practice of the researcher, who is a registered nurse (Canadian Nurses Association, 2008). In addition, the researcher was bound by provincial legislation referred to as the Personal Health Information Act (PHIA). A confidentiality pledge is signed by all healthcare employees, and is a legal agreement which indicates that healthcare providers cannot share identifiable personal information about

patients, families or co-workers with anyone other than the original source of the

information unless permission has been obtained to share said information (Manitoba

Health, 2011). To maintain confidentiality and anonymity prescribed by PHIA, as well as

well as to comply with regulations set by the ENREB, all data were kept in a secure locked

office during the duration of the study, and participants did not reveal identifiable details

about the patients discussed in their interviews. Once the study is complete, the data will be

stored for a period of 5 years, and then destroyed using the confidential waste system and

policies of the participating healthcare facility.

Autonomy. In nursing research, autonomy refers to respect for the individual

participating in the study, and is present when the individual is able to make an informed

and uncoerced decision regarding their participation in the study (Streubert Speziale &

Rinaldi Carpenter, 2007). Informed consent is present when the participant has full

understanding of what his/her level of participation entails and what will be done with the

information collected by the researcher, and is comfortable proceeding with participation

(Streubert Speziale & Rinaldi Carpenter, 2007). All participants in this study participated of

their own volition, and were informed about the degree of involvement in the study as part

of the consent process. Participants were informed that they had the right to withdraw from

the study at any time free of repercussions (Streubert Speziale & Rinaldi Carpenter, 2007;

Walker, 2007). No participants withdrew from the study.

At the end of the individual interview, participants were asked if they were

interested in being contacted to participate in a focus group to discuss the preliminary data

analysis. However, the researcher also stressed that they were in no way obligated to

participate further in the study. Although the researcher worked in the same department as

potential participants, there was no duality in the work/ researcher relationship as there was no direct professional relationship between the researcher and the participants. The participants were employed on the acute inpatient unit, while the researcher was employed in an outpatient unit. The researcher was not in a position of authority over the nurses on the neuroscience unit.

In an effort to further respect the preferences and autonomy of participants, interviews were arranged at a time a place which was convenient for the individual nurse. They were informed that the anticipated length of the interview was 60 to 90 minutes, so were prepared to spend this length of time in the interview if necessary, with this information also being noted in the consent. The researcher reviewed the consent form with all participants, secured their signature, and allotted time for questions prior to beginning the interview process. This discussion included the potential benefits, as well as potential risks, of participating in the study. Benefits included being part of a nursing research project that will contribute to building on the paucity of literature surrounding nurses' experiences of caring for patients who are dying following a stroke. Potential risks included the participants being emotionally overwhelmed, or distressed, by discussing their experiences in providing this care.

Non-maleficence. Non-maleficence in healthcare refers to the ethical and moral value of not causing harm to patients, or in this case to the participants of the study (Streubert Speziale & Rinaldi Carpenter, 2007). While it was anticipated that sharing their experiences of providing care to the dying might evoke uncomfortable feelings or memories, the intention was not to cause distress to participants, but rather to allow them the opportunity to share their experiences. Participants in both the individual preliminary and

follow-up interviews were made aware that the interview could be stopped at any point in time if it was becoming too difficult for them to proceed. In the event that a participant became unduly distressed, the researcher was prepared to connect the participant with the Employee Assistance Program if agreeable to the participant. This was not required for any of the participants.

Beneficence. Beneficence refers to the use of actions that have the intention of promoting the wellbeing of others. Beneficence was achieved in this study by protecting the privacy and confidentiality of the participants. Privacy is protected by ensuring that the identification of the participant cannot be discerned by non-research personnel (Streubert Speziale & Rinaldi Carpenter, 2007; Walker, 2007). Confidentiality ensures that only authorized individuals have access to restricted information (Streubert Speziale & Rinaldi Carpenter, 2007; Walker, 2007). All study participants were assigned a unique code number known only to the researcher. The list of participants' names and their corresponding code number was kept in a locked drawer, separate from signed consents. All data collection forms, field notes and audiotapes were identifiable only by the assigned study number.

Summary

This chapter presented information regarding: i) the design used to conduct the study; ii) the study setting and sample; iii) recruitment approaches; iv) data collection methods; and v) data analysis procedures. Steps taken by the researcher to ensure the rigor of the project were described. Ethical considerations taken by the researcher in conducting the study were explained. The next chapter will present the findings of the study.

Chapter 4: Findings

The essence of nurses' experiences in caring for patients who had sustained acute intracranial hemorrhages and were not expected to survive is the focus of this chapter. The major themes and sub-themes related to the essence are presented and illustrated by data exemplars drawn from the interview data. A description of the demographic characteristics of study participants is also provided.

Demographic Characteristics of the Sample

Nine nurses participated in this study. The demographic characteristics of the sample are summarized in Table 1. The ages of the participants were collected using age range groupings. Participants were found in all age categories, from the lowest range of 20 to 29 years of age to 50 to 59 years of age. Their years of experience in nursing ranged from five to thirty-six years (average 13.7 years), and their years of experience in neuroscience nursing ranged from two to thirty-five years (average 12 years). Six of the participants were female and three were male. In regards to educational preparation, two participants were licensed practical nurses, four held registered nurse diplomas, one held a post- diploma baccalaureate nursing degree, and two held baccalaureate degrees in nursing. One of the nine participants held certification in neuroscience nursing from the Canadian Nurses Association (CNA). Five participants had received palliative care theory in their basic nursing training, but only one of the five had been exposed to the care of palliative patients in a clinical rotation as part of that training.

The Essence of Nurses' Experiences

'Striving and struggling' emerged as the essence of what it is like to care for patients who were dying after having experienced an acute intracranial hemorrhage. While

neuroscience nurses strove to provide optimal palliative care to these patients, they also frequently struggled in their attempts to do so. The word "strive" is a Middle-English term from the 13th century meaning "to devote serious energy or effort", or "to struggle in opposition" (Merriam-Webster Dictionary, 2011). Upon reviewing the experiences shared by the participants, it was evident that they did strive to provide the best possible care to hemorrhagic stroke patients and their families. In the course of putting forth this serious effort, however, nurses indicated that they sometimes also struggled to be able to provide palliative care. Interestingly, the term "struggle" is also a 13th century word which means " to contend with an adversary or opposing force" or "to contend resolutely with a task" (Merriam-Webster, 2011). Thus, striving indicates an effort to improve or optimize a situation, while struggling infers that despite the effort being put forth an individual is not able to meet his or her goals. Nurses in this study strove to provide ideal palliative care, but also encountered struggles in their efforts to do so.

Three themes which exemplified and supported the overall essence of "striving and struggling" were identified in this study. These themes included: i) providing physical care, ii) providing psychosocial care, and iii) providing culturally-sensitive care. The inherent striving and struggling that occurred within each of these themes will be presented with supporting data exemplars. Factors evident in the data influencing nurses' experiences of striving and struggling will also be described.

Providing Physical Care

Striving to provide physical care: "They need to be comfortable". Within each of the interviews, participants were able to clearly articulate the physical care needs of patients who were dying after experiencing an intracranial hemorrhage. Nurses in this study

described the ways in which they strove to provide physical care that afforded dying

patients some level of comfort. For some participants, essential aspects of such care

involved attending to hygienic needs, and regular turning and repositioning of the patient.

This type of physical care was highly valued by nurses in this study and was the type of care

they themselves would want to receive were they in the patient's position. One participant

stated:

> "For me… my definition… is that person as comfortable as I would like to
>
> be? So I am feeling fresh and clean; I am pain-free. I have a clean mouth; I
>
> have clean sheets." (04)

Physical care was also seen as being an intervention that families would appreciate

for their loved ones. Such care was perceived as a visible indicator by participants that the

nurses had given sufficient attention to the patient versus abandoning the individual. This

nurse shared her thoughts:

> "What's important is, you know, we need to make sure this person is
>
> comfortable... and that the family feels that they are still being cared for.
>
> They are not just being left to die, you know… There's nothing nicer than for
>
> a patient's family to come in and they're clean, and their hair's been washed
>
> and they're shaved. You know what… the bottom line is it looks like the
>
> patient's been cared for. All those things." (02)

Another nurse echoed similar sentiments:

> "I would hate to think that somebody dies on (this unit), and didn't think they
>
> got the best care. But truly, that's what I want them to feel. That their loved one
>
> got the care they needed. And that they feel that they were cared for, you know,

when they died." (02)

 Nurses participating in follow-up interviews reiterated the importance of ensuring that patients were physically comfortable, and that no signs of physical symptom distress were evident. Nurses in this study equated the absence of physical symptom distress with a comfortable death. This nurse noted:

> "It would be one where if I were to look at the patient, I don't see the patient grimacing. There doesn't seem to be any, um, overt signs of discomfort, be it tachypnea, audible respiratory crackles, grimacing... if I were to do a pulse, they wouldn't be tachycardic. Any of those sort of things." (11)

 Three participants, each of whom had worked on the unit for more than five years, felt that they needed to take a leadership role in ensuring that dying patients were physically comfortable. They recognized that because some of their more junior colleagues might be uncomfortable in providing palliative care, interventions aimed at ensuring patient comfort might not get implemented. This participant perceived that some of his co-workers were not always comfortable in caring for dying patients, and felt a sense of responsibility to ensure the proper care was provided for the sake of the patient and their family:

> "I think in my position even if I feel that it is uncomfortable, I have to show my co-workers that I am comfortable whether I am or not. Being one of the charge people on the floor… I have to be the one who takes charge and does it." (01)

 Follow-up interviews corroborated that nurses saw themselves as taking a lead role in ensuring that patients were comfortable at the end-of-life. In particular, nurses indicated that they would not delegate such care solely to healthcare aides, who typically provided the majority of physical care to patients. In the same way that they assumed more

junior nurses were often not comfortable in providing palliative care, participants believed

that healthcare aides may be uncomfortable as well. This belief resulted in senior nurses

perceiving that they needed to be more involved in the direct physical care of palliative

patients not only for the patient's benefit, but for the staff as well. Perceptions documented

by the researcher in her field notes that further support these conclusions include entries

about nurses valuing spending as much time as possible with palliative patients, and

identifying that the provision of hygiene care was an opportunity to accomplish this goal.

The tone which nurses used in discussing comfort care was confident and warm-hearted.

Healthcare aides were responsible for the hygiene care needs of the majority of patients on

the acute neurosciences unit, but in caring for palliative patients, nurses believed that it was

essential that they themselves take a lead in the patients' physical care. In their follow-up

interview, this participant explained:

> "It's (division of labor) supposed to be 50-50, but I would say it's primarily,
> probably healthcare aides. But in the palliative patient I believe that it would
> be, um, nursing would take more of a focal position in that. Like I think the
> unit assistants tend to do the patients that are still, um… not that these
> (palliative patients) aren't active. They'd (non-palliative patients) be active
> treatment, where this would be active care. So they, they tend to be doing
> active treatment ones, where nursing would be more the primary drivers in
> getting healthcare aides to help them WITH a turn, rather than the healthcare
> aide going in and saying "oh, we need to turn this patient", it would be the
> nurse that would go in and say "we need to go turn the patient in room 19" or
> whatever." (11)

Managing physical symptoms through medication administration. Nurses shared

that physical symptom management, which is typically achieved through the administration

of medications, was a priority in the nursing care plan to ensure that patients were as

comfortable as possible. Specific symptoms that nurses identified as being prevalent among

hemorrhagic stroke patients included pain, dyspnea, and gurgling respirations. The

management of pain, through the regular administration of sufficient amounts of medication

with the specific intention to prevent suffering, is illustrated in the following exemplars:

> "We are giving medication regularly... that's another part of the process. Giving lots
>
>   of pain control so they are not suffering..." (07)

> "We make sure that they're comfortable. Like giving them morphine, like, you
>
>   know, so that they're comfortable." (08)

Nurses identified that while the needs of acute care patients needed to be met,

symptom management of palliative patients was also a very important nursing intervention.

The task of administering medications in order to manage symptoms did not take excessive

amounts of time to complete, and thus was readily accommodated within the nurse's busy

patient assignment. When explaining the minimal time impact that medication

administration can have on their daily workload, this nurse explained:

> "Medication- wise, that's something that personally I'd be looking at… the comfort
>
>   aspect. If I knew that that patient was uncomfortable, I would make sure that that
>
>   medication had been given prior to doing (other interventions) because this takes
>
>   three minutes to do. Maybe five (minutes) to draw up and give." (10)

In addition to managing pain, nurses spoke of administering medication to manage

upper airway secretions that patients were not able to clear:

"We can maybe give them medications to lessen those secretions. Like

scopolamine. Like if they're moaning in pain, or grimacing, or clenching and we

can give them the medication we need to treat that stuff." (05)

Participants talked about the importance of managing dyspnea, both to ensure the

patient's comfort, but to also allay the distress of family and nursing staff that bears witness

to labored breathing. This nurse explained:

"He was really having a difficult time breathing, and if he had just been lying there

then I would have been okay with it. It's just that I could not see him struggling,

and you know what… families and nursing staff… we react to that." (02)

This participant continued to share a specific instance in which she identified that

she needed to encourage a colleague to use adequate amounts of opioids to treat dyspnea

and make the patient more comfortable. The importance of managing this symptom as

regards its effect on the family is again mentioned in this exemplar:

"I say to her… "Give him more fentanyl, give him more fentanyl". And she says,

"I just gave it to him". (I say) He's having trouble. You have to give him more

fentanyl. You know, because the family really struggles with it…" (02)

Misguided striving in symptom management. In an interview with one of the study

participants, it was apparent that some of her striving as regards the use of medications to

manage physical symptoms was not well informed. One facet of this misguided striving

concerned the intent or purpose of administering opioids to dyspneic patients. This

participant did acknowledge that the objective of administering morphine was to minimize

pain and dyspnea symptoms, which would be an appropriate end-of-life care intervention.

She shared:

"You know, they are just gasping air, and you think they need a bit of support. And

the morphine isn't really helping, even though they are giving them massive doses

to depress respirations. Then giving a bit (oxygen)… 2 litres isn't going to hurt."

(06)

Misguided striving was evident, however, at the point at which the same nurse spoke

about continuing to administer opioid analgesics even when patients experienced related

side effects. Though the nurse did mention that the administration of morphine was known

to cause respiratory depression and hallucinations, she nonetheless persisted in the

administration of the medication as an automatic part of the care plan, even when these side

effects were assessed to be present. However, rather than being identified as adverse side

effects of opioid administration that required a re-evaluation of the medication that patients

were receiving, respiratory depression and hallucinations were seen as acceptable side

effects of opioid medications by this particular study participant. Interestingly, this nurse

opted to discuss changes in morphine dosages with the patient's husband as opposed to the

physician or other members of the health care team, and cast the patient's family in the role

of the ultimate decision maker regarding medication administration:

"I asked the husband actually if he wanted me to continue giving the 10 mg of

morphine every hour and he said, "What do you think?" And I said, would you like

to talk to her more often? Would you like to spend more time with her now? And

it's your decision… it's not me who's making the decision. It's you and your wife

and what's best for her." (06)

The following exemplar further demonstrated misguided striving as the nurse relied

on the families' wishes in providing physical care without consideration of empirical data in

the management of physical palliative care. Misguided striving was evident as the nurse's comments indicated that she believed that if she held the morphine dose to allow the patient to be more awake, she would also be able to control when the patient would die. It is conversely inferred that if the medication was given, that there would be a greater chance of the patient dying on that day. This participant explained:

> "And just last night they were praying that she would go because today was her daughter's birthday. So they don't want her to go today. They asked... I asked the husband actually if he wanted me to continue giving the 10 mg of morphine every hour, and he said, "what do you think?" And I said, would you like to talk to her more often? Would you like to spend more time with her now? And it's your decision... it's not me who's making the decision. It's you and your wife and what's best for her. You know, and I said, "you know we're looking after her, but we need to look after you too" Sort of like supportive care for both. So I said, "If you want me to, I will give it." So he said "Whatever you think is best" So I... I think... now that she's more perky, she's talking, she's hanging things (motions in air)... not really talking, but she mumbles words. But she doesn't understand, but it makes him so happy to see her moving her eyes, and opening her mouth and mumbling words. And so I tell the family I'll cut the doses until... you know... and the families get there. They don't want to see their Mom go away today. " (06)

In a follow-up interview, this participant confirmed that there was a belief amongst nurses that it was most appropriate to administer medication consistent with family member wishes, rather than basing her assessment on the clinical needs and goals of care of the patient:

"I think it would have to be with the peer involvement, family involvement... you

know what you're told. The family says that they want it every hour, well then I

believe you should give it every hour, 'cause that's their wishes." (10)

Some participants felt that regular use of opioids for symptom management was a

routine part of end-of-life care to prevent and manage pain and dyspnea. Nurses also

believed that doing so could potentially have the consequence of hastening death, but

persevered as their primary intent was that of ensuring comfort. One participant found that

the perception that opioids might hasten death impacted her approach to patient care,

causing her to pause and consider the needs and perspectives of the family before

administering the medications to ensure that families were not distressed and that the patient

was not experiencing discomfort. This participant also saw that families desired regular

opioid administration to prevent the patient from suffering, and considered this in her

decision-making process. As noted earlier, this same participant withheld opioids at one

point, believing that she would be able to delay the timing of the patient`s death. Although

her primary intention was that of promoting comfort, this particular participant

demonstrated a knowledge deficit in the use of opioids at the end of life.

When asked about common practices and assessments on the unit when

administering opioids for symptom control, participants in the follow-up interviews

indicated that though not held by them personally, it was the belief of some nurses on the

unit that continued morphine administration helped to ease the transition to death. This

participant remarked:

"And again, you'll get the... you'll get people saying well, why aren't you giving

morphine every hour? It will help through the process."(10)

Conversely, in follow-up interviews, a different participant stressed the importance of the nurse making decisions about medication administration based on ongoing assessment data:

> "You know you've been taught as a nurse to give medication as needed and if you don't feel the patient is in pain, or is showing signs of pain, should you be giving them morphine every hour just 'cause it says it? I don't think so." (10)

This statement confirms that there is a variation in understanding regarding the use of opioids in end-of-life care. It is also noteworthy that it was more experienced nurses who participated in follow-up interviews and clarified that assessment for non-verbal signs of pain or dyspnea was essential prior to administering opioids to manage symptoms at the end-of-life.

Struggling to provide physical care: "Your priority would be the person needing more than comfort care". A major struggle described by participants in this study concerned finding time during their shift to provide care for dying stroke patients. Nurses explained that prioritization of care was affected by the acuity of other patients, the curative focus of the unit, and the dominance of the medical model on the ward. Nurses identified that they struggled with the acuity and busyness of the unit in trying to attend to the needs of the palliative care patients, in large part due to the fact that acute care patients were given priority when nurses organized and structured their work assignments. Moral beliefs about the potential role in hastening death that removal of an endotracheal (ET) tube in dying stroke patients might cause, as well as the emotions experienced when caring for dying patients, were factors that emerged in the data that at times, limited the abilities of nurses to fully participate in the provision of comfort care at the end of life. Each of these

factors will now be described in detail, supported with data exemplars.

    Patient acuity and workload challenges. Nurses in this study reported that, at times, they struggled to provide optimal physical care to dying stroke patients. A consistent point of tension for these nurses was meeting the physical care needs of dying patients, while also attending to the needs of acute neuroscience patients on the unit. The acuity of acute care patients was identified by participants as being a significant barrier to being able to spend adequate time caring for palliative patients and their families. This nurse explained:

> "But, uh, it's difficult because here they are in an acute setting and you don't, uh, have the time to spend with the family and with the patient that you would hope to have in a quieter setting." (01)

This particular participant talked about the way in which the acuity and busyness of the unit impacted the provision of what she described as 'compassionate caring' and shaped the inability of the nurse to provide aspects of care that were beyond the basics:

> "I think, um, how busy our unit is, is a huge barrier because you want to go in and spend time with these people... like in their last days. You want to provide that respect and that dignity... compassionate caring... and you don't always have the time to because we are a busy surgical unit. You know you have 5 patients on a day shift, you're going in there and you're doing your basic care needs to be done and making sure they're turned and all that stuff. You don't get to sit and talk and do all those little things that maybe you'd want to do on a day shift, you know. The man gets a shave, and you know, do those things that are nice." (05)

As a result of the acuity of the care setting, this participant found that it was

necessary to organize the care of all of the patients in his assignment, and determined that

the priority of care was directed towards the patients who were not palliative. He explained:

> "Well I would say that the workload is the reason you don't have that time. You
>
> know you have 3, or 4, or 6 other patients, that you just don't have time to be with
>
> them as well, so you look at it as far as prioritizing; your priority would be to the
>
> person who is needing more than comfort care." (01)

While time constraints were seen to be due to the acuity of the unit, nurses were not

specific as to what they might do differently if they were allowed more time to provide

palliative care. In follow-up interviews wherein this issue was more fully probed, nurses

identified that their approach to care would be based on the needs of the family, rather than

specific tasks or interventions that might optimize patient care. One participant said:

> "It's very dependent on the family. I would never say I would do more mouth care.
>
> I would never say those sorts of things, because I don't know. Some families, I
>
> would spend less time in the room. Because they really don't want me there. Other
>
> families I would make tea for. Other families I would do more mouth care. Like
>
> whatever that family felt was... important so you and how do you determine that?
>
> You ask. "You know, this is what my plans are for the day… is there anything else
>
> you'd like me to be doing? This is my only patient today. I'm here for you. What
>
> would you like me to give to you?" They might say nothing. Well ok, nothing.
>
> Others will say, can you get me a TV? Ok I'll see what I can do about that. Like
>
> it's very individual..." (11)

In organizing their time caring for dying stroke patients, nurses also tried to focus on

the patient's family. Nurses reported that they struggled to have enough time to provide

comfort care, and recognized that these time constraints had an impact on the experiences of

the families in the final days of the patients' lives. This participant explained how having

limited time to spend with the patient might be misconstrued by family members:

> "Um, well first and foremost, it's really sad to say, but of course you have to take to
>
> consideration like the more acute patients first. And then sometimes the family
>
> would be distressed... they think that you've forgotten about them. Which is not the
>
> case. Which is never the case." (03)

The potential for survival. In addition to patient acuity and workload challenges, it

was evident in the data that the potential for patient survival influenced which patients

received priority when nurses were providing care. Nurses felt that they needed to focus

their attention on the patient whom they could potentially help to survive and recover with

their care. Thus, the care needs of hemorrhagic stroke patients who were not expected to

survive could wait if necessary, as nurses believed that interventions were not going to

change the fact that the patient was going to die. This participant's comment about

palliative care patients captures the hierarchy by which patients are viewed by some health

care professionals on the unit:

> "Because they are low man on the totem pole… they truly are… It's not that the
>
> staff don't want to give the care, but you've got a fresh post-op coming, or a brand
>
> new admission coming, or you know, you've got 4 other patients that, or 3 other
>
> patients that are sick... you know... they're pretty stable (palliative patients)." (02)

When discussing the issue of patient priority in follow-up interviews, nurses

reinforced that the decision to prioritize the care of acute patients over palliative care

patients was motivated by the fact that acute care patients had the potential to survive:

"I wouldn't say that it's higher need. I think you know that I think the nurses would

be focused more on somebody that they can assist saving." (10)

While acknowledging the lower priority of interventions when providing palliative

care on the acute neurosciences unit, nurses were focused on the time that the tasks might

take away from their other obligations, rather than the potential to improve the quality of

palliative care for these patients with their actions.

The curative focus of the unit. In addition to patient acuity, and the potential for

survival, the curative focus of the unit was also a factor that caused nurses to struggle when

caring for dying stroke patients. This nurse explained:

"I think it's the prime... the... the philosophical foundation of the unit is one of

treatment and not saying that a palliative patient is not to receive treatment, because

those care things are treatment for them... we come from a very curative... so that

active treatment is trying to cure that person. The palliative patient, we're not going

to cure, so hence, I'm not curing you, I'm not fixing you... you're a lesser of a

priority. Which is fundamentally wrong... in my opinion." (11)

Dominance of the medical model in influencing care. Nurses believed that the

focus on who could and could not be cured emanated from the medical model of care which

dominated the care culture on the unit on which they worked. Moreover, as expressed by

this participant, the medical model influenced the way in which nurses cared for patients:

"That's the priority... the physician tells me I need to cure this one. The nurse

thinks that they must follow suit. And if you go against the stream of "oh, you

know what, the palliative care patient needs my care because... they can have

their... I don't know... antibiotic in half an hour. Where in this person (the palliative

patient), I will do the mouth care first. That would just... it's one curative, and two

the nurse thinking that medicine always trumps some sort of nursing care we were

are to do. It's nursing always thinking that medicine is more important than nursing

and it's not necessarily... in my belief system, that's not true." (11)

The acuity of the unit, focus on cure, and the dominance of the medical model of

care were factors that led nurses to believe that a different care environment may be more

suitable for patients who are dying of an intracranial hemorrhage. In this exemplar, the

participant portrays the palliative care unit as a better environment for patients:

"Maybe they'll get them a bed on a palliative care unit. And that's a nicer way to

go, rather than going on (the neurosurgery unit)… that's a bit more hectic. A little

more fast paced. It's noisy. It's not always the most ideal place for clients to pass."

(07)

Identifying physical environment constraints. Nurses identified the physical

environment of the hospital unit as a factor that caused them to struggle in caring for dying

stroke patients. The location of the rooms, the lack of privacy, and the mixing of palliative

and non-palliative patients in double occupancy rooms were all seen to negatively influence

patient care. The impact of the acute care environment was articulated by this participant:

"The ward itself is probably the only barrier I think, just because the ward isn't

designed for the relaxed, calming atmosphere that you want families and patients to

have. You don't have a view; you don't have that hotel-ish calm which you'd like

to have. You know, you may have a patient next door who is post-head injury, is

aggressive and confused and banging their table. It's those kinds of things that are

the biggest downfall." (07)

Nurses identified that the best way to improve the negative impact of the physical environment and busyness of unit was to attempt to place the dying patient in a private room. In addition to providing a quieter and calmer environment, a private room was thought to allow the patient and their family the opportunity to have a degree of privacy. Nurses valued their ability to provide families time alone with their loved in the last hours to days of the patient's life, as they recognized that it was a difficult time for all involved. Unfortunately, a private room was not always available. Nurses expressed their frustration regarding the lack of available privacy:

> "..sometimes we can't even give them a private room because we have semi-private
> rooms and we're just so full all the time that often they have to share a room with
> someone else. Like, we try to accommodate. Like if we think they are getting close
> to the end, we will try and give them a room to themselves, but we can't always... I
> think that impacts the family more than it really impacts our care." (05)

This participant related the lack of availability of a private room to general health care system and bed utilization constraints. She acknowledged:

> "We would like to have a single room for the patient. But you know what, because
> we only have 28 beds on this unit, and it's the only neurosurgical unit in the
> province, um, rarely do we have empty beds, so um, palliating someone in a private
> area here is basically unheard of…" (02)

Creating privacy was a further challenge for nurses as the unit had only double-occupancy rooms. In light of the value placed on having privacy by participants, nurses attempted to be as creative as possible to facilitate a private space for the patient and family whenever possible. This nurse confirmed:

"We do not have a private room. What we will try to do if we know someone is

dying, or if someone is close, we will try as hard as we can to keep that bed beside

them empty. Or put them in a corner of step-down, but the families don't get a lot

of privacy depending on the bed situation... It's sad that we can't provide that."

(01)

The lack of privacy was seen as having an impact, not only on the dying patient and

their family, but also on the other patient in a double-occupancy room. Nurses thought that

the non-palliative patient in the room would be very aware of the fact that their roommate

was dying, and that this realization could be distressing to the non-palliative patient:

"We have double rooms... that's disgusting... We try very hard to put patients who

are comfort care in a private room and block the other bed. For quietness, for

dignity, and all those sorts of things. As well as for the psychological distress of the

roommate. Like it's not nice when the person next to you is dying... it's not nice."

(04)

This participant shared a specific incident in which a double room would have been

very uncomfortable for the non-palliative patient:

"I walked on and it sounded like a jamboree coming out of bed nine. They were

playing their guitars, they were singing… and loud! All the way down the hallway

you could hear it. If the person in the next bed… Yes, it was a real celebration, and

that's great. But thankfully we could block the next bed. You know, there were like

50 people in the room… like it was a full room… it's not comfortable for the

person in the next bed."(04)

As evidenced by this exemplar, nurses participating in follow-up interviews

confirmed the importance of trying to secure a private room for the emotional benefits it

afforded palliative patients and families, and non-palliative patients and their families:

> "The space, ultimately. Uh, the closed door to allow people to weep without feeling
>
> that they have to do it quietly. Like if you want to wail, you can close the door and
>
> you can wail. It's not only for the privacy of the patients. I do believe, and I know
>
> that I've heard "he died last night" when in the semi-private room... the two
>
> patients are lying there. It's distressing to them. It's very distressing to the other
>
> patient that's in the room when the other person dies. "(11)

Privacy was seen as a luxury which was valued by patients, families and staff alike.

Participants struggled to ensure that areas of privacy were created as the physical

environment and hospital system permitted.

Perceiving a lack of nursing expertise in palliative care. While confident in their

abilities as neuroscience nurses, overall, participants felt that they lacked adequate palliative

care expertise to provide optimal palliative care to dying stroke patients. Rather, they

believed that trained hospice and palliative care health care professionals were better able to

provide such care. This nurse reflected:

> "I think that it could be done better in palliative hospice... those professionals...
>
> those nurses, those doctors, those aides even. That's what they deal with everyday
>
> and that's their job." (05)

Unsurprisingly, the participants' ideal solution was to transfer patients to a

specialized palliative care unit. For those stroke patients who survived more than a few

days, the participants endorsed that a palliative care unit may be more appropriate care

environment. Nurses did recognize that if the patient's condition was more unstable, that

perhaps a transfer was not always reasonable. This nurse explained:

> "Sometimes they have that window of opportunity. That window is very small on
>
> some. Others, it can be a bit longer so they have time. Maybe they'll get a bed on a
>
> palliative care unit. And that's a nicer way to go." (07)

The participants' perceived lack of unit expertise significantly impacted their experiences and perceptions in providing care in that they did not possess complete confidence that comprehensive palliative care could be provided in the acute neurosurgical care setting.

Recognizing the impact of moral values and beliefs on the ability to provide palliative care. While striving to provide physical care to palliative stroke patients, nurses identified that they sometimes experienced situations which they found emotionally distressing. When participating in the provision of palliative care, nurses were at times, asked to perform interventions which they found to be in conflict with their moral values and ethical principles. This nurse was unable to personally remove an endotracheal tube (ET) from a patient, despite the fact that this task had been discussed and written as a physician's order. This participant indicated that if she participated in removing the ET tube, she would feel personally responsible for the death of the patient, rather than the patient dying because of the stroke. She described her feelings this way:

> " ... When they do palliative, and they say, "OK, take out the ET tube", I can't do
>
> it… I guess more of my belief. For me, it's then me that takes away somebody
>
> else's life so I can't do it. I let somebody… whoever. So if it's comfort care and
>
> they take out everything. I would remove the IVs and whatever other tubing, but
>
> not the (motions to her mouth). And that's my belief. Well, I will tell them. I can't

do it. They can't force me right?" (08)

Although this nurse reported that she did not find other aspects of providing palliative care ethically problematic, removal of an ET tube evoked significant distress for her. However, this participant indicated that in order to deal with this situation, she simply refused to perform the task, relying on her nurse colleagues or the physicians to carry out the removal of the ET tube instead.

Neuroscience nurses faced challenges in providing physical care to dying stroke patients. The acute care environment, physical environment constraints, a perceived lack of palliative care expertise and conflicting personal moral values were identified as factors influencing their experiences in caring for patients who were dying as the result of an ICH.

Providing Psychosocial Care

Nurses in this study identified that an important part of their work involved providing psychosocial care to the families of dying stroke patients. As patients who presented with an intracranial hemorrhage often had a sudden decreased level of consciousness, and/or were unresponsive, nurses indicated that they directed a considerable amount of care towards the patient's family and significant others. The striving and struggling experienced by nurses in providing psychosocial care are described in the following section.

Striving to Meet Families' Support and Information Needs: "It's going to happen… there's nothing you can do, so let's make it an easy time." The sudden onset of the patient's illness and the experience of being in an acute health care setting resulted in families needing psychosocial support and information. In the context of striving to provide psychosocial care and information to families, the following sub-themes emerged: i)

developing relationships with families; ii) trying to soften the blow for families; iii)

acknowledging personal experiences; and iv) engaging multidisciplinary resources.

Study participants viewed psychosocial support as an essential component of care

that focused on emotional needs of the family. This nurse explained:

> "Psychosocial care is caring for more than the person… than the physical needs of
>
> the person. It's caring for also the mind. Now, the person with the blunted GCS,
>
> you can't determine what they themselves ... on a psychological level might need,
>
> but you can determine it from their family members. So if the wife is overtly
>
> distressed beside the bed, "Is there something I could get for you? Is there someone
>
> I could call for you?" You might just sit and let the wife speak to you about
>
> whatever it might be… that this is his birthday today, or it's our anniversary, or
>
> whatever it is. Its addressing more than the mouth care, the dry… it's addressing
>
> feelings and emotions." (11)

Nurses also viewed providing psychosocial support to the family members of

palliative patients as being the most significant, albeit time consuming aspect of care:

> "It's actually, in my mind, one of your heaviest patients because you're to be in
>
> there a lot. A lot… providing that support to the family member."(04)

Developing relationships with families. In their efforts to address family members'

information and support needs, nurses believed it was necessary to build relationships and

develop rapport with families, and that this in turn, created a more comfortable space and

experience for families. Acknowledging that families were in a stressful and likely

unfamiliar situation, participants identified that it was crucial for them to simply be quietly

present for families, to recognize and respect the unique needs and perspectives of families,

and to be available to speak with families when questions or psychosocial concerns arose.

Participants recognized that each family situation was unique, and that each family had

different needs and expectations of the nursing staff. While some families preferred to

spend more time alone with the patient, others sought out the nursing staff to talk and share

memories about the patient's life. One nurse reflected that the sharing of these memories

contributed to relationship development between the families and nurses, and supported the

ability of nurses to continue to provide psychosocial support:

> "But I think that to speak to families about these types of things, where you can
>
> bring up some of those good things (memories), or funny things that these people
>
> have done, that you know are very precious to the family. You have to have some
>
> kind of relationship." (02)

Being present, in and of itself, was thought to be an effective way to provide support

to family members and develop relationships with them. When asked about the role of

nurses in supporting family members when it was clear that patients were transitioning from

curative to palliative care, this participant reflected:

> "Well, first and foremost, it's actually to, uh, of course, be a shoulder to cry on at
>
> times. And an ear that listens to the patients… uh patients' families. Grief, sorrow,
>
> and just to comfort them." (03)

The simple gesture of "being present" was seen as being a significant intervention

nurses used to support families. This participant spoke of the underlying purpose for

providing psychosocial support to families:

> "It's like going to a funeral. You know what… you're not going for the person,
>
> because you know that person's dead. You know, you're going for the people that

are standing, you know. Um, and so that you know what… you provide the care the

best you can for the people that are the… the family, you know." (02)

Providing psychosocial support to the families was seen as a vital component of

palliative care, with nurses recognizing that the time at end of life was special and

meaningful for patients and families. Study participants acknowledged that this time may

be the last moments or days that patients and families had to spend together. This nurse

shared:

> "You know what… you need to do for the families because this is the last thing
>
> they can do for their loved one (be present). You know, I think sometimes, we
>
> forget about that. That these individuals… this is the last time… even though the
>
> patient is unresponsive… where she's alive (softer voice). And you know what,
>
> that means so much to family. And so, you know, we need to really need to bend
>
> over backwards in order to try to make it as good a situation as we can." (02)

Nurses spoke about the importance that physical space played in helping them to

develop their relationships with families. Participants stressed both the importance of a

space on the in-patient unit that afforded privacy, as well as an area of comfort in which

families felt safe and welcome. This space was seen as one in which families could

physically be with the patient, and have conversations that were important at the end of life.

As one participant noted:

> "When we can have a private room, I like the room to be set up for the patient's
>
> family. That there's water and juice and have and things that are comfortable in the
>
> room so that the family can speak and have some discussion amongst themselves."
>
> (02)

In follow-up interviews nurses provided more specific information about how they went

about trying to create a comfortable space for families:

    "I usually bring water and Kleenex… whatever they need… and try to, you know,

    create a relaxing environment for them as much as much as we can in a situation

    that's not usually one that they want to be in." (10)

When a private room could be secured for the patient and family, nurses felt that this

allowed the family to be free to express their true emotions. The importance of privacy was

discussed in the follow-up interviews, with participants confirming that privacy was not

only for the patient, but for the family as well:

    "... the closed door to allow people to weep without feeling that they have to do it

    quietly. Like if you want to wail, you can close the door and you can wail. It's not

    only for the privacy of the patients…" (11)

Interventions that were implemented to create a more comfortable and supportive

environment for families were seen to contribute to the building of therapeutic relationships

between families and nurses, and also created opportunities for the nurses to be in the room

and connect with families.

    Trying to soften the blow for families. Nurses in this study reported that signs of

patient deterioration or functional decline were not always recognized by families who often

remained hopeful for improvement. When this occurred, study participants were concerned

that families would be surprised and shocked when the time came that the patient died. In

order to minimize these negative feelings for families, nurses attempted to soften the blow

by providing families with gentle hints about the clinical deterioration of the patients. When

nurses were asked by families about how the patient was doing or how long it would be

until they died, nurses strove to provide honest answers, not wanting to create a false sense

of hope for the family:

> "Well, something that I always, uh, find myself trapped and they ask me how long
>
> it will take till the patient dies. And uh… I can't… it's always varied how my
>
> response will be… I don't want to give the family false hope, and at the same time,
>
> I don't want to keep them, like waiting (to hear that death is imminent)." (03)

Nurses indicated that they would intentionally approach families and describe for

them cues about the patient's clinical decline to ensure that families were in tune with the

reality of the patient's situation as understood by health professionals, and to keep them

from being blind-sided by the demise of the patient. This participant shared her thoughts

about the role of nurses in this regard:

> "I believe nursing has a very important role. Giving the family information in a
>
> timely manner, but at their own rate, so that when they're approached by the
>
> physician and the physician says, "It's not looking good", and then they're ready.
>
> They're at a point where they can hear that." (04)

Nurses also helped prepare families by coaching them to engage in some important

activities and conversations with a relative who was imminently dying. This nurse

explained:

> "To be prepared for the situation you are about to see, because I think for most
>
> people who aren't in the hospital, it's very devastating, and to just have that one
>
> person who can explain things and make you understand. It's going to happen...
>
> there's nothing you can do. So let's make it an easy time. To be with your loved
>
> one. Spend some time with them. Say your goodbyes. These are the things I would

find most important. You remind family that sometimes it's not the worst thing that

can happen. Because I've seen families lose a loved one… a quick heart attack, or a

traumatic accident, and they're gone. Whereas, palliative care, horrible as it is,

you're there with you loved one. And you're able to be there for their last few

moments of life. And that's a special thing." (07)

Nurses identified that they were the best positioned members of the healthcare team

to speak with families about the clinical decline of the patient:

"Well I believe that we're there 24/7, and I believe that we [nurses] are the best

person for families to communicate with because we give the most accurate

information in a way that the families can understand, and we tend to change our

descriptions and our definitions from what we get from the family members." (04)

Listening to families was an ongoing intervention, with nurses checking in on

families regularly to ensure they were well, and to indicate to families that they were

available to them if needed. This participant recounted:

"He [the patient's husband] was crying. He was distraught. And I went in and I just

said, "You know, I just thought I would check in and see how you are, and if

there's anything I can do, just let me know." (07)

Acknowledging personal experience. One participant recounted how the personal

experience of being the family member of a dying person underscored for him the

importance of ensuring that nurses provide families with psychosocial care. His negative

experience with what he perceived as insensitive, uncaring nurses served as a powerful

motivator for him to provide optimal palliative care and thus prevent other families from

having to endure a similarly negative experience. He explained:

"When I lost my father, it was during the strike. It was probably the worst time to

lose someone because the nursing staff was extremely angry… and I found it hard.

Like I remember him profusely sweating and in a lot of pain… I remember asking

for a fan, which I thought was a reasonable request, and the snappy answer that I

got was not exactly a very soothing response. I always said if I ever end up in a

situation where I'm looking after somebody, I really pray I will never be that way

with somebody else." (07)

Some nurses found that the experience of providing psychosocial support to families

was uplifting to their own spirit. In being present to support families, nurses identified that

they too benefited from this intervention. This particular participant described how caring

for patients at the end of life could be emotionally beneficial to him as well:

"I always found that rewarding to be at someone's side. To learn from them. You

mean, we're all mortal. And for me, I learn a lot, and gain a lot. I gain strength that

when my time comes I can be the same way." (07)

Personal experience created a degree of comfort with death and dying that allowed

the nurse to be positive about providing psychosocial support to family members of dying

stroke patients. This participant explained:

"Beautiful. Beautiful in a sad sort of way because you know these people. You'll

probably never see them again, but I've just felt a connection with many families

where I was there for them in a time of their need and that's the reason I do this

job. A lot of it… the reward at the end of the day is phenomenal, and I wouldn't

change it at all." (07)

Engaging multidisciplinary resources. In order to meet the psychosocial care and

information needs of family members, study participants stated that they had ready access to various multidisciplinary resources within their tertiary care facility. These nurse-initiated resources included aboriginal services, the hospital ethics committee, the psychiatric nurse liaison, and translation services, with the most frequent referrals being made to palliative care, social work and the spiritual care team. Nurses indicated that referrals to these various resources were based on the determined needs of the patient and/or their family, with the hope of enhancing the psychosocial supports for the patient/family unit. Palliative care referrals were made to ensure symptom management was adequate. This participant explained:

> "Often palliative care comes in to oversee and make certain that there's nothing that wasn't suggested that's suggested" (07)

In circumstances in which there were financial concerns for the family, or in which families required more of an ear to listen than nurses thought they could provide, participants would involve social work as a resource for the families:

> "Uh... so like social work for sure. It would be social work and the palliative care nurse. Are two for sure. Like social work would be more for the family." (05)

In their efforts to provide psychosocial care for families, nurses explored the extent to which religious or spiritual beliefs might afford a sense of comfort to families. Participants would delve into discussions with families to determine if spirituality was an important aspect that needed to be included in the plan of care. This participant explained:

> "I believe in God. I try not to bring that into the conversation. If I can sense that someone is Christian, or has a belief in God, I find it very comforting to bring that into the conversation." (07)

Participants readily consulted spiritual care to ensure that the needs of these individuals were attended to appropriately:

> "Well if they need a spiritual person, we call the spiritual office. If they have a preference, if they need to arrange for some kind of funeral and they don't have any, we give them support for that. We give them an option. We can call the people for them." (06)

The findings indicated that nurses attempted to provide holistic care through collaboration with multidisciplinary allied health groups, with a focus on striving to provide comprehensive psychosocial support. While the resources identified by nurses in this study were not exhaustive of all resources in the facility, participants spoke of the departments which they consulted most routinely and there was awareness that allied health supports are available if needed. This participant confirmed that she believed that available resources were adequate to meets the patients' and families needs:

> "We have spiritual care. We have Aboriginal Services if that's what the patient's ethnic background (is). We have social work if we need them. We can get the family whoever they would like. Like if they want a Catholic priest, we get a Catholic priest… it's not a big deal." (07)

Siloed striving: underutilization of external ward resources. Interview data indicated that although they were aware of resources external to the unit that might help them in meeting family members' psychosocial care and information needs, nurses appeared to underutilize such resources. In sharing their stories of patient care, the use of allied health resources such as social work, spiritual care services, aboriginal health services and palliative care were not offered spontaneously as part of the experience. Only after probing

by the researcher during interviews, however, did nurses identify the presence of these

resources. In contrast, reliance on nursing peers as a resource was mentioned more

frequently than consultation to resources or services from outside the unit. While reliance

on peers is a positive action, it was also limiting in that allied health professionals possess

skills and expertise that might have enhanced the extent to which the psychosocial care and

information needs of family could have been met. Nurses' reliance on internal unit

resources was evident in the following exemplar:

> "Well, we like, uh, first and foremost, my colleagues. They're a good resource.
>
> Especially those more experienced than I. Um, sometimes we also… I tend to ask
>
> the charge or CRN (clinical resource nurse), the nurse educator. Well, so basically
>
> what resources we have on the ward… that is what we utilize." (03)

In speaking with the participants, it was evident that there was a strong sense of

collaboration amongst peers on the ward, and that nurses found this resource very

accessible, but subsequently limited their incorporation of other specialties to support their

practice:

> "Other nurses on the ward can make suggestions. You know, we're not always
>
> 100% on our game. You can have a bit of an off day… not thinking… you just
>
> didn't think about it. Other staff members can be really great. Did you offer the
>
> other family members something to drink? Did you… IV team. IV team can put in
>
> lines and things like that. Hypodermoclysis." (07)

Nurses were aware that they could call in resources, such as the psychiatric nurse

liaison, to help them develop a care plan for a family who was struggling emotionally, or to

help nursing staff debrief after a critical incident. Despite access to this resource, however,

participants preferred to rely on their nursing colleagues:

> "But I find that the staff… the majority of them… supports each other and they're
>
> able to talk about these things and I think that's a big thing for them. Um, you
>
> know we haven't really called in the psych nurse liaison to help them grieve for
>
> anything like that. A lot of them get along really well and so have collegiality, this
>
> friendship… so they can discuss (sic)." (02)

Senior nurses on the unit saw themselves as being a resource for less experienced

nurses, which in turn fostered the development of peer support and the use of nursing

colleagues as resources on the unit. This was evident in the perspective shared by this

nurse:

> "I think in my position, even if I feel that it is uncomfortable, I have to show my
>
> co-workers that I am comfortable whether I am or not. Being one of the charge
>
> people on the floor I have to be the one who takes charge and does it." (01)

If the nurses could not find the necessary support from each other, they continued to

seek answers from resources within the unit by turning to the physicians for additional

information. When asked about what additional resources were present within the facility to

support nursing practice, participants responded:

> "I usually go to my charge nurse and take a second opinion. I don't just do the
>
> decision on my own. I give all the best care I could... the nursing part of it…
>
> physically and emotionally supporting them. But if there's any action needing a
>
> second opinion, especially in nursing… I ask my charge nurse, or I will… and then
>
> we… if she can't make the decision as well, we talk to the doctor." (06).

Nurses strove to meet patients' and families' support and information needs on a

consistent basis. Developing relationships with, and trying to soften the blow for families, acknowledging personal experiences, and engaging multidisciplinary resources were all part of the participants' experience in providing psychosocial care.

Struggling to Meet Families' Support and Information Needs: "The emotional attachment… is the hard part as a nurse." Participants in this study identified that they encountered struggles in their efforts to meet the psychosocial care and information needs of family members of dying stroke patients. These struggles included: i) dealing with the emotional impact of caring for family members of the dying; ii) responding to family anger; iii) detaching emotionally from the patient; iv) experiencing feelings of uncertainty and helplessness when communicating with families about prognostic information; and v) concerns about upsetting or displeasing family members in discussions about discontinuing nutrition and hydration at the end of life.

Dealing with the emotional impact of caring for family members of the dying. Nurses found that at times, they were overwhelmed by feelings of emotion in the course of caring for family members of dying stroke patients. This nurse explained how she found the emotional reactions of a family member difficult to handle:

> "I cried. Every time I come out of the room. Like this morning is a good example.
> The husband… I don't really know… we don't usually see a man crying, and
> experiencing those types of emotions. It's really… I cried. I cried with him. I came
> out crying and I talked my emotions to my co-workers (sic) and tell them it's really
> difficult to see… to see him suffering like this. I gave advice… a little bit here and
> there... as much as I could avoid the personal issues." (06)

The emotional impact of providing support to family members was also affected at

times by the past personal experiences of the study participants. Many of them had

experienced the death of a loved one, and their shared stories verified that those experiences

had an effect on their nursing practice and the ways in which they approach patients and

families. One participant's personal experience with death elicited significant negative

emotions, and had an impact on her life outside of the workplace:

> "Like what I said. Because I experienced losing someone before --it's difficult. I
>
> cried quite a bit. I bring it home and I think about it. I think about the patient. I
>
> think about the family." (06)

This same participant found that with repeated professional exposure to death, she

was able to cope with providing end-of-life care to dying patients. Although the task

remained challenging, the emotional impact experienced by the nurse was lessened. This

participant confided:

> "Difficult on my own. Like what I said… combining the personal and professional
>
> points of view. Every time I have a patient… I will tell you this… 6 years ago I
>
> refused to look after a palliative care because of my own emotions. I cried all the
>
> time. I couldn't handle it. But now it's easier… combining the professional and
>
> personal one (sic) because I relate my feelings and emotions to them." (06)

Responding to family anger. Even nurses, who felt confident in providing end-of-

life care, identified that they sometimes struggled to be provide support to families who

were angry. In this exemplar, the participant spoke of how she struggled with her inability

to respond effectively to family member anger:

> "Some families have a really difficult time. We see anger. We just had a recent
>
> incident with a husband who lost his wife. She had a cranioplasty, was doing well

enough, and they went to put the bone flap back on and she deteriorated… he went

from being a really easy-going, friendly guy I got along with really close… to a

person that was unapproachable. And I felt that was really difficult because I find

it… difficult in that I could almost always find a way to calm things and settle

people down. In this situation, I was unable to do that." (07)

In follow-up interviews, participants spoke in more detail about how family anger

made it difficult for the nurse to be present to provide support. Study participants explained

that they had empathy for the patient and their family, and recognized that family anger was

a coping mechanism used in response to the impending death of the patient. Despite this

understanding, some nurses found that physically removing themselves from the caregiving

situation was necessary. In some instances, this meant that nurses asked to have their

patient assignment changed. This nurse explained:

"You could ask you know, if it's a very key person in the relationship, say it's the

husband of the wife... you could say, you know what, can we swap. Not ideal cause

people don't usually like to swap during a shift, but maybe the next day they

cannot get the assignment back. Um, if it's very, very distressing, I know in the

past... I've gone in for a more junior nurse as the more senior nurse to kind of

buffer... you know that kind of thing." (11)

Physical detachment was seen as a mechanism used by nurses to protect themselves

from the distress experienced when attempting to provide psychosocial support to families

who were angry. This nurse described that in the midst of her struggling, she still tried to

understand and respond to the anger of the family:

"Take a break and then, try to understand where the family's coming from.

Because quite often I can see the point of the physician, and I might not necessarily

see the point of the family, so take a break and go back and say, ok, where are they

coming from. Is it based on guilt, is it based in... You Tube videos of hope, is it

like... where is it? And quite often, time helps us process... like it's too much

information at one time. Maybe they just need 2 hours to process the information.

Maybe they have a few more questions that I could answer." (11)

When nurses were the recipients of families' anger, they recognized the families'

behavior to be part of the anticipatory grieving process. This participant shared how family

anger impacted her personally:

"The emotional attachment and dealing with them emotionally is the hard part as a

nurse. You're dealing with the family and their loss. They're going through that

grieving period already." (05)

In addition to the recognition of the anticipatory grief of families, nurses recognized the

emotion of anger as a normal response by the families to the sudden change in the patients'

health status, rather than a direct attack on their person:

"You know, people who are not ready to deal with what's going on. You know,

they'll blame nursing, or they'll blame the family members." (01).

Nurses struggled to provide psychosocial care to families who were angry, and

sometimes found it necessary to physically remove themselves from the patient, the family

and the care environment. Physical detachment of the nurse from the bedside was perceived

to be beneficial to minimize the distress experienced by the nurse, but was also seen to

sometimes lead to the need for the nurse to detach emotionally as well.

Detaching emotionally from the patient. Nurses in this study identified that it was

not possible to be emotionally engaged with every palliative patient for whom they provided care. Although nurses continued to attempt to maintain a sense of professionalism in the provision of the tasks of physical care, participants found that they needed to detach and remain emotionally distant at times. This technique enabled nurses to protect themselves from becoming emotionally involved and psychologically upset with the situations that patients and families found themselves facing. This participant explained how emotional detachment was critical for the health of the nurse:

> "I think there's a certain detachment you have to have when you deal with these kinds of patients (sic), and with the family too. It's a hard thing to deal with… Because I think if you don't… if you get too involved in every single patient that comes in… we do get, I mean we don't get a lot, but we do get more than the average surgery ward, you know. You really start becoming too involved… It can affect you. It can affect your daily life. It can affect your relationships, your coping abilities. So I think you do need to step back a little bit and... you know... kind of be there to do the things you need to do with the utmost dignity and respect." (05)

Some nurses found that if they did not detach from certain situations, the effects of the experience would spill over to affect their personal life outside of the workplace. This participant explained how emotional involvement in palliative care affected her personally:

> "Sometimes, I, like I just cry. Because it's like emotionally, and I bring my work home (sic). I think of it… I think of it, but it doesn't help me... because for me, that would be like my family. Like I'm putting myself into their position as the family." (08)

Emotional detachment was seen as the only way in which nurses would be able to remain

emotionally strong, and be able to continue to provide care. This participant shared:

> "I get through it... rather I'm used to it because I don't see them on a daily basis. But you have to deal with your emotion. And you can't get...you can't bring them all in your heart... and then... you get through it." (06)

Not all nurses agreed with the need to detach from patients. In follow-up interviews, when asked if they thought that emotional detachment was necessary, one nurse stated:

> "I don't personally. I can be involved as much as I need to be." (10)

It should be noted, however, that the other participant who was interviewed in follow-up endorsed that a certain degree of detachment was required. Detachment was seen by the participant as the only way to provide care effectively:

> "I believe in some... I believe it's necessary... Don't put your husband in the bed. Don't put your sister in the bed. Yes, it's someone who's really truly loved, and to this family is very important, then you can feel sad that there's sadness, but it's not your sadness. That's the difference." (11)

It was evident from the interviews with nurses in this study that the majority of them believed that emotional detachment was useful as a coping mechanism when they were struggling to provide psychosocial support to families.

Experiencing feelings of uncertainty and helplessness when communicating with families. Nurses in this study understood that part of providing psychosocial care to families involved providing them with information about the patient's condition and plan of care. Though they wanted to engage families in such conversations, participants identified that they found it difficult and/or were hesitant to answer questions, particularly those dealing with prognostication. Prognostication for patients with an intracranial hemorrhage

is difficult for health care providers to establish due to the fluctuating level of consciousness demonstrated by the patient, as well as the unknown potential response that the patient might have to treatment (Reilly & Bullock, 2005). This reality contributed to feelings of uncertainty and helplessness as nurses were unable to provide definitive answers in response to family questions. This nurse explained:

> "Um, it's... I'm not... I'm used to it but every time I encounter somebody, especially if the family are asking too many "whys"... and I always say that the whys that you are asking right now... all the questions are not answerable by yes and no... I can't give you these answers." (06)

The following statement exemplifies the anxiety that this participant experienced, and how she felt "trapped" by the questions being posed by families who wanted to know how long the patient would live:

> "Well something that I always, uh, find myself trapped and they ask me how long it will take till the patient dies. And, uh... I can't... it's always varied how my response will be." (03)

This participant also spoke of her personal distress in not being able to provide a concrete answer to a family's inquiry due the uncertainty of prognostication. In this exemplar, the nurse attributed some of her uncertainty to challenges in assessing the patient due to the patient's decreased level of consciousness:

> "She wasn't responding to us in any sort of way we could interpret. Patients and families often want to know that, oh, it's going to happen tomorrow at seven o'clock; it's going to happen at nine o'clock. They're... it just doesn't happen, right?" (04)

Based on her professional experience, this participant felt a lack of control and frustration when she was not able to give a specific answer to family members:

"You wait. You wait and you wait and you wait. And I guess that's why the situation was exceptionally frustrating for me because I didn't have control." (04)

This same participant subsequently perceived that her professional credibility was affected due to this uncertainty. She believed that uncertainty also affected her ability to effectively support families, as she did not have a pool of concrete responses to draw upon in the acute neurosurgical care setting. She explained:

"I can only compare it to critical care. Critical care we have lots of bells and whistles, and we have lots of ways of predicting things... and I guess that's why I felt frustrated in this one situation. In the fact that... in the past... I could say, 'You know, your uncle will not be here tonight'". (04)

The sudden change in a patient's clinical status often evoked numerous questions from family members. These questions in turn evoked feelings of uncertainty and helplessness in nurses when they were questioned by families as to why nurses were not able to prevent the patient from deteriorating. This study participant explained:

"A female patient who was in her fifties had actually four consecutive strokes, and uh, went from being fully oriented, unable to move one side, but to a point that she was dying the next day... it's something that you think and you hope in hospital could be prevented, but in this case it wasn't. " (01)

Follow up interview data suggested that feelings of uncertainty and helplessness in communicating with families about prognostication contributed to participants' focus on physical care, and their tendency to avoid interactions with family members. This nurse

explained:

> "Probably, uh… the physical care probably doesn't... isn't impacted, but probably
> that, um, the verbal communication because the staff don't know what to say, they
> probably prefer to not say anything. So they go in and say, like, 'I'd like to turn'
> and ask the family to leave, and then call them back in and not really say anything
> to the family." (11)

Though nurses identified the importance of providing emotional support to families
as part of providing psychosocial care, it was evident from the data that rather than engage
families in discussions about end-of-life care, nurses felt more comfortable in redirecting
families to talk directly to the neurosurgeon. This participant stated:

> "I'm not going to talk about the advanced care plan. I would tell the doctor... the
> doctors are the ones who are going to talk to them. But I would just comfort them.
> The family... you know… take them aside and see what they need." (08)

Interview data indicated that communication regarding symptoms, prognostication
and general issues related to end-of-life care were considered to be the domain of the
physician. Four study participants viewed conversations about these issues as being outside
of their scope of practice as nurses. If the family had questions, or if the patient's plan of
care was unclear, these four participants indicated that they would call upon the physician to
speak with the families to clarify the goals of care or answer questions about the patients'
clinical status. This nurse explained:

> "Well, we always ask the doctor to talk to the family. Um, like you know, they deal
> with them because they're the ones who usually like, you know, we can always
> be... like you know, we can always suggest, but they are the ones who do all the

writing about the patient and care plans." (08)

Participants in this study explained that when patients were admitted to the acute neurosciences unit from the intensive care unit or emergency department, discussions with family members surrounding end-of-life care had sometimes already taken place. Neuroscience nurses were thus often on the periphery of the initial discussions regarding end-of-life care decisions. This nurse believed that the strong presence and guidance of the physician were required in order for the family to feel comfortable with treatment decisions. She said:

> "Sometimes they come from ICU all ready and that's already decided. The doctor
> has spoken with the family and that's (palliative care) what they've decided. Um,
> and it sometimes happens on our unit where, um, it's usually the physician that gets
> the ball rolling. They talk to them about what they want... what the patient would
> want." (05)

It was clear in the interviews with participants that regardless of where the end-of-life conversations occurred, reliance on physicians to assume the responsibility for initiating discussions about palliative care hindered the involvement of nurses in providing families with this information education themselves. Participants suggested that nurses remained largely outside of these conversations even after initial conversations had already occurred, expecting that the physician should be responsible for facilitating ongoing dialogue.

> "Um, and then, just kind if, if they want to go more into that I would arrange for a
> physician to come to speak to them... to that." (05)

While the practice of calling upon the physician to answer all of the families' questions was not seen as being the most ideal approach by one study participant, it was

nonetheless described as being the accepted practice on the unit. This participant stated:

> "Usually the physicians, and then the physicians have a family meeting. That's
>
> kind of how I've seen it. Do I believe that that's the best way to do it? No." (04)

When asked in follow-up interviews about what approach might be better suited to address families' psychosocial care and information needs other than relying on physicians, participants still opposed nurses taking a leadership role in this regard. In this exemplar, a medical resident, or allied health professional were identified as members of the team better positioned to provide family with information:

> "Again, we're getting into the rest of the healthcare team. You know… the
>
> residents." (10)

Although it was not clear as to why reliance on the physicians was not seen as ideal, it was evident from the data that nurses in this study were uncomfortable initiating or sustaining conversations with family members about the goals and interventions for dying stroke patients. As a result, they did not assume a leadership role in this regard, and preferred to defer any such communication be led by the physician.

Concerns about upsetting or displeasing family members. In addition to struggling with conversations about prognostication which made them feel uncertain and helpless, nurses in this study also indicated that they worried about having to be involved in conversations with family members about whether or not to initiate or discontinue artificial nutrition and airway support. Study participants appreciated that making decisions about the withdrawal of treatments was difficult for family members of dying stroke patients. This nurse explained that she understood why families might agree to withdrawing some types of treatment but not others.

"Well it depends where the person comes from. So if you're coming from ICU, or

from anywhere on the ward... and you've already got oxygen going... you've

already got tube feeds going… and you've already got antibiotics going... although

it's a little bit easier to go, "I don't want any more antibiotics"... but if you have

these… oxygen and food are very primary sort of needs. So if you have them

going, it's really very hard for families often to say… to stop those. It's quite a

basic sort of need. If you do Maslow's Hierarchy of Needs, air and food are the

bottom, right? So for someone to say, I think it's probably easier for them to say,

"Oh, don't give them antibiotics" because that kind of seems like more... because

that's treating. But don't feed them… that's kind of saying… oh, you can't have a

glass of water. " (04)

Nonetheless, such conversations were identified by nurses as having the potential to

result in disagreements between nurses and family members, resulting in family members

being upset and displeased with health care providers. Nurses in this study expressed their

concern and desire that family members be "happy" regarding care decisions that were

made. Inherent in ensuring that families were happy appeared to be the need to acquiesce to

family demands. This nurse stated:

"They have the right to make choices, so we try to please them. If you don't please

the family as well, it's difficult… it's a big dilemma." (06)

The data suggests that several strategies were used by nurses and members of the

wider health care team on the neurosciences unit to minimize the potential that family

members would become upset about end-of-life care decisions that were made. One

strategy identified by participants was not to initiate conversations about discontinuing

nutrition and hydration with families in the first place. This participant identified that

avoidance of such dialogue was a pattern of practice among some members of the health

care team. She explained:

> " In my experience, I've found that some physicians don't even like to bring up the
>
> conversation of tube feeding until the family brings it up because it is such an
>
> ethical issue I think for some people. And, um, I definitely notice a trend that it's
>
> not brought up until family brings it up." (05)

This participant talked about the fact that there was a qualitative difference

regarding never initiating an intervention versus discontinuing it that was problematic for

families:

> "Um… you know where it becomes a complicated process of we start them? If
>
> you start them, nursing staff have trouble withdrawing it... but if there ever is a
>
> situation where they' re started, it's a real bitch to try to get them d/c'd. They
>
> struggle with that. You know… better not to start it." (02)

Although nurses in this study avoided initiating conversations about discontinuing

intravenous hydration in dying stroke patients, they identified that they had resources to

support their conversations with family members when the families approached them with

questions regarding this aspect of patient care. This participant explained:

> "And actually we have one particular article, um, that explained to staff that dying
>
> of dehydration is not a bad death. As long as you give them good mouth care, and
>
> so their mucous linings are all well lubricated, etc. It's not a horrible death." (02).

It was evident from the interview data that another strategy nurses used to avoid

becoming involved in these kinds of difficult conversations with families was to defer to

physicians. Physicians were once again identified as the member of the health care team who assumed the lead in talking to family members about discontinuation of interventions. Follow-up interviews revealed that though nurses would identify for physicians that these types of conversations with families needed to occur, and that nurses were present during such conversations, they did not appear to make any kind of significant contribution to the dialogue:

> "Usually it ends up being nursing that brings to topic up (to the physicians).. and
>
> then the physicians have a family meeting. That's kind of how I've seen it." (04)

A third strategy that was used to avoid upsetting families regarding discontinuing treatment was that of meeting families half way to try and keep the peace. For example, even though participants believed that it was not appropriate to maintain an aggressive regimen of tube-feeding for a dying stroke patient, rather than completely discontinuing it, the infusion rate would be cut back. This participant explained:

> "Always discussions with the family. And sometimes, you know what… we end up
>
> still continuing the tube feed, but we do cut the amount." (02)

Despite the fact that discontinuing food and fluids in dying stroke patients is one that has ethical dimensions to it, the majority of study participants did not cast these issues as being ethically problematic. This appeared to be because they were able to find resolution using other nurses or physicians as a resource to avoid any conflict:

> "I usually go to my charge nurse and take a second opinion. I just don't do the
>
> decision on my own. I give all the best care I could (sic)... the nursing part of it...
>
> physically and emotionally... supporting them. But if there's any action that needs a
>
> second opinion... making decisions in a medical, you know, situation, I ask my

charge nurse, or I will... and then we... if she can't make the decisions as well, we talk to the doctor and say, " this is what the family… blah., blah, blah (sic)… It works out. It always works out." (06)

The one participant who did express concerns regarding the withdrawal of nutrition for a particular patient stated that he found himself wondering at times if the patient who was not fed was succumbing to his/her injury or was starving to death. He stated:

"We've had a lot of special events as far as ethical issues on starving somebody. If they're breathing on their own, supplying them with tube feed, IV fluid (sic), is something that's not… something that we can provide. And to take that away… are they dying because they're not getting nutrition? Are they dying because of what's going on in their head? It's a fine line as far as ethics." (01)

For cases in which he wondered what the most appropriate approach to care regarding nutrition and fluids might be, he was aware that the hospital had an ethics committee to which he could consult, but found that by the time the response was attended to, the patient had died and the consult was no longer required. When asked what resources he had to support his care in situations in which he questioned whether fluid and nutrition should be discussed, this nurse replied:

"I think personal experience helps more than, uh, things that the hospital has to offer. Ethics department, you know... consults usually are made out to them, but they usually don't respond in the time frame that you'd want them to." (01)

Despite struggles faced in approaching discussions regarding fluids, nutrition and airway support, participants indicated that families were, at times, more open to discussing the removal of a nasogastric or endotracheal tube because families perceived that the tube

was causing the patient some degree of discomfort. The presence of these tubes resulted in the patient having an unnatural appearance—something that was difficult for families to see. This difficulty was believed to impact family members' decision making, causing to them more readily agree to discontinuing artificial nutrition. This nurse related:

> "If they have a tube sticking out of their nose, right, it's easy for them to say, 'Take that tube out of their nose. That doesn't look like Mom, or that doesn't look like my sister'… ". (04)

Nurses empathized with families, recognizing that the patients did not always look like themselves, and that this was also an uncomfortable experience for some families. Nurses in this study appreciated that seeing patients with all of these tubes in place provided a less than ideal vision for families to remember:

> "Like what an awful vision to remember of your loved one. Of having this big hose coming out of your nose and you have these tape marks all over your face. Because you're trying to keep it in." (02)

Care of the dying stroke patient involved providing psychosocial care and support to their family members. While study participants strove to provide psychosocial care to families, they also struggled in their efforts to provide this care.

Providing Culturally-Sensitive Care

Striving to be Culturally-Sensitive: "You just have to ask the questions."
Nurses in this study identified that they cared for dying stroke patients and their families from a variety of different cultural backgrounds. Participants were also aware that responses to grief were culturally mediated, and spoke about the importance of framing the care they provided to dying patients and families taking cultural needs into account. Sub-

themes identified within the theme of striving to be culturally sensitive included recognizing

variations in traditions and rituals, and recognizing translation needs.

    Recognizing variations in traditions and rituals. Based on the responses of the

participants, it was evident that they cared for culturally diverse patients on the

neurosciences unit. Nurses recognized that variability also existed within each given

culture, and indicated that it was important not to make assumptions regarding patients' and

families' care needs based on stereotyped cultural understandings. The experience of the

following nurse confirmed these thoughts:

> "There's quite often a lot of different cultures on the unit... not saying that
>
> everyone who comes from the Philippines is exactly the same... because they're
>
> not... just like not everyone from Canada is the same... people who are Polish, they
>
> might have different ways of dealing with the death process. So you have to ask
>
> them." (04)

    Nurses also understood that acceptance and accommodation of the individual

patient's and family's cultural beliefs were essential to meet their specific care needs:

> "We are a multicultural country so we experience a lot of that, and um, I think it's
>
> more on being flexible on what they prefer and what they want." (06)

When participants were unsure if the patient had culturally-specific rituals that were

important at the end of life, they stressed the importance of simply speaking with the family

about this issue to ensure that cultural care needs were being met. This participant

explained:

> "Well, first and foremost, I would ask the family... "what do they want?" And how
>
> do they want things done. And then I start off inject (explain) some general

practices that we do on the ward, and if it fits with their culture (sic). And if not, then just shy away from that. I find I haven't had any problems." (03)

This strong sense of cultural awareness was confirmed in a anecdote shared by a nurse in his follow-up interview, where he identified the lengths that nurses on the unit would go to in order to ensure patients' and families' cultural needs were respected:

"… we had one where I think she was Asian and they wanted this music playing until the funeral... even to go down to the morgue with music playing. Which, um, I think what we ended up doing was getting a headset and so that it didn't spook somebody else bringing somebody else into the morgue and having music playing underneath the (cloth)... and so that was what we ended up doing was getting an ear bud and sending the patient with it. Now how long the battery lasted or anything else? But the family felt that that was important and we did what we could to accommodate their request." (10)

Within the context of cultural awareness, nurses were also cognizant of differences in communication styles of individuals from various cultural groups. This participant noted specific observations from his experiences:

"I find that culturally speaking.. Caucasian patients are a bit more vocal. They're a bit more assertive. Um, I find Asian cultures, well I mean Filipinos actually... I would say for the Chinese and Japanese (too)... I find them… they know how to verbalize their response... vocalize what they want I mean. Um, I also find the Indian culture... from India... to be a bit more vocal of what they want." (03)

Recognizing translation needs. With the presence of a culturally diverse patient population, nurses indicated that there were also diverse translation needs for patients and

families whose first language was not English. Nurses needed to rely on the support of

translation services within the centre to ensure that families understood what the health care

team was trying to communicate, as well as be certain that the nurses understood what the

families were trying to express. For more commonly encountered languages, nurses were

readily able to access translation services to assist their practice:

> "Usually... for rare instances. You'd find like when someone speaks Ukrainian or
>
> Russian or Portuguese. uh... service is quite... it's faster." (03)

With the presence of multiculturalism amongst the patients and families, nurses

exhibited an awareness of the need for culturally-sensitive care, and incorporated this

appreciation into their efforts in providing end-of-life care.

Struggling to Provide Culturally-Sensitive Care: "Miscommunications always

happen." Despite striving to provide culturally sensitive care, nurses in this study indicated

that they experienced struggles in doing so. Those struggles included: i) encountering

translation challenges; ii) lacking cultural knowledge; iii) systemic constraints; and iv)

acknowledging the nurse's own cultural beliefs.

Encountering translation challenges. Nurses in this study identified that it was

important to draw upon translation services within the facility as part of providing end-of-

life care to patients and families whose first language was not English. Although the

hospital provided a broad range of translation resources, nurses sometimes found that they

were unable to meet translation needs for all patients or families. At times, no translators

had the ability to translate languages or dialects that were less common. Without proper

translation, effective communication was not possible, and added to the challenges in

providing care. This nurse provided an example of the struggles she had encountered:

"Language barriers for one...The patient was a Buddhist from China, and like, uh

Mandarin was her first language. It was really hard to convey what we want, and

the family as well (sic). They were really hard. Kind of speaking English... it was a

huge barrier. Just a means of communicating what you feel, what you desire for

these people... miscommunications always happen." (03)

Miscommunication, as a result of gaps in translation services, created challenges for

nurses which led to circumstances in which it was difficult to assess the true needs of the

patient and family.

Lacking cultural knowledge. Nurses understood the importance of respecting

requests for specific cultural rituals. Participants strove to meet the cultural needs of every

patient and family, but their own perceived lack of knowledge about different cultures and

their associated rituals made the provision of culturally sensitive care challenging at times.

Nurses found that there were instances in which they were not entirely knowledgeable about

the culture and rituals of the patient for whom they were caring and did not have resources

available within the hospital to answer culturally-specific questions. Despite their best

efforts and desires to meet the patients' and families' needs, nurses did not always know

how to go about having that need met. This was particularly true when the patient was not

from a white Anglo-Saxon background. This participant explained:

"One thing I think we probably lack... and I don't think it's just this unit... it's

probably all over… is that unless you're a white Anglo-Saxon individual,

sometimes we struggle with the traditions... some of the Aboriginal... the chanting

at the bedside. We've had some Hindu people where they want the body for "x"

period of time. And in the room." (02)

Perceived systemic constraints. Perceived systemic constraints and pressures were also seen to impact the nurses' ability to provide culturally-sensitive care. With some rituals consuming a significant amount of time, nurses found that they were sometimes caught between honoring the rituals and meeting the demands of the system. For example, the nurses had a strong desire to respect and accommodate the requests of families of dying patients, but in turn, experienced bed utilization pressures. Limited time and the demand for an open bed played a factor in the following exemplar:

> "And sometimes, like, it's a horrible thing to say, but... I talk about "celestial discharges". Because you know, you need these people to pass on, you know, because we need the bed for someone who is having surgery. And it sounds so harsh, and so that you know that you have a patient's family, who their religious or ethnic background says, "you can't touch this body for 10 hours"... I can't remember what religious belief this was, but we could not touch the body for this long period of time. I think 10 hours... I think I'm stretching it... but something like 6 hours. And we needed... that's one thing the nurses are uncomfortable with. After the patient dies, we need to transport that body. But you know what, some of these cultures and beliefs... they need them to stay there for a while… you need to do (this) for the families because this is the last thing they can do for their loved one."
>
> (02)

Nurses found themselves struggling to meet the cultural care needs of patients and families because of the need to respond to bed utilization demands, and facilitate the admissions of patients who were requiring acute neurosurgical intervention. Although the needs of the families were forefront in their thoughts, participants always were also aware

of, and struggled because of, systemic constraints.

Acknowledging nurses' own cultural beliefs. Some nurses recognized that their personal cultural beliefs had an impact on their nursing practice. They also recognized that their culture influenced their experiences and attitudes in providing care to patients who were dying. One participant identified how he believed his culture influenced his feelings about providing palliative care:

> "I'm not that comfortable with the whole taking care of palliative patients just because of, I would say, culture. It plays a very big role in that… being (of a certain race), it's quite hard to be vocal about things. Uh, I tend to be a little more reserved. If, let's say a relative of mine were to die, it would probably be best to have it in the confines of the family to discuss our sorrow, or grief, and if… if we're more comfortable talking about it, that's the time we actually talk to other people about it. It's culturally sensitive." (03)

This participant exhibited a strong personal cultural identity which influenced his perception of grief and he was aware that it affected his approach in providing end-of-life care.

Nurses in this study indicated that cultural diversity had an impact on their practice in the provision of palliative care. They strove to identify traditions and rituals which might be significant for the patients and their families, recognizing that language individuals who provided translation services were a critical aspect of their care team. Despite these efforts, however, instances did arise in which nurses encountered challenges in providing the care which they desired. Gaps in translation services, a lack of cultural knowledge for every patient for whom they cared, systemic constraints and the nurses' own cultural beliefs were

found to impact the nurses' ability to provide culturally-sensitive palliative care in all circumstances.

Summary

This chapter presented a description of the demographic characteristics of the study participants, and detailed the essence of the lived experience of neuroscience nurses caring for a patient dying from hemorrhagic stroke on an acute neurosciences hospital unit. That essence, "striving and struggling to provide optimal end-of- life care, consisted of three major themes. They included: i) providing physical care, ii) providing psychosocial care, and iii) providing culturally sensitive care. Data exemplars were provided which illustrated and supported the major themes and sub-themes. The next chapter situates the findings of this study within relevant literature, describes the limitations of the study, and provides recommendations for nursing practice, education, and research.

Chapter 5: Discussion of the Findings

Chapter five will discuss the results of this phenomenological study. The chapter will begin with an overview of the main essence of nurses' lived experience; that of "striving and struggling" to provide optimal palliative care. Next, the major themes and sub-themes supporting the essence will be discussed in light of relevant literature. Limitations of the study will be addressed. The chapter will conclude with recommendations for nursing practice, education, and research.

The Essence of the Nurses' Experience:

"Striving and Struggling" to Provide Optimal Palliative Care.

The overarching essence of this study indicated that neuroscience nurses in an acute care setting strove to provide optimal end-of-life care to patients who were dying after having experienced an acute intracranial hemorrhage. They also struggled in attempting to provide such care. Nurses performed their duties with the intent of ensuring that the patients and families experienced a "good death". This involved ensuring that patients were comfortable and that families had as positive an experience as possible. It also involved providing care that met the unique needs of each patient/family dyad, and was of the caliber that nurses themselves would like to receive were they or their loved ones in the patient's position. With a focus on physical comfort for the patient and emotional support for the family, participants stated that they strove to provide care that demonstrated respect for the patient and the family, which in turn, was seen to also afford the patient a degree of dignity.

Supporting Themes

Three major themes underpin the essence of "striving and struggling" to provide optimal end-of-life care. Those themes include: i) providing physical care, ii) providing

psychosocial care, and iii) providing culturally-sensitive care. Each of these themes and

their sub-themes will be discussed in relation to existing literature about the care of dying

stroke patients, and select palliative care literature

Providing Physical Care

  Striving to Provide Physical Care. Interviews consistently revealed that

participants' primary goal was to ensure that patients were comfortable. Whether attempting

to meet physical care needs or managing symptoms with medications, participants in this

study had a strong focus on this aspect of care. Sub-themes within striving to provide

physical care included: i) attending to physical care needs; ii) perspectives of a comfortable

death; iii) their leadership role; and iv) misguided striving in symptom management.

  Physical care needs. One way that nurses strove to ensure patient comfort was by

attending to hygiene needs. Nursing measures aimed at ensuring the physical comfort of

patients dying as the result of an acute intracranial hemorrhage are not well documented in

either neuroscience nursing literature or textbooks. However, general health care literature

supports the importance of attending to hygienic needs. For example, evidence-based

clinical practice guidelines developed to manage the discomfort and risk of infection caused

by incontinence associated dermatitis include keeping the patient's skin clean and dry

(Doughty et al., 2012). These basic hygienic measures are consistent with the approach to

care described by participants in this study to ensure patient comfort.

  Another way that nurses strove to ensure comfort involved the regular repositioning

of patients. No neuroscience nursing literature was found that addressed the issue of

repositioning dying stroke patients, but both the general health care and palliative nursing

literature speaks to this issue. In regards to the palliative care population, Sibbald, Krazner,

and Lutz (2011) report that diminished systemic perfusion that occurs as death draws near coupled with ischemia to pressure points place dying patients at risk for the development of pressure ulcers. Given the findings of a systematic literature review conducted by Langemo and Brown (2006) concluding it is inevitable that patients will develop skin ulcers near the end of life, attention to patient repositioning would appear to be an important comfort related intervention.

In a systematic review of electronic databases MEDLINE and CINAHL from 1960 to 2008, Krapfl and Gray (2008) reported that though limited, evidence suggests that patients who are bedbound on a standard mattress should be turned every two hours to minimize the incidence of pressure sores. The frequency of turning for patients nursed on a pressure redistribution mattress could be decreased to every four hours, with a focus of ensuring that the patient's heels were not resting on the bed (Krapfl & Gray, 2008). The authors also concluded that despite these recommendations, patients who were higher risk, such as those at the end of life, might still develop pressure sores. Repositioning was nonetheless still suggested as an intervention that aimed to minimize the development of pressure sores, and consequently promote patient comfort.

The high risk of pressure sore development in palliative patients was confirmed in a healthcare literature review by Stephen-Haynes (2012) which examined the prevention, development and treatment of pressure ulcers. Ageing, chronic disease and end-of-life were circumstances which were considered to predispose patients to pressure sore development as these conditions result in physiological deterioration and hypoperfusion of the skin. In some cases, development of specific pressure sores (known as Kennedy terminal ulcers if seen at the end of life) was seen as inevitable over bony prominences due to "skin failure"

(Galvin, 2002; Stephen-Haynes, 2012). Despite this high risk of skin breakdown in palliative patients, interventions aimed at prevention reported in the literature include keeping the skin clean, dry, and moisturized and repositioning patients to minimize hypoperfusion. Patient tolerance dictates how frequently patients should be repositioned (Stephen-Haynes, 2012). These actions are consistent with interventions proposed by participants in this study to promote patient comfort.

A prospective cohort observational study by Barker et al. (2012) reviewed Australian nurses' implementation of practice guidelines, specifically looking at the use of pressure score flow sheets, the accuracy risk assessment tools for care plan development, and the use of pressure prevention interventions. Using a purposive point prevalence approach, and including inpatient medical, critical care and emergency units, 1045 charts were reviewed at baseline, and then 1, 3, 4, and 8 years later. With the implementation of practice guidelines, the incidence of pressure sores decreased from 12.6 % to 2.6% over six years. It was thus concluded that the use of prevention strategies, one of which was patient repositioning, was essential for high risk patients. Air mattresses and continence aids were also indicated to be effective tools of care, but were not measures identified by the neuroscience nurses in the current study.

In the current study, nurses' knowledge of how to provide comfort care to dying patients appeared to be based on their personal and professional experiences rather than on empirical literature. This method of providing care is congruent with the Theoretical Model for Care of the Dying as proposed by Quint (1967), who proposed that nurses who did not receive clinical education in palliative care tended to adopt the behaviors of others in the proximal clinical setting. Participants in the current study believe that they provided

quality comfort care to patients and families, and this perception was reinforced by their peers on the neuroscience unit. Moreover, only one of the nine participants in this study reported having received specific clinical education in palliative care. Though not the focus of this research, the experiences shared by study participants appear to support the postulates in Quint's model regarding lack of education in palliative care and the adoption of behaviors consistent with one's peer group.

In speaking about the importance of providing care that ensured patient comfort, nurses in this study stated that they attempted to provide the patient and family with the type of care that they themselves would like to receive. The concept of providing care that one would want for themselves or their family was echoed in a descriptive qualitative study in which healthcare aides ($N = 5$) were interviewed to determine expert behaviors in the care of the dying in a personal care home (McClement, Wowchuk & Klassen, 2009). The results indicated that the overarching theme of care was "caring as if it were my family" (p. 452). These healthcare aides shared their experiences of patient care behaviors which allowed them to provide physical and psychosocial support, and plan their care to reflect the type of care that they would like to have for their own family. This approach to care is consistent with the findings of the current study.

Kothari and Kirshner (2006) describe the phenomenon of 'caring as if it were my family' as "golden rule thinking", or in other words the act of assigning one's own beliefs and perspectives to the circumstances which the patient is in, in order to help decide the correct actions in a given situation. In a review of literature regarding decision-making, the use of "golden rule thinking" was seen most commonly in caring for patients with disabilities, as well as when providing end-of-life care. Although well intentioned, this style

of patient care was seen as potentially misguided as it might result in care being planned

based on the preferences of the professional caregiver, rather than those of the patient

(Kothari & Kirshner, 2006). It is suggested by the authors that it is preferable to engage the

patient or family in conversation about the patient's preferences rather than assume that they

would want to receive the same type of care that is seen as ideal by the healthcare provider

(Kothari & Kirshner, 2006). The "golden rule" approach is thus potentially problematic in

that it may disrespect patients and erode their autonomy in directing their own care.

Nurses in the current study indicated that the implementation of measures aimed at

ensuring physical comfort would demonstrate to families that the patient was being cared

for and not abandoned. The importance of acknowledging the perspective of families was

confirmed in the work of Auon, Bird, Kristjanson and Currow (2010). These researchers

developed and validated a measurement tool to assess the degree of satisfaction experienced

by family members of terminally ill patients. FAMCARE-2 is a seventeen item tool which

measures families' perceptions of end-of-life care, with categories including the

management of physical symptoms and comfort, provision of information, family support,

and patient psychological care. In their efforts to validate this tool in both community and

acute care settings, the authors hand delivered the surveys to patients in these care settings

($N = 497$). Although FAMCARE-2 is not focused solely on the perceptions of physical care

in ensuring families feel supported and satisfied with patient care, it does address and draw

attention to the needs of families, and identifies aspects of physical care which are deemed

to be essential for the family to be part of the end-of-life process, and to not feel abandoned

(Auon et al., 2010). Nurses in this study did not provide patient care informed by the use of

a tool to measure family satisfaction; however, they were aware of the need to be certain

that families were satisfied. Families' perceptions were forefront to the nurses in planning

and implementing patient care.

     Perspectives of a comfortable death. Study participants perceived that if the

unconscious dying patient did not exhibit any physical symptoms, the patient had

experienced a 'good death". As a result, nurses' efforts in caring for dying stroke patients in

this patient care setting were found to be strongly focused on physical symptom

management. Although not present in the neuroscience literature, this emphasis on

symptom management is very similar to that found in other end-of-life care nursing

literature. Kristjanson et al. (2001) conducted an exploratory qualitative study in Australia

in which they sought to examine nurses' perceptions of a "good death" and a "bad death".

Patient-related, family-related and nurse-related opinions were identified as contributing to

perceptions of a good death, but the absence of illness-related symptoms was found to be

the most significant factor in determining if a death experience was optimal. When

symptoms could be anticipated and controlled, and the patient experienced no loss of

dignity, nurses believed that the patient experienced a "good death". If there were any

physical signs of suffering due to symptoms, staff perceived that the patient was

experiencing a "bad death". This characterization is congruent with the perspectives of a

good death expressed by nurses in the present study.

     Participants in the current study demonstrated a focus on patient-centered care in

their practice, with the primary goal being on tasks that would ensure patient comfort. In

2010, Peterson et al. undertook a qualitative grounded research study examining the

experiences of nurses caring for dying patients and explored what was specifically stressful

to nurses about their experiences. After interviewing 15 nurses and nursing students, the

authors concluded that there were multiple factors affecting the experiences of the nurses, but that the focus to ensure that the patients were comfortable was at the core of their efforts. Nurses wanted "to do everything they could to alleviate suffering" (p. 184). These beliefs about the importance of ensuring patient comfort are similar to those found in the current study.

Only one study was located that focused on the physical nursing care of palliative stroke patients (Fields, 2007). This case study was based on experiences in a neurological intensive care unit and explored the extubation of a patient and the subsequent general care to be provided. While the author did comment on the need for nurses' involvement in palliative care, the primary role of nursing was to ensure that the patient was clean and comfortable. Outside of this direction, other suggested interventions focused on consultation to multidisciplinary resources, with the goal of care being to meet the physical, psychosocial and spiritual needs of the patient. There was no description or rationale provided regarding the provision of basic care needs, nor was there discussion of the direct role of nursing in providing either physical or psychosocial palliative care. Unfortunately, although this case study was derived from experiences in a neurological ICU, the descriptions of care provided were rather general.

Leadership role. Nurses in this study who described themselves as being more senior on the neurosciences unit believed that it was their responsibility to provide guidance and support to less experienced nurses who were caring for dying patients. These nurses believed that professional experience was a significant factor in the development of understanding and expertise in the provision of palliative care. In providing support and leadership to other nurses, senior nurses recognized that they were also concurrently

supporting and optimizing patient care. There was a lack of specific data in the

neurosciences or palliative care literature addressing this issue, but this idea is consistent

with care models proposed by Benner (1984) and Quint (1967).

Patricia Benner (1984) proposed that nurses could acquire skills and knowledge over

time as long as they were also exposed to education and experience in their area of practice.

She proposed that nurses incorporated theory into the development of their skills from

"novice to expert" over time, with development of their practical knowledge and

understanding. During data collection, it was the impression of the researcher that an

increased level of confidence was evident in participants who had more years in nursing and

neuroscience nursing. Thus it is possible that more senior nurses had progressed along

Benner's continuum of "novice to expert" (1984) and were more competent and

comfortable in providing palliative neurosurgical care. However, because it was not the

goal of this study, this assertion was not systematically examined.

In addition to tending to hygiene needs and repositioning patients, nurses in this

study strove to ensure patient comfort by administering medications to manage physical

symptoms. Medications were most often administered to manage pain, dyspnea and upper

airway secretions. Within the stroke literature, there were no nursing articles located

discussing the pharmacological management of end-of-life symptoms. Plonk and Arnold

(2005) presented a medical perspective of end-of life care in stroke patients, and noted that

common terminal symptoms included pain, respiratory secretions, agitation, anxiety,

constipation, pressure sores, and incontinence. In Canada, Blacquiere et al. (2009)

retrospectively reviewed the charts of 104 patients admitted to an acute stroke unit over a

two-year period to examine existing clinical standing orders for end-of-life stroke care, and

to determine the extent to which palliative care for stroke patients was optimal. Medications received by 90.4% of palliative stroke patients included morphine, scopolamine, lorazepam, and midazolam administered either sublingually or subcutaneously.

One of the symptoms most commonly identified by participants in this study that required treatment with medication was pain. Pain is described as a physiological and emotional response to external and internal stimuli that is processed and developed within the complex neuroanatomy of the brain (Hickey, 2009; Schnakers & Zasler, 2007). In a literature review examining the assessment and treatment of pain in unconscious patients, Schnakers and Zasler (2007) found a possible disconnect between the motor and sensory components of the brain, which meant patients were less aware of any physical noxious stimuli and pain. The authors reported that while non-verbal cues such as facial grimacing, moaning, vital sign changes, diaphoresis, and flexion or extension of the upper limbs can be indicators of pain, these responses may simply be a sign of awareness rather than pain. Research examining cerebral blood flow patterns using Positron Emission Tomography (PET) imaging simultaneously with the painful stimulation of a medial nerve, has demonstrated interruptions in metabolic patterns in the brain. This response suggests that there is a lower conscious perception of pain in the unconscious patient. Without the ability to confirm the experience of pain verbally, Schnakers & Zasler (2007) recommend that health care providers continue to treat non-verbal signs of pain as a precaution, and that pain management in an unconscious patient should incorporate the use of non-verbal pain scales.

In the current study, participants did not report the use of a pain scale, or any other method of pain assessment in the care of dying stroke patients. Rather, participants relied on their personal and professional experience in performing symptom assessments in

unconscious patients. However, consistent with the recommendations of Schnakers and

Zasler (2007), some of the participants did utilize non-verbal cues to guide their assessment

of stroke patients' pain, and help inform decisions regarding the administration of

analgesics. One participant identified that the palliative care pain service was a resource

that could be accessed to help with pain management in dying stroke patients.

A review of nursing practice guidelines suggests that there is little in the way of

specific information to help nurses manage pain in dying stroke patients. The Registered

Nurses Association of Ontario (RNAO) has separate Best Practice Guidelines for both

stroke patients and for patients in the final days of their life. However, the RNAO Stroke

Guideline focuses on care of the recovering patient only, while the RNAO Final Days

Guideline does not review assessment of pain in the unconscious patient. RNAO suggests

that nurses use the Brief Pain Inventory (BPI) Scale (RNAO, 2011a) to assess pain in

palliative care patients, but this scale is not appropriate for use in the non-verbal, non-

responsive stroke patient population. In the assessment of pain in non-verbal stroke

patients, best practice guidelines recommend the use of a tool such as the Wong-Baker

Faces Pain Rating Scale to evaluate pain (RNAO, 2011b). This may also be difficult to

apply to the stroke patient population who is unconscious, as facial expressions are more

difficult to interpret accurately.

Nurses in the current study stated that they managed patient symptoms of dyspnea

and labored breathing by administering morphine. It was evident from this study that

relieving these symptoms also helped to alleviate the distress experienced by families and

staff who bore witness to it. In a retrospective case study reported on by Tice (2006),

dyspnea was a common, subjective end-of-life symptom seen in 45-95% of patients with

varying life limiting illnesses, though the incidence for stroke patients specifically was not noted. Medical interventions such as bronchodilators, steroids, antibiotics, diuretics, opioids and even paracentesis were reported by Tice (2006) as interventions aimed at managing dyspnea. Because patients were unconscious, nurses in the current study relied on their own assessments, and the perspectives of families to determine the presence of uncomfortable breathing and the need to intervene with medication.

Mazzocato, Michel-Nemitz, Anwar and Michel (2010) presented a Swiss medical perspective of palliative care symptoms in stroke patients. There were 142 patient deaths from stroke in their hospital from 2000 to 2005, and 42 of these patients were referred to the palliative care program. The authors retrospectively reviewed the 42 charts (26%), and reported that 69% of these patients exhibited pain and 81% were noted to have dyspnea. For those patients who were unable to verbally communicate their symptoms ($n = 39$), observed non-verbal signs of symptom issues were documented by unspecified healthcare workers which supported the need for medical management. Nonverbal signs of dyspnea were found to be present in 81% of patients, and included the symptom of upper airway secretions. Pain was evident in 69 % of patients. It was noted that the other 74% of stroke patients were not consulted to the palliative care team, but it is unclear as to why they were not referred. This may have been because they were perceived to be asymptomatic, which would impact the true incidence of symptoms experienced by palliative stroke patients in the study.

Mazzocato et al. (2010) also noted that opioids were most commonly used for effective management of pain and dyspnea at the end of life. While their study supports the use of medications for symptom management and patient comfort in dying stroke patients, it

also confirmed that there is a paucity of assessment tools available to guide stroke patient

assessment and intervention at the end of life (Mazzocato et al., 2010). Despite a lack of

symptom assessment tools, the nurses in the study conducted by Mazzocato and colleagues

used their knowledge of non-verbal assessment to guide their nursing care and intervention,

which was consistent with the findings of the current study.

Nurses in this study discussed the use of scopolamine to minimize noisy airway

secretions in dying stroke patients. This finding is consistent with measures used to manage

airway secretions in the palliative literature, where the use of anticholinergics was noted as a

routine intervention for the management of this symptom. In the previously discussed study

by Blacquiere et al. (2009), scopolamine was noted in the list of medications automatically

ordered for patients who were deemed palliative, with the goal of managing upper airway

secretions.

Nurses in the current study administered scopolamine not only to ensure patient

comfort, but also to ensure that the family felt that the patient was comfortable. It was

assumed by study participants that the upper airway secretions needed to be controlled by

medications. Research examining the extent to which family members are distressed by the

presence of airway secretions in dying patients has produced contradictory findings. Wee,

Coleman, Hillier and Holgate (2006) conducted an interpretive qualitative study in which

they interviewed 27 bereaved family members individually about their experiences with

their family member at the end of life. Twelve of the 27 participants (44.4%) noticed a

change in the patients' breathing patterns, but only five of these same persons (18.5%) were

distressed by the sounds related to upper airway secretions (Wee et al., 2006).

These findings stand in contrast to the results of a follow-up study again conducted

by Wee et al. (2006a). Wee and colleagues again conducted a qualitative interpretive study, and interviewed a new group of bereaved family members ($N = 17$) who had been aware of upper airway secretions while their family members were dying. In this second study, it was found that ten (58.8%) of the participants were distressed by this symptom, and interpreted the sound as being a sign of pain or uncontrolled symptoms, a sign of choking or drowning, or as a sign of impending death. However, seven family members (41.2%) viewed secretions as a normal, acceptable symptom at the end of life. The authors concluded that the assumption that families were always truly distressed by the sound of upper airway secretions was not supported by the evidence. Rather, it was suggested that communication with families about their individual interpretations and concerns be addressed to determine if the use of scopolamine was necessary, rather than assuming that the sound should be treated to minimize family distress (Wee et al., 2006a).

Misguided striving in symptom management. There was evidence in this study that nurses were sometimes misguided in their management of symptoms in dying stroke patients. One participant in this study indicated that her decision as to whether or not to administer morphine was sometimes guided by the psychosocial aspects of the clinical situation. This nurse stated that she withheld morphine with the belief that she might be able to delay the death of the patient because the family had expressed the wish that they did not want the patient to die on a certain special day. While this participant believed that her intentions in administering morphine were in the best interest of the patient and their family, this nurse was misguided in her efforts in providing symptom management at the end of life.

Using opioids to promote comfort with the understanding that a possible, though not intended, consequence of opioid administration may be the death of the patient is referred to

as the "doctrine of double effect" (Baumrucker et al., 2009; Hawryluck & Harvey, 2000; Rurup et al., 2010). One participant was certain that her actions could have the consequence of hastening death. In listening to this nurse speak, she experienced emotional distress in trying to decide how and when to administer morphine due to this personal belief that she held. There was no evidence of malice in this participant's story, as her intentions were to improve the patient's comfort and support the family. Based on Quint's Model for Care of the Dying (1967), it is possible that other nurses with whom this participant has worked also hold this belief. Such a belief may be perpetuated over time as nurses share their personal and professional experiences, rather than rely on empirical data to guide their practice. It is also possible that this nurse's knowledge base around the use of opioid analgesics in care of the dying was inadequate.

The doctrine of double effect is discussed widely in health care literature, though no papers were located in which this issue was discussed as regards the end-of-life care of stroke patients. There is a significant body of literature addressing the doctrine of double effect published from authors in the Netherlands, where euthanasia is legal. In a culture where the administration of opioids is used for both palliation of symptoms and euthanasia, there appears to be a more open discussion regarding the intent of the administration of opioids. In a Dutch study by Rurup et al. (2010), the researchers sent out a questionnaire to physicians in order to determine their views on the use of opioids for pain management. Four hundred and six physicians completed the questionnaire for a 41% response rate. The authors reported that 91% of respondents recognized that when opioids were titrated to match pain levels, opioids did not hasten death. However, 10% of the sample reported that they purposefully gave a slightly higher than necessary dose with the purpose of hastening

the patient's death. There was no evidence in the present study that patients received slightly higher than necessary doses of morphine, but one nurse believed that when she gave the prescribed dose, the patient was actually more likely to die sooner rather than naturally. When asked about analgesic administration, nurses in the present study identified that they commonly administered morphine to dying stroke patients ranging between five to ten milligrams, with no mention made of needing to escalate the doses in any cases. Without an escalation in dose, such as was discussed by Rurup et al., there was no evidence that the intent of nurses in this study was anything other than that of ensuring physical comfort of patients.

Hawryluck and Harvey (2000) discussed the doctrine of double effect in the hope of clarifying the principle, linking the virtues of fidelity to trust, compassion, courage, temperance, justice, prudence, and integrity to intentions. The awareness of this effect has been found to impact some practitioners' approach to pain management for fear of being accused of having ill intent. These Canadian authors clarified that ethical issues arose based on the moral intent and motives of the health care provider with analgesic administration. It was not evident whether or not the orientation to the neurosciences unit contained information about the use of opioids at the end of life and the principle of double effect, but inclusion of this information would support the nurses in their clinical practice. Specifically, obtaining clarity about the meaning of the doctrine of double effect and its application to clinical practice would appear to be an important action that would help to alleviate the concern nurses experience when administering opioids to dying patients.

An issue regarding a lack of knowledge about the use of opioids at the end of life contributed to the misguided striving that was identified in this study, and was found to not

be unique in this clinical setting. Fineberg, Wenger and Brown-Salzman (2006) reported

that a knowledge deficit regarding opioid use in palliative care may impede healthcare

providers in their administration of opioids, which subsequently may result in poor

symptom control. Using a quantitative approach and convenience sampling, these authors

surveyed hospital healthcare workers ($N = 381$), including nurses, physicians, spiritual care

staff, respiratory therapists and social workers. Their goal was to learn about the

perspectives of these participants in regards to unmanaged symptoms at the end of life, as

well as their knowledge about the use of opioids at the end of life. Nurses accounted for

68% ($n = 250$) of participants, and only one participant of the total number had cared for a

patient who had died during their shift in the prior six months. Regardless, 58% of

participants expressed comfort in caring for imminently dying patients ($n = 220$), and 55%

were confident in opioid administration ($n = 209$). With these levels of confidence,

participants believed that opioids were used for symptom management (75%), but also held

alternate beliefs regarding the purposes of opioid administration at the end of life. These

purposes included family comfort (91%), relieving suffering in the absence of physical pain

(81%), shortening the dying process (37%), and transitioning to palliative care (10%)

(Fineberg et al., 2006). These alternate perceptions of opioid use at the end of life suggest

that some nurses may have knowledge deficits about the purpose of opioid administration in

dying patients. Such knowledge deficits could result in misguided striving on the part of the

nurse who is trying to ensure the physical comfort of the dying patients—a finding

demonstrated in this study.

The distress experienced by the nurse as a result of her/his misguided striving may

have impacted the patient's symptom management, as it resulted in the nurse withholding

analgesics at times. In European consensus guidelines regarding opioids for pain control, it

has been suggested that patients experience a lessened risk of respiratory and cognitive

depression when regularly scheduled opioid administration is implemented. Patients are

able to develop a tolerance to the medication and experience fewer side effects after

receiving the opioids for two to three days, while still having relief from pain (Hanks et al.,

2001). In withholding or modifying a scheduled opioid analgesic, the patient may not only

have inadequate symptom relief, but is also at higher risk for the development of the side

effects which the nurse is attempting to avoid. As this aspect of pain management practice

was not examined in detail in the current study, this would be an area for future research.

Struggling to provide physical care. Participants struggled in their efforts to

provide the optimal quality of physical comfort care to dying patients. Nurses believed that

these struggles were due to several factors. These included the acuity of the patient care

area, constraints caused by the physical features of the unit, a lack of unit expertise in

providing palliative care, and the nurse's personal moral values. Accordingly, nurses

perceived that the provision of physical care to dying stroke patients in the acute care setting

was less than ideal, and at times, not even possible due to these challenges.

Patient acuity. The level of patient acuity on neuroscience units is high. In addition

to caring for acutely ill neurosciences patients, nurses in this study were also assigned to

care for dying stroke patients. Thus, participants found that in organizing their care plans,

they were required to choose between attending to patients with acute care needs *and*

patients with palliative needs. Participants stated that there was only so much time on a

shift, and that attending to all of the needs of all patients was not physically possible. While

the impact of patient acuity on nurses' ability to provide care for stroke patients in an acute

neurosurgical setting has not been examined specifically in the literature, studies examining

this issue have been conducted in other acute surgical and medical settings. In a Canadian

study, Thompson et al. (2006) studied nurses' perceptions ($N = 10$) of quality palliative care

on an acute medical unit in a tertiary care hospital. The authors found that one of the factors

which affected the ability of the nurses to "be present" with dying patients and their families

was the acute care ethos of the medical unit. Similar to the findings of this current study,

nurses who participated in the study by Thompson et al. (2006) often found themselves in a

position in which they felt that they needed to choose between the acute medical patient and

the palliative patient when organizing patient care. The nursing care of acute medical

patients who began to deteriorate, or who developed a "crisis", were prioritized over the

perceived stable needs of the dying patient. Nurses in the study by Thompson et al. (2006)

concluded that they could not provide the care which they desired to the dying patient

within the context of the acute care environment.

The acuity of the unit not only was seen to limit the nurses' ability to provide

physical care, but also limited the time they could spend participating in this care during the

moments when they were actually able to be with the patient. Time constraints, as a result

of patient acuity, significantly affected the nurses' ability to provide care beyond that of the

basics of physical hygiene care. The challenge of time constraints impacting nurses' ability

to provide care to palliative patients has been previously reported in the literature. In an

American study conducted by Peterson and colleagues (2010), nurses and nursing students

working in a variety of clinical settings reported that they did not have adequate time to

spend with palliative patients, only had time to provide the most basic of care, and provided

families with less attention than was ideal. Though the clinical settings were not described

in this study and the perspectives of students informed the findings, it appears that time

constraints are a constant challenge for nurses in trying to provide end-of-life care.

In talking about their struggles in providing care to dying stroke patients,

participants in the current study often stated that due the "chaos" of the neurosurgical

environment it was their preference for patients to be cared for on a palliative care unit.

Nurses were under the impression that the inpatient palliative care units were more peaceful

and "hotelish" in nature. The literature suggests that these impressions are inaccurate.

Street, Love and Blackford (2005), in describing a palliative care unit designated for the

care of medical patients, reported that the unit experienced 30-35 deaths per month. The

patients on these palliative care units exhibited a higher degree of symptom burden than

patients dying on a non-palliative medical unit, and required the same multidisciplinary care

as required by patients on the non-palliative acute care units. Street and colleagues (2005)

reported that because of high patient acuity, nurses on the palliative care unit found that

even they could not always meet the complex care needs of their patients. Thus the

perceptions of nurses in this study regarding the peaceful nature of the palliative care unit

are inaccurate.

While there was a perception by the participants of the current study that nurses in

the palliative care unit would have more time and resources to provide a broader scope of

palliative care, Gardiner, Cobb, Gott and Ingleton (2011) demonstrated that palliative care

units are possibly equally as busy as the acute care units, and that nurses working there have

similar demands on their time as do acute care nurses. In their British qualitative study, the

authors conducted eight different focus groups ($N = 54$) and separate individual interviews

($N = 4$) including physicians, nurses and allied health professionals who worked in acute

medical units and hospice settings. A lack of social supports, fewer referrals to a palliative

care team for non-malignant illnesses, and a focus on interventionist care were all seen as

factors which inhibited true palliative care philosophies from being applied to elderly

patients in the acute care setting. As patients with non-malignant illnesses, who are often

elderly, are not recognized to be dying until they are near the end, palliative philosophies for

these patients are not usually applied until the final days of their life. This results in less

than optimal care for these patients along the trajectory of their decline (Gardiner et al.,

2011). Subsequently, the authors concluded that palliative care for the elderly who find

themselves in an acute care setting with a non-malignant illness is often less than optimal.

As seen in the findings of this current study, the acute care ethos can impact the timely

recognition of the end-of-life patient needs and the application of palliative care

philosophies.

   The potential for survival. Nurses in this study indicated that the needs of acute

care patients were prioritized above the needs of the palliative care patients because acute

care patients had the potential for survival that dying patients did not. Participants identified

that assessments and interventions for post-operative patients, or those with an acute trauma

injury, were a priority because of the potential that these interventions would optimize

recovery.

   The dying stroke patients for whom nurses in this study provided care were

sometimes elderly. Further to the British study conducted by Gardiner and colleagues

(2011) previously described, some health care provider participants reported that they did

not believe that palliative care was meant to be provided in the acute care setting. Other

participants believed that there was more of an acceptance of death in the elderly in the

general population as "they've got less to live for" (Gardiner et al., 2011, p. 235). These

findings of Gardiner and colleagues, combined with the findings of Thompson et al. (2006)

who reported that nurses in acute care felt pulled between the acute care patients and the

palliative patients, suggests that patients' potential for survival and age played a factor in the

nurses' struggles to provide physical care. This literature is consistent with the experiences

of nurses in this study.

   The dominance of the medical model. Participants in the current study indicated

that the presence and dominance of the medical model for patient care on the unit influenced

the way in which they prioritized the needs of the acute care patients above the needs of

palliative care patients. The attending physicians on the unit were neurosurgeons who were

trained with a focus on surgical intervention and cure. Nurses believed that physicians

viewed the monitoring and care of the surgical patients to be a priority, and thus believed

that the role of the nurse was to also direct primary attention to the monitoring and care of

surgical patients.

   The traditional medical model promotes a physician-directed hierarchy in the

healthcare system. In such a model, the physician is seen to be at the top of the hierarchy of

care, and the nurse is in a supportive role of implementing the interventions determined by

the physician to be most appropriate (Brown & Seddon, 1996). This data explains and

supports the perceptions of participants in this current study that the medical model

influences nurses' efforts in prioritizing the needs of the acute care patient over the needs of

the palliative care patients.

   Brown and Seddon (1996) reviewed the curricula of both nursing schools

($N = 14$) and medical schools ($N = 4$) in Australia, and found that while nursing education

contained 21% of anatomy and physiology content, medical schools courses contained 48% of content focused on physiology. While the differences in this aspect of education are not unexpected, the authors suggest that the larger quantity of physiology education provided to the medical students is one reason for the prominence of the medical model in healthcare. The authors also reviewed *the Australian Journal of Advanced Nursing* and the *Medical Journal of Australia,* and found that overall there were significantly more general papers published in the medical journal ($N = 240$) versus the nursing journal ($N = 23$) for the period of one year. This difference was believed to be the result of a greater acceptance of a research and a publishing focus in medicine, as well as a lack of clarity by nursing on how they contribute to patient care (Brown & Seddon, 1996). Educational curriculum and a strong research focus, combined with the lack of an introduction of an alternative model of care, have resulted in the ongoing prevalence of the medical model in guiding patient care.

The medical model of care was discussed in an editorial by Shah and Mountain (2007) in which they sought to determine a more contemporary meaning for this term. The most recent definition proposed that the medical model is "is a process whereby, informed by the best available evidence, doctors advise on, coordinate or deliver interventions for health improvement" (Shah & Mountain, 2007, p. 375). The wording, "health improvement" alone gives one the sense that the main goal of patient care within a medical model is to aim for healing and recovery. Although this is an optimal goal, not all patients can recover, so this medical model, which is prominent in most health care settings, does not seem to fit the palliative care approach. For patients with more extensive strokes who were on the neuroscience unit and who were known to be dying, there was no hope for recovery or health improvement. Therefore, nurses believed that because there was little to

do to help these patients, dying stroke patients were assigned a lower priority than acute

patients when organizing nursing care.

Physical environment constraints. Participants in this study believed that a private

room was an essential component of palliative care as it allowed families an intimate

environment in which to spend their final days with the patient. Nurses perceived that they

were unable to provide ideal palliative care when they were unable to provide this

environment for the patients and their families. In her neurosciences nursing text regarding

patient care, Hickey (2009) suggested that a quiet space that minimized the noise from the

rest of the unit improved patient comfort because such a space lessened external stresses.

However, the extent to which these stated outcomes actually result because of patients being

cared for in a quiet space have not been examined empirically. Concern regarding the lack

of a private room for dying patients was also reported in a study by Thompson et al. (2006),

in which the perceptions of the quality of end-of-life care were evaluated on an acute

medical unit. One of the conclusions of this grounded theory study was that nurses found

that they sometimes needed to manipulate the physical environment to best support the

patient and family. Nurses believed that they accomplished this goal by attempting to create

privacy for the patients and families, and by "relaxing the normal rules of the unit" (p.174)

regarding visiting hours. The authors' findings supported the need to facilitate a more

optimal physical environment for the family as well as the patient who is the room mate of

palliative patient in a double occupancy room.

Nurses in this current study were also concerned that the lack of a private room

negatively impacted non-palliative patients who had to share a double occupancy room with

someone who was dying. Their concern was related to the fact that in sharing the room, the

second patient was required to witness the dying experience of the palliative patient and the

emotional expression of the patient's family and had nowhere to escape. Nurses in this study

felt that such a situation was unacceptable, as it affected the experience of both the patient

and the roommate. This perspective was echoed in an editorial in which the author shared

her experience as the hospice visitor of a dying patient who was in a semi-private room

(Behuniak, 2009). Behuniak noted that although there was a curtain in the room, it only

provided visual privacy. The dying patient was exposed to the actions and sounds of other

patients, visitors and staff. Personal and private conversations between dying patients and

their family members were rarely truly private because the roommate and/or their family

were always within close proximity. The roommate would have to experience conversations

about death and funeral planning, as well as the smell of incontinence and possible wound

odors emanating from the dying patient. Consistent with the nurses in the current study,

Behuniak questioned the dignity of a person not being allowed to die in a peaceful and

private environment.

Nurses in this study indicated that hospital bed utilization processes were the main

factor contributing to the lack of a private room in which to care for dying stroke patients

and their families. Nurses stated that there was always a demand for a neurosurgical

hospital bed; a situation made all the more acute by the fact that the unit from which nurse

participants were recruited was the only neurosurgical unit for the province. Although

several articles were located discussing the different aspects of bed utilization, only one was

related to the specific pressures identified in this study. Menec, Bruce and MacWilliam

(2005) performed a retrospective review of all charts in all of the acute care hospitals from

1996 to 2000 in a large Canadian city ($N = 9356$). Their goal was to see if there were

patterns in the appropriateness of hospital admissions during high volume periods of patient

visits to the emergency departments. Using InterQual's 1999 ISD Clinical Decision Support

Criteria, Menec et al. (2005) concluded that 96% of admissions during high volume periods

were appropriate, but that "bed blockers" were also a factor in the bed utilization system.

The "bed blockers" were identified as patients who became non-acute after having their

illness stabilized and whose needs could be suitably met in a non-acute care setting. Of the

admissions analyzed, 31% of patients' admitted days were spent with them being non-acute,

9% of the inpatient days were spent waiting for home care; 8% of days were spent waiting

for diagnostic testing, and 5% of patient days were seen to be better suited for care to be

provided in a palliative care setting. The ethos that acute care beds should be used for acute

care patients only was a value shared by nurses in this study, and contributed to systemic

pressures experienced in providing end-of-life care to dying stroke patients.

A lack of single, private rooms was also cited as a challenge in a grounded theory

study performed by Casey et al. (2011), in which the researchers examined factors that

supported positive end-of -life care in acute care and long-term care settings. Involving 304

long-term care facilities and 23 acute care hospitals in Ireland, Casey and colleagues used

purposive sampling to recruit 33 nurses for individual interviews. The authors developed a

model which represents the concept of dying well; this central concept was found to be

influenced by the physical care environment, the possibilities of getting to know the patient,

as well as the philosophy and organization of care in the setting in which it is provided

(Casey et al., 2011). When discussing the influence of the care environment, nurses felt

strongly that being able to provide a private room at the end of life allowed the patient and

family dignity. These same nurses, however, also found that this was rarely possible due to

the lack of single rooms, as well as the priority of those rooms available to be assigned to

patients who were under infection control isolation precautions. These findings are

congruent with the experiences and perspectives of nurses in the current study.

     Perceived lack of nursing expertise in palliative care. It was evident that nurses

who participated in this study had a preference for moving their patients to a palliative care

unit. They had this preference because they believed that the nurses in a palliative care unit

possessed a greater expertise in the provision of palliative care. This belief was an

extension of the perception that palliative care units were quieter and staffed by nurses who

were highly skilled in providing palliative care. While participants in the present study felt

confident in the provision of neurological care, they did not possess the same degree of

comfort and confidence in the provision of palliative care to stroke patients. In their

grounded theory study examining nurses' experiences in caring for dying patients, Peterson

et al. (2010) also reported that nurses expressed concerns in being able to provide care for

dying patients, as they felt that they did not possess expertise that allowed for these patients

to receive the best care possible.

     As the literature suggests that increasing numbers of people will die in an acute care

setting (Gardiner et al., 2011), it will be crucial that all healthcare providers have some

knowledge in providing end-of-life care and an awareness that palliative care is a

philosophy of care rather than a place of care. Although palliation of patients with an ICH

has not been focused on in the literature, end-of-life care is on the continuum of stroke care

and awareness of this aspect of care in the acute neurosurgical setting needs to be increased.

There was no literature located discussing this aspect of the nurses' experiences within the

context of providing palliative care to these patients.

Personal moral values and beliefs. There was some suggestion in the literature that a nurse's moral values and beliefs contributed to the struggle in providing comfort care**.** One participant expressed reservation in having to act on a physician's order to remove an endotracheal (ET) tube. Although this particular participant was aware that she was legally covered by the hospital policy to remove the breathing tube (Hickey, 2009; Sykes, 2004), she believed that doing so was a violation of her personal values because she perceived it as an action that would bring about a precipitous end to the patient's life. In reality, the underlying disease was the cause of the patient not being able to protect his/her airway independently, and the patient had been artificially supported to the point at which the tube was removed (Reilly & Bullock, 2005; Sykes, 2004).

This specific nurse experienced some dread and distress in anticipation of receiving the order from the physician. Because a colleague was prepared to implement the order, the participant was able to find a solution to the situation in which she herself would not be required to extubate the patient. Having to face and organize an alternative solution to her problem did result in a degree of struggle for the nurse in providing palliative care. The participant was able to make a choice to stand up for her personal values and found a solution that prevented her from participating in what she viewed as an ethical violation (Corley, 2002; Webster & Baylis, 2000).

The issue of ET tube removal has been discussed in the critical care literature. In one study, a narrative questionnaire was administered to a convenience sample of critical care nurses ($N = 31$) with the goal of examining the experiences of nurses who participated in the withdrawal of mechanical ventilation (Kirchhoff, Condradt, & Anumandla, 2003). Participants reported on patients' physical sensations and symptoms, time until death, and

environmental conditions, but did not comment on any personal emotions or ethical concerns experienced as a result of participating in extubating the patient.

In an interpretive phenomenological study aimed at examining the lived experience of critical care nurses who participated in the withdrawal or withholding of treatment, Halcomb, Daly, Jackson and Davidson (2004) interviewed nurses ($N = 10$) to glean meaning from their experiences. Themes uncovered included: care and comfort, tension and conflict, do not harm, nurse-family relationships, and invisibility of grief and suffering. Nurses focused on supporting families in the decision-making process, ensuring comfort for the patient and supporting the family in the loss of their loved one. Within these experiences, nurses did not express any concern regarding their role in the actual withdrawal of an ET tube, but rather experienced grief and personal sadness in recognizing the loss of life. Although they did find that this grief may stay with them outside of the workplace, there was never a question about the process of withdrawing treatment.

In a healthcare literature review, Canadian authors, Reynolds, Cooper and McKneally (2005) examined the ethical considerations of withdrawing life-sustaining treatments as well as guidelines to support the care of patients in these circumstances. The literature review suggested that although healthcare providers recognize the need to withdraw treatment when death is inevitable and the underlying disease is not reversible, they nonetheless experience a sense of personal responsibility about the event that is unavoidable. This reaction may be due to the fact that the intent in removing the ET tube is not to kill the patient, although withdrawing the airway support will hasten the patient's inevitable death. Reynolds et al. (2005) further discuss religious and cultural factors, prognostic uncertainty, variability in medical practice, advances in medical technology, and

legal concerns as influencing the context of decisions made. Both personal responsibility and personal moral beliefs were cited as reasons to not participate in removing the ET tube in the current study, and reflect similar experiences found in the healthcare literature.

Providing Psychosocial Care

As presented in Chapter 3, the sudden onset of the patient's stroke combined with the experience of being in an acute health care setting resulted in family members of stroke patients needing psychosocial support and information from the health care team. Addressing these needs falls under the umbrella of providing psychosocial care to family members. Though it was time-consuming, nurses in this study viewed providing psychosocial care to families as an essential part of their work. This perspective is consistent with Kehl's (2006) assertion that psychosocial care of patients and families is crucial component of care as it improves the quality of the patients' and families' experience at the end of life. The following sections will discuss the striving and struggling that nurses experienced in their efforts to provide psychosocial care in relation to the literature.

Striving to meet families' support and information needs. The World Health Organization (WHO) definition of palliative care (2012) cites a holistic focus of care towards the patient and their family, encompassing the physical, psychosocial, emotional and spiritual realms. After the physical care needs of the patient were met, participants in the current study shifted their focus towards providing psychosocial care of the family. In striving to provide psychosocial care, participants in the present study: i) developed relationships with family members; ii) tried to 'soften the blow' of the patient's impending death for families; and iii) drew upon multidisciplinary resources to help ensure that support

families' support and information needs were met. Nurses also acknowledged the role that

their personal experiences played in the way they provide psychosocial care to families.

These findings will now be discussed in light of existing literature.

     Developing relationships with families. Nurses believed that 'being present' was

the most important intervention they could offer to the family of the patient. By being

present, nurses could develop rapport with families, and be available to address their

questions. Nurses recognized that the presence of someone who demonstrated that they

were interested and cared about the patient and family was comforting to the families, and

led to the development of a therapeutic and open relationship that was supportive of family

needs.

     Although the notion of 'being present' was not identified in the neurosciences

nursing literature, it is discussed in the palliative care literature. Within the results of their

Dutch qualitative study examining nurses' perspectives of providing palliative care in an

acute care setting ($N = 10$), Georges et al. (2002) found that nurses viewed 'being present'

as an essential role of nurses in that it positioned them to not only be supportive, but

allowed them to assess concerns and develop relationships with families. Similarly, in their

grounded theory study examining nurses' perceptions of quality end-of-life care on an acute

medical ward, Thompson et al. (2006) also identified that nurses perceived that the role of

nursing was to 'be there' for patients and families. By 'being there', nurses were able to

provide psychosocial support and answer questions that families had (Thompson et al.,

2006). Although the research studies conducted by Georges et al. and Thompson and

colleagues did not take place on neurosurgical units, they were conducted on acute care and

academic clinical settings— features of the unit on which nurses in this study practiced.

Participants in the current study explained that in order to develop a sense of rapport with families, they frequently encouraged family members to share memories of the patient. This practice was not documented in the neurosciences literature, but appeared in the palliative care literature. Albinsson and Strang (2003) conducted a qualitative study interviewing family members of patients to examine their existential perspective of caring for patients with end-stage dementia ($N = 20$). In their data analysis, these Swedish authors derived four themes which included: "freedom-choices-responsibility, existential isolation, death, and meaninglessness" (Albinsson & Strang, 2003, p. 228). An important finding of Albinsson and Strang's study that is relevant to the current study is that in an attempt to find meaning in death, families found it helpful to share memories with those persons who were experiencing the dying process with them (Albinsson & Strang, 2003). Future work is needed to explore the impact that neuroscience nurses' efforts in encouraging families to share memories has as regards the development of the nurse-family relationship.

Though it is intuitive to believe that encouraging families to share such memories will be helpful, the literature suggests that this might not always be the case for some family members. The presumed benefits of engaging family members in sharing memories of the patient reported in the literature include helping families retain an attachment to their dying loved one, as well as maintain their own sense of identity in their grief (Baddeley & Singer, 2010). American researchers Baddeley and Singer suggest, however, that sharing memories, or personal narratives, may be problematic for families and can potentially lead to disagreement and conflict between family members if they individually ascribe a different meaning to the narrative. Silent memories are those personal family memories which are not verbalized, but are rather internalized and kept private. Each family member,

with their silence, has the opportunity to frame their memories within their own context and

formulate a version of the memories that best allows them to cope with and manage their

personal grief (Baddeley & Singer, 2010). Future research is needed to evaluate the actual

impact that memory sharing of families of dying stroke patients has on family members'

experiences of receiving psychosocial support from nurses.

Another way in which nurses attempted to develop relationships with families was

by providing a private room in the patient's final days. Privacy for personal conversation

between families and nurses that a private room would afford was seen as ideal to develop

more meaningful and effective relationships with families. Nurses believed that families

were more open with their thoughts and feelings when they were not sharing a room with

another patient. This belief was also endorsed by the findings of Thompson et al. (2006)

and Behuniak (2009), as previously discussed.

Trying to "soften the blow" for families. When caring for palliative stroke patients,

nurses expressed concern that although the families had been told of the prognosis, they still

may not understand the severity of the situation and would become overwhelmed with

shock when the patients did die. In an effort to minimize this shock, nurses would attempt

to soften the blow of death for families by offering information about their nursing

assessments and observations of the patients' clinical condition, even if this information was

not sought out by the families. By providing such information, nurses aimed to ensure that

the families were aware of the obvious functional decline of the patient.

Providing information about the patient's condition in the service of 'softening the

blow' for families was not discussed in the neurosciences literature, but was evident in the

palliative care and critical care literature. Stayt (2009) conducted a descriptive

phenomenological study exploring the emotional impact on nurses who were caring for

families of patients who were dying in a critical care setting after experiencing an acute

illness ($N = 12$). Using purposive sampling of nurses in a critical care unit in a teaching

hospital, this author found nurses experienced many different emotions, with common

themes including the perceived significance of death, establishing trust, information giving,

empathy, intimacy, and self-preservation. Of relevance in these findings is that the

participants in Stayt's study believed that the sharing of information did help to develop

relationships with families, even if sometimes the information which they shared was 'bad

news' for families. Nurses would attempt to balance hope and honesty in an attempt "just to

soften the blow" (p. 1271). Participants in Stayt's study found this experience distressing,

as they were not always comfortable in confirming the patients' grim prognosis with

families, but believed that by gently doing so, they were able to minimize the anxiety

experienced by families (Stayt, 2009). Consistent with the findings in the current study,

nurses in Stayt's study attempted to "soften the blow" for families by gently sharing the

reality of the situation, even when their support was not solicited.

The general healthcare literature indicates that the manner in which information is

shared with family members influences their response to it. The role of the nurse in

breaking bad news and sharing information in the acute care setting was examined by

Warnock, Tod, Foster and Soreny (2010) through the use of a descriptive survey

($N = 236$). Using Likert scales, this questionnaire explored how often nurses actually broke

bad news, what barriers nurses experienced in providing bad news, the perceived experience

of breaking bad news, any training nurses had received to perform this intervention, and

how long they had worked as a nurse. Warnock et al. (2010) found that few nurses

consistently delivered bad news ($N = 53$), but more consistently provided support to families

after the physician had relayed information to families (N = 131). The approach of

supporting families after they received the bad news was similar to that of nurses in the

current study who did not see it as part of their role to directly deliver bad news. Rather,

they preferred to follow-up with families after the physician had primary contact and

provide support by clarifying any additional questions which the families may have.

Much has been published regarding approaches for effective communication with

patients and families in end-of-life care. Buckman (2001) presented guidelines discussing

the role of communication skills in medical palliative care. Tools such as the CLASS

protocol outlines the strategies to consider when broaching a difficult conversation, and

includes the following components: context or setting, listening skills, acknowledging

emotions, strategies for communication management, and a summary plan with closure in

the conversation. Each of these areas was further expanded on to discuss body language, as

well as other non-verbal actions such as touch, which have been found to communicate

support and understanding to patients and families (Buckman, 2001). A second guideline

presented was the SPIKES protocol, a derivation of the CLASS protocol, which included:

setting, perceptions of the patient, invitation from the patient to talk and share, knowledge

sharing about medial facts, exploring emotions and empathizing, and strategies/ summary.

These steps were very similar to the CLASS protocol, and offered some professional

structure and guidance to health care professionals who might be uncertain about how to

communicate effectively with patients or families (Buckman, 2001). The literature also

suggests that these various approaches to communication are applicable for nursing practice

(Kaplan, 2010; Rosenzweig, 2012). Given the importance of skilled and sensitive nurse-

family communication in end-of-life care, future research is needed to explore neuroscience nurses' perspectives regarding their perceived role in communicating prognostic information with family members, their awareness of communication strategies to structure such conversations, and perceived barriers in being able to engage in such dialogue.

As part of their efforts in "trying to soften the blow" for families, nurses encouraged families to verbally communicate with the often unconscious patient, with the underlying belief that patients with a decreased level of consciousness may be able to hear and understand. Nurses viewed this communication as essential as it allowed family members to share final thoughts and feelings with the patients, and hopefully minimize any feelings of regret that might develop in the bereavement period. The belief that unconscious patients may be able to hear and understand has been debated in the neurosciences literature, although the true experience of these patients is unclear as it is not possible to verify this verbally with unconscious patients.

Cruse et al. (2012) examined the relationship between the pathophysiological state of patients and the observable versus covert levels of functioning they experienced. Using a convenience sample of twenty-three patients in a British hospital who were considered to be vegetative or non-responsive due to brain injury, the authors asked the patients to visualize themselves moving a specific limb. The researchers then observed the patients' physical responses to sound and command using the revised Coma Recovery Scale for consistency, and compared these findings to the simultaneous motor imaging electroencephalography (EEG) measurements. In 22% ($N = 5$) of cases, patients were visibly observed to be responsive to the command, with concurrent brain activity evident on their EEG (Cruse et al., 2007). It was noted, however, that patients demonstrating an awareness and response to

the stimulus, had all suffered a traumatic brain injury. In contrast, participants who had

suffered a stroke ($N = 8$), did not demonstrate any behavioral or EEG changes when

examined. Though the findings of Cruse et al.'s study are limited because of its small

sample size and recruitment occurred at only two hospital sites, it suggests that perhaps the

unconscious stroke patient cannot truly hear what is being said, and that encouraging

families to speak to the patients in the final days of life is solely an intervention directed at

supporting the emotional and psychological health of the families at the bedside. Studies

are needed to provide a better understanding of the experiences of the unconscious patient,

and how best to interpret their responses.

Nurses in the current study helped prepare families by coaching them to engage in

important activities and conversations with a relative who was imminently dying. The

palliative care literature supports the importance of such activities for families. Clukey

(2008) conducted a qualitative study in the United States in which she interviewed bereaved

family members, whose loved one had been in a hospice, to gain a better understanding of

their experiences with anticipatory grief ($N = 9$). Seven participants were interviewed

within a year of the patient's death, one at 36 months, one at 108 months. Interview data

revealed that the process of anticipatory grieving included five steps: realization, caretaking,

presence, finding meaning, and transitioning to death. Families were better able to cope and

work through these steps, if they were able to participate in care giving activities which

allowed them to connect with the patient, and maintain a sense of normalcy. Consistent

with the findings of the present study, this included families and patients sharing memories

or stories from the past with each other (Clukey, 2008). The extent to which nurses in the

present study believed that coaching families to engage in these activities might help

families better cope with their loss in the bereavement period was not explored with study participants.

A phenomenological study was conducted by Sutherland (2009) to examine the meaning of being in transition to end-of-life care among female partners of spouses with cancer ($N = 8$). The findings from that study suggest that the act of reviewing and talking about the relationships they had with their spouse and recounting their spouses' achievements enabled participants to attend to unfinished business, and redefine their relationships and move forward. The meaning that such activities provide was identified by Sutherland as consistent with the work of individuals experiencing anticipatory grief, and suggests the importance of health care providers encouraging discussions that support meaning making in those whose loved ones are dying. In encouraging families to speak with the dying patient, nurses in the current study were affording families an opportunity to say all that they felt they needed to say before the patients died, with the hope that they would have no regrets. Even though patients in the current study were unresponsive, nurses believed that these conversations were of benefit to the family to help them cope with the death. Though the spouses in Sutherland's study were not identified as being unresponsive, both her findings and the findings of the current study suggest the importance of encouraging families to speak about their loved ones, their futures, and uncertainties that are being experienced as the patient transitions to the final phase of illness.

In their efforts to soften the blow for families, participants in the current study believed that nurses were physically best positioned to provide psychosocial support to families of dying stroke patients as nurses have a constant presence at the bedside. They are available to speak with families whenever called upon, and strove to be present to support

the family emotionally, and respond to questions whenever family sought them out. Research examining the importance of nurses "being present" or available for the patients and their families (Georges et al., 2002; Simon, Ramsenthaler, Bausewein, Krischke, & Geiss, 2009; Thompson et al., 2006) has been conducted, and supports this role for nurses.

No data were found which discussed the impact of physical proximity and the roles of nurses specifically in this regard in either the palliative care or neurosciences literature, although data does exist in the palliative care literature which discusses the disadvantages of the physical proximity of the nurse in providing care. Peter and Liaschenko (2004) explore the potentially positive and negative effects of the physical proximity of nurses in the context of moral ambiguity and moral distress. In their review of nursing literature, these authors found that the nurse-patient relationship was supported by the nurses' defaulted proximity to patients in the care setting. Due to their role, nurses were best positioned to respond to the needs of patients, but face challenges based on the intensity, duration and resources of the relationship. Resources which were considered to be critical to the support of patient care included: actual time to spend with patients, adequate staffing levels, and multidisciplinary resources. The authors concluded that moral obligations, due to the nurses' proximity to the patient, result in nurses striving to meet as many of the patients' needs as possible (Peter & Liaschenko, 2004).

According to Peter and Liashencko (2004), when nurses perceived that they did not have enough time to afford patients, or did not have adequate staffing to meet the needs of patients, they attempted to modify their care plans. In circumstances in which nurses were physically and emotionally overextended, and were subsequently not able to engage in interaction with patients or families, nurses needed to compromise their efforts. When

physician resources were not available, nurses found themselves needing to independently

order tests and investigations. In each of these aspects of care, nurses needed to

compromise their values and even work outside of their scope of practice in order to ensure

patient care needs were met (Peter & Liaschenko, 2004). The authors concluded that such

compromise leads to moral ambiguity, in which the nurse needs to balance his/her own

values against the reality of their environment. When unable to find a satisfying solution to

their ambiguity, nurses were at risk to develop moral distress. If this occurred, they were

more likely to begin to display avoidance behaviors towards the patient, which further

impacts moral ambiguity (Peter & Liaschenko, 2004). As nurses were in physical

proximity, they had an obligation to provide patient care, but at times, this placed them in a

challenging moral position when they were unable to sustain the nurse-patient relationship

on terms which satisfied their personal and professional values (Peter & Liaschenko, 2004).

Nurses in the current study were aware of the advantages of their being readily available at

the bedside to provide patient care, but did not identify these more perilous risks associated

with their role as discussed by Peter and Liaschenko.

Acknowledging personal experience. The findings of this study indicate that

personal experience with death and dying influence nurses' perspectives regarding the

provision of psychosocial care to dying stroke patients and their families. No English

language literature on this topic within the context of palliative stroke care was located,

however, work conducted by Simon et al. (2009) supports the assertion that a nurse's

attitude indeed influences the nature of care he/she provides. Simon and colleagues

conducted a qualitative study in Germany to describe and determine the meaning and

influence of nurses' core attitudes in providing palliative care, and examined how they

interact with patients and their families. These authors described core attitudes as being

personally held attitudes of which the individual is aware, and which affect the way in

which the person approaches the world around them. Content analysis of transcribed

individual interviews ($N = 10$) revealed that personal and professional life experiences were

seen to frame a nurse's future perspectives and possibly guide future behaviors.

Personal characteristics which defined cores values in palliative care were found to

include authenticity, mindfulness, honesty, appreciation, openness, personal presence and

responsibility. Core values were evident and experienced in relationships and

conversations, and were found to affect individual behaviors. Behaviors which were

influenced an individual's core values included their perception of others, the authenticity of

active listening, how openly one gets involved in relationships, and the efforts put forth to

create a conducive space in which to provide care (Simon et al., 2009). Each of these

characteristics combined were found to affect the manner in which a nurse views and

approaches patient care. If nurses embraced the personal characteristics discussed by Simon

and colleagues, their relationships with patients and families were found to be deeper and

more meaningful, as this behavior resulted in nurses being more active and attentive in

listening to the needs of the patients (Simon et al., 2009). The degree of investment in and

development of core values were found to be influenced by personal and professional

experiences, and may explain the influence of personal beliefs and values as expressed by

participants in the current study.

Research conducted by Kristjanson et al. (2001) also speaks to the influence of

personal experience with death as influencing the care that nurses provide. A descriptive

qualitative study was conducted in which palliative care nurses' ($N = 20$) perceptions of a

good versus a bad death were explored. Within their findings, it was evident that personal experience with death was a factor for the participants and resulted in them wanting to ensure that they supported a "good death" for their patients. On a personal level, nurses felt that friends and family did not support, nor did they understand, the need for nurses desire to care for dying patients. Participants in Kristjanson et al.'s study also felt that they could not necessarily live up to the expectations of friends and family who expected that nurses should always be altruistic and caring in their actions simply because they worked in the field of palliative care. In some cases, nurses had experienced a negative death with a family member, leading them to strive to ensure that others did not suffer in a similar manner. Regardless, these beliefs framed the personal expectations which nurses held for themselves in providing palliative care, with the latter finding of a negative experience with death being similar to the experience of participants in this study.

Neuroscience nurses in this study derived a great deal of personal satisfaction in being present with families and sharing the final days of the patients' lives with family members. One nurse in the current study also expressed that he found the experience of providing palliative care to be rewarding and personally uplifting to his own spirit. While there were no articles discussing this aspect of providing end-of-life care in the neurosciences literature, relevant research was evident in the palliative care literature. Wu and Volker (2009) conducted a descriptive qualitative study examining the experiences of nurses providing palliative care in a hospice setting in Taiwan ($N = 14$). Major themes derived from interview data included: entering the hospice specialty, managing everyday work, living with the challenges, and reaping the rewards. Within the theme of reaping rewards, nurses expressed that they were energized and felt quite happy in providing end-of-

life care, as they could see that patients and families benefited from receiving physical and

psychosocial support. Participants subsequently felt that these positive perspectives

translated into the nurses having more meaningful personal relationships outside of the

workplace as well. Overall, they felt that the experience was very rewarding (Wu & Volker,

2009). Although nurses in the current study were not asked to elaborate on the positive

effects of care giving carrying over into their personal lives, they did share experiences

similar to that of the nurses in Wu and Volker's study, and felt privileged to be supportive

of patients in their final days.

In a Chinese study exploring nurse-patient relationships in palliative care, Mok and

Chiu (2004) interviewed nurses who worked in a hospice setting ($N = 10$) as well as patients

who were the recipients of care ($N = 10$), and found similar experiences as those presented

by Wu and Volker (2009). On analysis of their individual interviews, the authors concluded

that themes explaining the nurse-patient relationship included: forming a relationship of

trust; being part of the family; refilling with fuel along the journey of living and dying; and

enriched experiences. Participants described providing end-of-life care as personally

rewarding and satisfying, and believed that they also developed deeper levels of patience

and appreciation in their personal lives (Mok & Chiu, 2004). These findings are similar to

the experiences of nurses in the current study in that nurses did express that they found

providing end-of-life care rewarding and satisfying.

Webster and Kristjanson (2002) conducted a descriptive qualitative study to describe

the meaning of palliative care from the perspective of six long-term palliative care workers.

Using purposive sampling, the authors interviewed Australian healthcare providers (a nurse,

a doctor, a social worker, a chaplain, a counselor, and a visiting volunteer) who had worked

a minimum of five years in the palliative care setting. Based on their findings, the authors

developed a conceptual framework of caregiver experience that had at its core the concept

of vitality, defined as "the capacity to live and develop" (Webster & Kristjanson, 2002, p.

18). One component of the vitality framework entitled, "a way of living" identified that

study participants derive a strong sense of fulfillment and personal growth in their work

with palliative patients and families. Participants shared how they found fulfillment in

sharing similar values and emotions with patients and families in the process of providing

care, and felt privileged to be present in the final days of an individual's life (Webster &

Kristjanson, 2002). The personal attributes of finding meaning and fulfillment when

providing palliative care, or feeling touched in the heart, were relevant within the context of

the current study, as nurses in the current study expressed having similar experiences in

their provision of end-of-life care.

   Engaging multidisciplinary resources. Nurses who participated in the current study

believed that they had access to a wealth of multidisciplinary resources which were readily

available to optimize the patient and family care experience based on their needs. Social

work, spiritual care, Aboriginal Health services, palliative care, the psychiatric nurse liaison,

translation services and the hospital ethics committee were viewed to be resources which

participants could consult as needed. There is evidence in the neuroscience nursing

literature that collaboration with a multidisciplinary team is seen as important in the

provision of holistic end-of-life care. Cowey's (2012) review of the medical and nursing

stroke literature and development of clinical practice guidelines for the care of dying stroke

patients revealed that engagement of the multidisciplinary team helped facilitate discussion

of the patients' treatment preferences, goals of care, and minimizing symptoms, and was

seen as most helpful when difficult discussions and decisions regarding issues such as fluids

and nutrition were required. However, Cowey (2012) also identified that there is a

preference amongst healthcare providers to possess both neuroscience and palliative care

knowledge in order to provide optimal care to patients and families in this population,

regardless of the availability of multidisciplinary resources. This finding is consistent with

what nurses in the current study reported.

Though not addressing the care of dying stroke patients directly, work by Yeager

and colleagues (2010) also speaks about the importance of a multidisciplinary approach in

delivering palliative care. In an effort to better structure their approach to palliative care,

Yeager et al. (2010) developed the "Embrace Hope" guidelines in a neurosciences intensive

care unit. With the input of a multidisciplinary team including neurosciences and palliative

care nurses, a neurosurgeon, a social worker, spiritual care persons, a unit clerk, a nursing

case manager, and a nurse practitioner, this team developed a checklist of interventions

which were seen as essential to support patients and families in providing end-of-life care.

In follow-up questionnaire evaluation of this tool, Yeager et al. (2010) found that nurses (N

$= 39$) believed that the guideline was effective in supporting more holistic patient care as it

ensured that all aspects of physical and psychosocial care were addressed for all patients.

The checklist was a reminder for staff to implement interventions for the patient who was

dying and helped ensure that bereavement support and acknowledgment of the patient's

deaths were part of the care plan. Acknowledgement of the patient's death was

accomplished through cards being sent from the staff to each family within one week of the

patient's death. Although the impact of this guideline has not been empirically validated, it

would appear to be a beneficial resource in the acute care setting wherein staff members

perceive that they do not always have the time to think of the psychosocial support of the

patient and family and want to be certain to provide meaningful and effective end-of-life

care.

In other palliative care literature, Street et al. (2005) conducted a mixed methods

study in Australia comparing the management of palliative care patients across twelve

different settings including acute palliative care and hospice units, geriatric rehabilitation

units, rural palliative care units, and long-term care settings. Individual interviews of

nurses, physicians and pastoral care staff ($N = 88$) and the Palliative Care Practices

Questionnaire (PCPQ) responses of nurses, physicians, pastoral care staff, and allied health

staff ($N = 421$) were used to examine practice in these different care settings. Although there

was a broad range of philosophies in palliative patient care in each of these areas,

multidisciplinary care was seen to be central to the provision of care across all of them.

Participants believed that family-centered care was critical to ensuring quality end-of-life

care, and that a collaborative multidisciplinary approach was essential to this practice (Street

et al., 2005). Acute care settings were found to have access to more extensive supportive

services, although services were not specific to palliative care philosophies. Specific

palliative care services, such as bereavement support and resources to meet individual

spiritual care needs, were not always available within the curative environment. The

importance of a collaborative multidisciplinary approach endorsed by the participants in the

work of Street and colleagues stands in contrast to the perspectives of nurses in the current

study who did not always appear to see the need for a multidisciplinary approach to care,

and rather, preferred to rely on their own expertise.

Assessing and supporting the spiritual care needs of patients and families was

viewed to be a significant aspect of striving to provide multidisciplinary psychosocial care by nurses in the current study. Nurses who stated that were comfortable to directly ask families about their religious or spiritual needs, also expressed that they themselves had personal spiritual and religious beliefs. The personal beliefs of those participants who did not discuss spiritual support during their interviews were not explored by the researcher.

No data was located regarding nurses' perspectives about the provision of spiritual care to dying stroke patients, and/or about the spiritual needs of stroke patients within the neurosciences literature. However, the importance of attending to spiritual care needs of dying patients in a multidisciplinary context has been discussed in the palliative care literature. In a nursing literature review conducted by Nussbaum (2003), the author concluded that spirituality needed to be forefront in care to balance the ever-developing focus on the physical technological aspects of care. The External Priority Index is a questionnaire which ranks patients' priorities about care received combined with the patients' overall satisfaction in each of the areas questioned. As part of the literature review conducted, the author includes the results of her hospital survey of inpatients in an American acute cardiology unit, which used this Index as a measurement tool. Survey results indicated that "meeting spiritual and emotional need" was rated as a high priority by inpatients (Nussbaum, 2003). Meeting patients' spiritual and emotional needs helps to promote spiritual health and well-being which in turn has a positive impact on physical health. The author suggests that multidisciplinary rounds that include a spiritual care provider may help ensure that patients' spiritual care needs are met. Such an approach would allow for early intervention, and subsequently a greater chance to remedy spiritual distress (Nussbaum, 2003). Although the participants in the current study were aware that

some patients and families had spiritual needs, they did not see a role for themselves in directly providing the care to meet those needs. Rather, they saw their role as initiating an automatic referral for patients who demonstrated a religious affiliation.

Nurses in the current study shared an awareness of the ethics committee as a resource which they could call upon if needed to help resolve ethical issues for patients and families. Participants noted that they did not utilize this resource routinely, as they believed that consults often took several days to be attended to, and patients often died before the consultant came to see the patient. This component of care was not located in the neurosciences literature, but was present in the palliative care literature. Christopher (2001) explored the functions of various American ethics committees in the collaborative process of end-of-life care. The author derived that members of these committees were involved in advanced care planning, discussions regarding resuscitation status, accessing psychosocial resources, evaluating pain and symptom management, and evaluating realigning treatment discussions (Christopher, 2001). By participating in these areas of care, ethics committees were seen to optimize an individual's palliative care. Although members of ethics committees could be found involved in specific cases, their role is considered to be directed to inform and support patient advocacy and system change. Persons who are part of this resource are often a resource for healthcare professionals, to assist them with difficult situations and subsequently function to guide more global clinical practice (Aulisio & Arnold, 2008; Christopher, 2001). As decisions regarding complex ethical circumstances are not always easily resolved, it is possible that with consults for patients with a prognosis of days, that there is simply not adequate time for the situation to be assessed and managed by the ethics committee, as found by the nurses in the current study. No literature was

located which examined this aspect of care.

In another review of the medical literature, Aulisio and Arnold (2008) attempted to determine why ethics committees exist and how they could contribute to clinical practice. The authors found that these committees serve to offer guidance on legal, moral, regulatory and professional issues that might arise during the provision of palliative patient care. The expertise of the committee members in balancing values, morals and the individual's preferences is invaluable in the healthcare system where complex decisions sometimes need to be made (Aulisio & Arnold, 2008). In addition to consultative services, ethics committees also serve to provide education about common ethical issues and participate in policy development. What is unique to ethics committees is that when they are consulted, their role is directed more so towards supporting the staff in their efforts to facilitate decision making process in the healthcare setting, rather than directly supporting the patient or their family (Aulisio & Arnold, 2008). The perspective and belief of nurses regarding the actual role of the ethics committee was not explored in any detail in this study.

Siloed striving: underutilization of external ward resources. Participants in this current study expressed a preference to rely almost exclusively on their nursing peers and physician support on the unit for support rather than calling upon multidisciplinary sources. Although nurses expressed that they believed that the acute care environment was not an ideal place to provide palliative care, participants expressed a confidence that they were able to effectively manage symptoms and psychosocial family care at the end of life. This resulted in consults to external ward resources on an ad hoc basis. This approach to care was determined to be a form of siloed striving, and was contrary to the best practices regarding involvement of multidisciplinary team members in patient care identified in the

literature. Within the neurosciences literature, two articles previously discussed

demonstrated that a lack of collaboration with multidisciplinary clinical resources was less

than optimal in providing patient care. Yeager et al. (2010) presented the outcome of a

project which was developed at their facility to support end-of life care in a neurosciences

intensive care unit using a multidisciplinary approach. With the primary goals of ensuring

patient comfort and positive lasting memories in an organized fashion, the group developed

a twelve item, "Embrace Hope" checklist to guide patient and family care. These

interventions demonstrated a desire for holistic care of the patient and family, and ensured

that there was a comprehensive plan for each patient who was expected to die. This plan

also facilitated and ensured that discussions regarding the patient's goals of care were

understood by the healthcare team, and normalized the dying process for staff on the unit.

        Cowey (2012) presented a literature review which supported the need for nurses to

have both neurosciences expertise, as well as palliative care expertise to best support the

patient in their final days. This was proposed to best be accomplished using a

multidisciplinary approach, and not to rely solely on stroke care knowledge. The practice

suggested in both of these articles (Cowey, 2012; Yeager et al., 2010) stands in contrast to

the practice of the nurses described in the current study who only occasionally consulted

outside services.

        The palliative care literature also supports a multidisciplinary approach to care,

rather than siloed striving. Kirsch (2009) presented a literature review paper outlining the

value of a multidisciplinary team in providing end-of-life care in general. The author

outlines the use of spiritual care, an ethics committee and other allied health resources as

assets to best communicate with and advocate for patients and their families when they are

facing complex physiological and psychological issues. The review was supported by a

variety of case studies that exemplified the use of a broader team of allied health resources

and its effects in end-of-life care. Kirsch (2009) concluded that a broader range of patient

needs were met when multidisciplinary approach was utilized. While nurses in the current

study expressed an awareness of the availability of multidisciplinary resources, it is not

clear that they fully comprehended the potential benefits to patients, as well as nursing

practice in expanding and structuring their end-of-life care resources.

As part of the reliance on internal unit resources for clinical support, participants in

the current study expressed the belief that nurses who were more senior on the unit were a

consistent resource for nurses with less experience. Senior nurses viewed themselves as

needing to be present for newer nurses, and newer nurses cited the more senior nurses as

their primary resource. This perspective was not discussed in the neurosciences literature,

but was present in general nursing literature. In a nursing journal editorial, peer mentoring

was noted to include knowledge development through the sharing of information and

experiences, with there being benefits to all involved (Chichester & Dennie, 2010). The

nurse in the role of mentor gains leadership skills, and the mentored nurse gains knowledge

without hierarchical pressures. Grossman (2009) presented a review of nursing literature

which discussed the reciprocal benefits of mentoring, with both parties gaining knowledge,

developing their communication skills, and developing professional relationships in a non-

judgmental setting. Both of these articles, however, view "peer mentoring" as existing

across different nursing fields, and not as standing alone within a specialty, as seen in the

current study. The reliance of participants on only nurses from within their unit may be a

result of their expertise in neurosciences, which they see as only being understood by those

who share this same knowledge.

Struggling to meet families' support and information needs. While nurses did strive to meet the psychosocial support and information needs of families of dying stroke patients, they also struggled in this regard. These struggles included: i) dealing with the emotional impact of caring for family members of the dying; ii) responding to family anger; iii) struggles with remaining connected when providing care; iv) experiencing feelings of uncertainty and helplessness when communicating with families; and v) concerns about upsetting or displeasing family members. These findings will be discussed in relation to existing bodies of relevant literature.

Dealing with the emotional impact of caring for family members of the dying. Nurses shared that caring for dying patients could be emotionally overwhelming. At times, they found themselves leaving patients' rooms crying, or still thinking about the patient and family when they went home at the end of their shift. Nurses relied on their colleagues and personal spiritual strength to support them in their struggles. No neuroscience nursing literature describing these types of struggles was located. However, the emotional experience of caring for the dying has been discussed in the palliative care literature. In the previously noted qualitative study, Georges et al. (2002) examined nurses' experiences in providing palliative care in an academic hospital setting ($N = 10$). Nurses in that study identified that they engaged in behaviors aimed at "avoiding emotional distress" ($n = 8$), and purposefully did not make an effort to respond to every psychosocial need of the patient and/or their family. Conversely, some nurses were found to be "trying to accept and cope with emotional strain" ($n = 2$), and did so by forcing themselves to spend time with the patient to help him/her cope with their emotional needs, despite their own emotional

anxieties. Participants in the study by Georges et al. identified that they needed to adjust their professional goals of cure and recovery, because they could not always completely resolve all symptoms experienced by patients in their care. In order to feel less emotionally overwhelmed, nurses in Georges and colleagues' study attempted to minimize their personal emotions by focusing on the physical care needs of patients. These findings are consistent with the experiences of the nurses in the current study, as they recognized that families had emotional needs, but tended to focus on the patients' physical care needs to avoid facing the emotional impact of providing palliative care

Further in the palliative care literature, White, Wilkes, Cooper, and Barbato (2004) presented the findings of their descriptive qualitative study examining the experiences of nurses who witnessed unrelieved patient suffering ($N = 9$). Derived themes included perceptions of unrelieved suffering, feelings experienced when faced with unrelieved suffering, bearing the burden, invasion of personal space, and factors influencing the impact of these experiences (White et al., 2004). Nurses were found to believe that they did not truly understand the overall suffering being experienced by the patients and families, and consequently were not able to improve the patients' physical or psychosocial symptoms when providing end-of-life care. This perception led to feelings of inadequacy, helplessness, frustration and sadness. While nurses did try to minimize these emotions by seeking support from work colleagues, some participants found that they dwelt on these concerns after work, and that this impacted their lives at home (White et al., 2004). Consistent with these findings, nurses in the current study, reported that on occasion they too felt overwhelmed by their emotions when providing palliative care, and dwelt on concerns about patients care after they were at home.

Nurses in the current study shared that, at times, they found that providing palliative care to patients elicited memories of negative personal experiences with death and dying. The recollection of these personal memories of the death of their own family members was found to contribute to the development of negative emotions and feelings of being overwhelmed when providing palliative care to stroke patients. With repeated exposure to caring for palliative patients, one of the nurses in this study believed that he/she was able to develop some personal inner strength and became less affected by the emotional impact of caring for dying patients. The impact of nurses' personal emotions in caring for dying patients was not located in the neurosciences literature, but research was identified in the palliative care and critical care literature. Hinderer (2012) presented the findings of her qualitative study in the critical care literature describing the lived experience of nurses caring for dying patients. Using purposive sampling and individual interviews ($N = 6$), the authors derived four themes: coping, personal distress, emotional disconnect, and inevitable death. Within the theme of inevitable death, nurses recognized that death was unavoidable and part of life, and that they needed to accept death in order to provide end-of-life care. Nurses also found, however, that accepting death was more difficult when they had experience with death in their personal lives, because providing palliative care elicited negative memories of the death of a love one. This experience is similar to that of nurses in the current study.

Responding to family anger. Nurses in this study identified that it was challenging for them to meet family members' information and support needs when families were angry. Nurses stated that families were often angry because of the suddenness of the stroke and the imminence of the patient's death. Nurses did attempt to empathize with families and

understood that the families lashed out in anger in response to their fear and anxiety in face

of their uncertain circumstances. Despite being empathetic, nurses found communicating

with families who were angry to be difficult, and identified the need to emotionally detach

from the families and patients, whether for a brief time, or more permanently through

having their patient assignment changed. There was no discussion of nurses experiencing

family anger in the context of caring for dying stroke patients in the neurosciences literature.

In the palliative care literature, Holst, Lundgren, Olsen and Ishøy (2009) present two

case studies with a review of relevant nursing literature to discuss factors contributing to

conflict resolution in challenges that arise in interpersonal family dynamics in a hospice

setting. It was acknowledged that when there was mistrust of the healthcare system by

families or conflict which was the result of long-standing family dynamics, patient or family

anger might result and be directed towards healthcare providers. Suggestions for effective

conflict resolution are offered, with these Danish authors focusing on the need to maintain

the focus on the needs of the patient and avoid trying to solve life-long problems.

Maintaining flexibility, avoiding splitting of opinions and sides within the healthcare team,

and setting limits were interventions offered to try to de-escalate family anger (Holst et al.,

2009). This is a contrary approach to that of the nurses in the current study, who avoided

the family and related conflict, which then prohibited resolution of the problem to be

initiated.

Rueth and Hall (1999) examined selected medical and nursing literature and

presented a review discussing patient and family anger at the end of life. Although anger is

viewed as a normal response in patients and families as a result of the stresses of the

circumstances and possible unresolved family conflict, anger has been identified as being

disruptive in the healthcare setting. When faced with feelings of loss, frustration, and helplessness, patients and families have been seen to direct their negative emotions towards the healthcare providers. Rueth and Hall (1999) state that nurses and physicians providing end-of-life care need to be skilled at responding to these challenging emotions, which requires them to be able to recognize that the anger response is not directed at them personally. It is believed that listening and allowing the angry party to express their concerns will help them to work through their emotions, and settle their distress (Rueth & Hall, 1999). These findings represent a therapeutic response to patient and family anger, which is contrary to the response expressed by nurses in the current study, who indicated that they found it best to avoid eliciting family anger, and give families space and time when they were upset.

In a review of graduate students' qualitative doctoral research results, Philip, Gold, Schwarz, and Komesaroff (2007) aimed to determine an effective approach to dealing with anger directed at physicians by patients and families. The findings were derived from the transcripts of nine different focus groups attended by nurses, physicians, social workers, and pastoral care workers ($N = 45$), These authors found that palliative patients and families often become angry as the result of feelings of neglect and delay in their medical management. When expected feelings of helplessness and loss are also present, this exacerbates the individual's frustration. Recipients of the anger have been found to feel hostile and defensive, and then may respond inappropriately in anger themselves. Philip et al. (2007) offer seven steps to use in an attempt to car for angry patients or families. They include: i) preparing the meeting area; ii) listening to their concerns; iii) involving experienced clinicians; iv) modifying their approach if anger persists; v) considering

behavior limits or guidelines for everyone involved; vi) ensuring the staff feel supported; and if necessary, vii) involving an outside mediator to assist both sides to resolve the conflict. This approach is believed to help to minimize patient and/or family anger, as well as support the healthcare team (Philip et al., 2007). While these steps are demonstrative of a therapeutic response to patient anger, nurses in the current study did not engage in this type of response.

Nurses in the current study also attributed family anger to be a part of the anticipatory grieving process. Hottensen (2010) defines this process as "a response to threats of loss of ability to function independently, loss of identity, and changes in role definition, which underlie fear of death" (p. 108). In this editorial, the author presents a case study and offers solutions to improve the grieving experience. Providing a supportive and safe environment, and assisting the family to find coping strategies that work best for their circumstances, were seen as techniques to minimize the stress associated with anticipatory grief (Hottensen, 2010). Each of these methods would require the nurses to proactively engage the family in care, which is not the approach chosen by participants in the current study. No empirical literature was located which examines the concept of engaging family members in an attempt to minimize anticipatory grief.

Struggling to remain emotionally connected with the patient. Nurses in this current study found that they needed to detach emotionally from the patient and family at times in order to avoid becoming too overwhelmed. This was accomplished by focusing their attention to the physical tasks and blocking out the emotional aspect of care. Within the relevant neurosciences literature, Calvin et al. (2007) presented the findings of their descriptive qualitative study ($N = 12$) examining the perceptions of nurses providing end-of-

life care in the neurological intensive care unit. The authors reported that nurses found that

"being positioned in the middle of the communication process" (p.146) presented challenges

which limited their ability to fully engage in providing psychosocial support. While nurses

desired to advocate for patients, they also were loyal to the ethos of the curative unit.

Nurses felt responsible for brokering the communications between the preference of the

patient and their families' versus the preferences of the physicians to ensure the voices of all

involved were heard. In some instances, this resulted in nurses feeling emotionally drained

and overwhelmed in providing care to dying patients and their families. Subsequently,

participants found themselves doing the most basic care and focusing on the physical care

tasks rather than providing extensive psychosocial support, as it was simply the easier and

less emotionally taxing aspect of care (Calvin et al., 2007). This perspective was congruent

with the experiences of the nurses in the current study.

Focusing on physical as opposed to psychosocial care as a strategy to prevent

feelings of being emotionally overwhelmed has been examined by several researchers

within the palliative care literature. One article examined the partial findings of a

correlation study discussing baseline stress levels in palliative care nurses ($N = 117$)

(Desbiens & Fillion, 2007). In this Canadian study, the authors used the results of

questionnaires, the COPE scale and meta-analysis to group the derived coping strategies.

Active coping strategies included behaviors such as seeking social support, prioritizing

dealing with and resolving the stressful feelings, and acceptance of the identified stress.

Passive coping strategies include behaviors such as denial, mental disengagement, turning to

personal religious and spiritual supports, and physical withdrawal from the situation.

Variations of each of these coping strategies were mentioned as techniques for coping with

difficult circumstances in their practice in Desbiens' and Fillion's study, but there was a

focus on needing to mentally disengage from families whom nurses found more challenging

to care for. Actual emotional detachment was rationalized by nurses in their study as a form

of professionalism. In doing so, participants were able to cope with the overwhelming

situations. In contrast, when nurses did not detach to some degree, they felt that they would

over-personalized the experience and dwell on the sadness of the dying patient (Desbiens &

Fillion, 2007). Consistent with the findings of Desbiens and Fillion, nurses in the current

study also viewed detachment as a healthy aspect of care, although this detachment limited

their physical involvement with the patient, and subsequently limited their ability to provide

information and support to patients and families.

The need to detach at work was also confirmed in the study by Georges et al. (2002)

in which the nurse participants recognized that they were exposed to emotionally painful

moments while caring for dying patients. Managing the emotional stress of being a

palliative care nurse was identified as a major theme in this study, with participants

believing that unmanaged stress would lead to professional burnout. The nurses in the study

by Georges et al. preemptively planned to work in their setting of palliative care for a

minimal time in their career in order to keep themselves from becoming affected personally.

Nurses also purposefully focused on the tasks of their assignment and shared their emotions

with colleagues to ease their struggles in providing psychosocial support while "being

present" for families. These latter behaviors are consistent with the experiences of the

neuroscience nurses in the present study in the acute neurosurgical setting.

Stayt's (2009) reported on the findings of her qualitative study examining the

emotional distress experienced by nurses ($N = 12$) providing end-of-life care in the intensive

care setting. The author also found that nurses perceived a need to distance themselves in order to minimize the effects of the emotional demands of care, and to maintain professionalism and control in the nurse-patient-family relationship. Distancing, or detaching emotionally, from the clinical situation, resulted in nurses focusing on task-oriented care (Stayt, 2009), which is similar to the findings of Georges and his colleagues, and Calvin and her colleagues. The findings of each of these authors are consistent with the perspectives of nurses who participated in the current study as well.

The concept of stress contributing to burnout in palliative care was examined in the literature by Pereira, Fonseca and Carvalho (2011). These Portuguese authors conducted a systematic review of fifteen empirical palliative care studies from nine different countries with the goal of reporting on the risks and incidence of burnout in palliative care health care providers. Half of the studies were conducted on oncology units, a setting in which the focus on cure is more prominent, and death is seen to be a failure-- a similar ethos to the neuroscience unit that the nurses in the current study worked on. Burnout was concluded to be the result of chronic emotional distress which occurs when an individual embraces and shares the suffering of the dying patient. While the incidence of burnout was reported to be similar across nursing specialties and fields, contributing factors included a lack of confidence in communicating with patients and families, and limitations in time to provide care and spend time with families. Actual acknowledgement and management of death and dying also affected the emotional distress and emotional burnout experienced by nurses as it placed nurses in a position to engage with the and family, increasing their risk of personal attachment and experienced loss (Pereira et al., 2011). Strategies to manage these emotional stresses were not discussed as part of this literature review. Nurses in the current study did

give themselves permission to disengage from emotionally charged circumstances, which allowed them to protect their own feelings in these more difficult situations.

Nurses within the current study reported that if they became emotionally overwhelmed in their efforts to provide families with psychosocial support, they sometimes found themselves continuing to think about their work when they went home. This preoccupation with work affected their ability to be fully present at home. This aspect of emotional distress was not located in the neuroscience or palliative care literature. In the psychology literature, however, Sonnentag, Binnewies, and Mojza (2010) reported on a qualitative longitudinal study ($N = 309$) in which they evaluated the effects between high demand jobs and psychological detachment, the effects of psychological detachment on long-term wellbeing, and the effects of emotional detachment on psychosomatic complaints and work engagement. Psychological detachment was defined as an emotional disconnect from the stressful situation. While this German and Swiss study was focused on "service workers" working with special needs individuals, their findings are relevant for discussion here as one of their outcomes evaluated the importance of detachment in order for the individual person to preserve their overall wellbeing (Sonnentag et al., 2010). The authors concluded that in high demand jobs which required physical, psychosocial, social and organizational skills, it was essential that individuals took time to emotionally remove themselves from the stresses of their workplace in the time they are away from work. Thus detachment was seen as important in allowing persons to maintain their emotional, cognitive and physical health (Sonnentag et al., 2010). Psychological detachment was seen as a healthy response to stress, but was discussed as occurring after work hours, and not while at work, as seen in the present study.

Experiencing feelings of uncertainty and helplessness when communicating with families. Nurses in this study received questions from family members asking about what was happening physiologically with the patient, as well as about prognosis. Nurses were able to answer some straightforward questions about the disease or care being given, but indicated that they were sometimes faced with questions which were outside of their personal comfort zone to answer. Such situations would lead to feelings of uncertainty and helplessness on the part of the nurse. Research suggests that such feelings are a common stressor for those caring for the dying. Peterson et al. (2010) conducted a mixed methods study examining the care stresses of nurses and nursing students ($N = 15$) caring for dying patients. Participants sometimes felt that they did not have the correct answers for patients or families, whether it was during daily interactions, or in follow-up to a discussion patients or families had held with the physicians. Nurses wanted to ensure that families received the right information, and feared misleading or upsetting them, which was congruent with the experiences of nurses in the current study.

As noted in the neurosciences literature, prognostication of stroke was also an uncertain process (Payne et al., 2009; Reilly & Bullock, 2005). This uncertainty contributed to the challenges in communication for nursing staff as there were no definite answers to some of the families' questions. In his medical literature review discussing the construction of culturally acceptable deaths, Timmermans (2005) wrote that there was a shift to attempt to de-medicalise deaths in hospitals and to focus more on the individual needs of the patients and families. At the same time, when there was a sudden or unexpected death, social order is questioned along with the ability of the medical system to control illness and disease (Timmermans, 2005). These two factors combined contributed to the challenges

faced by participants in the current study. There were no definite answers available from the nursing or medical literature regarding palliative stroke trajectories and symptoms, so nurses found themselves feeling helpless when faced with questions seeking a specific answer.

When presented with questions regarding changes in the treatment goals, fluids or nutrition, nurses felt that these topics were out of their scope of practice and this was a barrier to them directly sharing knowledge with families, as well as was self-perceived to minimize their credibility as competent nurses. Whether this was related to personal discomfort or a professional value was unclear based on the data. Prior to receiving orientation about facilitating and communicating the advanced care planning process, the participants in Seal's study (2007) perceived that they were not completely comfortable in speaking with families about palliative care, and subsequently did not feel that they adequately advocated for the needs of the patient. Nurses felt uncomfortable discussing death with families, and were intimidated by the physicians' strong belief in curative interventions. Seal (2007) found that nurses did not initiate the first conversation with families about patient's goals of care or perceived treatment preferences as they did not see it as being their role. Nurses were cautious and would wait to call upon the physician to respond to these concerns.

In a prospective, non-randomized control trial, Seal (2007) surveyed a study group ($N = 82$) and control group ($N = 81$) of nurses prior to them receiving education on care pathways to support patient advocacy in end-of-life care, and also surveyed both groups six months after the intervention (study group $n = 74$; control group $n = 69$). Participating nurses in the study group worked in the areas of palliative care, renal care, intestinal surgery

and respiratory care, and participation in the training session was not synonymous with

participation in the Seal's study as only fifty-two of a possible 142 nurses engaged in the

education on their units. Participants in the control group worked in areas including

neurology, hematology/oncology and coronary/cardiac care. The post-test survey results,

which were not linked to the pre-test results to determine individual participant's

experiences, indicated that the nurses' overall confidence in patient advocacy was

significantly improved when compared to the pre-survey results in the study group and the

post-survey results in the control group (pilot $p < .001$; control $p < .05$). Eighty-four percent

of nurses in the study group expressed confidence in palliative patient advocacy post-

intervention compared to 49% pre-intervention. Within the control group post-survey

results, only 42-55% of participants expressed confident in this same aspect of care. Nurses

recognized that they were capable of participating in and initiating conversations

surrounding the transition to end-of-life care (Seal, 2007). While Seal also conducted focus

group interviews pre- ($n = 18$) and post- intervention ($n = 3$), low participant enrollment in

the follow-up phase does not allow these results to be significant to the findings of the

study. The nurses in the current study also experienced a lack of confidence in their

communications, similar to the nurses in Seal's study prior to intervention. Perhaps

education regarding communication in palliative care would result in nurses in this current

study developing increased confidence in their clinical practice as well.

In their qualitative study of neuroscience ICU nurses' perspectives of providing end-

of-life care, Calvin et al. (2007) found that while nurses viewed themselves to be pivotally

positioned between the patient and physician in the communication process, they also were

cautious in acting in this role. Nurses did not always feel that they were qualified to answer

the patients' or families' questions, and were concerned that their answers may cause the

families to ask more questions and upset the physician. To work around this concern,

nurses would provide information to families which would make them have more questions,

and then ask the physicians to speak to the families to address these questions. Participants

did not want to overstep the authority of the physicians or complicate the medical care plan.

While some questions about nursing care could be addressed, questions about topics such as

prognosis or hydration were seen to be outside of the nurses' scope of practice (Calvin et al.,

2007).

When not confident with their communication skills when believing that

conversations were outside of their scope of practice, nurses in the current study would call

upon the physician to come and answer these more difficult questions. Calvin et al. (2007)

and Peterson et al. (2010) both found that while nurses advocated for the information needs

of patients and families, there was a strong reliance on the physicians to be the persons to

provide this information. Nurses were not comfortable taking ownership of the education

and psychosocial support of families, which is consistent with the experiences of nurses in

the current study.

The focus on the communication of knowledge within the context of palliative care

was demonstrated in the qualitative study by Calvin et al. (2007). The authors found that

nurses viewed themselves in the role as educator when they were providing guidance to

families by helping families to understand what the patient was experiencing, although

uncertainty was a factor in their responses. When families had made, and then began to

question their decision about accepting palliative care for the patient, nurses would work to

support the decisions made by families through education of the disease process and review

of the expected outcomes.

The experiences of the nurses in the current study were similar to that of the nurses in Calvin's study, as they strove to ensure that families had all the information they needed to be at peace with their decisions and the care plan. Participants in the current study, however, did not always feel comfortable in sharing information on all aspects of care, and did not see that it was the role of the nurse to fully facilitate the transition to end-of-life care. This lack of comfort with speaking with families was an extension of uncertainty and helplessness experienced by nurses and contributed to the challenges with communication in palliative care.

Related gaps in education. Nurses in the current study perceived that they lacked knowledge in the end-of-life symptoms for stroke patients, which impacted their ability to confidently answer families' questions. There was no data located in the neurosciences literature on this aspect of care. In the palliative care literature, however, Rønsen and Hanssen (2009) identified the need for structured palliative care resources and education to improve helplessness and uncertainty. These authors evaluated the outcomes of the experience of seasoned nurses who participated in post-graduate palliative care module being taught at a college in Norway. The course included traditional lectures, narrative discussions, ethics discussions and physical exercises in the form of neuro-motor stimulation (i.e. crawling on floor slowly). The course work and its outcomes were assessed for their effectiveness in discussion with students ($N = 68$) who provided verbal feedback on the course during the program and at the end of the course. Students also wrote a retrospective review of the course. In their findings, the authors identified that students found that the variety in teaching approaches was effective in encouraging them to self-

reflect on their practice, and helped to build confidence in communication with patients and families in palliative care, including more difficult circumstances. Education of the staff subsequently led to them perceiving that they were able to better support families with education as part of their psychosocial care. This study further confirms the need for nurses to receive education on communication in palliative care in order to improve their confidence and proficiency in this aspect of care. Eight of the nine participants in this study did not have clinical instruction in communication in end-of-life care, which may have impacted their negative experiences in providing psychosocial support to families.

The value of palliative care education as a tool to support nurses in providing psychosocial care to their palliative patients was earlier established by Degner and Gow (1988) in a longitudinal quasi-experimental study involving university students. Guided by Quint's theoretical model of care for the dying (1967), Degner and Gow evaluated the impact of a nursing education intervention comparing third-year nursing students who received a specifically-focused palliative care theoretical and clinical course ($N = 102$), to nursing students who received palliative care education in an integrated approach throughout their four year program ($N = 94$) and third-year non-nursing university students ($N = 73$). Using a self-devised questionnaire and in person interviews, researchers described participants' self-perceived competency, comfort and anxiety in providing care to dying patients. Questionnaires and interviews were conducted prior to the variable of palliative care intervention being administered, as well as one year later after all participants had graduated from university ($N = 112$).

Degner and Gow (1988) found that while all participants had high levels of death anxiety in the pre-test, only nurses in the experimental group (who received a dedicated

palliative care education), indicated a lower level of death anxiety in their post-test.

Attitudes towards dying were positive in the experimental group in the pre-test period, and

remained unchanged in the post-test. Due to a lack of randomization in this study, it is not

clear what the significance of this result indicates. Other factors in the personal lives of the

participants may have contributed to these findings. Nurses who had received focused

palliative care education also expressed a greater degree of comfort in the provision of

palliative care at one year post- graduation, compared to the nurses who received integrated

palliative teaching. Degner and Gow's results (1988) do provide support for Quint's model,

and based on the study findings the authors concluded that a required course in palliative

care theory in combination with clinical experiences in caring for dying patients and their

families helped to decrease feelings of anxiety in caring for the dying and resulted in nurses

feeling more comfortable in engaging with dying patients and their families.

When looking at the demographic characteristics of the nurses who participated in

the current study, five of the nine nurses received education in the form of a theoretical

palliative care course as part of their professional training, but only one of the nine had an

opportunity to participate in a clinical component of palliative care. The models proposed

by Quint (1967) and the findings of research conducted by Degner and Gow (1988), suggest

that the lack of exposure to palliative care clinical practice as part of their education may

have contributed to the experiences of the participants in this study. The findings of other

research studies discussed also support the need for some form of palliative education to

better support nurses in the provision of palliative care (Calvin et. al., 2007; Rønsen &

Hanssen, 2009; Seal, 2007).

Concern about upsetting or displeasing family members. Nurses in this study

expressed concern about upsetting or displeasing family members with regards to discussions about discontinuing airway support and nutrition and hydration at the end of life. Though there was empirical evidence on which to guide the practice of not hydrating dying stroke patients, and participants indicated that they would readily talk to family members about this evidence, they also indicated that they would readily concede to families who were adamant that fluid replacement be one of their goals of care for the patient. When there were discussions as to whether or not to initiate enteral feeding measures, nurses indicated that they, and physicians, always accommodated the request of the family in this regard. Agreeing with family members' requests about interventions related to nutrition and hydration were viewed by nurses to be a positive approach to care in that they were supportive of the families' preferences and minimized families' distress, and also allowed the nurses to avoid any conflict with the families. While one nurse did question whether withdrawing, or not initiating, enteral feeding would cause the patient to "starve to death", he still readily modified the hydration and nutrition care plans as requested by families in order to avoid upsetting them, even if this meant withdrawing enteral nutrition support. This avoidance behavior was consistent with all participants, and was seen to be influenced by prognostication challenges, as well as general difficulties in discussing hydration and nutrition issues.

In the neurosciences nursing literature, Payne, Burton, Addington-Hall and Jones (2010) conducted a descriptive qualitative study exploring the perceptions and preferences of patients ($N = 28$) and non-related families ($N = 25$) who were the recipients of end-of-life care after the patient had an acute stroke. While patients who survived the stroke were accepting of their illness, they were found to not want to receive too much information, and

would prefer to be able to go home and carry on with their lives. Patients were more

concerned with the impact of the illness on their families. Families, on the contrary, were

found to be seeking honesty regarding the prognosis of their loved one's illness, and desired

to be informed about the feasibility and usefulness of possible interventions (Payne et al.,

2010). While families wanted empirical data to support their decisions, they found that

health care professionals expressed frequent uncertainty in the prognosis of stroke, and also

uncertainty in their rationale for proposed interventions, including medication

administration.

Payne et al. (2010) also found that families sensed that healthcare providers

struggled with the transition of moving to a "do not resuscitate" comfort focus, while still

providing active interventions. These perceived behaviors of uncertainty are similar to

those exhibited by the nurses in this study. While participants in the current study desired to

be supportive of families in this difficult time, they struggled to fully disclose information

and have open discussions about dying, as they were personally uncomfortable with always

fully acknowledging the impending death of the patient when decisions about fluid and

nutrition were still be considered. Subsequently, nurses stated that they supported a

palliative care approach, but also supported IV and tube feeding interventions without

acknowledging the "bigger picture" of the patients' experience and how these interventions

affected the patients and their families. A gap in the participants' palliative care education,

again, may have contributed to this perspective.

Nurses in this current study indicated that they strove to provide care based on the

wishes of the unconscious patients as presented by their families. While nurses practiced

within the *Standards of Practice for Registered Nurses* (CRNM, 2009) in regards to

respecting the wishes of the patient and family, it is not clear if participants were advocating

for informed decision making in support of the patients' wishes or best interests (CNA,

2008). In the *Code of Ethics for Registered Nurses* (CNA, 2008), it is written that in order

for nurses to practice ethically, they must "promote and respect informed decision making"

(p.11). As part of these efforts, nurses are to advocate for patients, which should include

ensuring that proxy decision-makers are supported in making informed choices for

interventions which reflect the patients' previously discussed goals of care. Rather than

using this approach, it appeared that nurses chose the path of least resistance to avoid ethical

conflict with families, and relied upon the physician to provide information to families as

the physician saw fit or as requested by families.

In a medical literature review, Timmermans (2005) discusses the concept of death

brokering as a way in which families' wishes are accommodated when providing end-of-life

care. Preferences regarding fluids and nutrition were seen to be culturally or religiously

based, causing families to have strong beliefs and values in making their decisions. While

the intent of these interventions was not life prolonging on the part of the healthcare team,

their actions provided spiritual peace and comfort to the family, and left them feeling that

they had supported an "ideal death" (Timmermans, 2005). Although it is debatable whether

the incorporation of such interventions was ethical when recovery was not expected,

Timmermans determined that decisions regarding the best course of actions were usually

considered on a case-by-case basis. Participants in this present study claimed that the

preferences of the patient and family often trumped any other discussion. The final decision

as to whether or not to proceed with these requests was determined in discussion between

the physician and recognized medical proxy or next of kin. This is ethically appropriate

based on the health care directive of the patient

  Nutrition. Recent literature has been inconclusive as to whether or not to provide

nutrition as an end-of-life intervention in those with an obvious terminal illness. As

nutrition is seen to be a human basic need, and a supportive intervention that minimizes

suffering, the withholding of enteral nutrition has been reported to cause distress to families

and healthcare providers (Winter, 2000). Winter (2000) found that while there were

benefits to nutritional support, there were also the potential for the patient to develop

troublesome symptoms. In randomized trials with cancer patients, there was no benefit to

survival or treatment response in patients who received enteral support versus those who did

not. Rather, there was a greater incidence of related complications in patients who received

supplemental nutrition, with patients developing infections at the gastrostomy tube site, and

nausea and vomiting. In the cancer patient population, eventual cancer cachexia was also

seen as a factor which did not support the use of enteral feeding (Winter, 2000). Although

the patients in the current study population were not suffering from cancer cachexia, the

finding that those who are dying do not experience thirst or hunger is information that might

help inform and guide discussions which healthcare providers have with families.

  One nurse in the present study did express concern regarding whether or not the

patient was "starving to death" (participant 01). In 1970, Cahill (cited in Winter, 2000)

conducted a study in which competent patients on a palliative care unit were allowed to eat

or drink as they felt able, and were able to report on feelings of thirst and hunger. It was

found that 63% of patients had no feelings of hunger leading up to their death, and the other

34% had only mild hunger when they were first enrolled in the study. Winter (2000)

concluded that if given the choice to eat and/or drink, dying patients voluntarily did

regularly do so, and did not have feelings of hunger or thirst, and experienced no additional

suffering as a result of these actions. A qualitative study conducted on palliative care unit,

performed by Van der Riet et al. (2008), arrived at similar conclusions to that of Winter.

Van der Riet et al. (2008) found that families and nurses had similar concerns regarding the

possibility that the patient was literally starving, but that patients reported not feeling

hungry or thirsty in their final days. Although it is not possible to examine the experience

of the unconscious patient regarding this aspect of end-of-life care, it is possible that those

in an unconscious state who do not receive hydration and nutrition are also not suffering

when supplemental fluid and nutrition are not provided.

Nurses in the current study expressed contradicting perspectives regarding nutrition.

Although they reported that they always complied with the preferences stated by families,

nurses also expressed concern regarding the initiation of enteral feeding in a patient with an

acute ICH amongst themselves and the health care team. Their most concerning aspect of

this care was that if the feeding was started and the patient did not awaken and improve,

then a discussion about withdrawing the tube feed may lead to the need for more difficult

conversations and decisions for the family and the physician. This may lead to anger and

distress for the families, which was something that nurses aimed to avoid. It was perceived

that avoiding the initiation of these supportive interventions was preferable, and helped to

avoid difficult conversations at a later time. These beliefs were based on professional

experiences and rooted in challenges with patients that had been on the unit in the past.

Although none of the participants referenced a specific case when asked, there was a

noteworthy incident found in the literature in which an elderly gentleman, who received

artificial feeding and did improve clinically, and subsequently family and health care

providers became embroiled in conflict. This case was reported on by Jotkowitz, Glick and

Zivotofsky (2010). This patient was initially cared for on the acute neurosciences unit and

then transferred to an alternate facility for longer term care. Despite persistent

unresponsiveness and recurrent infections many months past his initial neurological injury

(actual length of time and diagnosis unstated), the patient's family refused to withdraw the

tube feeding that had been initiated at the family's request. Religious beliefs were cited for

their decision. The resulting discord led to a public legal battle and additional stress for the

family and direct care providers in the final days of the patient's life (Jotkowitz et al., 2010).

The conflicts which are represented in this case exemplify the challenges which the nurses

in the current study hoped to avoid in their acute care setting by agreeing with the family.

Participants' straightforward compliance with family requests may result in conflict,

regardless, only at a later date and in a different setting. In deferring conversations

regarding nutrition, participants are protecting themselves from conflict, but may be simply

deferring the issue from the perspective of families.

A lack of proactive communication between nurses and families regarding the

impact of fluids and enteral feeding on the clinical trajectory of the patient was common in

the provision of palliative care in the acute neurosciences setting in the current study. As

previously noted, nurses frequently referred to the practice of having physicians speak with

the families about these matters. Nurses perceived that the involvement of the physicians

resolved their challenges with hydration and feeding, as it was perceived that physicians

also always agreed to proceed as families requested. While decisions regarding treatments

were based on the patients' clinical illness, prognosis, and potential for quality of life,

decisions regarding hydration and nutrition were based on the wishes of the families. A

greater awareness of related empirical data and incorporation of this data, into the decision-making process would help to ensure that evidence-based practice is implemented to optimize patient care. An increased understanding of this aspect of palliative care may also increase confidence in the nursing staff with enhanced pro-active communication between nurses and families.

In a review of healthcare literature, Krishna (2011) discussed the "duty of palliative care" (p. 487) in regards to the ethical issues of nasogastric feeding at the end of life. The writings were based on the practices within the Asian culture. Nasogastric feeding was culturally pursued to keep the patient from literally starving to death. The ethical discussion amongst the healthcare team was seen to focus on the need to respect the wishes of the patients and families, despite what the healthcare team might view to be the best treatment approach. It is the role of the healthcare team to inform the patients and families of their clinical condition and the goals achievable (or not) in regards to nasogastric feeding in order to ensure that the families are making an informed decision. In cases in which the families hold different values regarding interventions at the end of life and choose options which are not congruent with the perspectives of the team, it may be necessary for the health care team to accommodate the wishes of the families to some degree (Krishna, 2011). In practicing in this manner, ethical practice is supported, and families experience a "good death". In making final decisions, the author suggests that a balance must be found between what is agreeable to the wishes of the patients or their families as proxy, as well as what is viewed to be a reasonable intervention or symptom burden from the perspective of the physician (Krishna, 2011). While nurses in the current study did focus on the wishes of the patient and/or family, this evaluation was not balanced with an assessment of the benefits and

burdens of proceeding with nutritional intervention as suggested by Krishna.

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) developed a position paper which outlines ethical considerations in artificial nutrition and hydration based on the evidence in the medical literature (Barrocas et al., 2010). Within their seventeen recommendations, issues surrounding nutrition in terminal a circumstance are addressed. It is suggested by the A.S.P.E.N. committee that a multidisciplinary approach to decision-making, in collaboration with the patient's family, is ideal in assessing nutritional replacement plans at the end of life. Using an evidence-based approach, combined with a discussion of the patient's preferences, was seen to best represent the wishes of the patient. In their discussion of the healthcare literature, Barrocas and colleagues (2010) further suggested that patients who were in a comatose state did not experience feelings of thirst or hunger, but those in a semi-conscious state may perhaps suffer from feelings of starvation. In situations in which the prognosis is grim, but not certain, as in the case of the stroke patients for whom nurses in the present study care, it is suggested that ethically, a time-limited trial of artificial nutrition is warranted. Only in cases in which the grim prognosis is definite, the burdens of nutritional replacement are overwhelming, or the patient's goals of care are clearly documented, is it reasonable to hold off on initiating tube feeds. It was evident that the nurses in the current study did respect the withholding of artificial nutrition in cases in which the prognosis was poor, but did struggle with concerns as to whether or not the patient was starving to death. These guidelines suggest that the concerns expressed by nursing were valid in relation to providing ethical end-of-life care.

Hydration. Although they were aware of and understood the literature regarding hydration at the end of life, nurses in the current study avoided proactively prompting

conversations about the initiation or continuation of artificial hydration whenever possible, deferring to the wishes of the patient and/or family. No data was located in the neurosciences literature on this aspect of end-of-life stroke care. In the palliative care literature, Huang and Ahronheim (2000) examined patients' symptoms in regards to hydration and nutrition at the end-of-life. It was found that dry mucus membranes and thirst were common symptoms in dying patients, but that there was no relationship between these symptoms and the fluid balance of the patient. These symptoms may exist despite hydration, which is something that the nurses in this study were aware of, and managed with frequent mouth care and sips of fluid as the patient is able. Only delirium was seen to potentially benefit from parenteral hydration (Huang & Ahronheim, 2000).

In a literature review conducted by del Rio et al. (2011), it was determined that hydration and nutrition at the end of life had an emotional impact on patients, families and health care providers. In circumstances in which families and caregivers did not accept that the patient's death was inevitable, they perceived that providing artificial fluid and nutrition would improve the patients' chances for recovery. Even in cases in which the families were understanding the prognosis, continuing with IV hydration was seen to provide families with some hope and the impression that everything was being done that was possible to afford the patient a chance to recover (Van der Riet et al., 2008). In this current study, patients who presented with a large intracranial hemorrhage were considered to have a poor chance of functional recovery, and were expected to die within days to weeks. Even with artificial parenteral support, death was deemed inevitable by the medical team due to the underlying illness. Families, however, were thought to interpret the action of not hydrating the patient as a more tangible intervention that ensured that death was near. When artificial

support was not offered to patients in the current study, nurses rationalized this approach to care in terms of the lack of potential for quality of life for the patients. Ethical dilemmas did not present due to the nurses' ability to rationalize these patient care decisions.

Related educational gap. In discussion of the findings of this study, along with review of the nursing literature, it became apparent that discussions surrounding tube feeds and hydration are not only important to families, but also to the health care team. Rather than passively agreeing with families to avoid conflict, there is a necessity for open and proactive communication in these circumstances. In the current study, nurses and physicians avoided actively engaging families in conversation regarding the patients' goals regarding fluid and nutrition. If a consensus regarding the patients' goals of care and the use of fluids and nutrition is not established in advance of the intervention being initiated using informed consent, subsequent ethical distress may result for families and health care providers, as was evident in the case discussed by Jotkowitz et al. (2010).

Participants in the current study were practicing ethically in respecting the personal and religious beliefs of patients, but struggled to address concerns regarding the goals of care for the patients if they felt that there would be any conflict or disagreement in the conversation. In a review of potential benefits and problems associated with enteral nutrition replacement, Best (2010) framed the discussion in terms of non-maleficence, respect for autonomy, informed consent, ordinary versus extraordinary treatments, justice and equity, and the role of nurses in the process. Referencing a nursing code of ethics from the United Kingdom, the author explained that insight into the clinical circumstances, an understanding of the proposed treatment and its' potential benefits and side effects, as well as respect for the patients' or families' decisions are essential to ensure that patient care is

ethical (Best, 2010). In the current study, a greater use of empirical data to help inform the

staff and families would help to guide discussions and promote the autonomy of the

patients. Challenges in providing psychosocial support might be lessened if neuroscience

nurses were more aware of the empirical literature which was available to support their

clinical practice.

Providing Culturally-Sensitive Care

Nurses in this study shared that they attempted to provide culturally sensitive care to

dying stroke patients and their families. Every effort was made to accommodate individual

rituals and traditions, and translator services in the hospital were accessed as much as

possible to facilitate communication between nurses and non-English speaking patients and

families. Although most cultural care situations were easily managed, participants did

encounter challenges in providing culturally sensitive care. These challenges were due to

factors related to systemic constraints, the nurse's own cultural beliefs and difficulties in

accessing translation services at all times of day for every dialect which nurses encountered.

Striving to be Culturally-Sensitive. Nurses in this study were aware of the

importance of attending to the various cultural needs and rituals that were important to

dying stroke patients and their families. Once they confirmed patients' and families'

cultural care needs, nurses worked to ensure that these needs were met. Within the

neurosciences literature, Yeung, Wong and Mok (2011) discuss the experiences of Chinese

patients who had survived and recovered from their stroke and were being discharged home.

Using purposive sampling, the authors interviewed patients at home one week after they

were discharged ($N = 15$). Yeung et al. (2011) found that culture impacted the patients'

perceptions of their illness, as well as response to recovery. Derived themes included:

"dynamic interplay of holistic concerns, cultural expression of illness experiences, social support 'paradox', and caring gaps in clinical management" (p. 2394). In the context of culture, patients viewed the onset of the illness as a sign of 'bad luck' as a result of their negative behavior in a past life, and used this rationale when questioning why they had a stroke. In order to maintain a sense of calmness and stability, which was seen to help the healing process, Chinese patients chose to accept the existence of the illness, and adopt an attitude in which they faced each day as it came. This cultural belief was seen to benefit the physical and spiritual health of patients (Yeung et al., 2011).

While family was viewed as an important source of support, Chinese patients were concerned with outward attention which they might receive if they exhibited signs of residual illness (i.e. a limp), as this would show persons in the outside world that they were sick, and would attract unwanted attention to their limitations. This display of potential weakness was distressing to the patient (Yeung et al., 2011). The belief that personal struggles with illness should be kept within the family in the Chinese culture is consistent with the perception expressed by a participant who noted that he believed that patients from Asian cultures were more private in their interactions with health care providers. While these perceptions lend insight into Chinese cultural influences and perceptions of health and illness with Chinese stroke patients, additional research is needed to explore the extent to which these findings have relevance for Chinese stroke patients and their families at the end of life.

Campinha-Bacote developed a Model of Cultural Competence (2002) in an effort to explain her own personal knowledge gaps she found with needing to identify with a specific ethnic and cultural group when she was the recipient of healthcare herself. The model of

cultural competence contains four facets. Cultural awareness was identified as an awareness of one's own culture as well as recognizing one's own biases and prejudices regarding other cultures. Cultural knowledge was defined as the practice of seeking information about other cultures in order to familiarize oneself with that which was unfamiliar. Within the context of healthcare, cultural knowledge also includes becoming aware of ethnic tendencies in disease prevalence and presentation. Cultural skills involves being able to collect data about the cultural preferences in regards to the patient and their presenting problem. The cultural encounter facet of the model of cultural competence refers to the description of the interaction between patients and healthcare providers about their culture. Finally, the facet of cultural desire concerns healthcare providers' desire to engage in dialogue with the patient or family with the intention of meeting their cultural care needs. Each of these facets of cultural care interacts and intersects to contribute to the development of cultural competency. The degree to which the participants in the current study were culturally competent as described by Campinha-Bacote cannot be determined without further systematic evaluation. However, from the data collected it appears that nurses did engage with patients and families in an effort to elicit information to help identify the presence of cultural care needs so that these needs could be addressed.

Research examining the impact of culture at the end of life has been conducted in the field of palliative care. Lobar, Youngblut and Brooten (2006) conducted a qualitative study in the United States to describe the end-of life practices of ethnically and culturally diverse groups of families. Researchers had observed differences in how various cultural groups grieve, and subsequently noted a gap in the literature regarding cultural death rituals in healthcare in the United States. A focus group involving fourteen master of nursing

students from varying religious and cultural backgrounds was conducted with individuals who were African-American ($n = 5$), white non-Hispanic ($n = 4$), white Hispanic ($n = 3$) and Asian ($n = 2$). Participants' countries of origins included the United States, Jamaica, Thailand, Philippines, Nicaragua, Cuba, Trinidad and Guyana. Focus group discussions examined personal experiences with death and dying, and the related cultural practices. Content analysis of focus group data identified several before death and after death themes which confirmed that there are cultural commonalities surrounding respect, prayer and celebration, and cultural differences in approaches to ceremony and ritual. Underlying religious beliefs strongly influenced individual beliefs and values. Nurses in the present study appreciated that inter- and intra-cultural variations regarding within and across cultural groups, and this recognition served as the impetus for them to make specific inquiry about the unique cultural needs of the patients and families for whom they cared.

A concept analysis was conducted in 2009 by Canadian researchers (Chan, MacDonald, & Cohen, 2009) to examine the relationship between culture and dying in an acute care setting. These authors identified that culture encompassed not only ethnicity, but also the care environment, and the culture of medicine and its effect on end-of-life care. In defining culture in a broader sense, these researchers defined cultural competence as possessing knowledge, skills and attitudes that demonstrate sensitivity and humanism in healthcare providers' approach to care delivery. Cultural competency in death was not only about ritual and ceremony, but acknowledgment of the family and the experience they were facing with their loved one. Thus, a culturally competent health care provider is required to look past the stereotype of a specific culture to determine the actual relevant needs of the patient and the family. The behavior of speaking with patients and families to identify their

unique cultural needs identified in this concept analysis is consistent with the findings of this study.

Nurses in the current study identified that culture can influence the ways in which family members communicate with members of the health care team. Though they did not stereotype family communication patterns based on culture, nurses did characterize families from certain cultural groups as being more vocal in regards to grieving and expressing their needs, while families from other cultures were characterized as were more stoic and reserved. Discussion of this observation of the cultural influence on communication styles was not located in the neurosciences or palliative care literature, but several relevant articles were found in the oncology literature. In a medical and nursing literature review discussing communication within the context of cultural competence in cancer care, Surbone (2008) notes the importance of effective communication in order to ensure that the needs of the family are met. It was found that different patients have a preference for how much information and what type of information that they wish to hear, but that variations in how patients and families viewed these preferences were often due, rather, to differences resulting from gender, age and education. The influence of culture on communication behaviors was not evident in Surbone's results, contrary to the findings of the current study.

Kelly and Minty (2007) presented a literature review examining end-of-life issues in the Aboriginal culture. These Canadian authors found that aboriginal peoples valued individual decision-making, but may want to have a community elder involved in communications with the healthcare team as a sign of respect for the elder. In addition, variations were evident regarding preferences in communication styles. Some Aboriginal persons preferred direct and open communications, while other patients or families

demonstrated a tendency to desire a more indirect approach in their verbal and non-verbal interactions (Kelly & Minty, 2007). Based on their literature review, the authors concluded that, although there are culturally-specific practices to be aware of, there are differences in cultural realities and values which are not always reflective of traditional Aboriginal beliefs. Kelly and Minty (2007) stress the importance of assessing the individual patient and family for their personal values and beliefs, so that respectful care based on these preferences is provided. Although nurses in the current study did not mention any specific cultural needs of the aboriginal peoples in their experiences, they did advocate for assessment of individual needs and preferences. This is consistent with the approach to care recommended by Kelly and Minty (2007).

In a literature review examining the impact of culture and family support in communicating with patients about their cancer diagnosis, American authors Ballard-Reisch and Letner (2003), noted that various cultures approached communication with health care providers differently, and that culture impacts their comfort with decision-making as well. This article demonstrated that there is the possibility of culturally-specific preferences in interacting with families, as expressed by the participants in the current study. As found in the other cited literature, however, nurses believed that they could not rely on stereotypical assumptions, so attempted to communicate with patients in a manner which respected their individual beliefs. As only literature reviews were located on this aspect of palliative stroke care and culture, further research is needed to examine the influence of cultural beliefs on communication styles of patient and families.

Recognizing translation needs. Participants in this study were confident that they possessed adequate resources to meet the cultural care needs of dying stroke patients and

their families as regards to translation services. Language translation services were easily

accessible for the more common languages such as French, Filipino, Polish, Ukrainian, or

any of the Aboriginal languages. Nurses identified that these services were essential in

enabling them to perform accurate assessments, and better understand the experience and

symptoms of the patients and families. Times during which nurses identified having a

translator were absolutely necessary included discussions about diagnosis, prognosis and

identifying the patient's goals of care.

No articles examining the issue of language translation services in care of the dying

were located in the neurosciences or palliative care literature, but there were articles found

in the general healthcare literature. In an effort to address the ethical, legal and safety

concerns that may arise without adequate translation services, a British nursing lecturer

wrote about her experiences in visiting a multicultural hospital in Spain (Ledger, 2002). In

sharing her experiences of communicating in a foreign language while not in the vulnerable

position of being a patient, this author reflected on the difficulties that such patients might

experience. Ledger (2002) concluded that non-Spanish speaking patients faced language

barriers in Spanish hospitals, vulnerability in regards to a lack of privacy, a lack of

understanding of rituals and values of the dominant Spanish culture. Subsequently, Ledger

hypothesized that these patients were at risk of being more vulnerable to receiving a lower

quality of care, as they received fewer assessments and experienced fewer interactions due

to communication challenge. These findings not only validated the need for language

translation services, but also demonstrated that these services are essential for competent

care to be provided. Nurses in the current study recognized the value and need for

translation services in their striving to ensure patient safety, as they felt that they could not

perform assessments or respond to the patients' needs accurately without the use of an interpreter.

In an effort to evaluate a Spanish-English translation tool which they developed, an American group evaluated the use of their reference card which held common phrases used in routine and surgical assessments (Bernard et al., 2005). These cards were to be used as a supplement to language translation services. After using this translation tool in clinical practice for seven months, a survey was sent to physicians ($N = 25$) and nurses ($N = 32$) to evaluate how effective this tool was in clinical practice. Although 97% of nurses found the tool easy to use, and 69% found the content of the card to be 'just right', 81% of nurses continued to primarily rely on colleagues for support with translation, 59% relied on a family member or friend if they were available, 53% used the cards, and 19% utilized an onsite human translator. The cards were not seen as a last resort, but the use of colleagues and families was likely more convenient for nurses who did not speak Spanish. Having this translation tool available was seen to be beneficial in supplementing translation services; however, this intervention still required more effort than simply obtaining assistance from an actual person who spoke Spanish fluently (Bernard et. al., 2005).

The essential need for translation services was also confirmed in an Australian descriptive nursing study, which was conducted to explore and describe the experiences of nurses ($N = 23$) in communicating with non-English speaking patients in an acute care hospital (Cioffi, 2003). The author found that when providing care to patients from different cultural groups, it was necessary for nurses to access and liaison with language interpreters. It was also vital to have access to bilingual healthcare workers, language charts, sign language or awareness of body language. Nurses made every effort to be

relaxed with non-English speaking patients from Europe and Asia, as they were empathetic

to the frustration non-English speaking patients must experience (Cioffi, 2003).   These

findings are similar to the outcomes of the study by Bernard et al. (2005). Cioffi discussed

only the formal facility translation services, and did not comment about the use of other

healthcare workers or families as a translation resource. It is possible that the translation

experiences of nurses was not captured in entirety by Cioffi, as other studies have

mentioned the need for nurses to rely on other staff and family to support their translation

needs. However, an awareness of the need for translation, as well as the efforts nurses in

the current study to secure translation services are consistent with Cioffi's work.

     Struggling to Provide Culturally-Sensitive Care. While it is evident that

participants were frequently successful in their efforts to provide culturally-sensitive care in

the acute care setting, they did share experiences in which they were challenged to meet

patient and families' cultural care needs. These challenges included perceived knowledge

gaps regarding different cultures, systemic constraints, and a lack of availability of

translation resources at all times of the day and night. The lack of consistently available

translation services led to challenges for nurses in communication with patients and

families. Personal cultural beliefs were also seen to impact the nurses' perception of

providing end-of-life care.

     Encountering translation challenges. While extensive translation services were

available in the hospital, they were not available twenty-four hours a day. In addition, while

services were available for the majority of languages, they were not always readily available

for some dialects (i.e. Mandarin). When services were not available, nurses were not able to

perform assessments as accurately, and they could not readily communicate with, and

support, family members during an emotionally distressing time. Nurses were concerned that the lack of available translation services could result in miscommunication between patients, families, and health care providers, and mistakes in care.

Research examining the availability of translation services was not identified in either the neurosciences or palliative care literature, but one relevant article was found in the general healthcare literature. The frustrations experienced by nurses due to a lack of access to translation services, as well as the legal and ethical implications arising from it, have been documented in the literature (Bernard et. al., 2005; Ledger, 2002). If there are not adequate resources to clearly assess and understand the patient, it may not always be clear as to accuracy of the chosen intervention. Evaluation and modification of the nursing care plan are critical components of the nursing process which are based on ongoing assessment. When nurses are fortunate enough to have family available to translate, this can be fortuitous, but can infringe on the privacy of the patient if there are health history details they do not want to share with family. For participants in the current study, it was unclear as to how gaps in translation services were addressed, but it is possible that they required support from family members at the bedside or staff members in the hospital, as discussed in the studies conducted on this subject.

Perceived cultural knowledge gaps. Nurses believed that they were not as knowledgeable about different cultures as they might be. For patients and families who were non-Caucasian and non-English-speaking, participants found that often did not have enough knowledge to be able to anticipate end-of-life care needs. This lack of knowledge was identified as making nurses feel uncomfortable. Nurses' discomfort with their perceived knowledge deficits regarding the influence of culture on the provision of either

palliative or non-palliative patient care was not located in the literature.

One article which did speak to the effects of gaps in cultural knowledge in healthcare was presented from the perspective of patients. Cortis (2000) conducted a descriptive qualitative study (*N* = 38) examining the experiences of Pakistani patients who were living in the United Kingdom, and received nursing care in the community hospital. The author found that participants interpreted the nursing interventions performed as uncaring and insensitive, as time was not taken to listen to the patient and attempt to understand what they truly needed. Although explanations of care were partially understood by patients, participants did not feel confident in asking follow-up questions as they felt that the nurses were too busy. In addition, participants perceived that nurses were uncomfortable spending time with patients of different races, as they were observed to spend time sitting and speaking at length with Caucasian patients, but not Pakistani patients. Cortis (2000) concluded that these patients believed that nurses did not demonstrate caring, empathy, and communication abilities. While it is not evident that nurses were truly uncaring, misconceptions and misunderstanding about cultural beliefs and preferences impacted the patients `perceptions of the quality of care which they were receiving.  The nurses in this current study were aware that their cultural knowledge deficits impacted patient care, and were quite certain that it was important to delve into the patients` and families` expectations in order to avoid circumstance such as those described by Cortis.

Accommodating end-of-life rituals within perceived systemic constraints. Nurses in this study were confident in their abilities to support and accommodate end-of-life traditions and rituals requested by patients and families. There were instances, however, in which nurses perceived that there were systemic constraints of the hospital which limited

these efforts. In a specific instance, families requested that a patient lie in place for eight to

ten hours after death. During this waiting period, nurses were consciously aware that

another patient was likely waiting to be admitted into the same bed from either the operating

room or emergency department. Nurses were aware that the facility in which they worked

had a finite number of beds to accommodate acute neurology patients, and experienced

tension and pressure in trying to balance the competing needs of patients and families with

the need of the hospital to accommodate other critically ill patients. None of the

participants described a request which they could not accommodate, but did refer to this

external pressure as challenging them in providing end-of-life rituals. Further research is

needed to more fully examine the impact of bed utilization on nurses' experiences in

providing culturally sensitive end-of-life care.

     Acknowledging personal influences. Participants in this study identified that their

own cultural backgrounds influenced their reactions to death and dying, and that these

reactions might differ significantly from the culturally mediated reactions of patients and

families. In this study, a nurse who believed that the discussion about and expression of

grief is a private family matter explained that it was difficult for him to engage with families

in communicating about issues of grief. This discomfort in communicating with families

who were more vocal in their expressions of grief and bereavement may have contributed to

this participant needing to emotionally detach

from the psychosocial aspects of care and focus primarily on tasks. This perspective of the

nursing experience in providing care has not been evaluated in the neurosciences literature,

but has been examined in the palliative care research.

     In a Swedish qualitative study, Ekblad, Marttila, and Emilsson (2000) led three

separate focus groups with hospice nurses ($N = 19$) to examine their perspectives regarding

cultural care issues at the end of life after they competed a three-day cultural workshop.

Nurses in the study were found to evaluate patients' and families' responses in relation to

their own Swedish cultural beliefs. Behaviors which were seen to be contrary to the local

cultural norm were identified as episodes of "cultural clashes". Staff also perceived that

families of different cultures were more involved in care and visited more frequently, which

was seen as interference in care. In light of an awareness of these perspectives, however,

participants recognized the value which they placed on their personal culture, as

subsequently identified a need to expand their own multicultural knowledge in general as

well as at the end of life (Ekblad et al., 2000). These findings are consistent with

perspective of nurses in the current study.

Limitations of the Study

The findings of this study must be viewed in light of its limitations. The first

limitation was the limited experience of the student. As a novice interviewer, she missed

opportunities to probe participants' descriptions and accounts in caring for dying stroke

patients that would have helped to more richly texture their caregiving experiences. As is

common when one is learning how to conduct research interviews, the student was initially

anxious in beginning data collection, and may have rushed through the interview schedule

versus taking time to more fully explore the nuances of the experiences that nurses shared.

The student herself was a skilled neuroscience nurse. While her skills in this area may have

helped increase her credibility among the study participants, the shared understanding of

neuroscience nursing and the care of dying patients may have resulted in missed

opportunities to deconstruct and carefully examine the claims that study participants were

making.

Additional study limitations related to the participant group themselves. All nurses were from one clinical unit, there were only nine participants in the initial interview process, and only two of the nine were interested in participating in the follow-up interviews. Thus while there was some evidence of recurring themes in the interview data, it is not clear about the extent to which the data are truly saturated (Streubert Speziale & Rinaldi Carpenter, 2007). There may also be evidence of a participant bias as those who are willing to participate in research may hold different perspectives than nurses who did not wish to participate. The perspective of non-participating nurses may or may not be consistent with the essence of striving and struggling to provide optimal end-of-life care identified by participants. Though the student was able to provisionally verify the findings with two participants, a more robust validation process would have been realized had the intended focus group validation process involving all nine nurse participants occurred.

While there was a significant diversity amongst the participants in terms of age, gender and clinical experience, the sample only consisted of nine participants. A larger number of participants might have allowed for a richer data set that would in turn have resulted in a more detailed understanding of nurses' experiences.

Implications of the Study

Implications for Practice. Although confident in providing physical patient care, nurses expressed a lack of confidence in communication skills when faced with speaking with family members who were present when a patient was dying. Education sessions on the patient care unit regarding communication styles and techniques at the end of life may prove valuable to improve the nurses' confidence, as this would provide them with tools to

apply to their clinical practice.

Due to time constraints resulting from the acuity of other patients on the unit, nurses in this study demonstrated varying degrees of comfort in providing optimal end of life care. To better support palliative patient care in the acute care setting, it may be beneficial to develop an evidence-based guideline or checklist for nursing which raises awareness of the multidisciplinary resources available in every case. Such a tool would increase awareness of potentially beneficial services of allied health professionals, prompting nurses to regularly assess the need for and consult additional resources as required. This may result in the provision of more consistent and comprehensive end-of-life care for the patients and families.

Nurses in this study identified the need to better understand the cultural nuances that can arise when providing end-of-life care to diverse cultural groups. The development of resources outlining these differences would provide nurses with an opportunity to learn about these nuances, and potentially increase their confidence in providing culturally sensitive care.

Nurses in this study reported that the work of caring for dying stroke patients and their families can be emotionally taxing such that at times, they bring their work home with them. Participants need to recognize the importance of utilizing resources at their disposal to help them debrief and work through emotionally challenging care situations. Potential resources available to nurses to help them work through emotionally challenging care situations with families include the psychiatric nurse liaison or facility the Employee Assistance Program.

Implications for Education. Some nurses in this study were not always clear as to

the purpose, proper dosing, and/or side-effects related to opioid administration. Competence in the use of opioid analgesics in care of the dying is essential if safe and effective care is to be provided. This goal might be achieved through repeated in-services on the nursing unit regarding opioids. Creating an increased awareness of the availability of the palliative care consult team as a resource if there are questions or concerns about opioid administration may also provide support for nurses in this regard.

Related to knowledge deficits regarding opioid administration is the finding that nurses in this study did not consistently use any type of pain assessment tools or guidelines to support their practice. Nurses administered opioids in response to patients' verbal and non-verbal cues, and the wishes of family members, but were not always confident as to whether or not the patient truly had pain. Education regarding the use of the Pain Algorithm, although not an empirically validated tool in unconscious neurological patients would arm the nurses with a tool that would allow for consistent use of analgesics for pain management. Although this tool is yet to be validated, it would provide a common approach and language for communication amongst the nurses, which may then lead to consistency in pain management interventions.

Nurses expressed feelings of inadequacy in their knowledge regarding end-of-life care for patients who had experienced an acute ICH. Although participants had received some theoretical palliative care training in their nursing education, only one had received both theoretical content in combination with clinical experience in palliative care. Nurses had also been orientated to work on the acute neurosciences unit where the ethos of the ward is curative in nature. Repeated in-services regarding basic palliative care philosophies, as well as palliative care issues that might arise in patients with an ICH may help nurses feel

more confident in providing end-of-life care.

Although nurses understood the anger expressed by families of dying stroke patients, they were not always comfortable or confident in knowing how to respond to families. As a result, nurses reported that they often needed to remove themselves physically and/or emotionally from clinical situations. Educational support regarding how to communicate with families at the end of life generally and strategies for dealing with family anger in particular, would provide the nurses with the skill to communicate more effectively when caring for families.

Implications for Research. Nurses demonstrated a lacked understanding regarding knowing how to use opioid analgesics in caring for dying stroke patients. Research examining neuroscience nurses' perspective regarding the use of opioids in palliative care would help to inform the specific gaps in nurses' knowledge in more detail. Identification of these gaps would guide the development of educational   interventions aimed addressing nurses' learning needs in this area.

Senior nurses perceived that junior nurses were less comfortable in providing palliative care when compared to more experienced nurses. Because this belief was not examined in detail in this study, further research is needed in this area to determine the validity of this belief and to identify areas of end-of-life care that junior nurses find problematic.

Healthcare aides were also perceived by nurses in this study as being uncomfortable in participating in end-of-life care with patients and families. This belief was also not explored in detail in the current study. Therefore, the actual experiences of healthcare aides in providing end-of-life care to dying stroke patients on the neurology unit needs to be

clarified with further research.

Though nurses in this study identified that they intervened to treat dying stroke patients' oral airway secretions, it was unclear if treatment of secretions was for the benefit of the patient, or the relieve anxiety experienced by families and nurses hearing these secretions. Further research is warranted to examine the drivers of this behavior in nurses.

When deciding whether or not to administer medications for symptom management, participants would regularly defer to the families' preference as to whether or not medications were needed, rather than considering their nursing assessment. Further research is needed to establish a greater understanding of why nurses engage in this behavior, and how they reconcile deferring this responsibility to individuals who do not have the training to make these care decisions.

Nurses found that time constraints impacted their ability to provide quality end-of-life care, and believed that the pressures on their time also impacted the families' perceptions of the quality of care which the patient received. Further research would provide a better understanding of the families' perception of time constraints in regards to the quality of patient care provided.

Nurses in this study identified that the way they practiced care was influenced by the dominance of medical model on the neurology unit. Further research is warranted to examine the nature of the power relationships that exist on the neurology unit, and explore the extent to which nurses believe that they have a professional responsibility in shaping patient care experiences and to determine the nurses' desire to change this approach to palliative patient care.

Nurses expressed strong beliefs that family members' care experiences were better

when the dying stroke patient could be cared for in a private, as opposed to a semi-private

room. The extent to which family members endorse this assertion needs further

examination.

Nurses also believed that it was unpleasant for a non-palliative patient to be cared

for in a semi-private room with a dying stroke patient. The extent to which this belief is

held by non-palliative patients who have received care in such a context needs further

exploration.

One nurse expressed ethical concerns in being directly involved in removing the ET

tube for patients who were deemed to be palliative. These concerns were not explored in

detail in the current study, and there may well be other aspects of providing care to dying

stroke patients that are ethically problematic for nurses. Further examination of the ethical

landscape for nursing providing care to dying stroke patients on acute neurology units

would be helpful.

Nurses in this study believed it was important to encourage family members to speak

with the patient to share memories as part of the anticipatory grieving process. In order to

gain a better understanding of how participants knew when and how to approach families to

engage them in this behavior, further research is warranted. The extent to which family

members find such encouragement from nurses helpful also needs to be examined.

In order to 'soften the blow' in regards to the inevitability of the patient's death,

nurses provided families with unsolicited information to help them to avoid being

blindsided when the physician came to deliver bad news about the patients' expected poor

prognosis. It was unclear if families found receiving such unsolicited information beneficial

or not. Further research is needed to determine the families' perceptions about this

intervention.

In sharing information with families, nurses assessed each individual situation to attempt to determine how much and what type of information each family member wished to receive. Participants recognized that each family had independent information needs. The process that nurses used to determine how and when to share what types of information was not explored in this study. Further research in this area would provide a greater understanding of the ways that nurses can most effectively meet family members' information needs.

Nurses referred to the fact that both their own culture and non-work related personal experiences with death and dying impacted their comfort level and beliefs when providing end-of-life care. These finding were not explored in detail in this study, but suggest the need for research examining the influence that one's culture and personal experience with death and dying has on the way that neuroscience nurses provide end-of-life care.

Study participants demonstrated evidence of siloed striving when providing psychosocial care in that they did not consistently consult other multidisciplinary resources to help in the care of dying patients and families. Further research to explore why nurses relied more readily on internal ward resources as opposed to the existing resources is needed. Nurses discussed consulting the hospital palliative care team, but were not always clear as to when and why this resource might be utilized. Research examining nurses' awareness of the role of the palliative care consult team and the type of support they can provide is needed.

Nurses in this study identified that they needed to detach from patient care situations at times in order to cope with the emotional impact of providing patient and family care.

Research is needed that both indexes the nature and type of emotional distress that nurses are experiencing, and explores the extent to which detachment from the care situations supports nurses in their attempts to manage their distress.

In attempting to cope with the impact of caring for dying stroke patients and their families, nurses identified that the stress of their work sometimes influenced their personal lives and at times, impacted their lives outside of work. Future research is needed to explore how prevalent such home life disruption is for nurses, and identify strategies to help nurses cope with their stress more effectively.

An additional cause of nurses' distress was related to the uncertainty in the prognosis of the patients, and how this uncertainty impacted communications with patients and families. Uncertainty led to feelings of frustration and helplessness. Research examining the ways in which nurses deal with this uncertainty and feelings of helplessness needs further study, as does the communication strategies that nurses might use with families when communicating about issues of uncertainty in end-of-life care.

Nurses identified that they were not directly involved in conversations regarding end-of-life care decisions, and relied exclusively on physicians to guide these discussions. Why nurses do not see a more prominent role for themselves in this aspect of care is unclear and merits further research. .

Nurses identified that they tried to avoid having conversations with family members about fluids and nutrition at the end of life. More research is needed to better understand the factors influencing this avoidance behavior, and the effect that is has on both nurses and family members.

The issue of what appears to be almost universal compliance with family member

requests also needs to be examined both from the perspective of nurses but the wider health care team as well. The perspectives of neurosurgeons would be particularly enlightening in this regard.

When caring for non-English speaking patients, nurse identified that they occasionally did not have access to the required translations services to support their assessment and care. The frequency of these occurrences, as well as how nurses managed to provide care despite these gaps in resources, warrants further research.

Summary

This purpose of this interpretive phenomenological study was to examine the lived experience of neuroscience nurses caring for dying stroke patients. The essence of nurses' experience that emerged from interviews with eight neuroscience nurses was that of striving and struggling to provide optimal end-of-life care. Specifically, nurses were engaged in striving and struggling in their efforts to: i) provide physical care, ii) provide psychosocial care, and iii) provide culturally-sensitive care. Chapter 5 discussed these study findings in light of existing literature. Recommendations for research, practice, and education suggested by the data were identified. Though the findings of the study must be viewed in light of the limitations identified in this chapter, this project is significant in that it represents a beginning attempt to better understand the experiences of neuroscience nurses caring for dying stroke patients—a topic that to date has received minimal research attention.

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Table 1: Demographics of Study Participants

Participants (N=9)		Palliative care education in nursing school	
Male	3	Classroom theory only	5
Female	6	Clinical component to education	1
		None	3
Age groups		Nursing experience (average years)	
20-29	2	Overall	13.7
30-39	3	Neurosciences	12
40-49	3		
50-59	1	Nursing education**	
		LPN	2
CNA certification in neurosciences*		RN	4
Yes	1	RN-BN	1
No	8	BN	2

Notes:

*Canadian Nurses Association Specialty Nursing Certification Examination

** Nursing education

LPN: licensed practical nurse

RN: diploma prepared registered nurse

RN- BN: post- RN baccalaureate registered nurse

BN: baccalaureate degree registered nurse

Appendix A: Educational Nursing Research Ethics Board Approval Letter

UNIVERSITY OF MANITOBA

OFFICE OF RESEARCH SERVICES
Office of the Vice President (Research)

CTC Building
208 - 194 Dafoe Road
Winnipeg, MB R3T 2N2
Fax (201) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

April 29, 2010

TO: Janice Nesbit   Advisor - S. McClement
Principal Investigator

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2010:048
"The Lived Experiences of Neuroscience Nurses Caring for Acute Stroke Patients Requiring End-of-life Care "

Please be advised that your above-referenced protocol has received human ethics approval by the Education/Nursing Research Ethics Board, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Evaline Saurette in the Office of Research Services, (e-mail evaline_saurette@umanitoba.ca, or fax 261-0325), including the Sponsor name, before your account can be opened.

- If you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Bringing Research to Life

Appendix B: Study Recruitment Poster

University of Manitoba: Faculty of Nursing
Graduate Studies

Opportunity for Nurses to Participate in a Research Project:

The lived experiences of neuroscience nurses caring for acute stroke patients requiring end-of-life care

Nurses working on (Neurosciences) are invited to participate in a nursing research study to discuss their experiences in caring for patients who are admitted to the ward after suffering a severe acute stroke, and are assigned supportive care only.

You qualify to participate in this study if:

- You are a registered nurse or licensed practical nurse
- You work routinely on (Neurosciences)
- You have clinical experience caring for patient who has suffered a severe stroke, and is not expected to survive his/her injury

Participation in this study is voluntary, and will involve an individual confidential interview with Janice Nesbitt RN to discuss your experiences, with the option to participate in a focus group meeting at a later date to provide feedback to Janice about the accuracy of her study findings. **You do not need to participate in the focus group in order to take part in the individual interview**.

****

This study has received ethical approval from The Education Nursing Research Ethics Board, The WRHA Access committee and the HSC Access committee. **If you are interested in participating, or have any questions about the study**, please contact Janice Nesbitt. Confidential voice messages can be left at this number any time. Alternatively, you can email Janice.

For concerns related to the administration of this study, please contact the Human Ethics Coordinator

Appendix C: Consent Form: individual interviews

Consent Form for Individual Interviews
University of Manitoba- Faculty of Nursing

Research Project Title: The lived experiences of neuroscience nurses caring for
acute stroke patients requiring end-of-life care

Researcher(s):   Janice Nesbitt, RN, graduate student, University of Manitoba

Student's Thesis Committee:

Dr. Susan McClement, Faculty of Nursing, University of Manitoba
Dr. Marie Edwards, Faculty of Nursing, University of Manitoba
Dr. Mike Harlos, Director, Palliative Care Program, Winnipeg Regional Health
Authority

This consent form, a copy of which will be left with you for your records and
reference, is only part of the process of informed consent. It should give you the basic idea
of what the research is about and what your participation will involve. If you would like
more detail about something mentioned here, or information not included here, you should
feel free to ask. Please take the time to read this carefully and to understand any
accompanying information.

You are being asked to participate in this study as you are either a Registered Nurse
or a Licensed Practical Nurse who has experience caring for patients who at the end-of-life
after experiencing acute onset of a severe stroke. The purpose of this study is to examine
and describe the lived experiences of nurses working in an acute neurosciences unit who
have cared for patients who are dying following an acute cerebral vascular accident (CVA).

Involvement in the study includes one face-to-face interview with Janice Nesbitt to
discuss your experiences caring for these patients. The interview will take place at a date,
time, and location mutually agreed between yourself and Janice. This may be in a meeting
room in the hospital, or at your home. All meetings are done outside of your scheduled
workday. It is expected that this interview will last 60-90 minutes, but the actual length will
be dependent upon how much you wish to say. The interview will be audiorecorded and
transcribed verbatim by Janice Nesbitt. All identifying information will be removed from
the transcribed interviews, and any names or other identify information will be replaced
with pseudonyms. Your identity and your participation in the face-to-face interview will not
be known to anyone other than Janice. A unique

Initials: _____

numbered code will be assigned to your transcribed interview and used as a reference in data analysis documents so that your identity remains anonymous. Information shared during the interview will be held in confidence, apart from anything that the researcher is required by law to report. In the event that the findings of this study are published, pseudonyms will be used in the place of names to maintain your confidentiality. Only Janice and her advisor, Dr. McClement will have access to the transcribed interviews.

Once the interviews are completed, data analysis will be done to determine common themes amongst the experiences of all of those who participate in this study. To accomplish this goal, it is necessary to audiotape and transcribe these interviews. All audiotapes, interview notes and transcribed interviews will be stored in a secured area in the researcher's office. A master list linking your identity and your assigned code number will be stored separately from study consent forms in order to maintain your anonymity and confidentiality. The findings from this study may be published or presented at scientific meetings. Data will be presented in aggregate form, and no names or other identifying information will be shared. .

To compensate you for your time and expenses for participating in this study, you will receive a Health Sciences Centre gift card for $25. This will be given to you at the end of the face-to-face individual interview.

Participation in this study is entirely voluntary. You are free to withdraw from the study at any time without repercussion. Please call Janice Nesbitt if you decide to withdraw. Confidential voice messages may be left at this number at any time. If you do chose to leave the study, none of the data you have provided will be used in the analysis. It will be destroyed and treated as confidential waste.

If you have any further questions about your participation in this study call Janice Nesbitt or Dr. Susan McClement.

Intls: _____

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Ethical approval for this study has been obtained from the Education Nursing Research Ethics Board at the University of Manitoba and permission to conduct the study has been obtained from the Winnipeg Regional Health Authority Research Review Committee, and the Health Sciences Centre Access Committee. If you have any concerns or complaints about this project you may contact Dr. Susan McClement or the Human Ethics Secretariat. A copy of this consent form has been given to you to keep for your records and reference.

_____

Participant's Signature   Date

_____

Researcher and/or Delegate's Signature   Date

After data analysis of the face-to-face interviews is completed, you will be given the option to participate in a focus group meeting. This additional meeting will be entirely voluntary. At this meeting, you will meet with the researcher and other study participants who have also taken part in individual interviews to hear about the preliminary findings from the project. You will also be asked to provide feedback regarding the researcher's interpretation of the experiences that have been shared. It is requested that all information shared between group members, including discussions regarding specific patient situations be kept confidential as per PHIA regulations. This group meeting will be held in a meeting room in the hospital. This meeting is anticipated to last 1-2 hours, depending on the amount of feedback and discussion that presents.

At this time, you are being asked to indicate if you consent to being contacted after the individual interviews are completed to discuss the possibility of attending this follow-up focus group meeting. Your preference in no way affects your participation in the individual study.

Please check "yes" or "no" and sign to indicate your preference:

☐   **Yes**, I consent to being contacted in the future about the possibility of attending a focus group meeting with other study participants

        Contact information: _____

☐   **No**, I would prefer not to participate in a focus group meeting.

_____
Participant's Signature   Date

_____
Researcher and/or Delegate's Signature   Date

Appendix D: Consent Form: follow-up interviews

Consent Form for Focus Group
University of Manitoba- Faculty of Nursing

Research Project Title: The lived experiences of neuroscience nurses caring for
acute stroke patients requiring end-of-life care

Researcher(s):   Janice Nesbitt, RN, graduate student, University of Manitoba

Student's Thesis Committee:

Dr. Susan McClement, Faculty of Nursing, University of Manitoba
Dr. Marie Edwards, Faculty of Nursing, University of Manitoba
Dr. Mike Harlos, Director, Palliative Care Program, Winnipeg Regional Health
Authority

This consent form, a copy of which will be left with you for your records and
reference, is only part of the process of informed consent. It should give you the basic idea
of what the research is about and what your participation will involve. If you would like
more detail about something mentioned here, or information not included here, you should
feel free to ask. Please take the time to read this carefully and to understand any
accompanying information.

You are being asked to participate in this study as you are either a Registered Nurse
or a Licensed Practical Nurse who has experience caring for patients who at the end-of-life
after experiencing acute onset of a severe stroke, and have participated in the initial face to
face interviews as a part of this study. The purpose of this study is to examine and describe
the lived experiences of nurses working in an acute neurosciences unit who have cared for
patients who are dying following an acute cerebral vascular accident (CVA).

Involvement in the study includes participating in a focus group meeting with other study
participants to receive feedback from the findings of the first part of this study, and allow
you an opportunity to provide feedback as to the accuracy of the interpreted finding. You
will also have an opportunity to discuss your experiences further with the other members of
the focus group. The interview will take place at a date, time, and location mutually agreed
between yourself and Janice Nesbitt. This will be a meeting room in the hospital. All
meetings are done outside of your scheduled workday. It is expected that this interview will
last 60-90 minutes, but the actual length will be dependent upon how much you wish to say.
The interview will be audiorecorded and transcribed verbatim by Janice Nesbitt. All
identifying information will be removed

Initials: _____

from the transcribed interviews, and any names or other identify information will be replaced with pseudonyms. Your identity and your participation in the interview will not be known to anyone other than Janice. A unique numbered code will be assigned to your transcribed interview and used as a reference in data analysis documents so that your identity remains anonymous. Information shared during the interview will be held in confidence, apart from anything that the researcher is required by law to report. In the event that the findings of this study are published, pseudonyms will be used in the place of names to maintain your confidentiality. Only Janice and her advisor, Dr. McClement will have access to the transcribed interviews.

Once the interviews are completed, data analysis will be done to confirm and modify common themes amongst the experiences of all of those who participate in this study. To accomplish this goal, it is necessary to audiotape and transcribe these interviews. All audiotapes, interview notes and transcribed interviews will be stored in a secured area in the researcher's office. A master list linking your identity and your assigned code number will be stored separately from study consent forms in order to maintain your anonymity and confidentiality. The findings from this study may be published or presented at scientific meetings. Data will be presented in aggregate form, and no names or other identifying information will be shared. .

To compensate you for your time and expenses for participating in this study, you will receive a facilty gift card for $25. This will be given to you at the end of the focus group meeting.

Participation in this study is entirely voluntary. You are free to withdraw from the study at any time without repercussion. Please call Janice Nesbitt if you decide to withdraw. Confidential voice messages may be left at this number at any time. If you do chose to leave the study, none of the data you have provided will be used in the analysis. It will be destroyed and treated as confidential waste.

If you have any further questions about your participation in this study call Janice Nesbitt or Dr. Susan McClement.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Initials: _____

Ethical approval for this study has been obtained from the Education Nursing Research Ethics Board at the University of Manitoba and permission to conduct the study has been obtained from the Winnipeg Regional Health Authority Research Review Committee, and the Site Hospital Access Committee. If you have any concerns or complaints about this project you may contact Dr. Susan McClement or the Human Ethics Secretariat. A copy of this consent form has been given to you to keep for your records and reference.

_____

Participant's Signature   Date

_____

Researcher and/or Delegate's Signature   Date

Appendix E: Interview Guide: individual interviews

Hello _____. Thank you for meeting with me today to discuss your experiences of caring for a patient who is dying after experiencing as acute stroke. I am going to ask you a few questions, and there are no right or wrong answers. I am interested in learning more about your personal experiences and perceptions about caring for these particular patients. I anticipate that this will take from 60-90 minutes, but will be dependent on how much information you wish to share.

Do you have ay other questions about the study before we begin?

To start, can you please complete this demographic page for me? (Appendix C)

I am going to ask you a few questions about you experience caring for patients who have been admitted following an acute stroke. For the purpose of this study, we are focusing on patients who have had an intracranial bleed, who were relatively healthy prior to admission, and are now suddenly unresponsive and not responding to medical or nursing management, and have been taken off calls, as they are not expected to survive. (Confirm that the patient population is understood).

Overarching Question:

Can you describe the experience of caring for a patient who is dying following an acute stroke?

Will follow this up with questions needed to clarify or expand on the answer to this question (for this and subsequent questions). Some areas of exploration within the first question may include:

- the kinds of care interventions that were provided
- to whom the care was provided (e.g. patient and family?)
- how confident the nurse felt in providing the care
- the feelings associated with providing care (positive and negative)

If not offered spontaneously by the participant, will ask if they are able to provide an example of a specific experience.

Follow-up Questions:

1. Can you describe how this experience differs from caring for other patients on your unit?
2. What supports your ability to care for this patient population?
   E.g.: physical resources on the
   Internal resources within the nurse
3. What, if anything interferes with your ability to provide care to this patient population?

At the end of the interview:

Those are all the questions that I had for you today. Do you have anything else that you would like to discuss or mention that has not come up yet?

Appendix F: Interview Guide: follow-up interviews

Hello _____. Thank you for agreeing to participate ion this focus group/ interview and for meeting with me today to discuss your experiences of caring for a patient who is dying after experiencing as acute stroke. I am first going to explain the findings of the initial interviews, including the common themes that emerged from those interviews. I am interested in learning from you if you believe that these findings accurately reflect your experiences and hope to learn more about your personal experiences and perceptions about caring for these particular patients. I anticipate that this will take from 60-90 minutes, but will be dependent on how much information you wish to share.

Do you have any other questions about the study before we begin?
Then:

- Will present summary of findings from primary interviews. Will be certain to keep examples to support themes anonymous.
- Will confirm interpretation of analysis of different themes
- Will list themes with examples and then go over each individually, allowing for discussion of each theme on its own.
- Will allow for discussion of personal experiences; intervening only to keep discussion on track of goals of follow-up meeting (i.e. confirmation of accuracy of interpretation of lived experiences)

Follow-up Questions:

- Can you describe how this experience differs from caring for other patients on your unit?
- What supports your ability to care for this patient population?
    - E.g.: physical resources on the
    - Internal resources within the nurse
- What, if anything interferes with your ability to provide care to this patient population?

At the end of the interview:

Those are all the questions that I had for you today. Do you have anything else that you would like to discuss or mention that has not come up yet?

Appendix G: Study Demographic Form

ID#: _____

Date of Interview:_____

Please indicate the correct answer for the following questions:

Age Group:

20-29 years   30-39 years   40-49 years

     50-59 years   60-69 years

Gender: Male   Female

Years in Nursing: _____

Years in Neuroscience Nursing: _____

What is the highest level of nursing education that you have obtained (please circle one):

Licensed Practical Nurse   Diploma   Post- diploma baccalaureate

     Baccalaureate   Masters

Do you hold any certifications with the Canadian Nursing Association? (circle answer):

Yes   No

If yes, what specialty? _____

Did you basic nursing education include any classes that addressed the care of palliative patients and their families?

Yes   No   Do not recall

If yes to question 7, did these classes include any clinical time in a palliative care unit?

Yes   No   Do not recall