11-14-2011

Factors Influencing Long-Term Health-Related Quality of Life Among Patients After Aneurysmal and Nonaneurysmal Subarachnoid Hemorrhage: A Dissertation

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"Factors Influencing Long-Term Health-Related Quality of Life Among Patients After Aneurysmal and Nonaneurysmal Subarachnoid Hemorrhage"

A Dissertation Presented

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DEDICATION

To my parents Arthur and Agnes McIntosh, who instilled a thirst for higher education in me at early age. They provided a sense that anything was possible as long as you tried your best and worked hard. To my partner, John Heaney, for putting up with me always being “forever a freshman” which decreased our time to do more exciting and fun activities. To my son, Colby McIntosh, for being the impetus for everything I have done in the last four years in hopes your life will be as happy, secure and blessed as mine.

ACKNOWLEDGMENTS

I would like to acknowledge my wonderful, dedicated and inspirational dissertation committee. Carol Bova, PhD, RN, ANP, who chaired my committee and always believed that I could become a PhD prepared nurse from day one, despite multiple life events. She never lost faith and gently refocused my work over the last four years. To my committee member, Ajith Thomas, MD who has been a friend and mentor to me over the last six year as we worked together in neurosurgery at Beth Israel Deaconess Medical Center in Boston. Despite being an extremely busy neurosurgeon he used his precious free time to review my work and more importantly help keep me sane when school and work were overwhelming. To my statistician, Sybil Crawford, PhD who made understanding difficult statistical concepts pleasurable. I am sincerely grateful for all of you.

I would also like to acknowledge the never ending support of my family and friends who stood by me all the way. In particular I acknowledge my sister, Fran McIntosh, who took precious vacation time to watch my son during my comprehensive exam which made a stressful time less stressful.

Thanks to faculty at the Graduate School of Nursing some of whom I have had the pleasure of being instructed and mentored by for two different degrees over the last 10 years. UMass Worcester GSN is truly an exceptional department within an excellent school.

ABSTRACT

Subarachnoid hemorrhage (SAH) causes 5% of all strokes and is responsible for about 18,000 deaths per year in the United States (Aneurysmal Subarachnoid Hemorrhage, 2008). The incidence of SAH has been estimated at 6 to 8 per 100,000 persons per year (Linn, Rinkel, Algra, & van Gijn, 1996). In nearly 15% (range 5–34%) of patients with SAH, no source of hemorrhage can be identified via four-vessel cerebral angiography (Alen et al., 2003; Gupta et al., 2009), resulting in two major types of SAH: aneurysmal (ASAH) and nonaneurysmal (NASAH). Anecdotal evidence and contradictory research suggest that patients with NASAH experience some of the same health-related quality of life (HRQoL) issues as patients with ASAH. The purpose of this quantitative survey design study was to compare health-related quality of life (HRQoL) 1 to 3 years post-hemorrhage in patients who have experienced a NASAH to those who have experienced an ASAH. This is the first US study to specifically investigate HRQOL in NASAH and the second study comparing HRQOL outcomes between aneurysmal and nonaneurysmal subarachnoid hemorrhage patients. Our results are comparable to the first study by Hutter and Gilsbach, (1995), which also found that the two groups are much more similar than different. There were no significant differences between 28 of the 36 demographic and clinical characteristics examined in this study. Our study confirms previous findings that there is a significant impact on employment for both hemorrhage groups and an even greater inability to return to work for the NASAH patients. The nonaneurysmal group had more physical symptom complaints while the aneurysmal group had more emotional symptoms. Lastly, both groups had low levels of PTSD, and these levels did not differ significantly between groups. However, PTSD and social support were shown by regression analysis to impact HRQOL for both groups. We recommend that clinicians assess for PTSD in all subarachnoid hemorrhage patients and

institute treatment early, which will decrease the negative effects on HRQOL. This may include offering psychological services or social work early in the hospital course to all SAH patients. Further research and policy changes are needed to assist in interventions that improve vocational reintegration after SAH. NASAH patients should no longer be referred to as having suffered a "benign hemorrhage." They have had a life changing hemorrhage that may forever change their lives and impact their HRQOL

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Running head: HRQoL in Aneurysmal and Nonaneurysmal Subarachnoid Hemorrhage Patients

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By

Arthur P. McIntosh

Submitted to the Graduate School of Nursing
University of Massachusetts Worcester in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

2011

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CHAPTER I

STATE OF THE SCIENCE

Introduction

Subarachnoid hemorrhage (SAH) causes 5% of all strokes and is responsible for about 18,000 deaths per year in the United States (Aneurysmal Subarachnoid Hemorrhage, 2008). The incidence of SAH has been estimated at 6 to 8 per 100,000 persons per year (Linn, Rinkel, Algra, & van Gijn, 1996). In nearly 15% (range 5–34%) of patients with SAH, no source of hemorrhage can be identified via four-vessel cerebral angiography (Alen et al., 2003; Gupta et al., 2009), resulting in two major types of SAH: aneurysmal (ASAH) and nonaneurysmal (NASAH).

ASAH is defined as bleeding into the subarachnoid space that surrounds the brain (i.e., the area between the arachnoid membrane and the pia mater). ASAH may arise due to spontaneous rupture of an aneurysm. It is a medical emergency that, even if recognized and treated in an early stage, can lead to death or severe disability.

NASAH is a nontraumatic, spontaneous SAH of unknown etiology, not visualized on a cerebral angiogram (Hermann & Zabramski, 2007). Patients who experience NASAH differ from those who suffer an ASAH. NASAH has been described as a benign entity (Alen et al., 2003; Beseoglu, Pannes, Steiger, & Hanggi, 2009; Gupta et al., 2009). The symptoms of NASAH differ slightly from those of ASAH, i.e., the headache generally starts over several minutes rather than the sudden thunderclap headache associated with ASAH (Rinkel et al., 1990). Patients with NASAH, who are typically younger and male, may report other symptoms such as nausea, vomiting and photophobia (Herrmann & Zabramski, 2007). In NASAH, the hemorrhage is classified as perimesencephalic or nonperimesencephalic. In a perimesencephalic hemorrhage the blood is confined to the cisterns around the midbrain and the center of the

bleeding is immediately anterior to the midbrain (Gupta et al., 2009). The population with perimesencephalic hemorrhage usually has a fairly benign and uncomplicated hospital course, whereas the nonperimesencephalic hemorrhage population tends to have more complications, similar to patients who have had ASAH (Alen et al., 2003; Beseoglu et al., 2009; Gupta et al., 2009; Hermann & Zabramski, 2007).

Anecdotal evidence and contradictory research suggest that patients with NASAH experience some of the same health-related quality of life (HRQoL) issues as patients with ASAH. Quality of life issues in the NASAH patient population have specifically been examined in five studies, four performed in Europe (Beseoglu et al., 2009; Brilstra, Hop, & Rinkel, 1997; Greebe & Rinkel, 2007; Marquardt, Niebauer, Schick, & Lorenz, 2000) and one in India (Gupta et al., 2009), with contradictory results. HRQoL was measured in many of these studies by tools such as the Rankin Score or Glasgow Outcome Scale (GOS), which are not good indicators of multidimensional domains of health-related quality of life. Patients in these studies might have been classified as having "good outcomes" or having a "benign hemorrhage," without having returned to their pre-hemorrhage level of functioning. No US studies published thus far have specifically studied HRQoL in the NASAH patient population. The setting of previous studies may be important as the majority of European countries have a government-run health care system. To understand HRQoL issues in the US NASAH patient population, this study will use a survey design. The goal of the study was to detect the strength of association and differences in HRQoL between patients who experienced a NASAH versus an ASAH in the previous 1 to 3 years. Factors influencing NASAH patients' experiences of HRQoL issues were determined and compared to and adjusted to those of ASAH patients.

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Purpose Statement

The purpose of this quantitative survey design study was to compare health-related quality of life (HRQoL) 1 to 3 years post-hemorrhage in patients who experienced a NASAH to those who have experienced an ASAH.

Specific Aims

1. To describe the physical, psychological, social, and vocational impact of nonaneurysmal and aneurysmal subarachnoid hemorrhage on patients at 1 to 3 years post-hemorrhage.
2. To examine differences in HRQOL between patients with NASAH and ASAH after controlling for severity of hemorrhage, age, and time since event.
3. To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and determining if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.
4. To describe management strategies used by patients with nonaneurysmal and aneurysmal subarachnoid hemorrhage that helped improve their HRQoL.

Aneurysmal Subarachnoid Hemorrhage

Incidence of ASAH

The international incidence of spontaneous SAH varies according to region, but affects approximately 7 to 9 of 100,000 people per year (de Rooij, Linn, van der Plas, Algra, & Rinkel, 2007). Although women have historically been considered more likely than men to suffer from SAH (de Rooij et al., 2007), newer epidemiologic research reveals that this difference occurs only after the sixth decade of life (de Rooij et al., 2007). The most common cause of SAH is trauma as the corticomeningeal vessels are ruptured (Suarez, Tarr, & Selman, 2006). Most

spontaneous causes of SAH are related to aneurysm rupture, which is the focus of this section (Suarez et al., 2006).

Diagnosis of ASAH

Rupture of an aneurysm releases blood directly into the cerebrospinal fluid (CSF) under arterial pressure (Greenberg, 2005). The blood spreads quickly within the CSF, rapidly increasing intracranial pressure. The bleeding usually lasts only a few seconds, but re-bleeding is common and occurs more often within the first day (Greenberg, 2005). Consistent with the rapid spread of blood, the symptoms of SAH typically begin abruptly, occurring at night in 30% of cases. The premier symptom is a sudden, severe headache (97% of cases), classically described as the "worst headache of my life." The headache is lateralized in 30% of patients, predominantly to the side of the aneurysm (Greenberg, 2005; Thomas, Edlow, & Goldstein, 2009). The onset of the headache may or may not be associated with a brief loss of consciousness, seizure, nausea, vomiting, or meningismus (Greenberg, 2005; Thomas et al., 2009).

SAH blood will usually be seen on a non-contrast computed tomography (CT) scan of the head in SAH spaces, sometimes encircling the circle of Willis. If no blood is seen on a head CT, the next step would be to perform a lumbar puncture to rule out blood in the cerebrospinal fluid (Thomas et al., 2009). Finding blood in the CSF confirms the diagnosis of SAH. Other diagnostic techniques, e.g., CT angiography (CTA) and magnetic resonance angiography (MRA), are noninvasive tests useful for screening and pre-surgical planning, but they do not achieve the resolution of angiography (Alen et al., 2003). MRA can identify aneurysms 3 to 5 mm or larger. The sensitivity of CTA appears comparable to MRA, as aneurysms smaller than 3 mm will be missed. Cerebral diagnostic angiogram has been considered the gold standard to

definitely diagnose or exclude aneurysm or arteriovenous malformations as the cause of subarachnoid hemorrhage (Thomas et al., 2009).

ASAH Hospital Course

ASAH patients are admitted to an intensive care unit where their neurological exam and vital signs are monitored closely (Greenberg, 2005; Hermann & Zabramski, 2007). Strict blood pressure control is important prior to repair of the aneurysm. The most recent American Heart Association guidelines recommend that "blood pressure should be monitored and controlled to balance the risk of stroke, hypertension-related bleeding, and maintenance of cerebral perfusion pressure" (Bederson et al., 2009, p. 1002). Bed rest with head of bed elevation greater than 30 degrees is recommended to maintain venous outflow and minimize blood pressure fluctuations (Thomas et al., 2009). The treatment of a ruptured aneurysm is based on location and size of aneurysm (Greenberg, 2005). Two methods are widely available but depend on the medical center's capabilities and surgeon preference. Open surgical clipping via craniotomy was once the traditional method for securing a ruptured aneurysm and is still used today (Bederson et al., 2009). However, the more commonly used method is an endovascular packing of the aneurysm with titanium coils. Each procedure has its own set of risks and benefits (Bederson et al., 2009).

Standard postoperative treatment includes monitoring the patient for cerebral vasospasm, a delayed complication that may develop several days to 2 weeks post-SAH, peaking 7 to 10 days after the event (Greenberg, 2005). Vasospasm may be asymptomatic or may lead to delayed cerebral ischemic infarcts, which can cause significant morbidity related to SAH (Greenberg, 2005). Nimodipine, a calcium channel blocker, has been shown to improve outcomes (risk ratio 0.67; 95% confidence interval, 0.55-0.81) of death or dependence (Bederson et al., 2009). When patients are confirmed to have vasospasm, they receive hyperdynamic therapy, i.e., intravenous

fluids and vasopressor medications to cause hypervolemia, hypertension, and hemodilution (Greenberg, 2005). Patients' blood chemistry results should be closely monitored for hyponatremia, a common complication of SAH (Hermann & Zabramski, 2007). Depending on the patient's neurological deficits, complications and presence of vasospasm will determine length of hospital course (Bederson et al., 2009; Greenberg, 2005; Hermann & Zabramski, 2007).

Nonaneurysmal Subarachnoid Hemorrhage

Incidence of NASAH. In nearly 15% of patients with spontaneous nontraumatic subarachnoid hemorrhage, no obvious source of hemorrhage can be demonstrated on diagnostic cerebral angiography (Alen et al., 2003; Gupta et al., 2009; Hermann & Zabramski, 2007; Wijdicks, Schievink, & Miller, 1998 a.b). Of these patients, 21% to 68% are known to have perimesencephalic hemorrhage (Gupta et al., 2009), which is typical in younger and male patients (Hermann & Zabramski, 2007). In perimesencephalic hemorrhage, the blood is confined to the cisterns around the midbrain and the center of the bleeding is immediately anterior to the midbrain (Gupta et al., 2009). Thus, the population of patients with perimesencephalic hemorrhage usually has a fairly benign and uncomplicated hospital course (Alen et al., 2003; Beseoglu et al., 2009; Gupta et al., 2009; Hermann & Zabramski, 2007). A significant percentage of the NASAH population presents a nonperimesencephalic pattern of blood, where the hemorrhage is located in the other subarachnoid, intracerebral, ventricular spaces (Beseoglu et al., 2009). For patients with this NASAH, the incidence, clinical course, and outcomes are not well described (Gupta et al., 2009).

NASAH Hospital Course. A gradual onset of a severe headache over several minutes has been reported in patients with NASAH (Hermann & Zabramski, 2007). Patients may also report

associated symptoms such as nausea, vomiting, and photophobia. These patients may also be reported by their significant others to have an altered level of consciousness (Hermann & Zabramski, 2007). Once the patient has had a full examination, other pertinent information should be obtained such as history of recent drug use, hypertension, polycystic kidney disease, and history of other aneurysms (Gupta et al., 2009; Hermann & Zabramski, 2007; Wijdicks et al., 1998a,b). Another important question is family history. Two family members in a study of 24 patients with perimesencephalic NASAH, were found to have a subarachnoid bleed from a brain aneurysm (Wijdicks et al., 1998a). Genetic predisposition to various vascular abnormalities, including intracranial aneurysms, has been well documented (Hermann & Zabramski, 2007; Wijdicks et al., 1998a).

A CT scan of the brain is usually the first step to rule out other pathologies that may mimic a subarachnoid hemorrhage (Hermann & Zabramski, 2007). CT angiography may be performed to determine the source of the hemorrhage. In patients with ruptured aneurysms the reported sensitivity is 86% (Alen et al., 2003; Hermann & Zabramski, 2007; Wijdicks et al., 1998b). However, the gold standard remains the diagnostic cerebral angiogram, which is likely needed to evaluate cerebral circulation for the source of SAH: aneurysm, ateriovenous malformation, or dural arteriovenous fistula (Alen et al., 2003; Hermann & Zabramski, 2007; Wijdicks et al., 1998b). A negative angiogram may be followed up by magnetic resonance imaging (MRI) scan of the brain and possibly spine to rule out a tumor and other vascular abnormalities (Alen et al., 2003; Hermann & Zabramski, 2007; Wijdicks et al., 1998b). In a significant percentage of patients with spontaneous subarachnoid hemorrhage, the initial angiographic studies do not reveal an aneurysm or other vascular abnormality; indeed, some of these patients' angiograms can yield false-negative results (Gupta et al., 2009). It is controversial

whether to repeat the cerebral angiogram from 5 days up to 6 weeks after initial bleed (Gupta et al., 2009; Hermann & Zabramski, 2007; Wijdicks et al., 1998b).

At this author's medical institution, protocols for NASAH include admission to an ICU setting for close neurological monitoring, further imaging with CTA, followed by diagnostic cerebral angiogram. If negative, the angiogram is followed by MRI of the brain and spine. These patients are also kept on bed rest, and given Nimodipine, a calcium channel blocker, and additional medication if needed to keep their blood pressure within a normal range. These protocols are consistent with previous reports (Hermann & Zabramski, 2007; Wijdicks et al., 1998a, b). Patients are monitored closely for vasospasm, which can occur in patients who suffer a subarachnoid hemorrhage but are uncommon in NASAH patients (Hermann & Zabramski, 2007). For example, vasospasm was reported in 4 of 24 nonaneurysmal patients (16%, Wijdicks et al., 1998b), in 2 of 65 patients (3%, Schievink, Eelco, & Spetzler, 2000), and in 1 of 26 patients (3%, Beseoglu et al., 2009). A case study report of vasospasm in perimesencephalic NASAH patients (Schievink et al., 2000) concluded that these patients are at risk for vasospasm and should be treated with prophylactic nimodipine, a calcium channel blocker shown to prevent major complications from vasospasm in SAH patients (Allen et al., 1983).

Vasospasm, if not quickly identified and treated, can lead to cerebral ischemia and stroke. Thus, some clinicians will observe this population in an ICU setting until the second angiogram is negative. If the second angiogram is negative and the neurological exam is normal, the NASAH patient will be transferred to the neurosurgical unit and observed for 1 to 2 more days until the headache or any other issues can be managed at home. NASAH patients often report anxiety about having another hemorrhage as well as concerns about headaches, short-term

memory problems, and going back to work (Greebe & Rinkel, 2007; Hermann & Zabramski, 2007).

Measures Used to Assess Health Outcomes in the SAH Population

Health outcomes have commonly been assessed in the SAH population using seven tools: the modified Rankin Scale (mRS), (Bonita & Beaglehole, 1988), Glasgow Outcome Score (GOS), (Jennette& Bond (1975), Barthel Index (Mahoney & Barthel, 1965), National Institute of Health Stroke Scale (NIHSS), (Brott et al., 1989), the Medical Outcomes Study Short Form-36 (SF-36),(The SF-36/org*)*, the Mini-Mental Status Examination (MMSE), Folstein, Folstein, & McHugh (1975)., and the Stroke-Specific Quality of Life Scale (SS-QoL) (Williams,Weinberger, Harris, Clark & Biller, 1999)). The first six instruments were compared in a prospective study on the utility of QoL health-outcome measures to assess 385 patients 3 to 12 months after intracranial aneurysm treatment (Kim, Haney, & Van Ginhoven, 2005). The study reported three main findings. First, the Barthel Index and NIHSS were not useful in the aneurysmal population, due to most survivors achieving maximal scores by 3 months. Second, the Rankin and Glasgow scales were poorly correlated with the MMSE and SF-36, indicating that patients with significant cognitive or QoL issues can be graded at a high level of function. This finding is not unexpected as the Rankin and Glasgow scales measure degree of disability and not QoL. Lastly, the Rankin, GOS, MMSE, and SF-36 showed statistically significant differences in outcomes for patients with different initial clinical presentations. The authors recommend that the recovery of ASAH patients should not be assessed only by a simple graded scale, but supplemented with MMSE and SF-36 assessments (Kim et al., 2005).

The seventh instrument, the SS-QoL was recently validated in 141 patients with ASAH (Boosman, Passier, Visser-Meily, Rinkel, & Post, 2009). The 49-item SS-QoL measures QoL in

12 domains: self-care, mobility, upper extremity function, language, vision, work, thinking, family roles, social roles, personality, mood, and energy. Internal consistency was good (alpha>.80) for all 12 domains (Boosman et al., 2009).

A recent meta-analysis by Noble & Schenk (2010) studied variables to explain poor health related quality of life after SAH. They included studies which HRQoL had been measured using a Sickness Impact Profile (SIP), Functional Limitation Profile, Functional Limitations Profile, Aachen Life Quality Inventory or MOS Short Form HRQoL questionnaire (Short Form 36 and Short Form 12). Twelve articles were examined, using the predictor patient age, sex of patient, age, clinical severity, bleed severity and cognitive impairment. Only the variable of physical disability (effect size .54) was found to be a useful predictor of poor HRQoL. Age also needs to be considered as a predictor value with an effect size of .20. The traditional variables cited in other studies such as sex, severity of bleed, clinical severity of bleed at the time of admission to the hospital, time between SAH and assessment of HRQoL have only minimal effects on patients' physical and mental HRQoL.

Quality of Life in the ASAH Population

Quality of life (QoL) after aneurysmal subarachnoid hemorrhage has been examined in eight European studies conducted in Germany (Hutter & Gilsbach, 1995; Hutter, Kreitschmann-Andermahr, & Gilsbach, 2001; Scharbrodt, Stein, Schriber, Boker, & Oertel, 2009), the Netherlands (Hop, Rinkel, Algra, & van Gijn, 1998; Hop, Rinkel, Algra, & van Gijn, 2001; Visser-Meily, Rhebergen, Rinkel, van Zandvoort, & Post, 2009;Wermer, Kool, Albrecht, & Rinkel, 2007;), and Spain (Katati et al., 2007). These studies demonstrate long-term QoL was predicted by neurological exam on admission, size of bleed, and age. The long term physical effects of ASAH effects physical/emotional health and have interfered with ability to work. The

first study examined, Hutter & Gilsbach (1995), is the only study that includes NASAH in its study population.

Quality of life was studied retrospectively 1- 5 years after their SAH, in 36 German ASAH and NASAH patients (Hutter & Gilsbach, 1995). About half these patients (51%) initially presented in the emergency department with an altered mental status and 93% had diffuse subarachnoid blood or clot on CT on arrival at the hospital. These data are important because NASAH patients generally have a small amount of blood or clotting and minimally altered mental status. Participants were assessed for QoL using an 11-item self-rated scale and a parallel version rated by their life-companions. The emotional state of participants was tested using the Freiburg Personality Inventory (FPI-R). Substantial impairments in QoL were reported by 50% of patients and their life companions, but proxy ratings were consistently lower. In particular, QoL was reduced in terms of motivation (41%), life satisfaction (48%), mental capacity (47%), free-time activities (52%), social relationships (39%), concentration (70%), free motor coordination (25%), and sleep (47%). Self-reported ratings on reduced motivation and free-time activities correlated well with FPI-R scores for loss of motivation ($r= 0.46$, $p<0.01$). Participants reported employment-related difficulties (n=5, 8%), lost their job or were demoted (n= 5, 8%), or had to retire (n=9, 15%). Depression was found in 17 patients (30%, Hutter & Gilsbach, 1995).

This study provided insight into the neuropsychological component of subarachnoid hemorrhage. The authors concluded that ASAH and NASAH patients did not differ significantly in cognitive deficits, depression, and daily life restrictions. However, the findings of this study were limited by the small sample, use of multiple complex instruments to assess cognition and depression, and the lack of a standard, multidimensional measure of QoL, as demonstrated by lack of measurement of the physical domain (Ware, 1987).

Quality of life was examined in 116 German patients 4 to 5 years after aneurysmal bleed to determine whether brain location of hemorrhage influenced QoL (Hutter, Kreitschmann-Andermahr, & Gilsbach, 2001). QoL was measured using the Aachen Life Quality Inventory, the German version of the Sickness Impact Profile (SIP), and found to be substantially influenced by patient's age, neurological state on admission, and bleeding pattern, but not by location of the aneurysm. These findings were validated in a cohort of 128 German SAH patients approximately 5 years post-hemorrhage (Scharbrodt, Stein, Schriber, Boker, & Oertel, 2009). Long-term QoL was predicted by neurological exam on admission, size of bleed, and age predicted long-term QoL. In that study, SAH negatively impacted QOL (measured by the SF-36) up to 5 years after the hemorrhage. The negative effects were most notable for, physical, social, and general health domains.

QoL was studied prospectively in 64 Dutch patients and their significant others (Hop, Rinkel, Algra, & van Gijn, 1998) using the SF-36, SIP, and a 0-100 visual analog scale (VAS) that self-rated well-being before and after the hemorrhage. VAS, ranging from 0 (poor) to 100 (excellent), with the following questions: "How did you do before your/your partner's hemorrhage?" and "How are you now?" Patients and partners were asked to respond by putting a mark on the scale, taking into account their integrated physical, psychological, and social well-being. Functional outcomes were assessed using the Rankin scale. QoL was often decreased on both SIP and SF-36 physical and psychosocial subscores of patients whose functional outcomes were reduced, but were independent (Rankin grades 1 to 3). Patients' outcomes were referenced to a Dutch population assumed to have little to no functional disability. Good physical outcomes (Rankin grade 0, independent and recovered) did not correlate with psychosocial well-being. Patients' employment issues were not addressed (Hop et al., 1998).

Quality of life in the same cohort of Dutch patients and their significant others was followed up 18 months later (Hop, Rinkel, Algra, & van Gijn, 2001). Again QoL was measured using the SF-36, SIP, and visual analogue scale, but functional outcomes were measured using a modified Rankin Scale (mRS). 32 patients (50%) improved at least 1 point on the mRS, in 23 patients functional outcome remained unchanged, 6 patients deteriorated 1 point on the mRS, and 3 died. QOL of patients and caregivers did not change in terms of SIP scores, but SF-36 scores improved QOL in patients with higher Rankin grades. On both instruments, QOL of all patients at 18 months was still lower than that of the reference population improved functional outcomes were correlated with higher SF-36 scores (assessed by subjective perceptions), but not with higher SIP scores (assessed by objective performance and behavior), contrary to intuitive expectations. Perhaps this finding is determined not so much by what the patient perceives they can do but rather what they can actually do. Patients who were able to return back to previous employment after the hemorrhage was very low, only 1 of 17 was able to return to their previous position. The authors concluded that functional outcomes improved significantly between 4 and 18 months post-SAH and seemed to be accompanied by improved QoL (Hop et al., 2001).

Similar findings have more recently been reported. For example, effects on employment, relationships, personality, and mood were studied in 610 Dutch patients on average 8.9 years after ASAH (Wermer, Kool, Albrecht, & Rinkel, 2007). Data on mood were collected using the Hospital Anxiety and Depression Scale (HADS). The majority of patients (59%) reported changes in personality, 26% stopped working, and 24% worked shorter hours. The long-term psychosocial effects of SAH were considerable even in patients who regained functional control.

QoL was examined in 70 Spanish patients 4 months after ASAH using the SF-36 (Katati et al., 2007). In 60% of these patients, the most affected dimension was the physical role, i.e.,

patients reported that their physical health interfered with their work and other daily tasks. The second most affected dimension was mental health, with 47.1% of patients suffering from depression, anxiety, and loss of control over their behavior and emotions. Katati et al. (2007) points out further evidence of similar findings by referring to the Hop et al., (2001) study that patients who have a Rankin score of zero (no physical disability) do not experience a reduction in their QoL, while those with a Rankin score of 4 (fully disabled) have severe deterioration. Finally, better QoL was predicted by male gender and absence of physical handicaps (Katati et al., 2007). Patients were assessed only 4 months after hemorrhage, when many may have only recently been able to return home. While these findings are useful for the acute care setting, they may not be applicable to long-term QoL, which was found to improve significantly from 4 to 18 months post-SAH (Hop et al., 2001). HRQoL was measured in 141 community-dwelling Dutch patients 2-4 years post ASAH (Visser-Meily, Rhebergen, Rinkel, van Zandvoort, & Post, 2009). HRQoL (measured by the Stroke-Specific Quality of Life [SSQOL] scale) was examined in relation to psychological symptoms (mood disorders, fatigue, and cognitive complaints), personality characteristics (neuroticism and passive coping style), demographic characteristics, and subarachnoid hemorrhage disease characteristics. Patients were relatively satisfied with their HRQoL and generally scored higher in the physical domain and lower in the emotional and social domains. HRQoL was most strongly and inversely correlated with mood problems (0.73) and fatigue (0.73), and positively correlated with cognitive function (0.56). The other important finding of this study was that a measure of disability (the Glasgow Outcome Scale) was not useful in predicting long-term HRQoL (Visser-Meily et al., 2007).

The above findings on ASAH patients (Hop et al., 1998, 2001; Hutter & Gilsbach, 1995; Hutter et al., 2005; Katati et al., 2007; Wermer et al., 2007) can be extrapolated to the NASAH

population. Generally, this latter population has smaller amounts of SAH blood (Alen et al., 2003; Beseoglu et al., 2009; Gupta et al., 2009) and a better neurological exam after initial hemorrhage (Alen et al., 2003; Beseoglu et al., 2009; Gupta et al., 2009; Hermann & Zabramski, 2007). These characteristics allow one to infer that these patients would have higher QoL both in the short- and long-term.

Quality of Life in the NASAH Population.

Quality of life issues in the NASAH patient population have specifically been examined in five studies, four performed in Europe (Beseoglu et al., 2009; Brilstra, Hop, & Rinkel, 1997; Greebe & Rinkel, 2007; Marquardt, Niebauer, Schick, & Lorenz, 2000) and one in India (Gupta et al., 2009), with contradictory results. HRQoL was measured in many of these studies by tools such as the Rankin Score or Glasgow Outcome Scale (GOS), which are not good indicators of multidimensional domains of health-related quality of life. Patients in these studies might have been classified as having "good outcomes" or having a "benign hemorrhage," without having returned to their pre-hemorrhage level of functioning. No US studies published thus far have specifically studied HRQoL in the NASAH patient population.

The first outcome study of perimesencephalic nonaneurysmal hemorrhage was completed in the early 1990s on 37 Dutch patients with persistent symptoms of headache and forgetfulness 18 months to 7 years post-hemorrhage (Rinkel et al., 1990). The authors concluded that within this time frame, NASAH patients were not at risk for rebleeding and their QoL was not reduced. The same group of researchers later assessed the impact of these subtle changes on QoL in a prospective study of 25 Dutch perimesencephalic hemorrhage patients 6 months to 6 years post-hemorrhage (Brilstra et al., 1997). QoL was assessed using the SIP supplemented with a few nonaneurysmal hemorrhage-related questions. Patients' SIP scores demonstrated less

dysfunction than for the reference population (in which the Dutch version SIP had been validated), but the difference was only significant for physical subscores measuring ambulation, mobility, and self-care ability. Of the 25 patients, 6 (24%) reported more dysfunction in the category of work than the general population. Eleven patients reported more headaches than before the hemorrhage, and 2 patients reported fear of re-bleeding. Finally, two patients thought that their quality of life had improved since the hemorrhage, which the authors speculated might be related to having been an ICU patient (Brilstra et al., 1997). The results of this study are limited by the small sample, wide span of post-hemorrhage time at which subjects were assessed, and non-significant findings for SIP scores.

In contrast, NASAH patients were reported to have considerable long-term psychosocial issues (Marquardt et al., 2000). The sample comprised 21 German patients diagnosed with perimesencephalic nonaneurysmal subarachnoid hemorrhage 5 months to 3 years earlier and discharged in good clinical condition without neurological deficits. Patients were interviewed to evaluate degree of subjective recovery, residual complaints, and present occupational findings, but no information was provided about measurement tools, specific questions, statistics, or the interview procedures. Eight patients (23%) considered themselves recovered and completely well, and 13 (62%) had residual complaints of headache, irritability, forgetfulness, depression, weariness, and reduced endurance. Of the 17 patients who had been working before the hemorrhage, 7 (41%) returned to their previous occupation, 9 (53%) retired from work, and 1 became unemployed (Marquardt et al., 2000). The results of this study are limited by the small sample and lack of information about measurement tools.

NASAH patients were previously found to not be at risk for rebleeding and to not have reduced QoL within 18 months to 7 years of hemorrhage (Rinkel et al., 1990). To determine the

longer term outcomes after NASAH, Greebe and Rinkel (2007) studied a cohort of 160 Dutch patients who had suffered a perimesencephalic NASAH between 1983 and 2005 (1-23 years post-hemorrhage). For patients who had died in this cohort, standardized ratios were used to investigate possible excess mortality compared to that of the general population in 2000, the median year of hemorrhage in the cohort. Mortality ratios in the cohort were indirectly standardized according to age and sex to account for patients changing age strata during the long-term follow-up. Functional outcomes were assessed in structured telephone interviews by asking two simple questions: 1) Did patients need help from another person with daily activities? 2) If not, did patients feel they had made a complete recovery? The authors provided references supporting the reliability and validity of these questions, but no psychometric parameters for their study (Greebe & Rinkel, 2007).

Of the 160 patients in the cohort, 11 had died for reasons mostly unrelated to NASAH (myocardial infarction [*n*=2], cardiac failure [*n*=1], cerebral infarction [*n*=1], hepatic failure [*n*=1], gastric cancer [*n*=2], colon carcinoma [*n*=1], and infection at old age [*n*=3]). Of the 149 living patients, 2 living in nursing homes were excluded (for reasons other than their NASAH). The remaining 147 patients were independent in activities of daily living, of whom 39 had symptoms including headaches or dizziness (*n*=7), fatigue (*n*=7), forgetfulness (*n*=12), and irritability (*n*=5), similar to those in a previous report (Marquardt et al., 2000). Greebe and Rinkel's study showed that patients with perimesencephalic hemorrhage have no long-term excess mortality compared with general population. This information is important to alleviate patients' anxiety about life expectancy and future bleeding and as evidence that insurance companies do not to impose additional liability based on patients' diagnosed with perimesencephalic NASAH hemorrhage.

Nonperimesencephalic subarachnoid hemorrhage was concluded to be a benign entity based on 34 NASAH patients having good outcomes based only on Glasgow Outcome Scale (GOS) (Gupta et al., 2009). Patients underwent brain imaging upon admission and if the no aneurysm was found, they were imaged again 4-6 weeks later. If the second scan revealed no aneurysm or other vascular abnormality, patients were labeled as nonaneurysmal SAH. Within this group, two types were identified: perimesencephalic SAH and nonperimesencephalic SAH. The incidence of hypertension/cardiac disease, diabetes and use of alcohol was higher in the NASAH population versus the ASAH group. The study results on nonperimesencephalic SAH need to be interpreted with caution, as 7 patients who died before the second imaging were excluded and may have contributed to findings that would have led to a different conclusion. This point was illustrated in a case study (Hermann & Zabramski, 2007) where two patients diagnosed with NASAH had very different outcomes, i.e., one developed vasospasm and required 2 weeks in an ICU, whereas the other was discharged home after 5 days.

Lastly, QoL, performance of activities of daily living (ADLs), and neurological outcomes were studied in 26 German patients who had suffered a NASAH from 4 to 69 months earlier (Beseoglu et al., 2009). Patients were divided into three groups: perimesencephalic SAH, perimesencephalic SAH with intraventricular involvement, and nonperimesencephalic SAH. Patients were mailed questionnaires that assessed QoL using the SF-36, ADL performance using the Barthel Index, and neurological outcomes by a short neurological status form (no reference given). Of 26 questionnaires mailed, only 19 were returned (9 from Group 1, 4 from Group 2, and 6 from Group 3). Neurologic condition was significantly better in Group 1 (pure perimesencephalic SAH) than in Group 3 (nonperimesencephalic SAH, $p=0.034$), and Groups 2

(perimesencephalic SAH + intraventricular hemorrhage) and 3 were not significantly different. Patients in Group 3 had longer hospital stays (median= 20.7 days) than in Group 1 (11.2 days).

Of the 19 patients who returned questionnaires, 2 (11%) had pronounced hemiparesis (both from the nonperimesencephalic group) and 1 had mild hemiparesis (from Group 1). All patients except the two with hemiparesis had high Barthel Index scores (95-100), indicating independence in ADL performance, but these outcomes were not significantly different among groups (p=0.364). GOS scores were also good or excellent in all three groups, with no difference among groups (p=0.486). Physical functioning (SF-36 scores) decreased in all three groups, but did not differ among groups (p=0.709). Patients in Group 1 had normal scores on role functioning, with significant reductions in Groups 2 and 3 (p=0.034). General health, particularly vitality was reduced in all three groups. Mental health was affected in Groups 2 and 3, decreasing their daily activities due to mental or emotional problems (p=0.045 for both items). Only 8 of 19 (42%) were able to return back to their jobs (Beseoglu et al., 2009).

The authors concluded that NASAH is a benign entity (Beseoglu et al., 2009). It may be more accurate to label perimesencephalic SAH without intraventricular hemorrhage a benign entity. This study clearly demonstrates that role functioning, mental health, and physical health can be significantly affected in nonperimesencephalic SAH. The ability to return to work was affected in all groups. However, the results of this study are compromised by the small sample which limits the conclusions that authors present, no psychometrics were presented, use of the Barthel Index to measure physical disability rather than HRQoL (except for the SF-36) and the wide range of time after hemorrhage.

Conclusion

Spontaneous subarachnoid hemorrhage has a high impact on society through loss of productive life years (Taylor, 1997). This may be even more significant in the NASAH perimesencephalic patient population as they are typically younger in age (Hermann & Zabramski, 2007). Knowledge of the disease factors that influence long-term outcomes after SAH is clinically important as such factors are possibly modifiable. Information about long-term prognosis is essential to patients and their families and has extensive emotional and economic consequences (Germano et al., 1998; Hackett & Anderson,2000). Exploring health related quality of life is extremely relevant to the NASAH population as existing studies lack consensus about whether HRQoL is even affected in NASAH. The five studies on QoL issues in NASAH patients also contradict themselves by labeling NASAH as a benign condition, but noting multiple HRQoL domains that are affected in these patients. NASAH patients were found to have residual complaints of headache, irritability, forgetfulness, depression, weariness, and reduced endurance (Greebe & Rinkel, 2007; Marquardt et al., 2000). A recent study confirmed that role functioning, mental health and physical health can be significantly affected in non-perimesencephalic NASAH (58% of NASAH patients were not able to return to work) (Beseoglu et al., 2009). Understanding what factors cause hardships in patient's lives would mean medical personnel could predict which patients are likely to need more support and require specific types of rehabilitation after suffering a NASAH.

A quantitative survey design study was conducted and to compare health-related quality of life (HRQoL) in patients who have experienced a NASAH to that of patients who have experienced an ASAH, 1 to 3 years post-hemorrhage. This author hypothesized that if both ASAH and NASAH patients are compared on the Hunt and Hess (Hunt & Hess, 1968) grading

system (used to classify the severity of a subarachnoid hemorrhage based on the patient's clinical condition), Fisher scale (Fisher, Kistler & Davis, 1980) (correlates the location and thickness of subarachnoid blood on CT with clinical outcomes), age, and adjusting for other factors will have similar HRQoL outcomes. This knowledge could assist researcher in developing targeted interventions that reduce the negative health consequences associated with both NASAH and ASAH.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

The framework for this proposed survey design study will be the Conceptual Model of Health-Related Quality of Life (Ferrans, Johnson-Zerwic, Wilbur, & Larson, 2005) which is based on the Health-related Quality of Life Conceptual Model (Wilson & Cleary, 1995). Using the Ferrans model in this study will allow for exploration and understanding of multiple variables that affect HRQoL in both NASAH and SAH populations. This chapter will trace the origins of QOL that led to the development of the concept health related quality of life (HRQoL), provide brief background on the Wilson and Cleary model and then analyze the Conceptual Model of Health-Related Quality of Life.

Quality of Life and Health Related Quality of Life

"Quality of life" as it applies to healthcare can be traced to the World Health Organization (1947) definition of health as a "state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity." The psychosocial or quality of life variables were introduced to clinical research by Karnofsky and Burchenal (1949) who measured cancer patients' performance status. They described criteria for subjective improvement in what is now considered quality of life: "The patient's subjective improvement is measured or described in terms of improvement in his mood and attitude, his general feelings of well-being, his activity, appetite, and the alleviation of distressing symptoms, such as pain, weakness and dyspnea" (Karnofsky & Burchenal, 1949, pp. 193-194).

In the ensuing 60 years, significant but complicated strides have been made in conceptualizing HRQoL and developing tools to measure it. Historically, HRQoL studies have been primarily descriptive, providing basic information on psychosocial needs and adjustment of various chronic disease populations (Aaronson, 1988). The concept has come into vogue because of patients' extended survival with chronic conditions that were once acute, terminal diseases. The number of diseases classified as chronic continues to increase (Murdaugh, 1997). In the past 15 years, HRQoL variables such as physical functioning, biological functioning, and general perception of well- being have become more important that the medical intervention or cure thus more prospective randomized control studies have been completed (Wilson & Cleary, 1995).

With further use of the concept of HRQoL, confusion resulted. Murdaugh in 1997 first discussed the use of multiple definitions and the interchangeable use of similar concepts by numerous authors in the HRQoL literature. The complexity continues today with varying definitions and instruments making it difficult to conceptualize HRQoL (Ferrans, Johnson-Zerwic, Wilbur, & Larson, 2005; Sajid, Tonsi & Bang (2008); Spranger & Swartz, 2008)

A Conceptual Definition of Health-related Quality of Life

A concept has been defined as a "complex mental formulation of an empirical experience" (Chinn & Kramer, 1999, p. 54), an abstract "cognitive representation" of perceptible reality formed by direct or indirect experience (Morse, 1995), or a term used to describe a phenomenon or a group of phenomena (Meleis, 2007). A concept denotes some degree of classification or categorization.

It is important to briefly define health and quality of life separately. The World Health Organization Quality of Life Group (1996) defines health as a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity. Health status refers to

whether individuals are free from the effects of disease and disability to be able to perform the functions they desire and to carry out usual activities required in day-to-day living (Murdaugh, 1997). Definitions of quality of life are associated with health and personal satisfaction, e.g., “a patient's general well-being, including mental status, stress level, sexual function, and self-perceived health status” (webMD.com, n.d.), and “your personal satisfaction (or dissatisfaction) with the cultural or intellectual conditions under which you live (as distinct from material comfort)” (dictionary.com, n.d.).

The health component of quality of life was defined by Ware (1987) as health status. Ware defined and measured the components of health status similarly to the commonly described domains of quality of life: physical health, mental health, social and role functioning, and general perceptions of well-being (Ware, 1987). The term “health status” was also preferred by Bergner (1989) instead of quality of life. Health status was described by Bergner (1989) as having six dimensions: physical functioning, mental functioning, social functioning, health behaviors, attitudes, and genetic foundation. Other conceptualizations of health status contain similar domains, with the most commonly reported being physical functioning, psychological functioning, and social functioning (Murdaugh, 1997). Similar domains are also used for conceptual models of HRQoL (Ferrans, Johnson-Zerwic, Wilbur, & Larson, 2005; Wilson & Cleary, 1995). In these models, patient outcomes, including overall HRQOL, are proposed to be related to both individual and environmental characteristics. The domain pathways include biological function, symptoms, functional status, and general health perceptions.

These domains of health are also used in definitions of HRQoL. For example, HRQoL is defined as encompassing domains of life directly affected by changes in health (Jaschke, Singer, & Guyatt, 1989). In the view of these researchers, HRQoL domains are aspects of life that

improve when a physician successfully treats a patient. A clinically significant change in HRQoL is indicated by a decline in a domain that leads a physician or health care provider to alter a medication or medical treatment (Jaschke et al., 1989).

HRQoL has been formally defined by federal and international agencies. For example, the National Library of Medicine (n.d.) defines HRQoL as "Patient outcome measures that extend beyond traditional measures of mortality and morbidity to include such dimensions as physiology, function, social activity, cognition, emotion, sleep and rest, energy and vitality, health perception, and general life satisfaction." Some of these measures are also known as health status, functional status, or quality of life measures (National Library of Medicine). The CDC (n.d.) defines HRQoL as referring "to a person or group's perceived physical and mental health over time." Lastly, the World Health Organization Quality of Life Group (1996) defines HRQoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of the environment."

The proposed study will be framed by the Conceptual Model of Health-Related Quality of Life (Ferrans et al., 2005). HRQoL is not specifically defined by Ferrans et al. (2005) or by Wilson and Cleary (1995), from whose work the Ferrans model is derived. However, HRQoL is delineated by what it excludes (Ferrans et al., 2005, p. 336): "this term excludes aspects of quality of life that are not related to health, such as cultural, political, or societal attributes. Examples are the quality of the environment, public safety, education, standard of living, transportation, political freedom, or cultural amenities. Unfortunately, the distinction between

health-related and non-health-related quality of life cannot always be clearly made. For example, air pollution contributes to chronic respiratory disease, and long dark winters contribute to seasonal affective disorder." Insight into Ferrans' thinking about HRQoL comes from her early definition of quality of life (Ferrans, 1990): an individual's feeling of satisfaction or dissatisfaction with significant domains of his her life.

After extensive research on quality of life, Ferrans (1997) proposed that a concept in general may not be synthesized into a coherent whole. It is generally agreed that HRQoL is a multidimensional concept (Murdaugh, 1997). However, despite an extensive literature review no commonly accepted definition could be found for HRQoL, and usually only operational definitions are provided as evidence of its domains.

Operational Definition of Health-related Quality of Life

As mentioned above, this study used the Conceptual Model of Health-Related Quality of Life (Ferrans et al., 2005), which is based on the Health-related Quality of Life Conceptual Model (Wilson & Cleary, 1995). For this study, the operational definition of HRQoL was based closely on both models' terminology and conceptualized relationships. Health-related quality of life is defined as an individual's feeling of well-being derived from such dimensions as biologic function, symptoms, functional status, health perception, and overall quality of life as influenced by attributes of one's developmental, psychological and environmental characteristics.

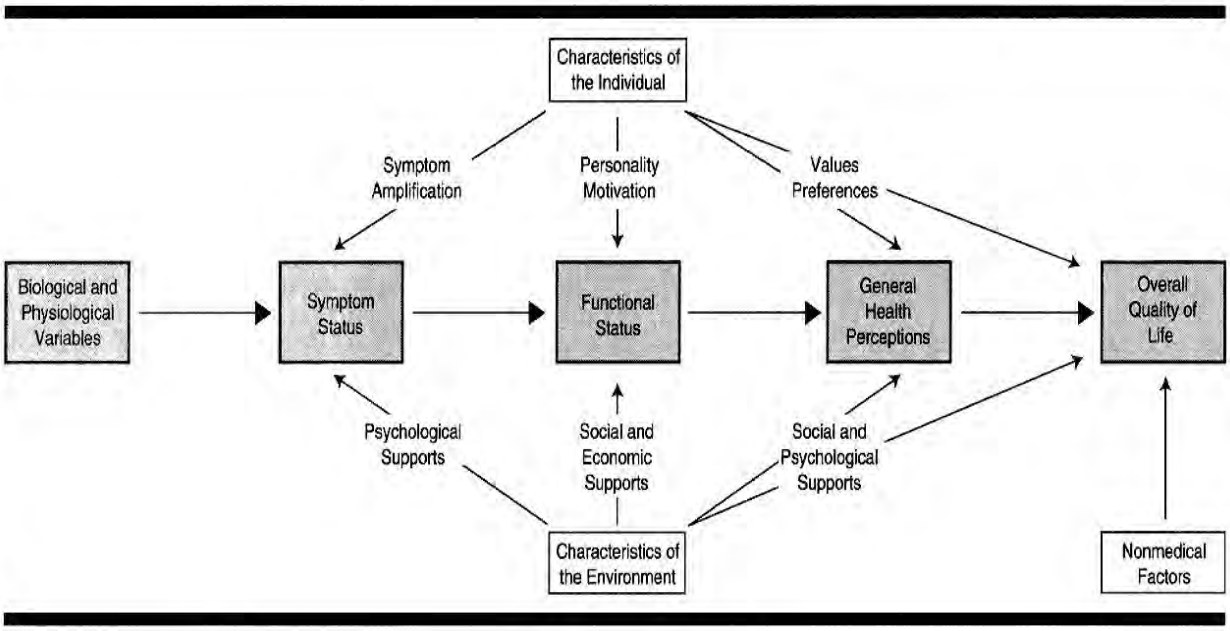


Figure 1. Relationships among measures of patient outcome in a health-related quality of the conceptual model from "A conceptual model of practice outcomes. Linking clinical variables with health-related quality of life: " by Wilson, I. B. & Cleary, P. B. (1995) p 61 JAMA Reprinted with permission from JAMA

The Wilson & Cleary (1995) model (Figure 1) uses measures of health that exist on a continuum of biological/physiological, psychological, social complexities forming causal pathways between each other and other concepts such as symptoms, functioning, general health perceptions and overall quality of life. The pathways do not apply a hierarchal order of importance. As one moves from left to right in the model, one moves outward from the cell to the individual to the interaction of the individual as a member of society. The goal of the Wilson and Cleary (1995) model was to help clinicians and researchers test causal relationships and provide effective patient outcomes. Wilson & Cleary use the term quality of life and health related quality of life interchangeably. The Wilson & Cleary model has been tested in a number of populations including heart failure Bennett et al., (2001), cancer Wettergren, Bjorkhom, Axdorph & Languis-Eklof (2004), HIV Sousa, Holzemer, Henry, & Slaughter, (1999) and

Parkinson's disease Chrischilles, Rubenstein, Voelker, Wallace & Rodnitzky, (2002). populations. In these studies the Wilson and Cleary model provided predictive values in the majority of the HRQoL domains. Bennett et al. found that social support were significant predictors of changes in health-related quality of life. Sousa et al. (1996) found that the model predicted 32% of variance in overall quality of life particularly in the symptom domain. Wettergren et al. and Churchilles et al. used the model to direct their choice of study design, research instruments, and rehabilitation program for patients with lymphoma and Parkinson's disease. The Wilson and Cleary model has provided clinicians a useful model that integrates both medical and social sciences paradigms to fully examine HRQoL. Ultimately, the Ferrans model (Ferrans et al., 2005) was chosen to guide my proposed study as it provided a structure that can guide researchers with consistent definitions and clarification of relationships which will lead to appropriate choices of measurement tools for this study. However, the major tenants of the Ferrans model are based solely on Wilson & Cleary's model.

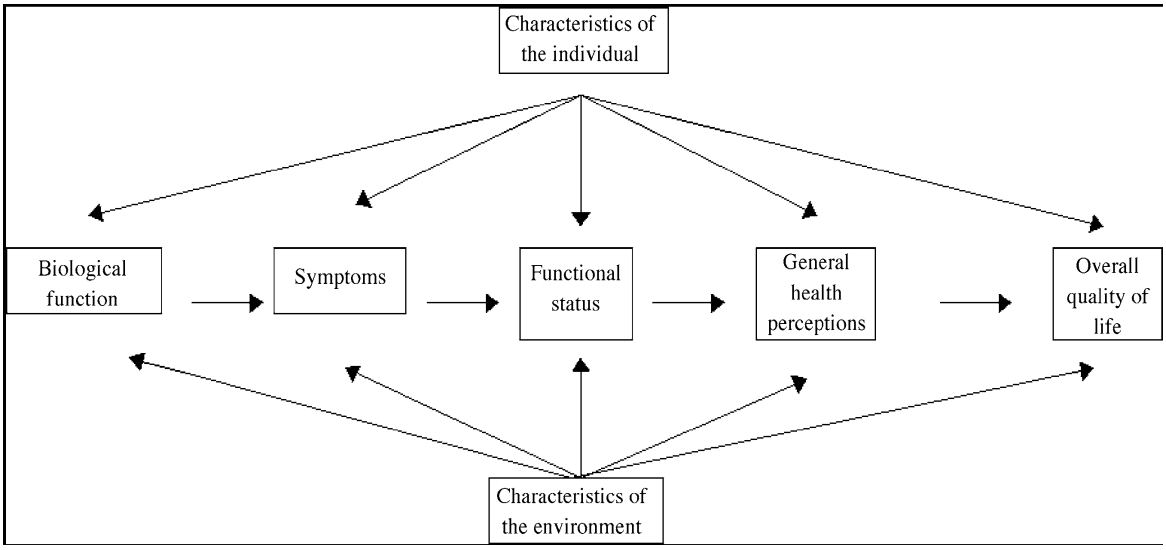


Figure2. Revised Wilson and Cleary model for health related quality of life from "Conceptual Model of Health-Related Quality of Life" by Estwing- Ferrans, C., Johnson Zerwic, J. Wilbur, J.E.,& Larson, J. L. (2005) Journal of Nursing Scholarship, 37, p344. Reprinted with permission from the Journal of Nursing Scholarship.

The Ferrans model (Ferrans et al., 2005) (Figure 2) is specifically designed to connect specific clinical factors in each domain to HRQoL. Using the Ferrans model in this study allowed for exploration and understanding of multiple variables that affect HRQoL in both NASAH and SAH populations. Prior to developing this model, Ferrans and her colleagues (Ferrans, 1997; Ferrans & Powers, 1992) developed the concept of quality of life (QOL) using several different research approaches to refine a conceptual model. To clarify the concept of QOL across cultures, Ferrans (1997) used qualitative research methods to determine the indicators associated QOL. QOL was also analyzed by factor analysis techniques to find clusters among its various domains (Ferrans & Powers, 1992). This information was used to develop a tool, the Quality of Life Index, to operationalize the concept of QOL and its dimensions (Ferrans & Powers, 1992). Ferran (p 336) does not provide an operational definition but defines what HRQoL is not "This term excludes aspects of quality of life that are not related to health, such as cultural, political, or societal attributes." The domains of HRQoL in this model were based on the defining work of Wilson and Cleary (1995), and expanded with multiple layers of influence from individual and environmental characteristics from earlier ecological models (Eyler et al., 2002; McLeroy, Bibeau, Steckler, & Glanz, 1998). These ecological models not only provide empirical support for Ferran's modifications of the Wilson and Cleary model, but also emphasize the role of factors outside the individual that influence behavior. Ferrans et al.'s (2005) model is modified the Wilson and Cleary (1995) model to provide a logical direction and form of the relationships between HRQoL domains. Specifically, the original model was revised in three substantive ways: (a) by adding arrows to show that biological function is influenced by characteristics of both individuals and their environment, (b) by deleting nonmedical factors, and

(c) by deleting labels on arrows since they restricted characterization of those relationships (Ferrans et al., 2005).

Lastly, in choosing a model to guide this study the author wanted one that had been used in a population similar to my target population, NASAH patients, since neurological patients may have cognitive deficits and their own set of complexities, requiring specific instruments to measure HRQoL (Daggett et al., 2009). The Ferrans et al. (2005) model has been used to frame a meta-analysis of adult traumatic brain injury survivors and found to clearly define and encompass the domains of HRQoL relevant to these patients (Daggett et al., 2009).

Operational Definitions

The operational definition of HRQoL used in this study was closely based on the terminology and conceptualized relationships of the HRQoL model proposed by Ferrans and colleagues (Ferrans, Zerwick, Wilbur, & Larson, 2005). In that model, health-related quality of life is defined as an individual's feeling of well-being in five domains biologic function, symptoms, functional status, general health perception, and overall quality of life. Each domain is influenced by one's individual and environmental characteristics. The five HRQoL domains and two sets of influential factors, which will be measured in NASAH patients, are defined below.

Biological function. This domain encompasses the "dynamic processes that support life," e.g., molecular, cellular and whole organ-level processes (Ferrans et al., 2005, p. 338). Biologic factors in SAH include brain functions, physical and psychological capabilities such as memory/cognition, hemiplegia or paresis and depression, which might be permanently changed in the NASAH patient population due to SAH. This domain should also include family history

(genetic predisposition) as having a first-degree relative with SAH has been linked to up to seven times higher risk for SAH than the general population (Bromberg et al., 2005).

Symptoms. Symptom status will be defined by participants' perceptions of physical, psychological, or psychophysical symptoms. Symptoms are commonly measured in terms of frequency, intensity, and distress using global, condition-specific, and symptom-specific instruments (Ferrans et al., 2005). Measuring symptoms with a condition-specific instrument is suggested by Ferrans et al. (2005). SAH symptoms may include short-term memory loss, weakness in one or more extremities, and anxiety.

Functional status. This variable is broadly defined as the ability to care for or perform one's social/role and psychological functions (Ferrans et al., 2005). This variable may be measured in NASAH patients as either decreased physical endurance/strength or cognitive function/memory.

General health perception. This variable is defined as participants' perceived overall health, which Ferrans et al. (2005) recommend measuring with the Medical Outcomes Study Short Form questionnaire (SF-36).

Overall quality of life. This variable is defined as participants' subjective well-being derived from all domains of HRQoL.

Individual characteristics. These characteristics are categorized as "demographic, developmental, psychological and biological factors that influence health outcomes" (Ferrans et al., 2005, p. 337).

Environmental characteristics. These characteristics are categorized as social (family or friends) or physical environmental (home, work place, or neighborhood) factors that influence health outcomes (Ferrans et al., 2005).

Summary

The Ferrans et al. (2005) model provides a sound conceptual framework which will help delineate the factors that can affect HRQoL in NASAH. The Ferrans model builds on a prior model, provides a theoretical basis, and has been used in a neurological patient population. The Conceptual Model of Health-Related Quality of Life (Ferrans et al., 2005) is an appropriate framework for examining the effects of a SAH and NASAH on HRQoL.

Chapter III

Methods

Introduction

A quantitative survey design study was proposed to compare health-related quality of life (HRQoL) 1 to 3 years post-hemorrhage in patients who have experienced a NASAH and in those who have experienced an ASAH. This author hypothesized that both ASAH and NASAH patients would have similar HRQoL outcomes when controlling for the influence of age, relative time since hemorrhage, and score on the Fisher scale (Fisher, Kistler & Davis, 1980). The Fisher scale correlates the location and thickness of subarachnoid blood on CT with clinical outcomes. This knowledge could assist researchers in developing targeted interventions that reduce the negative health consequences associated with NASAH.

Purpose Statement

The purpose of this quantitative survey design study was conducted to compare health-related quality of life (HRQoL) 1 to 3 years post-hemorrhage in patients who experienced a NASAH to those who experienced an ASAH.

Specific Aims

1. To describe the physical, psychological, social, and vocational impact of nonaneurysmal and aneurysmal subarachnoid hemorrhage on patients at 1 to 3 years post-hemorrhage.
2. To examine differences in HRQOL between patients with NASAH and ASAH after controlling for severity of hemorrhage, age, and time since event.
3. To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and determining if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.

4. To describe management strategies used by patients with nonaneurysmal and aneurysmal subarachnoid hemorrhage that helped improve their HRQoL.

Design

This study used a quantitative design that focused on objectivity, control, precise measurement, and quantification of data to describe, predict, or determine cause-and-effect relationships (Whitmore & Melkus, 2008). Specifically, a survey design was used to examine and compare the relationships among HRQoL, clinical outcomes, and patient demographics in both NASAH and ASAH patients.

Sample and Setting

The NASAH population is extremely small, consisting of 15% (range 5-34%) of patients with nontraumatic SAH where no source of hemorrhage can be identified via four-vessel cerebral angiography (Alen et al., 2003; Gupta et al., 2009). Prior studies with NASAH subjects have included 19-160 subjects **(**Beseoglu et al., 2009 N= 19; Gupta et al., 2009 N=34; Greebe & Rinkel, 2007 N=160; Marquardt, Niebauer, Schick, & Lorenz, 2000 N=160; Brilstra, Hop, & Rinkel, 1997 N=25). Men and woman with NASAH were recruited from Beth Israel Deaconess Medical Center (BIDMC), from a database of 320 SAH patients were treated between 2006 and 2010.

Power analysis – A power analysis for Aim # 3 was conducted: *To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and determining if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.* Using an alpha level of 0.05, 7 predictors, effect size of .20 and 80 subjects demonstrated a power of .89.

Participants for this study were initially recruited via mail from SAH patients in the BIDMC database. To comply with Health Insurance Portability and Accountability Act (HIPAA) regulations, a letter on BIDMC letterhead was mailed to these patients' last known home address informing them of the purpose of the study and requesting them to participate in the study with attached to the instrument package. A self-addressed stamped envelope was enclosed for their response. Potential subjects were also given an e-mail address and telephone number to reach the PI if they had a question or preferred to contact the PI directly. They were asked to return a blank packet if they did not want to participate in the study. Patients who did not contact the principle investigator within 3 weeks received a reminder card by mail. Three weeks from the reminder card mailing a second complete mailing was sent. After the three non-responses, we assumed the the subject did not want to participate.

Inclusion/Exclusion criteria. Participants were required to satisfy the following inclusion criteria: (a) diagnosed with nontraumatic SAH and two diagnostic cerebral angiograms negative or positive for aneurysm (Alen et al., 2003), (b) diagnosed with NASAH or ASAH more than 1 year, but not more than 3 years from data collection, (c) free from any physical disability unrelated to ASAH or NASAH, (d) $\geq$ 18 years old (to provide informed consent), (e) mentally capable of giving informed consent (determined by their ability to contact the investigator to participate in the study, following the study directions, complete the questionnaire items and return the questionnaire in the self-addressed envelope), (f) able to read and speak English.

Instruments

The study variables were measured using six instruments: the Stroke-Specific Quality of Life scale (SS-QOL; Williams, Weinberger, Harris, Clark, & Biller, 1999), 12-Item Short Form

Health Survey (SF-12; Ware, Kosinski, & Keller, 1996), Duke–UNC Functional Social Support Questionnaire (FSSQ; Broadhead, Gehlbach, DeGruy, & Kaplan, 1988), a researcher-developed NASAH-specific questionnaire for effects on HRQoL, a researcher-developed demographic questionnaire (Table 2) and a PTSD scale by the Trauma Awareness & Treatment Center (TATC) was used to explore the issue of PTSD. Each instrument is described in detail below.

Table 1

Alignment of Domains of HRQoL, Instruments to Measure Domains, and Study Aims

Domain	Instrument	Study Aim
Biological function	SF-12	1,2
Symptoms	SF-12	1,2
Functional Status	SS-QOL	1,2,3
General Health Perception	SF-12	1,2
Overall Quality of Life	SS-QOL/SF-12	1,2
Individual Characteristics	Demographic Information NASAH-Specific Questionnaire	1,2,3
Environmental Characteristics	Demographic Information NASAH-Specific Questionnaire Duke–UNC Functional Social Support Questionnaire (FSSQ)	1,2,3

SS-QOL. The SS-QOL is a validated, patient-centered outcome measure that holistically assesses health-related quality of life specific to patients with stroke (Williams et al., 1999). This instrument was chosen instead of the Quality of Life Index (QLI; Ferrans & Powers, 1985), which was first considered since it was developed by the author of the proposed study's framework. However, the QLI was not consistent with this study's aims and was less specific than the SS-QOL for the domains affected by SAH.

An initial pool of 78 items was developed for the SS-QOL from interviews with ischemic stroke survivors (Williams et al., 1999). Psychometric analysis of these items led to a final pool of 49 items grouped into 12 domains: mobility, energy, upper extremity function, work/productivity, mood, self care, social roles, family roles, vision, language, thinking, and personality. The SS-QOL is scored, as an unweighted average of domain scores and ranges from 1.0 (worst) -5.0 (best). Domain scores are unweighted averages of the individual items in that domain and also range from 1.0 – 5.0. responses rated. The 5-point Likert scale response options range from1 (total help/couldn't do it at all/strongly agree) to 5 (no help needed/ no trouble at all/strongly disagree). The scores are averaged item ratings; they tend to have a normal distribution and can be analyzed as a continuous variable.

The internal consistency reliability (Cronbach's alpha) of the SS-QOL in 34 individuals with stroke ranged from adequate (alpha = 0.75 for work/productivity subscale) to excellent (alpha = 0.89 for self-care), suggesting strong internal consistency (Williams et al., 1999). The SS-QOL had excellent 2-week test-retest reliability (r = 0.92) when administered by a trained interviewer to 47 stroke survivors (Williams et al., 2000). The SS-QOL also showed excellent inter-rater reliability (r = 0.92) when administered 2 hours apart by two different trainers interviewers to 24 stroke survivors (Williams et al., 2000). In 141 ASAH patients, the SS-QOL showed good internal consistency reliability for all 12 domains (alphas >.80) (Boosman Passier, Visser-Meily, Rinkel, & Post, 2009).

All SS-QOL domains have been shown to be unidimensional, with good internal reliability (Cronbach's alphas > .73), excellent test-retest and inter-rater reliability (alphas > .92 for overall and individual domain scores), and to have good construct and known-groups validity (Williams et al., 1999). In addition to the 49 items used in scoring, 13 items at the end of the

questionnaire can be used to categorize how much the stroke affected each domain and overall quality of life. These items will be used to assess the subjects perception of how their quality of life has been altered since their subarachnoid hemorrhage.

In this study, the SS-QOL was completed by self-report. However, the reliability and validity of self-report administration of the SS-QOL has not been previously reported. Therefore, this approach was pilot tested in 2 patients and the reliability of the SS-QOL was evaluated for the total study sample. Permission to use this instrument has been granted by Dr. Linda Williams, author of the SS-QOL.

SF-12. This instrument was developed for the Medical Outcomes Study, a multi-year study of patients with chronic conditions (Ware et al., 1996). The short-form survey instrument was designed to reduce respondent burden while achieving minimum standards of precision for group comparisons involving multiple health dimensions. The SF-12 includes a subset of 12 items from the SF-36 and was developed for applications where two summary scores (physical health [Physical Component Summary] and mental health [Mental Component Summary]) might be sufficient (Ware et al., 1996). The SF-12 was designed to measure general health status from the patient's point of view. The SF-12 includes 8 concepts commonly represented in health surveys: physical functioning, role functioning physical, bodily pain, general health, vitality, social functioning, role functioning emotional, and mental health.

The 12-item Physical Component Summary and 12-item Mental Component Summary showed excellent to good 2-week test-retest reliabilities (r=0.89 and 0.76, respectively) in the general US population (n=232) (Ware et al., 1996). These summary scales also showed adequate to excellent validity in tests comparing the SF-12 to the SF-36. The alphas for 12-item Physical Component Summary ranged from 0.43 to 0.93 (median=0.67) in 14 relative validity tests that

compared the SF-12 and SF-36. Alphas for the Mental Component Summary ranged from 0.60 to 1.07 (median=0.97) in 6 tests involving mental criteria that compared the SF-12 and SF-36 (Ware et al., 1996).

The SF-12 has not been tested in SAH patients, but the SF-36 has been found to be reliable in numerous studies on SAH patients (Katai et al., 2007; Kim, Haney, & Van Ginhoven, 2005; Noble & Schenk 2010; Sharbrodt et al., 2009). Each study recommended using the SF-36 as part of assessment outcomes as it was better at predicting long-term outcomes than other instruments such as the Barthel Index, National Institutes of Health Stroke Scale, Rankin scale, and Glasgow Outcomes scale (Kim, Haney, & Van Ginhoven, 2005; Scharbrodt et al., 2009).

The SF-12 was mailed to participants for self-completion. The SF-12 has been validated to use as a self-administered instrument (sf-36.org). Permission to use the SF-12 was granted from QualityMetric Health Outcomes.

Duke-UNC Functional Social Support Questionnaire (FSSQ) This instrument was used to measure a subject's perception of the amount and type of personal social support they have received since their subarachnoid hemorrhage. The instrument takes 5 minutes to complete and it may be self administered (Broadhead, Gehlbach, DeGruy, & Kaplan, 1988). Internal consistency for this instrument is excellent (Cronbach's alpha .81 - .92) across racial groups and study sites and data points (Bellon Saameno, Delgado Sanchez, Luna del Castillo & Lardelli 1996). The FSSQ item response options are on a 5-point scale ranging from 1 (much less than I would like) to 5 (as much as I would like). Higher scores reflect higher perceived social support.

The PTSD Questionairre. The PTSD questionnaire is adapted from the Trauma Awareness & Treatment Center (TATC). Permission to use was granted by Dr Larry Beall who is the director of the program. He is unaware of the exact origin of the scale. In researching other

PTSD scales it appears to be very similar to the Trauma Screening Questionnaire (TSQ) (Brewin, Rose, Andrews, Green, Tata, McEvedy & et al., 2002). Both scales consist of 10 questions, 5 of which are the exact same questions and the remainder questions have similar in content. The TSQ items are derived from from DSM-IV criteria and describe either re-experiencing symptoms or avoidance and numbness symptoms (Brewin et al., 2002). Psychometric data from two samples indicated for PTSD screening purposes, the TSQ enables excellent levels of prediction when measuring symptoms sensitivity, specificity, positive predicative and negative predicative power. The TATC PTSD questionnaire was chosen over the TSQ as the questions were more appropriate for a population who has suffered a medical trauma rather than a violent event. The TATC PTSD questionnaire is short contains items necessary to for accurate PTSD diagnosis and it is written in simple language.

SAH-specific questionnaire on HRQoL. In order to provide a more specific understanding of the long-term effects of NASAH and ASAH on HRQoL, participants self-administered a researcher-developed questionnaire (Table 2). The questionnaire items are aligned with the study aims to gain information that might be used in future interventions with the NASAH population.

Table 2 SAH-Specific Questionnaire on HRQoL

Aim	Question
1. To describe the physical, psychological, social, and vocational impact of nonaneurysmal and aneurysmal subarachnoid hemorrhage on patients at 1 to 3 years post-hemorrhage. 3. To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and determining if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.	1. Were you employed before your SAH? 2. If yes, have you returned to your position or equivalent position? 3. If no, do you feel your inability to return to prior or equivalent position is related to your SAH? 4. Have you been denied any type of health or life insurance because of your SAH?
2. To examine the effects of symptom status, functional status, and support (psychological, economic, and social) on HRQoL of these patients.	1. Do you feel your overall quality of life has been affected by SAH? 2. Do you suffer specific physical, emotional, or psychological symptoms as a direct result of your SAH? If so, please list the symptoms
4. To describe management strategies used by patients with nonaneurysmal and aneurysmal subarachnoid hemorrhage that helped improve their HRQoL.	1. Did you receive outpatient physical therapy as a result of your SAH? If so, for how long? 2. Did you receive outpatient occupational therapy as a result of your SAH? If so, for how long? 3. Did you receive outpatient speech therapy as a result of your SAH? If so, for how long? 4. Did you need any psychological therapy after SAH? If so, for how long? 5. Did you use or receive a treatment/procedure that helped your recovery from SAH? 6. Is there any type of service you wish you had available to you during your recovery?

Demographic questionnaire. Study participants were asked to indicate their age, gender, race, education level, marital status/support systems, use of alcohol/tobacco, and family history of SAH. Epidemiological factors such as cigarette smoking, alcohol consumption, hypertension,

and family history of SAH are all independent risk factors of SAH (Juvela, 2002). Beseoglu, Pannes, Steiger & Hanggi (2009) have found a correlation between hypertension and smoking in the NASAH population. PTSD has been found to occur in the subarachnoid hemorrhage population and was recently recommended as area that needs further research in this population (Noble & Schenk, 2010) A simple 10 question PTSD scale by the Trauma Awareness & Treatment Center (TATC) will be used to explore the issue of PTSD further in this population.

Survey Design

Survey methodology is used to measure variables by asking people questions and then to examine relationships among the variables. In this study the surveys attempted to capture health related quality of life after a subarachnoid hemorrhage.

A recent meta-analysis by Noble & Schenk (2010) studied variables to explain poor health related quality of life after SAH. Twelve articles were examined, using the predictor patient age, sex of patient, clinical severity, bleed severity and cognitive impairment. Only the variable of physical disability (effect size .54) was found to be a useful predictor of poor HRQoL. Age also needs to be considered as a predictor value with an effect size of .20. The traditional variables cited in other studies such as sex, severity of bleed, clinical severity of bleed at the time of admission to the hospital, time between SAH and assessment of HRQoL have only minimal effects on patients' physical and mental HRQoL. This study examined the HRQoL outcomes for both ASAH and NASAH and examine their differences by controlling for size of hemorrhage, distinguishing between perimesencephalic and non-perimesencephalic bleeding pattern, age, time since event in multivariate analyses.

Procedures

All procedures related to this study were approved by the BIDMC IRB and UMMS IRB. All subjects that met inclusion criteria were mailed a packet with the following items: cover letter, demographic questionnaire, SS-QOL, SF-12, FSSQ, PTSD questionairre and SAH-specific questionnaire. If subjects chose not to participate (mentioned in the cover letter) they were instructed to return a blank questionnaire in the self-addressed envelope. These subjects did not receive any additional mailings. The subjects were provided a phone number to contact the principal investigator to clarify questionnaire items or address any concerns related to the items. If needed, the principal investigator offered to arrange appointments with neurosurgeons, neurologists, physical therapists, and occupational therapists at BIDMC. Three weeks later, a follow-up reminder card was mailed to participants. Two weeks later, a second complete mailing with an instrument package was sent to those who had not yet responded. Thank you notes and $5 gift cards were sent within one to two week from the time a returned package was received.

Data Management – Prior to the mailings the instrument packets each subject's packet were coded with a unique research number. A list of the subjects' names and contact information and the unique ID number were kept in a locked drawer in the PI's office. This list was destroyed once the final statistical procedures were completed. The paper packets were locked in a file cabinet at BIDMC. Once returned packets were received the data were entered into the SPSS data base created for this study was managed through a secure drive to store de-identified data in the form of SPSS. The SAH-*Specific Questionnaire on HRQoL* and Demographic Questionnaire were analyzed via SPSS to yield appropriate descriptive statistics (mean, standard deviation, percentages). SPSS was used for scoring the SS-QOL. Scores were computed for the overall SS-QOL or as well as individual domain scores. According to SSQOL administrative guide, missing

items are handled in the following way: if more than half of the items in a given domain are missing that domain is not scored and the resulting overall SS-QOL score is an average of the remaining domain scores. If less than half of the items in a given domain are missing, the scored items are averaged and rounded to the nearest integer. This imputed item score is then substituted for the missing item(s).

The SF-12 results were expressed in terms of two meta-scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The SF-12 is scored so that a high score indicates better physical functioning. All 12 questions have a specific standardized value for each item response In order to convert each item response into both physical and mental standardized values according to a SF-12 conversion table (sf-36.org, 2010). Those numbers are then summed, the physical standardized values across all 12 items and add 56.57706 to create the SF-12 PCS score (sf-36.org, 2010). The mental standardized values are summed in a similar fashion and add 60.75781 to create the SF- 12 MCS score. The mean=50, SD=10 in the 1998 general U.S. population that has made scales and summary measures easier to interpret for the SF-12Health Survey (sf-36.org, 2010). QualityMetrics provided a database to score all our SF-12 questionnaires.

The PCS and MCS scores have a range of 0 to 100 and were designed to have a mean score of 50 and a standard deviation of 10 in a representative sample of the US population (sf-36.org, 2010). Scores greater than 50 represent an above average health status. Scores of subjects with a score of 40 function at a level lower than 84% of the population (one standard deviation) and people with a score less than 30 function at a level lower than approximately 98% of the population (two standard deviations). Since the SF-12 PCS and MCS scores are directly weighted functions of SF-12 items, the amount of missing data will have a significant impact on

the imputed value. As the number of missing SF-12 items increases, the available information and predicting power from SF-12 items diminishes. The QualityMetric Incorporated's MDE software algorithms reduced the bias in estimates of missing responses, and made it possible to compute scale and summary scores for many respondents who would have otherwise been lost due to missing data (sf-36.org, 2010).

Data Analysis The primary research question and specific aims were answered separately using SPSS version 19 and specific scoring information for the SSQoL and SF-12. Descriptive statistics were used to provide a general understanding of the population through the demographic questionnaire. The PTSD questionnaire and FSSQ only required simple addition to determine if PTSD and social support were present.

The first step was to print the data file and cross check the data from the original instruments. All errors found were corrected. The distributions were examined along with analysis of the frequencies for each variable. Missing data were examined and specific instrument instructions were followed as to whether the subject's data can be used if missing data were found. The reliability of the instruments was calculated to determine the cronbach's alphas. The value was compared to other studies that have used these instruments. This was particularly important for the SS-QOL which has not been tested as a self-administered instrument in the past. Lastly there was a need to transform data that did not meet the assumptions of parametric analysis. The assumptions of parametric analysis were assessed using tools such as histograms, scatterplots and boxplots.

For the first specific aim **(***To describe the physical, psychological, social, and vocational impact of nonaneurysmal and aneurysmal subarachnoid hemorrhage on patients at 1 to 3 years post-hemorrhage*) descriptive statistics, including Mean, Median, Standard Deviation

were used to describe the physical (SS-QOL/SF-12), psychological (SS-QOL/SF-12), social (SS-QOL/SF-12/Demographic Questionnaire and Subarachnoid Questionnaire on HRQoL) and vocational impact (NASAH-Specific Questionnaire on HRQoL) of the study participants. The scores of the SSQoL and SF-12 were compared using two sample independent t-tests or Mann Whitney tests depending on the distribution. For the second specific aim (To *examine differences in HRQOL between patients with NASAH and ASAH after controlling for severity of hemorrhage, age, and time since event)*and third specific aim (*To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and determining if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.)* table 3 describes the statistical procedures to used based on the level of measurement for each part of both aims. A $p \leq .05$ was considered significant. Note employment status was measured by inability to return to work or to equivalent position due to subarachnoid hemorrhage as a dichotomous outcome.

Table 3 Statistical Procedures for Aim 2 and 3

Level of Measurement for outcome variables	*Statistical Procedure Used*
SF-12 (**symptom status**) Interval scale	ANCOVA/linear regression
SS-QOL (**functional status**) Interval scale	ANCOVA/linear regression
SS-QOL/SF-12/ FFSQ/PTSD/Demographic Questionnaire and SAH-Specific Questionnaire on HRQoL (Nominal and interval scales)	Logistic regression ANCOVA/linear regression Binomial logistic regression Descriptive Statistics with linear regression

For the fourth specific aim (*To describe management strategies used by patients with nonaneurysmal and aneurysmal subarachnoid hemorrhage that helped improve their HRQoL*.) Very few subjects answered these questions so the management strategies were combined into like categories and percentage of responses were calculated and compared between those with ASAH and NASAH.

Conclusion

The quantitative survey design was chosen to study the NASAH population. This study examined the HRQoL outcomes for both ASAH and NASAH and examined their differences by controlling for size of hemorrhage, distinguishing between perimesencephalic and non-perimesencephalic bleeding pattern, age, time since event in multivariate analyses. Approximately 109 SAH subjects were available at BIDMC to be considered as potential subjects for matching for the years 2006-2010.

The instruments were chosen to align with the study aims and the domains of the study framework (Ferrans et al., 2005). Subjects were recruited by mail and self-administered instruments sent by mail. Respondent burden was minimized by using instruments (the SS-QOL, SF-12, demographic and NASAH-specific questionnaires) that can be completed in 30-35 minutes. The SS-QOL was validated for self-completion. Factors influencing NASAH patients' experiences of HRQoL issues were determined and compared to an adjusted to those of ASAH patients.

Chapter IV

Results

Introduction

This chapter presents the results of the pilot study, descriptive data on subjects' characteristics, and regression analyses. Regression models were designed to address the specific aims. The chapter also presents subjects' responses to open-ended questions, reliabilities (Cronbach's alphas) of instruments used to collect data, and comparison of these reliabilities with those from previous studies using the same instruments.

Pilot Study

A pilot study was conducted with 5 ASAH subjects (due to the limited number of NASAH subjects) to assess three survey characteristics: (1) response time to return the surveys, (2) completeness of surveys returned, and (3) test procedures. Of five instrument packages mailed, two were returned and required no modifications as both were thoroughly completed. Results of the pilot study indicated dysfunction in both the physical and emotional domains. Both subjects had aneurysmal hemorrhages approximately 24 months since the event. They had moderate levels of PTSD and high levels of social support.

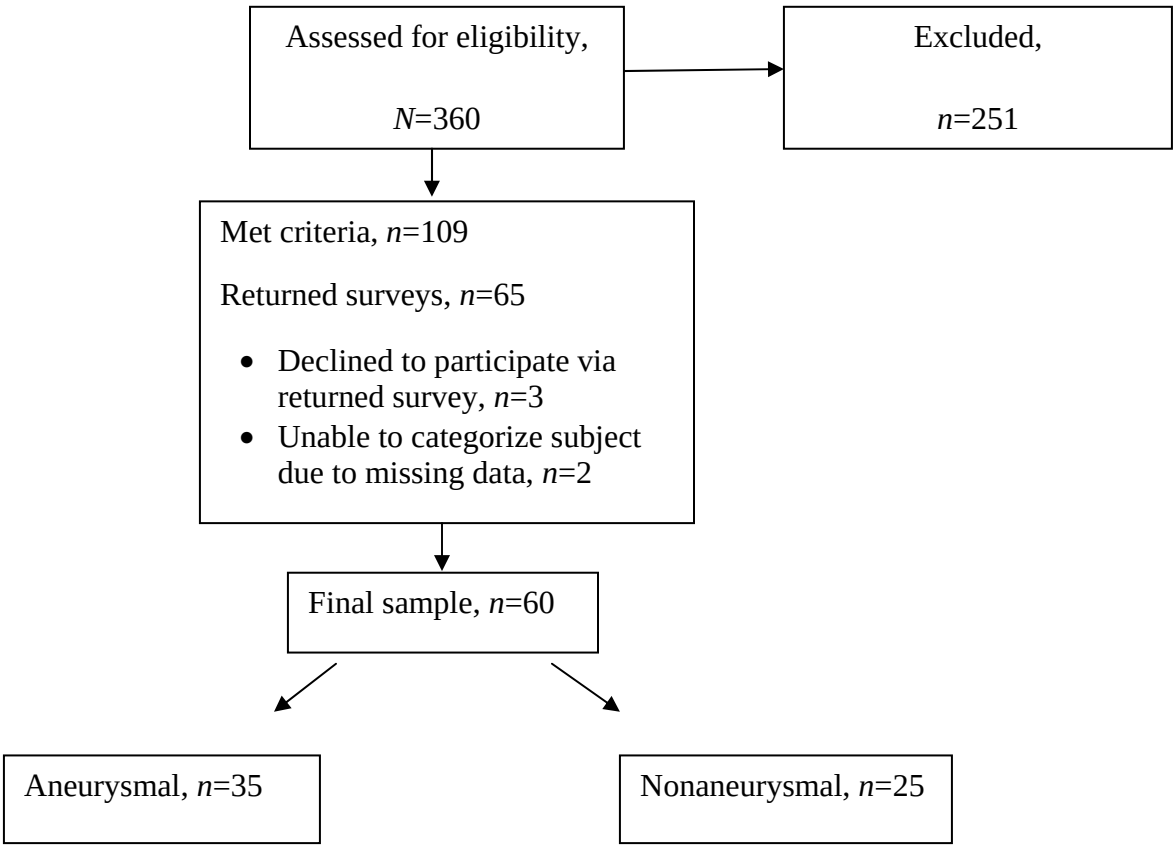
Sample Selection

Subjects were identified by diagnosis-related group (DRG) category 430 (subarachnoid hemorrhage). Of 360 potential subjects identified, 109 met the selection criteria (Figure 1). Common reasons for the 251 subjects excluded included: traumatic subarachnoid hemorrhage or no subarachnoid hemorrhage, only one diagnostic cerebral angiogram performed, English was

not primary language spoken. Surveys were mailed to these 109 eligible subjects, of whom 65 returned surveys; seven surveys were undeliverable. Of the 65 returned surveys, three were not completed (subjects declined to take the survey), and two could not be used (subjects could not be identified and categorized). Thus, the overall response rate was 59%. The final number of subjects was 60, of whom 35 (58%) were aneurysmal and 25 (41%) were nonaneurysmal. This distribution of type of hemorrhage (aneurysmal versus nonaneurysmal) is consistent with the usual population of subarachnoid hemorrhage patients at Beth Israel Deaconess Medical Center. From 2006 to 2010, 37% of patients were nonaneurysmal subarachnoid hemorrhage patients.

Figure 3

Flow Diagram of Sample Selection



Subject Characteristics

The demographic and clinical characteristics of subjects classified as aneurysmal versus nonaneurysmal are shown in Table 4. These two groups did not differ significantly by gender, race, education, relationship status, alcohol/smoking use, insurance denial, physical or emotional symptoms, or perceived quality of life after subarachnoid hemorrhage. However, they did differ by Fisher grade, employment, as well as participation in physical therapy (PT) and occupational therapy (OT). Aneurysmal patients had significantly greater Fisher grade scores than nonaneurysmal patients. This difference was expected given that intraparenchymal and intraventricular blood can occur as part of aneurysmal rupture. Due to the large size of these hemorrhages, aneurysmal patients generally have more physical disability and require physical and occupational therapy, explaining the significant difference in PT and OT participation in these groups. Only 52% of nonaneurysmal patients remained employed in the same position post subarachnoid hemorrhage versus 63% of aneurysmal patients (p=.033).

Table 4

Demographic and Clinical Characteristics by Type of Subarachnoid Hemorrhage

	Aneurysmal		Nonaneurysmal		Total	
Characteristic	*n*	%	*n*	%	*N*	%
Fisher Grade (Fisher's exact=**0.027**)						
<1 mm thick or none	1	2.90	3	12.00	4	6.70
>1 mm thick	10	28.60	13	52.00	23	38.30
Parenchymal /IVH	24	68.60	9	36.00	33	55.00

Characteristic	Aneurysmal		Nonaneurysmal		Total	
	n	%	*n*	%	*N*	%
Gender (Pearson chi2(1) = 0.3801 P = 0.538)						
Male	14	40.00	12	48.00	26	43.30
Female	21	60.00	13	52.00	34	56.70
Race (Fisher's=1.000)						
American Indian	1	2.90%	0	0.00	1	1.70
Asian	1	2.90	0	0.00	1	1.70
Black or African American	1	2.90	0	0.00	1	1.70
Hispanic	1	2.90	1	4.00	2	3.30
White	30	85.70	23	92.00	53	88.30
Other	1	2.90	1	4.00	2	3.30
Education (Fisher's=0.123)						
Some high school	5	14.30	0	0.00	5	8.50
High school graduate	13	37.10	6	25.00	19	32.20
Associate degree	4	11.40	4	16.70	8	13.60
Bachelor degree or higher	13	37.10	14	58.30	27	45.80
Relationship status (Fisher's=0.506)						
Single	7	20.60	2	8.00	9	15.30
Married	20	58.80	18	72.00	38	64.40
Divorced	5	14.70	3	12.00	8	13.60
Widow	0	0.00	1	4.00	1	1.70
Unmarried partner	2	5.90	1	4.00	3	5.10
Alcohol (Pearson chi2(1) = 0.3590, P = 0.549)						
Yes	15	44.10	13	52.00	28	47.50
No	19	55.90	12	48.00	31	52.50

Characteristic	Aneurysmal		Nonaneurysmal		Total	
	n	%	*n*	%	*N*	%
Smoker (Pearson chi2(1) = 0.5889 P = 0.443)						
Yes	8	24.20	4	16.00	12	20.70
No	25	75.80	21	84.00	46	79.30
Family history of SAH (Fisher's=**0.034**)						
Yes	7	21.20	0	0.00	7	12.70
No	26	78.80	22	100.00	48	87.30
Person completing survey (Fisher's=0.249)						
Self	28	80.00	24	96.00	52	86.70
Help from family/friend	3	8.60	0	0.00	3	5.00
Completed by family/friend	4	11.40	1	4.00	5	8.30
Employed (Pearson (chi2(1) = 4.8615 P **=0.027**)						
Yes	29	85.30	15	60.00	44	74.60
No	5	14.70	10	40.00	15	25.40
Employed in same position post SAH (Fisher's=**0.033**)						
Yes	21	63.60	13	52.00	34	58.60
No	8	24.20	2	8.00	10	17.20
Non applicable	4	12.10	10	40.00	14	24.10
Insurance Refusal (Fisher's=1.000)						
Yes	2	5.90	1	4.20	3	5.20
No	32	94.10	23	95.80	55	94.80
Subject perceived QOL change (Pearson chi2(1) = 0.9221, P=0.337)						
Yes	18	54.50	10	41.70	28	49.10
No	15	45.50	14	58.30	29	50.90

Characteristic	Aneurysmal		Nonaneurysmal		Total	
	n	%	*n*	%	*N*	%
Physical Symptoms since SAH (Pearson chi2(1) = 2.2445 P = 0.134)						
Yes	23	71.90	12	52.20	35	63.60
No	9	28.10	11	47.80	20	36.40
Emotional symptoms since SAH (Pearson chi2(1)= 0.4329 P=0.511)						
Yes	17	48.60	10	40.00	27	45.00
No	18	51.40	15	60.00	33	55.00
Participated in PT (Pearson chi2(1) = 6.6379 P = **0.010)**						
Yes	23	65.70	8	32.00	31	51.70
No	12	34.30	17	68.00	29	48.30
Participated in OT (Pearson chi2(1) = 4.3073 P = **0.038)**						
Yes	14	41.20	4	16.00	18	30.50
No	20	58.80	21	84.00	41	69.50
Participated in speech therapy (Fisher's=0.223)						
Yes	6	18.20	1	4.50	7	12.70
No	27	81.80	21	95.50	48	87.30
Received psychiatric counseling (Fisher's=1.000)						
Yes	5	15.20	3	12.00	8	13.80
No	28	84.80	22	88.00	50	86.20
Received other types of treatment (Pearson chi2(1) = 0.0476 P= .827)						
Yes	8	24.20	5	21.70	13	23.20
No	25	75.80	18	78.30	43	76.80

Continuous variables linked to time or specific instrument scores are shown for subjects classified as aneurysmal versus nonaneurysmal in Table 5. These groups did not differ significantly by age, time since hemorrhage, and time smoking or drinking alcohol, nor did they differ significantly in their PTSD, FSSQ, SS-QOL, and SF-12 scores. The only significant differences were their time participating in PT and OT, which confirms the findings in Table 1. In other words, aneurysmal patients are offered more PT/OT services, and when they both have services, the aneurysmal group participates longer in both physical and occupational therapy.

Table 5

Distribution of Continuous Variables by Hemorrhage Type

Variable	Aneurysmal			Nonaneurysmal			p_1[a]	p_2[b]
	Mean ± SD		*n*	Mean ± SD		*n*		
Age	55.71	± 11.3	35	59.28	± 10.7	25	0.223	
Time since SAH, months	30.49	± 11.6	35	27.84	± 9.7	25	0.356	0.435
Time smoking, years	8.03	± 15.4	33	4.4	± 11.1	25	0.323	0.393
Drinks per week	2.3	± 4.1	34	3.2	± 4.3	25	0.399	0.361
Duration of PT, weeks	15	± 35.6	34	2.84	± 5.6	25	0.097	0.011
Duration of OT, weeks	7.91	± 18.9	33	1.44	± 5.0	25	0.101	0.034
Duration of speech therapy, weeks	3.5	± 10.7	32	0.09	± 0.4	22	0.142	0.181
Duration of psych, weeks	3.0	± 10.2	32	1.08	± 4.5	24	0.393	0.579
Duration of other TX, weeks	3.0	± 10.	29	3.6	± 11.7	20	0.85	0.74

			2							8
PTSD Score	1.83	±	0.9	35	1.74	±	0.9	24	0.69	0.369
FSSQ Score	4.33	±	0.8	33	4.4	±	0.8	24	0.758	0.535
Overall QOL - SS-QOL	3.66	±	0.9	34	3.97	±	1.0	24	0.247	0.111
SF-12 PCS score	43.07	±	10.1	34	46.36	±	9.9	21	0.242	0.155
SF-12 MCS score	37.83	±	9.5	34	37.29	±	12.2	21	0.855	0.742

[a] p_1 : significance determined by t-test

[b] p_2 : significance determined by Wilcoxon rank-sum (Mann-Whitney) test

The SS-QOL subscale scores of aneurysmal and nonaneurysmal subjects are compared in Table 6. Of the 12 SS-QOL subscales that measure specific domains of health-related quality of life, two had significantly different scores between the groups. The aneurysmal population had worse scores in the mood and personality domains. The mood domain indicates interest in social interactions and overall view of one's future. The personality domain indicates one's general daily disposition or changes to personality since subarachnoid hemorrhage. Overall the two groups were homogenous in their SS-QOL scores, similar to the findings in Table 1.

Table 6

Distribution of SS-QOL Subscale Scores by Group

SS-QOL Subscale	Aneurysmal mean ± SD	*n*	Nonaneurysmal mean ± SD	*n*	p_1[a]	p_2[b]
Mobility	3.96 ± 1	34	3.99 ± 1.3	24	0.921	0.532
Energy	3.25 ± 1.1	34	3.51 ± 1.4	24	0.43	0.174
Upper Extremity	4.0 ± 1.2	34	4.21 ± 1	24	0.488	0.237
Work/Productivity	3.97 ± 1.1	34	4.2 ± 2.5	24	0.641	0.890
Mood	3.54 ± 1.1	34	4.06 ± 1.1	24	0.082	**0.045**
Self-Care	4.22 ± 1	34	4.33 ± 1.0	24	0.656	0.184
Social Roles	3.3 ± 1.3	34	3.79 ± 1.3	24	0.171	0.197
Family Role	3.68 ± 1.2	35	4.06 ± 1.1	24	0.214	0.130
Vision	4.14 ± 0.9	34	4.36 ± 0.8	24	0.335	0.163
Language	3.85 ± 1.2	34	4.13 ± 0.9	24	0.35	0.620
Thinking	3.01 ± 1.2	34	3.29 ± 1.2	24	0.404	0.383
Personality	3.09 ± 1.2	34	3.69 ± 1.1	24	0.055	**0.049**

[a] p_1 : significance determined by t-test

[b] p_2 : significance determined by Wilcoxon rank-sum (Mann-Whitney) test

The overall distributions (mean, standard deviation, range) for all continuous variables are shown in Table 7. These continuous variables include age, cigarette and alcohol use, and overall PTSD and FFSQ scores. These results demonstrate that the subarachnoid hemorrhage patients, as a group, had low levels of PTSD and high levels of social support.

Table 7

Overall Distribution of All Continuous Variables

Variable	*n*	Mean	SD	Range	
				Min	Max
Age, years	60	57.20	11.09	25.00	85.00
Cigarette use, years	58	6.47	13.74	0.00	49.00
Drinks per week	59	2.66	4.17	0.00	15.00
Duration of PT, weeks	59	9.85	27.78	0.00	200.00
Duration of OT, weeks	58	5.12	14.87	0.00	100.00
Duration of speech therapy, weeks	54	2.11	8.35	0.00	52.00
Duration of Psych, weeks	56	2.18	8.23	0.00	52.00
Duration of other TX, weeks	49	3.24	10.72	0.00	52.00
PTSD Score	59	1.79	0.88	1.00	3.90
FSSQ Social Support	57	4.36	0.81	1.63	5.00
Subjective QoL	58	3.79	0.98	1.36	5.43
SF-12 PCS score	55	44.33	10.07	21.80	59.14
SF-12 MCS score	55	37.62	10.51	4.91	53.35
SS-QOL Mobility	58	3.97	1.13	1.00	4.83
SS-QOL Energy	58	3.35	1.25	1.00	4.75
SS-QOL Upper Extremity	58	4.09	1.09	1.33	4.83
SS-QOL Work Productivity	58	4.06	1.81	1.00	14.50
SS-QOL Mood	58	3.76	1.13	1.17	4.83
SS-QOL Self-Care	58	4.26	0.98	1.50	5.00
SS-QOL Social Roles	58	3.50	1.33	1.00	5.00
SS-QOL Family Roles	59	3.83	1.17	1.00	5.00

SS-QOL Vision	58	4.23	0.86	1.25	5.00
SS-QOL Language	58	3.97	1.07	1.40	4.80
SS-QOL Thinking	58	3.13	1.23	1.00	4.75
SS-QOL Personality	58	3.34	1.17	1.00	4.75

The reliabilities (Cronbach's alphas) of instruments are presented in Table 8. All instruments in this study had excellent reliability. All alphas were at least as high if not higher than those of published studies. This study is the first to have tested the SS-QOL scale as a self-administered scale, and it proved to have excellent reliability.

Table 8

Cronbach's Alpha Reliabilities for Study Instruments

Instrument	Reliability from other studies	Overall Study reliability (Cronbach's α)	Aneurysmal reliability (Cronbach's α)	NonAneurysmal reliability (Cronbach's α)
PTSD	Not available	0.912	0.902	0.942
FSSQ	0.81-0.92	0.924	0.926	0.924
SF-12	0.76 (for aneurysm patients)	0.894	0.877	0.914
SS-QOL	>0.73 for all domains	0.953 (0.979 for subscales)	0.982 (0.957 for subscales)	0.976 (0.946 for subscales)

Subjects' responses to open-ended questions about physical and emotional symptoms experienced due to subarachnoid hemorrhage are shown and compared in Table 9. The subjects' self-identified symptoms were grouped in like categories. The nonaneurysmal group had more physical symptom complaints, except for headaches, weakness and visual disturbance. The

aneurysmal group had more emotional symptoms. Interestingly, only the nonaneurysmal group had a fear of a second subarachnoid hemorrhage.

Table 9

Responses for Physical and Emotional Symptoms on Aneurysmal-Specific Questionnaire

	Type of Subarachnoid Hemorrhage				*Total*	
	Aneurysmal		Nonaneurysmal			
	n	%	*n*	%	*n*	*p*
Physical Symptoms						
Yes	23	71.9	12	52.2	35 (63%)	0.314
No	9	28.1	11	47.8	20 (36.4%)	
Emotional Symptoms						
Yes	17	48.6	10	40.0	27(45%)	0.511
No	18	51.4	15	60.0	33(55%)	

Table 10

Detailed Responses for Physical and Emotional Symptoms on Aneurysmal-Specific Questionnaire

	Type of Subarachnoid Hemorrhage					
	Aneurysmal		Nonaneurysmal			
	n	%	*n*	%	% Difference for NASAH	% Total

	Type of Subarachnoid Hemorrhage					
	Aneurysmal		Nonaneurysmal			
	n	%	*n*	%	% Difference for NASAH	% Total
Physical Symptoms						
Headache	8	23	5	20	-3	22
Fatigue	3	8	6	25	+17	15
Numbness or decreased sensation	2	5	1	4	-1	4.5
Trouble sleeping	2	5	4	16	+11	10
Dizziness/Balance	2	5	5	20	+15	12
Weakness	2	5	1	4	-1	4.5
Visual disturbance	2	5	1	4	-1	4.5
Incontinence	0	0	1	4	+4	4
Emotional Symptoms						
Memory loss	8	23	3	12	-11	18
Anxiety	11	32	4	16	-16	25
Depression	7	20	2	8	-12	15
Unclear Thinking	4	11	1	4	-7	8
Fear of second SAH	0	0	4	16	+16	16

Two separate questions from two separate instruments (the Aneurysmal-Specific and SS-QOL Questionnaires) are compared in Table 11. This comparison is important since the main purpose of this study was to determine the effect of subarachnoid hemorrhage on health-related quality of life. The responses to the first question from the Aneurysmal-Specific Questionnaire ("My overall quality of life is the same as before my SAH") were almost identical to responses

to the question on the SS-QOL # 13 ("My overall QoL is …"). Among nonaneurysmal subjects, 14 (58%) and 13 (59%) perceived their overall quality of life had not changed since the subarachnoid hemorrhage on the Aneurysmal-Specific and SS-QOL questionnaires, respectively. For aneurysmal subjects, 15 (45%) and 16 (49%) perceived no change on the Aneurysmal-Specific and SS-QOL questionnaires, respectively. These results show consistency in subjects' responses to very similar questions. The two groups were further tested by collapsing quality of life overall to 1=a lot worse than before to a little worse than before (1st 3 categories) and 2=the same as before my hemorrhage. The findings show both questions have similar responses. . Subjects that stated No to "My QoL has been affected by my SAH" are more likely to say the "Overall QoL" is the same as before. Fisher's exact= 0.000.

Table 11

Perceived Effect of SAH on Quality of Life (QoL) Measured by Aneurysmal-Specific and SS-QOL Questionnaires

	Type of Subarachnoid Hemorrhage				Total	
	Aneurysmal		Nonaneurysmal			
Question	*n*	%	*n*	%	*N*	%
My QoL has been affected by my SAH (Aneurysmal-Specific Questionnaire)						
Yes	18	54	10	41	28	47.5
No	15	45	14	58	29	51.5
My overall QoL is: (SS-QOL)						
A lot worse than before my SAH	4	11	2	9	6	10
A little worse than before my SAH	5	14	3	13	8	13.5

	Type of Subarachnoid Hemorrhage				Total	
	Aneurysmal		Nonaneurysmal			
Question	*n*	%	*n*	%	*N*	%
Somewhat worse than before my SAH	10	28	4	18	14	23
The same as before my SAH	16	49	13	59	29	54

Specific Aim 1: To describe the physical, psychological, social, and vocational impact of nonaneurysmal and aneurysmal subarachnoid hemorrhage on patients at 1 to 3 years post-hemorrhage.

The two groups did not differ significantly in mobility, energy, upper extremity, self-care, vision, and physical functioning between groups (Table 12). However, the two groups differed significantly in mood and personality as previously demonstrated (Table 6), with the aneurysmal group having more dysfunction (Table 13). On the other hand, the two groups did not differ in their overall SF-12 mental health component score (Table 13) nor in amount of social support (Table 11). Each group scored high on the Duke FSSQ (Table 14), and did differ significantly in terms of vocational impact of the subarachnoid hemorrhage (Fisher's exact = 0.033) (Table 15). It appears that the nonaneurysmal subjects are less likely to be employed in the same position then aneurysmal subjects after the subarachnoid hemorrhage. However, the nonaneurysmal subjects they were less likely to be employed prior to subarachnoid hemorrhage (p=0.027).

Table 12

Physical Impact of Subarachnoid Hemorrhage by Hemorrhage Type

	Aneurysmal		Nonaneurysmal		p_1[a]	p_2[b]
SS-QOL Subscale	Mean ± SD	*n*	Mean ± SD	*n*		

Mobility	3.96	±	1	34	3.99	±	1.3	24	0.921	0.532
Energy	3.25	±	1.1	34	3.51	±	1.4	24	0.43	0.174
Upper Extremity	4	±	1.2	34	4.21	±	1	24	0.488	0.237
Self-Care	4.22	±	1	34	4.33	±	1	24	0.656	0.184
Vision	4.14	±	0.9	34	4.36	±	0.8	24	0.335	0.163
SF-12 Physical Component Score (PCS)										
	43.07	±	10.1	34	46.36	±	9.9	21	0.242	0.155

[a] p_1 : significance determined by t-test

[b] p_2 : significance determined by Wilcoxon rank-sum (Mann-Whitney) test

Table 13

Psychological Impact of Subarachnoid Hemorrhage by Hemorrhage Type

	Aneurysmal				Nonaneurysmal				p_1[a]	p_2[b]
SS-QOL Subscale	Mean ± SD			*n*	Mean ± SD			*n*		
Mood	3.54	±	1.1	34	4.06	±	1.1	24	0.082	**0.045**
Thinking	3.01	±	1.2	34	3.29	±	1.2	24	0.404	0.383
Personality	3.09	±	1.2	34	3.69	±	1.1	24	0.055	**0.049**
SF-12 Mental Component Score										
	37.83	±	9.5	34	37.29	±	12.2	21	0.855	0.742

[a] p_1 : significance determined by t-test due

[b] p_2 : significance determined by Wilcoxon rank-sum (Mann-Whitney) test. This was used as the histogram distribution was not normal, thus the Mann-Whitney test was used and the results are now the reference results for this table.

Table 14

Social Impact of Subarachnoid Hemorrhage by Hemorrhage Type

SS-QOL Subscale	Aneurysmal Mean ± SD	*n*	Nonaneurysmal Mean ± SD	*n*	p_1[a]	p_2[b]
Social Roles	3.3 ± 1.3	34	3.79 ± 1.3	24	0.171	0.197
Family Role	3.68 ± 1.2	35	4.06 ± 1.1	24	0.214	0.130
FSSQ Score	4.33 ± 0.8	33	4.4 ± 0.8	24	0.758	0.535

[a] p_1 : significance determined by t-test

[b] p_2 : significance determined by Wilcoxon rank-sum (Mann-Whitney) test

Table 15

Vocational Impact of Subarachnoid Hemorrhage by Subarachnoid Hemorrhage Type

	Aneurysmal		Nonaneurysmal		Total	
	n	%	*n*	%	*N*	%
Employed in the same position post SAH						
Yes	21	63.60	13	52.00	34	58.60
No	8	24.20	2	8.00	10	17.20
Non applicable	4	12.10	10	40.00	14	24.10

Fisher's=**0.033**

Specific Aim 2: **To examine differences in HRQOL between patients with NASAH and ASAH after controlling for severity of hemorrhage, age, and time since hemorrhage**

The two groups did not differ significantly in SF-12 physical component scores (Table 16-18), even though the PCS score of the nonaneurysmal group was 3.30 units higher than that of the aneurysmal group. The relationship between PCS and age was not linear, especially skewed far to the left. Therefore, age was divided into categories, creating the need to treat age

as a categorical (rather than continuous) variable in regression analysis. The relationship between PCS and time was linear. However, the relationship between PCS and type of hemorrhage was not significant after adding age, time and Fisher score to the regression model (Table 19).

The adjusted and unadjusted associations among variables are shown in Table 20. The coefficients for type of hemorrhage in the unadjusted model were developed from the model MCS=type of hemorrhage. The coefficients in the adjusted model for type of hemorrhage came from the model MCS=type of hemorrhage + Fisher score + age + time since hemorrhage. Although the difference between MCS scores of the two groups was still not significant, including the Fisher score, age, and time increased this difference. The MCS score of the nonaneurysmal group was 2.03 units lower than that of the aneurysmal group (p=0.565).

The overall average SS-QOL scores for aneurysmal and nonaneurysmal subjects were 3.66 and 3.97, respectively. The coefficients for type of hemorrhage in the unadjusted model came from the model SS-QOL overall=type of hemorrhage (Table 21). The coefficients in the adjusted model for type of hemorrhage came from the model SS-QOL overall=type of hemorrhage + Fisher score + age quintile + time since hemorrhage. In both the unadjusted and adjusted models, SS-QOL did not differ significantly by type of hemorrhage. The unadjusted model shows that overall SS-QOL was 0.53 units greater for the >1mm thick group than for the intraparenchymal group (*p*=.037). This significant association disappeared when other factors were adjusted for. The unadjusted model shows a significant difference between the 1st and 4th age quintiles. The overall SS-QOL score of the 4th quintile was 0.70 units greater than that of the 1st quintile. Similarly, the overall SS-QOL scores of the 1st and 5th quintiles were associated, with SS-QOL score for the 5th quintile 0.89 units higher than for the 1st quintile. This association was not as strong in the adjusted model, where only the 5th quintile groups still showed a

significant association. Overall SS-QOL score was not significantly associated with time post hemorrhage in either model.

Table 16

SF-12 PCS (Physical Component Score) by Type of Hemorrhage

Type of Hemorrhage	*n*	Mean	SD	Range	
				Max	Min
Aneurysmal	34	43.06559	10.13899	59.14	22.57
Nonaneurysmal	21	46.36476	9.86555	57.41	21.8
Total	55	44.32527	10.07403	59.14	21.8

Table 17

Linear Regression for PCS by Type of Hemorrhage (N=55; Outcome variable =PCS)

Type of Hemorrhage	Coefficient	SE	*P* (t-test)	95% Confidence Interval	
				Lower	Upper
Aneurysmal [a]	0				
Nonaneurysmal	3.299	2.786	0.242	-2.288	8.886

[a] Baseline category

Table 18

Linear Regression PCS by Type of Hemorrhage (N=55; Outcome variable =PCS^2)

Type of Hemorrhage	Coefficient	SE	*P* (t-test)	95% Confidence Interval	
				Lower	Upper
Aneurysmal [a]	0				

Nonaneurysmal	287.965	229.901	0.216	-173.158	749.088

[a] Baseline category

Table 19

PCS Score by Hemorrhage Type after Adjusting for Age, Hemorrhage Type, and Time since Hemorrhage

		Outcome Variable PCS, *n*=55				Transformed Outcome Variable PCS[2], *n*=55			
		B? β?	SE	95% CI	*p*[a]	B? β?	SE	95% CI	*p*[a]
Type of hemorrhage									
Aneurysmal [a]		0				0			
Nonaneurysmal		2.372	3.111	-3.891 to 8.635	0.450	218.00	258.10	-301.53 to 737.53	0.403
Fisher Score					0.561				0.600
Intraparenchymal [a]		0				0			
≤1mm thick		2.763	6.836	-10.998 to 16.524	0.688	198.304	567.09	-943.20 to 1339.81	0.728
>1mm thick		3.536	3.331	-3.169 to 10.241	0.294	278.687	276.33	-277.54 to 834.91	0.318
Age Quintile, years					0.915				0.961
1 [a]	<49.2	0							
2	49.2 to <56	1.554	4.807	0.748 to -11.229	0.748	116.857	3.9872	-685.72 to 919.43	0.771

3	56 to 60.6	0.166	4.419	-8.730 to 9.062	0.970	-21.503	366.61	-759.45 to 716.44	0.953
4	60.6 to <65.5	1.164	4.912	-8.723 to 11.051	0.814	49.158	407.45	-770.99 to 869.30	0.904
5	>65.5	3.970	4.516	-5.121 to 13.061	0.384	241.206	374.65	-512.92 to 995.33	0.523
Time post hemorrhage, months		0.151	0.146	-0.143 to 0.445	0.307	12.616	12.124	-11.789 to 37.021	0.304

[a] Baseline category; PCS^2 is transformed because PCS was not normally distributed.

Table 20

Transformed SF-12 Mental Component Score (MCS) Scores by Hemorrhage Type after Adjusting for Age, Type of Hemorrhage, and Time since Hemorrhage

	Unadjusted				Adjusted			
	B? β?	SE	95% CI	*p* [a]	B? β?	SE	95% CI	*p* [a]
Type of hemorrhage								
Aneurysmal [b]	0				0			
Nonaneurysmal	-0.54	2.94	-6.44 to 5.36	0.947	-2.03	2.76	-7.58 to 3.52	0.565
Fisher Score								
Intraparenchymal [b]	0				0			
<1mm thick	-7.25	6.26	-19.81 to 5.31	0.307	-6.23	5.82	-17.92 to 5.47	0.338
>1mm thick	3.69	2.93	-2.18 to 9.56	0.108	2.19	2.87	-3.59 to 7.96	0.288
Age	0.44	0.11	0.21 to 0.67	<0.001	0.43	0.12	0.19 to 0.67	<0.001

	Unadjusted				Adjusted			
	B? β?	SE	95% CI	*p* [a]	B? β?	SE	95% CI	*p* [a]
Time post hemorrhage, months	-0.05	0.13	-0.31 to 0.21	0.584	-0.03	0.12	-0.27 to 0.21	0.725

[a] *p* is from transformed data.

[b] Reference group

Table 21

Transformed Stroke Scale Quality of Life (SS-QOL) Score by Hemorrhage Type after Adjusting for Age, Type of Hemorrhage, and Time since Hemorrhage

	Unadjusted				Adjusted			
	B? β?	SE	95% CI	*p*[a]	B? β?	SE	95% CI	*p*[a]
Type of hemorrhage								
Aneurysmal [b]	0				0			
Nonaneurysmal	0.30	0.26	-0.22 to 0.82	0.167	0.20	0.26	-0.32 to 0.72	0.381
Fisher Score								
Intraparenchymal[b]	0				0			
≤1mm thick	-0.48	0.50	-1.49 to 0.52	0.519	-0.61	0.54	-1.70 to 0.48	0.345
>1mm thick	0.53	0.26	0.01 to	0.037	0.46	0.28	-0.11 to	0.09

			1.06				1.02	9
Age Quintile								
1[b]	0				0			
2	-0.006	0.395	-0.80 to 0.79	0.725	0.064	0.43	-0.79 to 0.92	0.689
3	-0.03	0.37	-0.77 to 0.71	0.990	-0.27	0.38	-0.99 to 0.54	0.609
4	0.70	0.38	-0.08 to 1.47	0.062	0.44	0.41	-0.38 to 1.27	0.271
5	0.89	0.38	0.14 to 1.65	0.014	0.79	0.38	0.03 to 1.54	0.031
Time post hemorrhage, months	0.000	0.012	-0.02 to 0.02	0.974	0.01	0.01	-0.01 to 0.04	0.230

[a] *p* was determined using transformed data.

[b] Reference group

Specific Aim 3: To examine the effects of employment status, PTSD, and social support (by adjusting for each variable) on HRQOL for patients with NASAH and ASAH and to determine if the adjustment accounts for any HRQoL differences between NASAH and ASAH patients.

The SF-12 PCS score of the unemployed group was 5.55 units smaller than that of the employed group (reference group), but this difference was not significant (p=0.093) (Table 22). The PCS score decreased significantly (p=0.013), by 4.19 units for every 1 unit increase in the PTSD score (Table 23). The relationship between PCS and social support was linear except for a small skewedness for the far left side. Thus, new social support categories (terciles) were created. The 2nd tercile group had a PCS score 1.32 units greater than that of the 1st tercile group (reference group), but this difference was not significant (p=0.665) (Table 24). Similarly, the PCS score of

the 3rd tercile group was 2.98 units greater than that of the 1st tercile group (reference), but this difference was not significant (p=0.409) (Table 24).

The association of the SF-12 PCS score with type of hemorrhage did not become significant when employment, PTSD score, and social support were added to model (Table 25). These extra variables did not explain more of the variance in PCS score between the aneurysmal and nonaneurysmal groups.

The SF-12 MCS score of the unemployed group was 3.15 units greater than that of the employed (reference) group, but this difference was not significant (p=0.373) (Table 26). MCS scores decreased significantly (p<0.001), by 7.12 units for every 1 unit increase in PTSD score (Table 26).

The MCS score for the 2nd tercile group was 4.85 units larger than that of 1st tercile (reference group), but this difference was not significant (p=0.107) (Table 28). However, the MCS score of the 3rd tercile group was significantly larger (p=0.009), by 7.71 units than that of the 1st tercile (reference group) (Table 28).

The association of the SF-12 MCS score with type of hemorrhage did not become significant when employment score, PTSD score, and social support were added to the model (Table 29). These extra variables did not explain more of the variance in the MCS score between the aneurysmal and nonaneurysmal groups.

Overall SS-QOL score of the unemployed group was 0.35 unit smaller than that of the employed (reference) group, but this difference was not significant (p=0.382) (Table 30). Overall SS-QOL score decreased significantly (p<0.001), by 0.82 unit for every 1 unit increase in the PTSD score (Table 31). Overall SS-QOL score increased significantly (p=0.001), by 0.53 units for every 1 unit increase in the FSSQ score (Table 32).

The association of the overall SS-QOL score with type of hemorrhage did not become significant when employment, PTSD score, and FFSQ score were added to the model (Table 33). These extra variables did not explain more of the variance in overall SS-QOL score between the aneurysmal and nonaneurysmal groups.

The results from Specific Aim 3 show that patients with higher PTSD scores (more PTSD) had lower scores on the SF-12 PCS and MCS as well as overall SS-QOL, indicating worse health-related quality of life. Patients with more social support (FSSQ) had higher overall SS-QOL scores, increasing their HRQoL. Adjusting for the effects of employment status, PTSD, and social support did not account for any differences in HRQoL between patients with NASAH and ASAH.

Table 22

Relationship between PCS Score and Employment Status, N=55

	B? β?	SE	95% CI	*p*[a]
Education				
Yes (reference)	0			
No	-5.55	3.14	-11.84 to 0.74	0.093

[a] *p* was determined from transformed data

Table 23

Relationship between PCS and PTSD Scores, N=54

	B? β?	SE	95% CI	*p*[a]
PTSD Score				
Per unit	-4.19	1.51	-7.21 to -1.17	0.013

[a] *p* was determined from transformed data

Table 24

Relationship between PCS and Social Support Scores, N=53

	B? β?	SE	95% CI	*p*[a]
FSSQ score – social support tercile				
1st tercile ≤4.125 (reference)	0			
2nd tercile >4.125 to 4.875	1.32	3.46	-5.62 to 8.27	0.665
3rd tercile >4.875	2.98	3.46	-3.97 to 9.93	0.409

[a] *p* was determined from transformed data

Table 25

PCS Score by Hemorrhage Type after Adjusting for Employment Status, PTSD and Social Support, N=53

	B? β?	SE	95% CI	*p*[a]
Type of hemorrhage				
Aneurysmal (reference)	0			
Nonaneurysmal	3.62	2.81	-2.02 to 9.27	0.196
Employed				
Yes (reference)				
No	-6.50	3.28	-13.09 to 0.096	0.061
PTSD Score				
Per unit	-3.62	1.58	-6.79 to -0.44	0.043
FSSQ score – social support tercile				
1st tercile ≤4.125 (reference)	0			
2nd tercile >4.125 to 4.875	-0.49	3.25	-7.02 to 6.04	0.950
3rd tercile >4.875	1.81	3.34	-4.91 to 8.54	0.591

[a] *p* was determined from transformed data

Table 26

Relationship between MCS Score and Employment Status, N=55

	B? β?	SE	95% CI	*p*[a]
Employed				
Yes (reference)	0			
No	3.15	3.34	-3.55 to 9.84	0.373

[a] *p* was determined from transformed data

Table 27

Relationship between MCS and PTSD Scores, N=54

	B? β?	SE	95% CI	*p*[a]
PTSD Score				
Per unit	-7.12	1.19	-9.51 to -4.74	<0.001

[a] *p* was determined from transformed data

Table 28

Relationship between MCS and Social Support Scores after Adjusting for Social Support, N=53

	B? β?	SE	95% CI	*p*[a]
FSSQ score – social support terciles				
1st tercile ≤4.125 (reference)	0			
2nd tercile >4.125 to 4.875	4.85	3.08	-1.33 to 11.03	0.107
3rd tercile >4.875	7.71	3.08	1.53 to 13.89	0.009

[a] *p* was determined from transformed data

Table 29

PCS Score by Hemorrhage Type after Adjusting for Employment Status, PTSD Score, and Social Support, N=53

	B? β?	SE	95% CI	*p*[a]
Type of hemorrhage				
Aneurysmal (reference)	0			
Nonaneurysmal	-0.57	2.16	-4.91 to 3.78	0.910
Employed				
Yes (reference)				
No	3.76	2.52	-1.31 to 8.84	0.178
PTSD Score				
Per unit	-6.71	1.21	-9.16 to -4.27	<0.001
FSSQ score – social support terciles				
1st tercile ≤4.125 (reference)	0			
2nd tercile >4.125 to 4.875	3.30	2.50	-1.72 to 8.32	0.172
3rd tercile >4.875	3.78	2.57	-1.39 to 8.95	0.089

[a] *p* was determined from transformed data

Table 30

Relationship between Overall SS-QOL Score and Employment Status, N=58

	B? β?	SE	95% CI	*p*[a]
Employed				
Yes (reference)	0			
No	-0.35	0.29	-0.93 to 0.24	0.382

[a] *p* was determined from transformed data

Table 31

Relationship between Overall SS-QOL Score and PTSD,

	B? β?	SE	95% CI	*p*[a]
PTSD Score				
Per unit	-0.82	0.10	-1.02 to -0.62	<0.001

[a] *p* was determined from transformed data

Table 32

Relationship between SS-QOL and FFSQ Scores, N=57

	B? β?	SE	95% CI	*p*[a]
FSSQ score – social support				
Per unit	0.53	0.15	0.24 to 0.83	0.001

[a] *p* was determined from transformed data

Table 33

Overall QOL Score by Hemorrhage Type after Adjusting for Employment Status, PTSD Score, and FSSQ Score, N=57

	B? β?	SE	95% CI	*p*[a]
Type of hemorrhage				
Aneurysmal (reference)	0			
Nonaneurysmal	0.26	1.84	-0.11 to 0.63	0.122
Employed				

Yes (reference)				
No	-0.18	0.21	-0.60 to 0.24	0.597
PTSD Score				
Per unit	-0.72	0.11	-0.93 to -0.51	<0.001
FSSQ score – social support				
Per unit	0.23	0.11	0.003 to 0.46	0.058

[a] *p* was determined from transformed data

Specific Aim 4: To describe management strategies used by patients with nonaneurysmal and aneurysmal subarachnoid hemorrhage that helped improve their HRQoL

Few study participants responded to questions about received or potential treatments. Only 11 subjects responded to the question on what they found helpful during their recovery process, and only 14 described other treatments they perceived could be helpful if they had been offered. The results in Table 34 demonstrate that patients used alternative therapies such as acupuncture or massage therapy. Subjects also found it helpful to have more information from both the neurosurgery team and rehabilitation facility during hospitalization or more frequent contact once discharged. They also cited home care requirements for additional nursing services or adaptive equipment. Finally, once the subjects were at home and processing the ramifications of a subarachnoid hemorrhage, they either benefited from or might benefit from social workers or support groups.

Table 34

*Other Treatments Found to Helpful after Subarachnoid Hemorrhag*e

Treatment	Type of Subarachnoid Hemorrhage	Total

	Aneurysmal		Nonaneurysmal			
	n	%	*n*	%	*N*	%
Acupuncture	1	2	0	0	1	1
Anxiety medication	0	0	1	4	1	1
Remained in contact with rehab	1	2	0	0	1	1
Earlier follow-up with neurosurgeon	0	0	1	4	1	1
Home adaptive equipment	0	0	1	4	1	1
Aide at home	1	2	0	0	1	1
Massage therapy	1	2	0	0	1	1
Neuro-ophthalmology	1	2	0	0	1	1
Support group	1	2	0	0	1	1
Visiting nurse	1	2	1	4	2	3

Table 35

Treatments Subjects Perceived Could Have Been Helpful Had They Been Offered

	Type of Subarachnoid Hemorrhage				Total	
	Aneurysmal		Nonaneurysmal			
Treatment	*n*	%	*n*	%	*N*	%
Additional PT	2	.05	1	.04	3	.05
More information about diagnosis/prognosis while hospitalized	3	.08	1	.04	4	.06
Social services	1	.02	0	0	1	.01
Speech and language therapy	1	.02	0	0	1	.01
Psychiatric counseling	1	.02	1	.04	2	.01
Insurance to pay for acupuncture	1	.02	0	0	1	.01

	Type of Subarachnoid Hemorrhage				Total	
	Aneurysmal		Nonaneurysmal			
Treatment	*n*	%	*n*	%	*N*	%
More follow-up with neurosurgeon	0	0	1	.04	1	.01
Support group	1	.02	0	0	1	.01

Summary

The results of this chapter and study were generated by analysis of quantitative data collected from six instruments. These results show that patients with aneurysmal and nonaneurysmal subarachnoid hemorrhage had more similarities than differences. This outcome is consistent with the underpinning hypothesis for this study, i.e., that the health-related quality of life of these groups would not differ significantly before and after controlling for severity of hemorrhage, age, and time since hemorrhage.

The nonaneurysmal group had more subjective physical symptom complaints, and the aneurysmal group had more emotional symptoms. However, the nonaneurysmal group had a lower SF-12 mental component score (MCS), by 2.03 units, than the aneurysmal group. Only the nonaneurysmal group feared having a second subarachnoid hemorrhage. The two groups differed significantly in their employment status; only 52% of nonaneurysmal patients were employed post hemorrhage in the same position as before their hemorrhage versus 63% of aneurysmal patients.

Both groups had low levels of PTSD, and these levels did not differ significantly between groups. However, PTSD and social support were shown by regression analysis to impact HRQoL. Subjects with higher PTSD scores (more PTSD symptoms) had lower scores on both the SF-12 and overall SS-QOL scores, indicating worse health-related quality of life. Subjects

with more perceived social support had higher overall SS-QOL scores, and greater HRQoL. Lastly, the subjects reported wanting more information about their diagnosis/plan of care during all phases of acute inpatient hospitalization, during rehabilitation, and upon discharge.

Chapter V

Discussion

Introduction

This chapter discusses the similarities and differences found in patients 12 to 30 months following an aneurysmal subarachnoid hemorrhage (ASAH) versus a nonaneurysmal subarachnoid hemorrhage (NASAH). The impacts of NASAH and ASAH on health-related quality of life (HRQOL), symptomatology and employment status are discussed in detail. Additionally, the effects of post traumatic stress disorder (PTSD) and social support on HRQOL are presented. Finally, the study limitations and implications for practice, policy and future research are discussed.

Of the 34 demographic and clinical characteristics examined in this study, only 6 were found to differ significantly between the ASAH and NASAH groups (Fisher grade, family history of SAH, employment before SAH, employment after SAH, and participation in physical therapy (PT) and occupational therapy (OT). ASAH patients had significantly greater Fisher grade scores than NASAH patients. This difference was expected given that intraparenchymal and intraventricular blood can occur as part of aneurysmal rupture, and such a difference is seen consistently throughout the literature (Beseoglu et al., 2009; Hutter & Gilsbach, 1995; Hutter et al., 2001; 2001; Katati et al., 2007; Zebian, 2011). Due to the large size of these hemorrhages, aneurysmal patients generally have more physical disability and require physical and occupational therapy, explaining the significant difference in PT and OT participation in these groups. Participation in physical and occupational therapy has not been specifically researched in any other studies. Only 52% of nonaneurysmal patients remained employed in the same position post subarachnoid hemorrhage versus 63% of aneurysmal patients. These findings are

counterintuitive as the ASAH patients generally have more physical disability and thus would be considered less likely to return to work. However, inability to work post NASAH has been frequently demonstrated in the literature (Beseoglu et al., 2009; Brilstra et al., 1997; Marquardt et al., 2000).

HRQOL

This is the second study comparing HRQOL outcomes between aneurysmal and nonaneurysmal subarachnoid hemorrhage patients. The first study, by Hutter and Gilsbach (1995), focused on cognitive deficits 1–5 years after subarachnoid hemorrhage. Hutter and Gilsbach concluded that no significant differences in cognitive deficits could be found between the two groups. They also measured HRQOL using the Freiburg Personality Inventory (FPI-R) by self-report and proxy ratings. Substantial impairments in HRQOL were reported by 50% of patients and their life companions self by self-rating. That self-reported finding is comparable to our study, as 41–55% of both groups reported their quality of life had been adversely affected by the subarachnoid hemorrhage. Hutter and Gilsbach recommended that patients and their families should be better informed about their SAH in order to make better decisions in the future about the need for extended services or the vocational impact of the SAH. Our participants reported wanting more information about their diagnosis/plan of care during all phases of acute inpatient hospitalization, during rehabilitation, and upon discharge.

To our knowledge, our study is only the second study to directly compare and contrast long-term HRQOL in patients who had ASAH and NASAH. Other studies have examined HRQOL in samples of either ASAH or NASAH patients.

The NASAH studies have contradictory results. For example, it has been suggested that NASAH patients have less dysfunction and that this type of hemorrhage is benign (Brilstra et al 1997).

The Bristla study was one of the first studies to specifically look at NASAH, and it concluded that NASAH was a “benign” condition. In contrast Marquardt et al, (2000) found that NASAH patients have considerable long-term psychosocial consequences post hemorrhage. For example, the majority of patients had residual complaints of headache, irritability, forgetfulness, depression, weariness, and reduced endurance at follow up. These findings are consistent with our study, which found residual complaints of headache, fatigue, memory loss and anxiety among our sample. In addition, the Marquardt et al., study also demonstrated similar employment issues as the current study. Of 17 patients who had been working before the hemorrhage, less than half returned to their previous occupation, 9 retired from work, and 1 became unemployed.

In contrast to the NASAH studies that focused on the consequences of a subarachnoid hemorrhage, many of the ASAH studies have tried to predict what factors predict long term HRQOL. Most recently, a meta-analysis by Noble and Schenk (2010) found that the traditional predicator variables of exam on admission and size of bleed do not explain impairment in HRQOL. Therefore, the cause of most HRQOL impairment after SAH remains unknown. Noble and Schenk (2010) suggested that only physical disability affected HRQOL (large effect size of 0.54). Age had a small-to-moderate effect size on HRQOL (effect size = 0.20). The situation is even worse for the impact to the mental health component of HRQOL, an area often significantly affected in SAH patients. Here, 90% of the variance remains unexplained by traditional predictors (Noble & Schenk, 2010). Using the Stroke Scale Quality of Life SSQOL instrument, we identified that only the aneurysmal population had worse scores in the mood and personality domains. The mood domain reflects interest in social interactions and overall view of one’s future. The personality domain indicates one’s general daily disposition or changes to personality

since subarachnoid hemorrhage. We recommend using the SSQOL tool to help narrow the variance found in the mental health component of HRQOL. Our study also confirms that mood disturbances and maladadaptive coping skills after SAH have been found in other studies (Visser-Meily et al., 2009).

Employment

Previous studies have demonstrated that returning to work is a major challenge for individuals who survive a SAH (Beseoglu et al., 2009; Brilstra et al., 1997; Hop et al., 2001; Hutter & Gilsbach (1995); Marquardt et al., 2000; Wermer et al. (2007). In this study, NASAH subjects were less likely then ASAH subjects to be employed prior to subarachnoid hemorrhage. We are unaware of any other studies that have looked at employment prior to subarachnoid hemorrhage. One possible explanation for this finding is that the NASAH group may have had more retirees in the cohort as the NASAH group was approximately 2 years older. The NASAH median age was 59.28 versus 55.7 for the ASAH group. Of those who were employed prior to their hemorrhage, fewer NASAH patients remained employed in the same position post-subarachnoid hemorrhage compared with ASAH patients. Prior studies have not directly compared the difference in employment status between both hemorrhage groups. However, employment status has been studied in both NASAH and ASAH samples. The nonaneurysmal studies suggested that NASAH patients have difficulty returning to a similar position or to work at all (Beseoglu et al., 2009; Brilstra et al., 1997; Marquardt et al., 2000). In fact, the 1997 Brilstra et al. study had only two significant findings, and one was inability to work. Brilstra et al. found that of the 25 patients, six (24%) reported more dysfunction in the category of work than the general population. In the 2009 study by Beseoglu et al., only 8 of 19 (42%) NASAH subjects were able to return to their jobs. In the one combined study of both groups by Hutter &

Gilsbach (1995), participants reported employment-related difficulties (n = 5, 8%), lost their job or were demoted (n = 5, 8%), or had to retire (n = 9, 15%). Only two ASAH studies looked at the effects of employment. Hop et al. (2001) found that 94% of patients were unable to return to the same work position, while Wermer et al. (2007) found that 26% of ASAH patients stopped working, and 24% worked shorter hours. This compares with our study which found the two groups differed significantly in their employment status; only 52% of nonaneurysmal patients were employed post hemorrhage in the same position as before their hemorrhage versus 63% of aneurysmal patients. The literature tends to suggest that the ASAH patients may have greater employment problems post hemorrhage compared to the NASAH patients. However, our findings contrast with this notion.

The variance between ASAH and NASAH changes when we compare the percent in same work position omitting, rather than including, those not employed prior to hemorrhage. There were a total of 21 ASAH and 13 NASAH working in the same position post hemorrhage. There were 29 ASAH and 15 NASAH employed prior to the hemorrhage which means comparing employed before and after hemorrhage 72% ASAH remained employed and 86% NASAH remained employed.

Our study confirms previous findings that there is a significant and similar impact on employment for both hemorrhage groups. It is not clear why NASAH patients in this study had more difficulty returning to their same position. One can hypothesize that perhaps baseline differences in education may account for different types of job responsibilities and therefore account for these differences between the two groups. The nonaneursymal group tended to have more bachelor's or graduate level degrees as compared to the aneurysmal group (58% versus 37%) and thus may have held positions that required higher levels of concentration or advanced

skills. These findings may also be related to our small sample size and the possibility that study respondents did not represent the actual population of SAH patients.

Long-term Symptoms.

To better evaluate the HRQOL in subarachnoid hemorrhage patients, we examined both physical and psychological symptoms. Our study found that the nonaneurysmal group had more physical symptom, while the aneurysmal group had more emotional symptoms. Of the 12 SS-QOL subscales that measure specific domains of HRQOL, two had significantly different scores between the groups: the aneurysmal population had worse scores on the mood and personality domains.

These findings differ slightly from other nonaneurysmal studies. The NASAH patient population has specifically been examined in five long term follow-up studies (Beseoglu et al., 2009; Brilstra et al., 1997; Greebe & Rinkel, 2007; Gupta et al., 2009; Marquardt et al., 2000). All of these studies found this group to suffer from symptoms such as headache, irritability, forgetfulness, depression, weariness, and reduced endurance. Our study confirmed the finding of headaches and reduced endurance, but the remaining symptoms found in the other studies were more consistent with the aneurysmal group symptoms. One recent study of aneurysmal patients that also used the SSQOL (Visser-Meily et al., 2009) found similar findings to our study. They found higher scores in the physical domain and lower scores in the emotional and social domains. All psychological symptoms and personality characteristics were strongly related to the total HRQOL score. Similarly, our study found lower scores in the mood and personality domains for the aneurysmal population in both the unadjusted and adjusted models. However, the SS-QOL overall score did not differ significantly by type of hemorrhage. The unadjusted model shows that overall SSQOL score was 0.53 units greater for the >1mm-thick group than for

the intraparenchymal group. This significant association disappeared when other factors such as age and time since hemorrhage were adjusted for. The other study that specifically looked at NASAH with intraparenychmal hemorrhage was Beseoglu et al., (2009). They found this specific group of NASAH patients to complain of reduced mental health, which they interpreted as leading to emotional problems and role limitations.

PTSD and Social Support

Three studies have used diagnostic criteria to identify and study PTSD in subarachnoid hemorrhage patients (Berry, 1998; Hutter, 2000; Noble et al., 2008). The most recent study, Noble et al. (2008), found PTSD to occur in up to 37% of a subarachnoid hemorrhage population. They found PTSD to be the single best predictor of patients' mental QOL, the domain most persistently impaired in both the short and long term. None of the other variables in their model (including clinical grade, and physical and cognitive disability) made significant contributions to the patients' mental QOL. Our study found that both groups had low levels of PTSD, and these levels did not differ significantly between groups. However, PTSD and social support were shown by regression analysis to impact HRQOL.

To our knowledge, this is the first study to examine the effects of social support, as assessed with the UNC Functional Support Questionnaire (FFSQ), on the HRQOL of aneurysmal and nonaneurysmal hemorrhage patients. Our results demonstrated that ASAH patients, as a group, had low levels of PTSD and high levels of social support. The results show that patients with higher PTSD score (more PTSD) had lower scores on the SF-12 PCS and MCS as well as overall SS-QOL, indicating worse HRQOL. Patients with greater social support had higher overall SSQOL scores, increasing their HRQOL. These findings suggest an association between perceived social support, PTSD, and HRQOL for both the NASAH and ASAH groups.

Fear of a second hemorrhage was a major concern for the NASAH patients. In our study, 28 % of participants were concerned about a second subarachnoid hemorrhage, and 85% of those concerned also had higher levels of PTSD. Interestingly, none of the ASAH patients were worried about hemorrhage recurrence. For the ASAH group, this may be a result of an immediate treatment and potential cure via coiling or clipping for their SAH, whereas there is no surgical treatment for nonaneurysmal hemorrhage patients.

Limitations

Several study limitations deserve mention. First, the sample size was limited, falling 20 subjects short of the goal sample of 80. Our final effect size was 0.75 based on using an alpha level of 0.05, HRQOL variables for both groups and an effect size of .20. However, given the rarity of a NASAH, the sample size of 25 for the NASAH group is similar to that reported in four of the five NASAH-specific studies. The small sample size, in some cases, necessitated a collapse in some variables in the regression analyses. Although the 59% survey response rate was excellent considering that the survey was mailed and that some subjects were three years post-hemorrhage, the 27-page questionnaire might have been overwhelming for some subjects. The survey was printed in large print for ease of completion, but the resulting length may have discouraged some patients from responding.

The sample may not have adequately represented the full range of SAH patients as severe-grade patients may have been unable to participate because of cognitive limitations. No screening tools were used to exclude subjects with cognitive deficits or to assist them in completing the questionnaire. Results are limited to English-speaking patients and those cared for at a large tertiary care facility only.

Due to the retrospective design of this study, many of the hemorrhages could have occurred up to up to 3.5 years earlier; thus, maturation issues should be considered. HRQOL physical issues may be influenced by natural aging or by an unrelated disease process other than hemorrhage that has occurred with time.

The NASAH population is heterogeneous in terms of perimesencephalic bleeding. We include a variable for the NASAH subjects to distinguish between perimescencephalic and nonperimesencephalic. The majority were nonperimesencephalic. We would recommend further study in future distinguishing outcome between these two groups, similar to the Beseoglu et al., study in 2009 which specifically looked at outcomes between the two groups.

As in any research, there may be a systematic bias in who agrees to participate. In this study, these participants may have been eager to participate because they felt that they were helping to advance research in this area, but it may also have been a cathartic process for them, or for patients who desired more follow-up.

Human Subject Issues

All instruments were chosen to reduce subject burden. The SS-QOL can be completed in 12 minutes, the SF-12, FSSQ and PTSD instruments can each be completed in 5-10 minutes, and the demographic and NASAH-specific questionnaires in approximately 15 minutes. The risks involved in using these instruments are minimal. The purpose of the study was explained in both the initial and follow-up mailings. Participants were able to contact the PI via phone whenever needed. Two subjects contacted the PI requesting follow-up appointments with the neurosurgeon, as the study reminded them they should have followed up. One of the two patients corresponded with the PI and had a number of questions about her NASAH and other

neurological issues. Five subjects wrote letters of gratitude for the care they received and for researching this subject area.

Clinical Implications

Nurses and other clinicians can potentially help improve several aspects of quality of life for SAH patients, including providing information about the affects of a SAH on HRQOL. Communication of information during all phases of hospitalization and follow-up was found to be crucial to our participants and their families.

Our participants reported wanting more information about their diagnosis/plan of care during all phases of acute inpatient hospitalization, during rehabilitation, and upon discharge. Hutter & Gilsbach recommended back in 1995 that both ASAH and NASAH patients receive psychological counseling. Clinicians and nurses can refer patients to an inpatient social work team or to a psychiatry consultation. Much of the angst may be reduced by teaching patients about the natural course of subarachnoid hemorrhages. Patients with NASAH particularly need to hear information that they are at no more risk for a second subarachnoid hemorrhage than any other population. Much fear could be reduced in this population if healthcare workers could share the information from the Greebe and Rinkel (2007) study of perimesencephalic NASAH subjects showing that patients with perimesencephalic hemorrhage have no long-term excess mortality compared with the general population.

Our results show that the nonaneurysmal population suffers from the same HRQOL issues that the aneurysmal population encounters. NASAH patients in previous studies have been classified as having a “good outcome” or having a “benign hemorrhage,” without having returned to their pre-hemorrhage level of functioning. Neurosurgery practices should consider referring NASAH patients to the same types of support services that the ASAH patients receive.

These would include physical, occupational and speech therapies. Many times, NASAH patients do not qualify for acute rehabilitation. In these cases, they should be given a referral for home occupational therapy for a home safety and cognitive evaluation. A referral to cognitive neurologists should be considered for every SAH patient, particularly those who have been identified by occupational therapy as having cognitive deficits. ASAH and NASAH patients should receive psychological counseling early in the course of hospitalization to alleviate potential PTSD symptoms. Recognizing that these patients might suffer from PTSD and implementing treatment/therapy for this condition may alleviate patient fears of SAH recurrence and promote significantly better outcomes and decrease the risk of PTSD. Noble et al. (2008) also recommended early psychological intervention and suggested that teaching patients not only about their SAH but also better coping skills early on might prevent PTSD and improve HRQOL.

Research Implications

This is the second study to use the SSQOL in the subarachnoid hemorrhage population. Our findings support the use of the SSQOL with both NASAH and ASAH patients as a self-administered tool. We would recommend using these instrument in future subarachnoid studies, particularly the subscales that provide direct information about both the physical and emotional ramifications of a subarachnoid hemorrhage.

Surprisingly, many of the HRQOL research studies still use instruments that examine disability rather than HRQOL. Kim et al., in 2005, recommended using HRQOL-specific instruments such as the Short Form (SF)-36 rather than graded scales such as the Glasgow Outcome Scale or Rankin scale. Our study used two HRQOL-specific tools (SSQOL and SF-12), which have been validated in the subarachnoid hemorrhage population. We recommend using

similar HRQOL instruments. As Kim et al. reported, non-HRQOL scales such as the Barthel Index and National Institute of Stroke Score (NIHSS) were insensitive to subtle differences in cognitive recovery and reported high scores (better outcomes) although the patients had significant cognitive deficits. These scales give disproportionate weight to physical disability relative to cognitive and behavioral impairment. After subarachnoid hemorrhage, major cognitive deficits have been noted with detailed neuropsychological testing, even in patients who appeared to be "normal," demonstrating the need to use other specific HRQOL scales that can also measure perception of health. We found that the SF-12 and SSQOL were self -administered with high levels of reliability.

Further large-scale research or multi-site studies are needed due to the low incidence of NASAH. We would recommend forming a NASAH research working group across multiple centers and multiple countries to compare and contrast findings in this population.

Policy Implications

One aspect of this study highlights the need to further understand the issue of employment post SAH. Unemployment or reduced employment affects both groups and certainly has consequences for our patients and society in general. These consequences may include financial hardship, debt, housing stress, family tension, boredom, alienation, and atrophying work skills. Beseoglu et al., (2009) discussed whether neurological rehabilitation should be considered for the NASAH population. This is usually not an issue for ASAH patients as they generally have greater physical needs and go to a rehabilitation center. Insurance companies would need to consider the cost analysis of neurological rehabilitation versus the long-term costs and consequences of unemployment and cognitive dysfunction. In the current study, three subjects 2 ASAH and 1 NASAH had been denied health insurance after their SAH. Further

research in this population may provide insurance companies with the evidence to support interventions.

Further policy work should involve collaboration on educational implications for NASAH patients. This was successfully done in 2007 by Hermann & Zabramski. Hermman, a nurse, and Zambramksi, a neurosurgeon, showed how neuroscience nurses can use evidence-based practice to reassure and educate patients, staff members, and the public to understand the clinical course of NASAH. This type of publication could be created focusing on the HRQOL of the SAH patients involving multidisciplinary teams from neurosurgeons, cognitive neurologists, neuroscience nurses, social workers and physical and occupational therapists. This type of collaboration is commonly referred to as “team science” research.

Conclusion

This study is the first US study to specifically investigate HRQOL in NASAH patients and to examine the variable of social support and its effect on HRQOL. This is the second study comparing HRQOL outcomes between aneurysmal and nonaneurysmal subarachnoid hemorrhage patients. Our results support Hutter and Gilsbach’s (1995) findings that the 2 groups are much more similar than different.

The nonaneurysmal group had more long-term physical symptoms, while the aneurysmal group had more long-term emotional symptoms. Only the nonaneurysmal group feared having a second subarachnoid hemorrhage. Both groups had low levels of PTSD, and these levels did not differ significantly between groups. However, PTSD and social support were shown by regression analysis to affect HRQOL. We recommend that clinicians assess for PTSD in all subarachnoid hemorrhage patients and institute treatment early, which will decrease the negative effects on HRQOL. This may include offering psychological services or social work early in the

hospital course to all SAH patients. Neurosurgery practices should consider referring NASAH patients to the same types of support services that the ASAH patients receive early on in the hospital course. Policy changes would include advocating with insurance companies for NASAH patients to have similar neurological rehabilitation or at least an outpatient assessment by occupational therapists. Further research and policy changes are needed to assist in interventions that improved vocational reintegration after SAH.

NASAH patients should no longer be referred to as having suffered a "benign hemorrhage." They have had a life changing hemorrhage that may forever change their lives and impact their HRQOL.

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APPENDIX 1—Study Instruments

Demographic Questionnaire

Directions: Please **circle** the most appropriate answer to the question and fill in the blank lines if the question applies to you. Please try to answer all questions. Subarachnoid Hemorrhage refers to the area of bleeding you had in your brain. It was the reason for your admission to Beth Israel Deaconess Medical Center.

1) What is your current age (in years)? _____ (fill in age)

2) Please indicate your gender: **Male (1)**

Female (2)

3) How long ago was your subarachnoid hemorrhage? Please answer in number of

months_____

4) Please indicate your race: **American Indian (1)**

Alaska Native(2)

Asian (3)

Black or African American (4)

Native Hawaiian or Pacific

Islander(5)

Hispanic(6)

White(7)

Other(8)_____ (please indicate)

5) Please indicate your education level: **Some high school(1)**

High school graduate(2)

Associates degree(3)

Bachelor's degree(4)

Graduate degree(5)

PLEASE CONTINUE TO THE NEXT PAGE

Other degree(6) _____ (please indicate)

6) Please indicate your relationship status: **single(1)**

married(2)

divorced(3)

widow(4)

partner not married(5)

7) Do you drink alcohol? **Yes (1)**

No(2)

If yes approximately how many drinks per week _____

8) Do you currently smoke cigarettes? **Yes(1)**

No(2)

IF yes, for approximately how long have you been smoking _____

9) Did you ever smoke cigarettes? **Yes (1)**

No (2)

If yes, for approximately how long did you smoke for _____

PLEASE CONTINUE TO THE NEXT PAGE

10) Has anyone else in your family ever had a subarachnoid hemorrhage?

Yes(1)

If yes, what is their relationship to you _____

No (2)

11) Who completed this survey:

1. I completed it myself

2. I completed it with a help of a family member or friend

3. A family member or friend completed it for me

PLEASE CONTINUE TO THE NEXT PAGE

Subarachnoid Hemorrhage Questionnaire

Directions: Please **circle** the most appropriate answer to the question and fill in the blank lines if the question applies to you. Please try to answer all of the questions. Thank you.

These questions refer to the subarachnoid hemorrhage you had in your brain which is bleeding into specific area of your brain

1)Were you employed before you had the subarachnoid hemorrhage? **Yes(1)**

No(2)

2) If you were employed, have you returned to the same position or an equivalent position?

Yes(1)

No(2)

Not Applicable(3)

3) If you were not employed at the time of the hemorrhage, do you feel your inability to return to a prior or equivalent
position is related to the subarachnoid hemorrhage?

Yes(1)

No(2)

4) Have you been denied any type of health or life insurance because of the subarachnoid hemorrhage?

Yes(1)

No(2)

5) Do you feel your overall quality of life has been affected by the subarachnoid hemorrhage?

Yes(1)

No(2)

6) Do you currently experience physical symptoms as a direct result of the subarachnoid hemorrhage?

Yes(1)

No(2)

PLEASE CONTINUE TO THE NEXT PAGE

If you currently have physical symptoms related to the subarachnoid hemorrhage - please list the physical symptoms below:

_____

_____

_____

7. Do you currently experience emotional, or psychological symptoms as a direct result of the subarachnoid hemorrhage?

Yes(1)

No(2)

If YES – please list these emotional/psychological symptoms:

_____

_____

_____

7) Did you receive outpatient physical therapy as a result of the subarachnoid hemorrhage?

Yes(1)

No(2)

If yes, for how long?_____

8) How helpful was physical therapy?

Very Helpful (2)

Somewhat Helpful (1)

Not Helpful (0)

9) Did you receive outpatient occupational therapy as a result of the subarachnoid hemorrhage?

Yes(1)

No(2)

PLEASE CONTINUE TO THE NEXT PAGE

If you received outpatient occupational therapy how long did you receive it for?
_____

10) How helpful was occupational therapy? **Very Helpful (2)**

Somewhat Helpful (1)

Not Helpful (02

11) Did you receive outpatient speech therapy as a result of the subarachnoid hemorrhage?

Yes(1)

No(2)

If yes, for how long?_____

12) How helpful was speech therapy? **Very Helpful (1)**

Somewhat Helpful (1)

Not Helpful (0)

13) Did you receive any psychological counseling as a result of your SAH?

Yes(1)

No(2)

If yes, for how long?_____

14) How helpful was the psychological counseling? **Very Helpful (2)**

Somewhat Helpful (1)

Not Helpful (0)

15) Did you use or receive any other type of treatment or service that helped your recovery from the subarachnoid hemorrhage?

Yes(1)

No(2)

PLEASE CONTINUE TO THE NEXT PAGE

If you receive other treatment or service what was it? _____

how long did you receive it?_____

16) How helpful were other treatments or service? **Very Helpful (2)**

Somewhat Helpful (1)

Not Helpful (0)

12) Is there any type of treatment(s) or service(s) you wish you had available to you during your recovery?

Yes(1)

No(2)

If yes, what type of treatment or service would you have liked?

_____
_____

PLEASE CONTINUE TO THE NEXT PAGE

Instructions: Please circle then number to indicate how much you have experienced each symptom in the past week, including today. Please answer all the items.

	Not at all **1**	**Somewhat** **2**	**Moderately** **3**	**A Lot** **4**	**Extremely** **5**
1. Upsetting memories of a your brain bleed that come into your mind over and over	1	2	3	4	5
2. Avoiding things, places or upsetting thoughts associated with the brain bleed	1	2	3	4	5
3. Loss of interests or participation in activities	1	2	3	4	5
4. Feeling isolated or alienated from other people	1	2	3	4	5
5. Flashbacks (feeling like the past upsetting event is happening in the present)	1	2	3	4	5
6. Always being on the lookout to make sure you don't experience the brain bleed again	1	2	3	4	5
7. Feelings of guilt or distress about the brain bleed event	1	2	3	4	5
8. Strong physical sensations (increased heart rate, sweating, etc.) when you are reminded about the brain bleed. **Continue to next page**	1	2	3	4	5

	Not at all **1**	**Somewhat** **2**	**Moderately** **3**	**A Lot** **4**	**Extremely** **5**
9. Feelings of numbness	1	2	3	4	5
10. Difficulty falling or staying asleep	1	2	3	4	5

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PLEASE CONTINUE TO THE NEXT PAGE

Duke–UNC Functional Social Support Questionnaire (FSSQ)

Here is a list of some things that other people do for us or give us that may be helpful or supportive. Please read each statement carefully and circle the number closest to your situation. Give only 1 answer per row.

	5. As much as I would like	4. Almost as much as I would like	3. Some, but would like more	2.Less than I would like	1. Much less than I would like
1. I have people who care what happens to me.	**5**	**4**	**3**	**2**	**1**
2. I get love and affection.	**5**	**4**	**3**	**2**	**1**
3. I get chances to talk to someone about problems at work or with my housework.	**5**	**4**	**3**	**2**	**1**
4. I get chances to talk to someone I trust about my personal or family problems.	**5**	**4**	**3**	**2**	**1**

5. I get chances to talk about money matters.	**5**	**4**	**3**	**2**	**1**
6. I get invitations to go out and do things with other people.	**5**	**4**	**3**	**2**	**1**
7. I get useful advice about important things in life.	**5**	**4**	**3**	**2**	**1**
	5. As much as I would like	4. Almost as much as I would like	3. Some, but would like more	2.Less than I would like	1. Much less than I would like
8. I get help when I am sick in bed.	**5**	**4**	**3**	**2**	**1**

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PLEASE CONTINUE TO THE NEXT PAGE

SF-12® Patient Questionnaire

Directions: Answer every question by circling the appropriate answer. If you are unsure about how to answer a question, please give the best answer you can and make a written comment beside your answer.

1. In general, would you say your health is:
Excellent (1)
Very Good (2)
Good (3)
Fair (4)
Poor (5)

The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or playing
golf:
Yes, Limited A Lot (1)
Yes, Limited A Little (2)
No, Not Limited At All (3)

3. Climbing SEVERAL flights of stairs:
Yes, Limited A Lot (1)
Yes, Limited A Little (2)
No, Not Limited At All (3)

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:
Yes (1)
No (2)

5. Were limited in the KIND of work or other activities:
Yes (1)
No (2)

During the PAST 4 WEEKS, were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

6. ACCOMPLISHED LESS than you would like:
Yes (1)
No (2) **SF-12® PLEASE CONTINUE TO THE NEXT PAGE**

7. Didn't do work or other activities as CAREFULLY as usual:
Yes (1)
No (2)

8. During the PAST 4 WEEKS, how much did PAIN interfere with your normal work (including both work outside the home and housework)?

Not At All (1)
A Little Bit (2)
Moderately (3)
Quite A Bit (4)
Extremely (5)

The next three questions are about how you feel and how things have been DURING THE PAST 4
WEEKS. For each question, please give the one answer that comes closest to the way you have been
feeling. How much of the time during the PAST 4 WEEKS –

9. Have you felt calm and peaceful?
All of the Time (1)
Most of the Time (2)
A Good Bit of the Time (3)
Some of the Time (4)
A Little of the Time (5)
None of the Time (6)

10. Did you have a lot of energy?
All of the Time (1)
Most of the Time (2)
A Good Bit of the Time (3)
Some of the Time (4)
A Little of the Time (5)
None of the Time (6)

11. Have you felt downhearted and blue?
All of the Time (1)
Most of the Time (2)
A Good Bit of the Time (3)
Some of the Time (4)
A Little of the Time (5)
None of the Time (6)

SF-12® PLEASE CONTINUE TO THE NEXT PAGE

12. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the Time (1)
Most of the Time (2)
A Good Bit of the Time (3)
Some of the Time (4)
A Little of the Time (5)
None of the Time (6)

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We would like to know how you're doing with activities or feelings that can sometimes be affected by a subarachnoid hemorrhage. Each question will ask about a specific activity or feeling. For each question, think about how that activity or that feeling has been **in the past week**. The first group of questions asks about how much trouble you have with a specific activity. Each question deals with problems that some people have after their subarachnoid hemorrhage. Circle the number in the box that best describes how much trouble you have had with that activity **in the past week.**

DURING THE PAST WEEK

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
SC1. I did have trouble preparing food?	1	2	3	4	5
SC2. I did have trouble eating, for example, cutting food or swallowing?	1	2	3	4	5
SC4. I did have trouble getting dressed, for example, putting on socks or shoes, buttoning buttons, or zipping?	1	2	3	4	5
SC5. I did have trouble taking a bath or shower? **Continue to next page**	1	2	3	4	5

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
SC8. I did have trouble using the toilet?	1	2	3	4	5
V1. I did have trouble seeing the television well enough to enjoy a television show?	1	2	3	4	5
V2. I did have trouble reaching for things because of poor eyesight?	1	2	3	4	5
V3. I did have trouble seeing things off to one side?	1	2	3	4	5
L2. I did have trouble speaking, for example, get stuck, stutter, stammer, or slur my words?	1	2	3	4	5
CONTINUE TO NEXT PAGE					

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
L3. I did have trouble speaking clearly enough to use the telephone?	1	2	3	4	5
L6. I did have trouble finding the words I wanted to say?	1	2	3	4	5
L7. I did need to repeat myself so others could understand me?	1	2	3	4	5
M4. I did lose my balance when bending over or reaching for for something?	1	2	3	4	5
M6. I did have trouble climbing the stairs?	1	2	3	4	5
M7.I did have trouble with needing to stop and rest when walking or using a wheelchair?	1	2	3	4	5
CONTINUE					
TO NEXT PAGE					

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
M8. I did have trouble with standing?	1	2	3	4	5
M9. I did have trouble getting out of a chair ?	1	2	3	4	5
W1. I did have trouble doing daily work around the house?	1	2	3	4	5
W2. I did have trouble finishing jobs that I started?	1	2	3	4	5
W3. I did have trouble doing the work I used to do?	1	2	3	4	5
UE1. I did have trouble writing or typing	1	2	3	4	5
UE2. I did have trouble putting on socks?	1 **NEXT**	2 **PAGE**	3	4	5

CONTINUE TO					
	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
UE3. I did have trouble buttoning buttons?	1	2	3	4	5
UE5. I did have trouble zipping a zipper?	1	2	3	4	5
UE6. I did have trouble opening a jar?	1	2	3	4	5

The next set of questions asks about how much you agree or disagree with each statement. Each question deals with a problem or feeling that some people have after their subarachnoid hemorrhage. Circle the number in the box that best says how you felt about each statement **during the past week**.

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
T2. It was hard for me to concentrate.	1	2	3	4	5
CONTINUE TO NEXT PAGE					

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
T3. I had trouble remembering things.	1	2	3	4	5
T4. I had to write things down to remember them.	1	2	3	4	5
P1. I was irritable.	1	2	3	4	5
P2. I was impatient with others	1	2	3	4	5
P3. My personality has changed.	1	2	3	4	5
	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
MD2. I was discouraged about my future	1	2	3	4	5
CONTINUE TO NEXT PAGE					

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
MD3. I wasn't interested in other people or activities.	1	2	3	4	5
FR5. I didn't join in activities just for fun with my family.	1	2	3	4	5
FR7. I felt I was a burden to my family.	1	2	3	4	5
FR8. My physical condition interfered with my family life	1	2	3	4	5
SR1. I didn't go out as often as I would like.	1	2	3	4	5
SR4. I did my hobbies and recreation for shorter periods of time than I would like.	1	2	3	4	5

CONTINUE TO NEXT PAGE					
	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
SR5. I didn't see as many of my friends as I would like.	1	2	3	4	5
SR6. I had sex less often than I would like.	1	2	3	4	5
SR7. My physical condition interfered with my social life.	1	2	3	4	5
MD6. I felt withdrawn from other people.	1	2	3	4	5
MD7. I had little confidence in myself.	1	2	3	4	5
MD8. I was not interested in food.	1	2	3	4	5
E3. I had to stop and rest often during the day.	1	2	3	4	5

E2. I felt tired most of the time.	1	2	3	4	5
CONTINUE TO NEXT	PAGE Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
E4. I was too tired to do what I wanted to do.	1	2	3	4	5

Now, we would like to ask how you feel you are doing today in some general areas compared to how you were **before your subarachnoid hemorrhage**. Please circle the number in the box that corresponds to whether each area is a lot worse, a little worse, or the same as **before** your subarachnoid hemorrhage. Please remember to compare how you are doing **today** with how you were **before your subarachnoid hemorrhage (SAH).**

	a lot worse than **before** my SAH	somewhat worse than **before** my SAH	a little worse than **before** my SAH	the same as **before** my SAH
1E. My energy level is?	1	2	3	4
2L. My speech is	1	2	3	4

3M. My walking is	1	2	3	4
CONTINUE TO THE	NEXT	PAGE		
4V. My vision is				
	a lot worse than **before** my SAH	somewhat worse than **before** my SAH	a little worse than **before** my SAH	the same as **before** my SAH
5UE. The use of my arms or hands is	1	2	3	4
6T. My thinking is	1	2	3	4
7MD. My mood is	1	2	3	4
8P. My personality is	1	2	3	4
9W. I do my jobs at home or at work	1	2	3	4
	1	2	3	4

10SC. I can take care of myself				
11FR. I do things for my family	1	2	3	4
	a lot worse than **before** my SAH	somewhat worse than **before** my SAH	a little worse than **before** my SAH	the same as **before** my SAH
12SR. I do things for my Friends.	1	2	3	4
13. Overall, my quality of life is:	1	2	3	4

SS-QOL V2.0

THE END

THANK YOU FOR YOUR PARTICPATION

PLEASE PLACE IN STAMPED ENVELOPE THAT WAS PROVIDED

Appendix 2 Mailing Materials

RESEARCH STUDY ON HEALTH RELATED QUALITY OF LIFE AFTER SUBARACHNOID HEMORRHAGES

Welcome! We are requesting your participation in a research study being conducted on patients who have suffered a subarachnoid hemorrhage in the last three years and were treated at Beth Israel Deaconess Medical Center. A subarachnoid hemorrhage is a type of brain bleed which occurs in the subarachnoid space in the brain. It can be caused by an aneurysm or by a venous vessel that bleeds without warning. In particular we are interested in your experiences and changes that have occurred in your life since this brain bleed. This study is being conducted by Chip McIntosh, NP, (PhD candidate at University of Massachusetts Worcester) and nurse practitioner for the division of neurosurgery at Beth Israel Deaconess Medical Center in Boston Massachusetts.

The survey on the following pages should take **less than 30 minutes** to complete. Most questions only require a simple circle. The information collected may help us to better understand the impact of a subarachnoid hemorrhage on your quality of life. The information may be used in future to help guide other research in order to improve quality of life for those patients who may develop a subarachnoid hemorrhage. We hope you will share your experiences with us through this study and we request you respond in a frank and open manner. To protect your privacy, the survey is confidential and no identifying information will appear on the survey form. Each survey will have a code number, however, to help us track participation rate, information connecting code numbers with specific study participants will be maintained during the 8 week data collection period and then this tracking sheet will be destroyed so no individual data can be connected back to an individual participant.

Although there are no known risks for your participation, the questions may prompt concerns or questions about events around your subarachnoid hemorrhage or future treatment. You may contact the researcher, (contact information below) to answer any questions or concerns.

Participating in this survey is purely voluntary. There are no consequences for declining to participate and you are under no obligation to take part in this study. There are no benefits for participation but we hope you will experience satisfaction knowing that your information may help inform the field about quality of life after subarachnoid hemorrhages. If you choose to participate a $5.00 gift card will be mailed to you once we receive your completed surveys. If you <u>choose not to participate</u> we would ask that you return the blank packet in the self addressed envelope.

Your completion and return of the survey in the enclosed self-addressed stamped envelope indicates your consent to participate. In order to further protect your confidentiality, please do not include any return address or other identifying information on the envelope or the survey itself.

If you have any questions about this research, please feel free to contact the researcher at the contact information below. If you have questions about the project's protection of human subjects, please contact the Human Subjects Protection Office at Beth Israel Deaconess Medical Center, 109 Brookline Ave Boston, MA 02215. Or via phone at 617-667-4524.

Sincerely, Chip McIntosh, NP, amcintos@bidmc.harvard.edu 617-632-7246

Reminder Card

Dear Sir/Ma'am:

You should have received a request to participate in a research study approximately 2 week ago. We are requesting your participation in a research study being conducted on patients who have suffered a subarachnoid hemorrhage in the last three years and were treated at Beth Israel Deaconess Medical Center.

The information you provide will help inform the medical field about quality of life after subarachnoid hemorrhages. If you choose to participate a $5.00 gift card will mailed to you once we receive your completed surveys. If you choose not to participate we would ask that you return the blank survey in the self addressed envelope. We hope you choose to participate and will send back your surveys soon.

If you have not received a packet or need a new one please contact Chip McIntosh, NP,

amcintos@bidmc.harvard.edu 617-632-7246.

If you have already returned your packet—thank you! Please disregard this message.

Thank You Card

Dear Sir/Ma'am:

Thank you so much for participating in the subarachnoid hemorrhage quality of life study. The information you have provided is extremely valuable. It may help patients who will suffer subarachnoid hemorrhages in the future. Thank you for your time and effort, enclosed is your gift card.

Sincerely,

Chip McIntosh, NP,

Clinical Manager and Nurse Practitioner Division of Neurosurgery

Beth Israel Deaconess Medical Center

PhD student in Nursing at UMass Worcester 617-632-7246