RACIAL DIFFERENCES IN TIME TO WITHDRAWAL OF CARE AFTER INTRACEREBRAL HEMORRHAGE

by

Kristen Marie Shaw

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As members of the Practice Inquiry Committee, we certify that we have read the Practice Inquiry project prepared by Kristen Shaw entitled “Racial Differences in Time to Withdrawal of Care After Intracerebral Hemorrhage and recommend that it be accepted as fulfilling the practice inquiry project requirement for the Degree of Doctor of Nursing Practice.

___________________________________________________ ____________________  Date: 4/16/2014
Matthew J. Gallek, PhD, RN, CNRN
Assistant Professor

___________________________________________________ ____________________  Date: 4/16/2014
Leslie Ritter, PhD, RN, FAAN
Professor

___________________________________________________ ____________________  Date: 4/16/2014
Kate G. Sheppard, PhD, RN, FNP, PMHNP-BC, FAANP
Clinical Associate Professor

___________________________________________________ ____________________  Date: 4/16/2014
Kazuma Nakagawa, MD
Special Committee Member

Final approval and acceptance of this practice inquiry project is contingent upon the candidate’s submission of the final copies of the practice inquiry project to the Graduate College.

I hereby certify that I have read this practice inquiry prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

___________________________________________________ ____________________  Date: 4/16/2014
Practice Inquiry Director: Matthew J. Gallek, PhD, RN, CNRN
Assistant Professor
STATEMENT BY AUTHOR

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SIGNED: Kristen Shaw
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ABSTRACT

Intro/Aims: Differences in end-of-life decision-making among minorities have been well described. However, among Native Hawaiian and Other Pacific Islanders (NHOPIs), this has not been well studied. Aim 1: Determine if differences in time to withdrawal of life support (WOLS) exist between NHOPIs and non-Hispanic whites (NHWs). Aim 2: If differences in time to WOLS between races are found, examine factors that may contribute to these differences.

Methods: A retrospective study was conducted on patients admitted to a primary stroke center in Honolulu with diagnosis of spontaneous intracerebral hemorrhage (ICH). Medical records were reviewed for occurrence of WOLS and time of WOLS. Unadjusted and multivariable logistic regression models were performed to determine associations between race and WOLS. Kaplan Meier analysis and Cox regression were performed to estimate survival time to WOLS and to compare these results between racial groups.

Results: 396 patients with diagnosis of spontaneous ICH were studied. Mean time to WOLS after ICH was found to be similar between NHWs and NHOPIs ($p = .925$). Prevalence of WOLS was significantly lower in NHOPIs in univariate analysis (odds ratio [OR] 0.35, 95% confidence interval [CI] 0.15, 0.80) and Kaplan Meier analysis predicted a significant difference in WOLS between NHOPI and NHWs within 30 days of ICH ($p = <.01$). However, in multivariate analysis, race was no longer significant when adjusted for age (OR 0.59, 95% CI 0.25, 1.43) and when fully adjusted (OR 0.68, 95% CI 0.20, 2.39). NHOPIs were significantly younger at the time of ICH when compared to NHWs ($p = <.001$) although ICH severity and presentation such as initial Glasgow Coma Scale, presence of intraventricular hemorrhage and ICH volume were similar ($p = .241$; $p = .604$; $p = .901$, respectively).
Conclusions: No difference in mean time to WOLS was noted between NHOPIs and NHW. However, secondary analysis showed WOLS was less prevalent after ICH in the NHOPI population compared to NHWs, although the significance of this finding was attenuated by age. NHOPIs in this population likely had a lower incidence of WOLS due to the fact that they presented with ICH at a significantly younger age, although small sample size also may have resulted in difficulty detecting variances between races.
CHAPTER ONE INTRODUCTION

Intracerebral hemorrhage (ICH) is a devastating type of stroke often resulting in a prognosis of disability and poor quality of life (Caplan, 1992). Withdrawal of life support due to this prognosis is cited as the most frequent cause of death after this injury. Due to the nature of the injury, patients are often unable to make medical decisions for themselves, such as how aggressively they would want to be treated, and therefore, the family or other surrogate often must make health care decisions for the patient, including the decision to withdraw medical care (Becker et al., 2001; Christensen, Mayer, & Ferran, 2009; Hemphill, Newman, Zhao, & Johnston, 2004; Naidech et al., 2009; Zurasky, Aiyagari, Zazulia, Shackelford, & Diringer, 2005).

Making the decision to withdraw life sustaining treatments for another individual is often difficult, as the values of the patient, the decision-maker and frequently others such as family or friends must be considered in light of the prognosis and degree of uncertainty of outcomes and unknown desires and life goals (Luce, 2010). Research has shown differences in end-of-life decision-making by minority groups in the United States; Black and Hispanic individuals are known to desire more aggressive care and are less likely to withdraw life sustaining treatments compared to non-Hispanic whites (Bardach, Zhao, Pantilat, & Johnston, 2005; Cooper, Rivara, Wang, MacKenzie, & Jurkovich, 2012).

Also culturally different than non-Hispanic whites, little is known about Native Hawaiian and Pacific Islander end-of-life decision-making or attitudes about withdrawal of care preferences. A more comprehensive understanding of the differences or similarities on end-of-life decision making among minorities in the United States would allow for identification of needs specific to various cultures and improve the healthcare process overall.
Background

**Intracerebral Hemorrhage**

Stroke is one of the leading causes of both disability and death in the United States, afflicting approximately 800,000 people every year (Go et al., 2013). Up to 15% of strokes are of the hemorrhagic variety known as an intracerebral hemorrhage (Qureshi et al., 2001). This stroke subtype is defined as bleeding into the brain tissue, also known as brain parenchyma, which disrupts the surrounding tissues and eventually causes formation of a hematoma (Caplan, 1992). Tissue disruption due to ICH can physically manifest in an individual in a variety of ways depending on the exact location within the brain, the speed of blood accumulation and the total volume of the hematoma (Caplan, 2009). Symptoms may progress slowly over a few days or can present and worsen within a very short amount of time from their onset. Signs of ICH may include headache, vomiting, weakness or numbness to one side of the body, difficulty speaking, and decreasing level of consciousness (Caplan, 2009). Hemorrhages occur most frequently due to acute or chronic hypertension, anticoagulation use, drugs or trauma, but can also sometimes be attributed to tumors or aneurysms (Caplan, 1992). In keeping with the dramatic initial presentation often observed at the onset, the sequela of ICH is usually equally striking, with a high rate of morbidity and mortality and an immense economic, social and psychological cost (Caplan, 1992). Withdrawal of life-sustaining treatment is often a consideration after ICH due to the high likelihood of decreased quality of life, and has been cited as the most frequent cause of death after ICH, often occurring soon after its onset (Becker et al., 2001; Christensen, Mayer, et al., 2009; Naidech et al., 2009; Zurasky et al., 2005).
Withdrawal of Care

Withdrawal of care is the withdraw of life-sustaining treatments; the choice to discontinue and further withhold life-sustaining therapies such as mechanical ventilation, blood pressure medications, antibiotics, or artificial hydration or nutrition (Curtis & Vincent, 2010). The goal of withdrawing care is not to quicken the death of the patient, although this may occur unintentionally, but rather to remove or stop procedures that may prolong life in a way that is not respectful of the patient’s autonomy or in the case of medical futility (Curtis & Vincent, 2010; Luce, 2010).

Legally, patients, or in the event that a patient is incapacitated, their surrogate decision maker, must approve all medical treatments and, therefore, also have the right to refuse such treatments (Luce, 2010). However, these rights are not unconditional and health care providers have a responsibility to ensure that the decision to withdrawal care is made in a legitimate manner (Luce, 2010). If a patient requests to forgo life-sustaining measures, the provider must validate that the patient has the capacity to make such decisions. This is done through careful assessment of the patient’s ability to process and grasp the information provided regarding their state of health and the ability to use this information to make personally-meaningful decisions and communicate the thought process clearly (Siegel, 2009). If a patient is unable to express their healthcare goals during hospitalization, previously written advance directives can be used to assist in understanding the patient’s desires and help direct care (Siegel, 2009).

Surrogate decision makers can be appointed by the patient through forms such as advance directives to make decisions in the event that they are unable to make decisions for themselves (Luce, 2010). In the event that the patient has not formally designated an individual and is
acutely ill and incapable of communicating, a surrogate can be then appointed (Luce, 2010). This individual is ideally the person who knows the patient well enough to make decisions based on knowledge of the patient’s wishes for health and life-related goals. Surrogates are often called upon to make decisions for the patient based on “substituted judgment” when their wishes are known to the surrogate, or simply decisions based on the best interest of the patient when their wishes are not known (Luce, 2010). In this instance, when making the decision to withdraw care, the same rules of capacity and assessment of capacity that apply to the patient, also apply to the surrogate in the event the patient cannot communicate their wishes (Luce, 2010). To justly represent the patient, the surrogate must be able to understand the diagnosis and determine whether the expected prognosis is aligned with the patient’s values and desires and what course of care to pursue. Regardless of who is making the decision, if the outcome is to withdraw care, it is often a difficult choice, as this will likely result in the death of the patient. Therefore, every situation is unique and timelines for actual care withdraw vary greatly.

The decision to withdraw care in patients after neurological injury such as ICH is potentially more difficult than in patients with medical injuries such as myocardial infarction or organ failure. In the latter group, the decision to withdrawal care becomes a more passive decision-making process as the body is mechanically shutting down, causing notable “physiologic futility and imminent death” (Mayer & Kossoff, 1999, p. para 20). This presumably causes less psychological burden or introspective guilt on surrogates or families members compared to patients with ICH, where the body is not necessarily visibly distressed, but brain function is deteriorating. In this situation, end of life decisions are based on issues less tangible then physical decline, such as quality of life (Mayer & Kossoff, 1999). This process is likely
emotionally challenging for the family and surrogate decision-makers, as it requires understanding of the prognosis, brain function, and how these relate to functional quality of life in terms of what would be acceptable to the patient.

**Racial Variations in Medical Decision-Making**

Studies of attitudes on end-of-life decision-making among minority groups in the United States have largely focused on blacks, Hispanics and Asians in comparison to non-Hispanic whites. Frequently, these studies cite desire for aggressive care to be higher among minority groups, while non-Hispanic whites are more likely to desire less aggressive care (Bardach et al., 2005; Cooper et al., 2012). Studies also describe minorities as less likely than non-Hispanic whites to have withdrawal-of-care or do-not-resuscitate orders written at the time of a patient’s death (Cooper et al., 2012). Regarding withdraw of life-sustaining treatments and aggressiveness of care, preferences are highly variable between racial groups. Studies have suggested mistrust in the healthcare system, language barriers, cost or spiritual beliefs as influencing these facts (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; K. S. Johnson, Kuchibhatla, & Tulsky, 2008).

**Native Hawaiian and Other Pacific Islander Variations in Medical Decision-Making**

Few studies on end-of-life decision-making or aggressive care preferences have been performed in the Native Hawaiian and Other Pacific Islander (NHOPI) population. Research that is available does not observe withdrawal of care or aggressive treatment preferences but does indicate that NHOPI have similar attitudes of other minority groups on aspects surrounding death and dying (Braun, Karel, & Zir, 2006; Braun, Onaka, & Horiuchi, 2001).
Statement of the Problem

Despite the racial disparities noted among various minority groups in withdrawal of care decisions, little is known about the end-of-life care choices in NHOPI at all, or in the context of any medical diagnosis (Bardach et al., 2005; Cooper et al., 2012). Additionally, the limited data available on NHOPI has been historically grouped, only recently being classified separately from Asians in the 2000 Census in the United States, which may have diluted previous research results (Hixson, Hepler, & Kim, 2012). In the literature that is available, Nakagawa et al. (2013) showed that although being female was an independent factor for early use of DNR order after ICH, there were no differences in the use of early DNR between white, Asian and NHOPI patients after ICH. However, although DNR orders likely imply decreased overall aggressiveness of care, this is not the same as withdrawal of life-sustaining treatments. In comparison to the existing research on the known reluctance of other minorities to pursue withdrawal of care after acute illness, this information has not been adequately studied in the NHOPI population (Bardach et al., 2005; Cooper et al., 2012).

Significance to Advanced Practice Nursing

The decision to withdraw care is a common occurrence and is the cause of death for the majority of patients in the adult intensive care units (Cooper, Rivara, Wang, MacKenzie, & Jurkovich, 2009; Sprung et al., 2003; Varelas et al., 2009). Doctorally prepared nurse practitioners (DNP) are prepared to provide healthcare for patients at a variety of care institutions and levels (AACN, 2006). This includes hospitalized patients who may be at the end of life due to acute illness. The decision to withdrawal life-sustaining treatments is often made between the patient’s family and the healthcare providers due to cognitive impairment of the patient
(Kirchhoff & Faas, 2007). The needs and dynamics of the patient and their family must be known and recognized during this period of critical illness, and it must be understood that these needs may differ between various cultures (Kirchhoff & Faas, 2007). As a patient advocate, the DNP’s understanding of family systems theory and holistic nursing care is pertinent when assisting a patient and family through the medical decision-making process. The DNP is prepared to diagnose, treat, educate and assist patients and families on their healthcare journey, therefore they must also be knowledgeable about end of life decision-making and variations between populations that may occur in terms of withdrawal of care preferences.

As described by the AACN (2006) essentials, the DNP is meant not to simply apply new knowledge in health care, but to also create this knowledge. The literature available in the NHOPI population is greatly limited, and the DNP is prepared to identify gaps in knowledge and utilize research to identify community problems, including the topic examined here, racial differences in withdrawal of care decisions. Beyond actual generation of knowledge, the DNP is uniquely prepared to then translate and apply the information to practice to improve the quality of healthcare. Along the same line of thought, the outcomes from this study can not only generate new knowledge for practice improvement, but also provides an additional research platform that can address why there are or are not differences in withdrawal of care practices in the NHOPI population.

The implications of this research and knowledge generation and translation are vast, especially in an area such as the city and county of Honolulu, where the NHOPI population is the highest in the nation (Look, Trask-Batti, Mau, & Kaholokula, 2013). In the realm of population health, consideration and awareness of cultural diversity directs the DNP to advocate to create
changes in health policy when disparities are noted (AACN, 2006). Outcomes from research describing differences in NHOPIs withdrawal of care practices may indicate the need for different services or policies to support the needs of this specific population to ensure equity and quality of care. Leadership skills and the knowledge of disparities in end of life decision making will assist the DNP in understanding nuances of cultural sensitivities and development of population-specific quality improvement initiatives for end of life care.

**Purpose**

The purpose of this study was to determine if differences exist between NHOPIs and other racial groups in time to withdrawal of care after hospitalization for patients admitted with ICH. Also, for differences that were found to exist, this study attempted to determine factors that may have contributed to these differences.

**Specific Aims**

Aim 1: Determine if differences in the time to withdrawal of care (withdrawal of life-sustaining treatment) exist between NHOPIs and non-Hispanic whites.

Aim 2: If differences in time to withdrawal of care are found between NHOPI and non-Hispanic whites, examine factors that may contribute to these differences.
CHAPTER TWO THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

Theoretical Framework

A novel application of Madeline Leininger’s Culture Care Theory was used as a framework to support this study. This theory highlights the importance and influence of culture on health and healthcare; The main purpose of culture care theory being to reveal and describe “culturally based care factors influencing the health, well-being, illness or death of individuals or groups” (M. Leininger, 2002, p. 190). These discoveries can then be used to provide improved care that is culturally meaningful to patients from various cultural backgrounds and ethnicities (M. Leininger, 2002).

Theoretical assumptions of culture care theory appropriate to guide this study include: 1) Care is considered a dominant theme in nursing, 2) Care must be culturally-based and scientific to truly promote health and well-being, or to face illness or death, 3) Social factors such as politics, education and religion, coupled with environment, influence culture care beliefs, and 4) All cultures have laymen and professional care practices which they understand and can be discovered by outsiders (M. Leininger, 2002; M. M. Leininger, 2006). Although these assumptions are known tenets of the qualitative method of research introduced and supported by Leininger, known as ethnonursing, this framework can also be applied to quantitative studies. The purpose of this study is grounded in discovering racial and ethnic disparities, which is the central purpose of culture care theory, and these disparities must be known to exist before the qualitative aspects can have reason to be examined (M. M. Leininger, 2006).

The presumptive reasoning for the need to conduct a statistical analysis focused on variations between racial groups can be explained through the Leininger’s Sunrise Model; the
conceptual model of the culture care theory (Figure 1). This model creates a descriptive dimension of influences to help explain care expressions, patterns and practices of individuals, groups, communities or institutions of varying cultures (M. Leininger, 1997). The rays of the Sunrise Model are factors such as educational economic, political, religious and technological influences. These create an environmental context when combined with other cultural elements, including language and values, which interact to create a comprehensive image of care beliefs and practices (M. Leininger, 1997). In this study, differences in care patterns and practices among racial groups in Hawaii will be seen as variations in time to withdrawal of care in ICH patients. Additionally, if differences in time to withdrawal of care are noted, Leininger’s Sunrise Model can also be used to guide the gathering of further information to explain the phenomena discovered in this research.

**Review of Literature**

This section will review the known literature relevant to this study. First, literature on ICH outcomes and mortality will be discussed, time to withdrawal of care in various medical conditions, not including ICH, will also be described. Second, literature describing withdrawal of care patterns and practices in patients with ICH will be discussed. Third, racial variations in withdrawal of care practices will be reviewed. Finally, literature on known cultural beliefs, health disparities and end-of-life care planning of the NHOPI population will be reviewed.

**Intracerebral Hemorrhage**

Mortality rates after ICH are high in both the short and long term. In a study examining predictors of short term mortality after ICH J. P. Broderick, Brott, Duldner, Tomsick, and Huster (1993) noted a 44% fatality rate 30 days after ICH. Additionally, by the end of the second day,
half of those deaths had already occurred (J. P. Broderick et al., 1993). In a study performed in Finland, Fogelholm, Murros, Rissanen, and Avikainen (2005) reported 51% of patients admitted to the hospital with ICH died within 28 days. The same study also found that 16 years after ICH female patients had a survival rate of less than 10%, and male patients, less than 4% (Fogelholm et al., 2005). A report of patients with first-ever ICH strokes in the United Kingdom showed 52% of patients did not survive after the first 30 days (Counsell et al., 1995). A study by Flaherty et al. (2006) viewed two cohorts of nontraumatic ICH patients, 10 years apart and found mortality rates at day 7, and 1 year were 31 and 59% for cohort one, and 34 and 53% for cohort two, respectively. A meta-analysis of ICH studies published from 1980 and later analyzed data from 36 studies with a total of 8000 individuals with ICH throughout 21 different countries (van Asch et al., 2010). This review reported that incidence of ICH did not decrease between the years 1980 to 2008 and found an average 30-day mortality rate of over 40% in patients with ICH (van Asch et al., 2010)

In addition to a high rate of mortality after ICH, morbidity and functional outcome are also likely to be poor in this patient population. The same meta-analysis by van Asch et al. (2010) noted that research on functional outcomes after ICH tended to be infrequent, but based on the available literature, independent function was achieved by 12 to 39% of patients. J. P. Broderick et al. (1993) showed only 10% of surviving ICH patients achieved independence at one month. As one month is a short observational period for functional recovery, Counsell et al. (1995) stated that only 21% of all ICH patients were functioning independently at six months. A study of functional outcome in Finland followed patients for an average of 32 months after ICH, finding that of the 35% of patients still alive, half of them were functioning independently and
the other half were either dependent on additional aid or needed constant assistance (Fogelholm, Nuutila, & Vuorela, 1992). It is concluded, in general, that poorer functional outcomes are linked to older age and severity of initial stroke (Dennis, 2003). However, high morbidity, or poor functional outcomes after ICH are not the only burden associated with this situation.

Financial and personal strains are also factors to be observed when considering the overall impact of ICH. Direct and indirect, or medical and lost productivity, costs of stroke were projected to be 71.55 billion and 33.65 billion dollars, respectively, in the United States in 2012 (Go et al., 2013). By 2030, due to expected increasing stroke prevalence, direct costs associated with stroke are projected to increase by 157% and indirect by 68% (Go et al., 2013). In comparison with ischemic stroke, ICH patients who are hospitalized often have a greater length of stay (LOS) and higher total costs of hospitalization (Christensen, Previgliano, et al., 2009)

A study of patients in Argentina noted an average LOS of 35.4 days for ICH and 13 days for ischemic stroke (Christensen, Previgliano, et al., 2009). 91% of ICH and 68% of ischemic stroke patients were admitted to the ICU, likely accounting for some of the differences in cost of initial hospital care, which was approximately 3 times higher in the ICH grouping (Christensen, Previgliano, et al., 2009). A Korean study comparing medical costs of stroke found that ICH had direct medical costs twice as high as ischemic stroke within the first year (Rha et al., 2013).

In addition to high mortality, and poor functional outcomes and financial outlooks, patients with ICH are also likely to have a decreased overall quality of life (Christensen, Mayer, et al., 2009). The Factor Seven for Acute Hemorrhagic Stroke (FAST) trial, was an international randomized trial looking at patient outcomes 3 months after ICH (Christensen, Mayer, et al., 2009). The study concluded that patients after ICH are highly likely to have low health-related
quality of life (HRQOL) related to poor outcomes in self-care, mobility, pain, activities of daily living, anxiety and depression (Christensen, Mayer, et al., 2009). Clearly, the economic, social and personal burdens associated with ICH are very high. Perhaps in the context of these hardships, do-not resuscitate (DNR) orders after ICH are not uncommon and likely indicate an overall reduction in aggressiveness of care, with the most frequently cited cause of death after ICH being withdrawal of care or medical support due to poor prognosis (Hemphill et al., 2004; Zurasky et al., 2005)

Withdrawal of Care in Various Medical Conditions

In a large study of mean time-to-decision of withdrawal of care of various ICU patients, the average time was 3 days (Sprung et al., 2003). In comparison, a study of post-operative cardiothoracic patients determined 11 days as the mean time-to-decision for withdrawal of care (Turner, Michell, Morgan, & Benatar, 1996). A large cohort study in Sweden noted an average time to decision of 7.5 days in patients with therapeutic failure, 1.6 days with poor prognosis with acute disease, 1.9 days for poor prognosis and chronic disease and 0.8 days for patients with previously documented withdraw preferences (Nolin & Andersson, 2003). A Lebanese study of patients most commonly diagnosed with multiple organ failure, cardiovascular failure, renal failure, or coma, concluded an average of five days to making the decision to withdraw care (Yazigi, Riachi, & Dabbar, 2005). In a study by Keenan et al. (1997) 40% of withdrawal of care decisions were made during the first two days of the ICU stay. Differences in diagnoses were noted as cardiac, post arrest and neurological cases determining withdraw 2-3 days after admission, patients with a diagnosis of sepsis 10 days after admission, and patients with respiratory failure at 22 days after admission (Keenan et al., 1997).
Beyond timing variances between diagnoses, patients with surrogate decision makers are noted to have a longer time electing to withdrawal care than those who made their own decisions or those who had advance directives (Torke et al., 2011). In a study by Torke et al. (2011), surrogate decision making required an average of 6.6 days, individual patients 3.2 days and 4.4 days for decisions made by the patient and surrogate together. In this study, less than one-third of the decisions to withdraw care were made independently by patients and more than one half were made solely by surrogates (Torke et al., 2011). The differences in timing of surrogate decisions are likely due to the emotional and ethical difficulties of making such complex medical decisions for others (Torke et al., 2011). It is estimated that 40% of medical inpatients do not have the capacity to make their own decisions about medical care and thereby require a health care proxy for decision-making (Raymont et al., 2004). It is probable that in a setting for critically ill patients such as an ICU, or patients with a diagnosis such as ICH, the percentage of patients who are incapacitated and unable to make their own medical decisions would be even higher.

Withdrawal of Care in ICH

In 2007 the American Heart Association (AHA) updated their guidelines on the management of ICH to include discussion about DNR orders and withdrawal of care (J. Broderick et al., 2007). Originally the guideline suggested healthcare professionals should certainly consider aggressive care and postponement of DNR orders during the first 24 hours after admission (J. Broderick et al., 2007). In 2010, a less direct update states that it is “probably recommended” to continue aggressive care and withhold DNR orders until at least 2 full days of hospitalization (Morgenstern et al., p. 2120). The basis for discussion or differing opinions seems to arise from the fact that ICH appears to have poorer outcomes because patients often have early
DNR orders, which frequently implies overall decrease in aggressiveness of care (Hemphill et al., 2004; Morgenstern et al., 2010). Thereby patients have early death as a result, which may not have occurred if full care was given (J. Broderick et al., 2007). However, withdrawal of care after ICH often occurs with the knowledge that although the patient may survive the insult with help of aggressive care, the poor prognosis, resultant medical suffering and change in quality of life would not be acceptable (Hemphill, et al., 2004; Zurasky et al., 2005).

Regardless of the AHA guidelines, DNR or withdrawal of care orders are often initiated early in ICH. This is evidenced by the fact that most research on timing of such orders differentiates only between early orders, occurring within the first 24 hours, and all orders thereafter (Hemphill et al., 2004; Nakagawa et al., 2013; Zahuranec et al., 2007). Discussions in the current literature minimally address time frames to withdrawal of care decisions beyond these measures. A study by Naidech et al. (2009) looked at timing of withdrawal of care in relation to patient’s ICH scores, a tool used for prognostication with progressively higher scoring of 0-5 indicating increasing risk of mortality 30 days after ICH (Hemphill, Bonovich, Besmertis, Manley, & Johnston, 2001). Results of the analysis demonstrated accelerated withdrawal of life support with increasing ICH scores (Naidech et al., 2009). Average time to death after hospitalization for a patient with an ICH score of 1-2 was 16 days, 4 days with a score of 3, and 0 days with an ICH score of 4-5 (Naidech et al., 2009). Regardless of time to the actual decision, withdrawal of care has been shown to be more likely to occur in individuals with cerebrovascular accidents versus those with congestive heart failure, myocardial infarction or pneumonia (Bardach et al., 2005; Wenger et al., 1995).

**Racial Disparities in Withdrawal of Care**
Variations in attitudes and decision-making surrounding end of life care have been noted in a high degree between different racial and ethnic groups, especially among minorities in the United States (Bardach et al., 2005; Cooper et al., 2012). Most noted and likely most studied diversities have been between Hispanic, black, Asian and white patients. An investigation of trauma patients throughout 12 states revealed that at time of death, withdrawal of care orders were written for 58% of white, 48% of black and 37% of Hispanic patients (Cooper et al., 2012). Another study including patients in all nonfederal hospitals in California found that white patients were twice as likely as Hispanic, black and Asian patients to have DNR orders within 24 hours of hospitalization for various diagnoses including angina, diabetes, chronic renal failure and stroke (Bardach et al., 2005). Shepardson et al. (1997) noted in their study of hospitalized patients after stroke, that being African American was an independent predictor for having any DNR order and having a DNR order within 2 days of hospitalization. Additional studies also demonstrated white patients were twice as likely as non-white patients to have orders for care limitations in the settings of a nursing home and a cancer center intensive care unit (Cardenas-Turanzas, Gaeta, Ashoori, Price, & Nates, 2011; Lu & Johantgen, 2011). Likewise, research has also described the higher incidence of white patients to have advance care planning documents such as power of attorney, and directives to withhold or limit care, when compared to black patients (Hopp & Duffy, 2000; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Welch, Teno, & Mor, 2005). Specifically after ICH, Zurasky et al. (2005) found that white patients were twice as likely as blacks to have care withdrawn and more likely to make the decision early in treatment, however, many black patients progressed to brain death and mortality rates between racial groups were the same in the end.
Native Hawaiians and Pacific Islanders

The United States Census Bureau considers the group NHOPI to include to Native Hawaiians, Guamanian/Chamorro, and others such as Samoans, Tongans, Micronesians and Fijians (Hixson et al., 2012). While currently accounting for less than 1% of the United States’ population, NHOPIs are one of the fastest growing groups in the country (Hixson et al., 2012).

Although there are many cultures within the NHOPI classification, such as Samoans and Micronesians, it is understood that one of the similarities among NHOPI populations is a sense of collectivism, versus the individualism often noted in white American culture (McLaughlin & Braun, 1998). Individualism, regarding the individual’s interests over that of the group’s, favors autonomy (McLaughlin & Braun, 1998). In regards to health care, individualism can explain a patient’s desire for information about their health and treatment options, self-determination, and the use of documents such as informed consent and advanced directives (McLaughlin & Braun, 1998). Cultures such as NHOPI, who favor collectivism, tend to consider the collective needs of the group over the individual’s (McLaughlin & Braun, 1998). In this setting, an individual other than the patient may make health care decisions, and all family members are likely to know details such as the patient’s diagnosis and treatment options (McLaughlin & Braun, 1998).

Specifically in the Hawaiian culture, caring for an ill family member is considered very important and is valued spiritually (McLaughlin & Braun, 1998). The word ‘kokua’ is the Hawaiian term often used to describe this concept of support or assistance within the culture (McLaughlin & Braun, 1998). It is hypothesized that because this specific cultural group is known to care for one another, plans by an individual such as advanced directives are not needed, because they know they will be cared for unconditionally (McLaughlin & Braun, 1998).
Though the population of NHOPI is comparably small to the rest of the nation, the health disparities of this group are disproportionately high. NHOPIs have a higher rate of death from cardiovascular disease (CVD) when compared to the rest of the state and die from CVD at an average age that is seven years younger (Aluli, Reyes, & Tsark, 2007; Balabis, Kromer-Baker, Tottori, & Salvail, 2007; Look et al., 2013). Specifically in the setting of hospitalized ICH patients, NHOPIs have been shown to be more than 10 years younger and are more likely to have diabetes and hypertension compared to their white counterparts (Nakagawa, Koenig, Seto, Asai, & Chang, 2012).

Health disparities are well described in research among racial minorities in the United States, including NHOPI (Prevention, 2011). In addition to having a higher health disparities, the NHOPI population mirrors other racial minority groups in the United States by also being less likely than white counterparts to have completed advanced directives or end-of-life care planning (Hopp & Duffy, 2000; Teno et al., 2007; Welch et al., 2005). A study by Braun et al. (2001), in the state of Hawaii, described 36% of whites and 22% of Hawaiians as having a living will, and 30% and 20%, respectively, as having a durable power of attorney. Additional studies on NHOPI have shown them to be less likely to have living wills and power of attorneys compared to both white and Asian population in the state of Hawaii (Braun et al., 2006). No research has been published on the NHOPI population in terms of withdrawal of life sustaining treatments or aggressiveness in end-of-life care. However, due to similarities with other minority groups such as increased health disparities and lack of advanced directives, it is reasonable to consider that NHOPI may be similar to other minority groups in withdrawal of care preferences, and thereby
this area warrants research (Braun et al., 2006; Braun et al., 2001; Hopp & Duffy, 2000; Teno et al., 2007; Welch et al., 2005).
CHAPTER THREE METHODS

Study Design

Overall design of this study was a retrospective medical chart review of patients admitted to The Queen’s Medical Center (QMC) with a primary diagnosis of spontaneous ICH from January 1, 2006 to August 31, 2010. Chart review of each patient was conducted to 1) determine if differences in the time to withdrawal of care (withdrawal of life-sustaining treatment) exist between NHOPIs and whites, and 2) if differences were found to exist, determine factors that may contribute to differences between NHOPI and whites in time to withdrawal of care. The study design, setting, sample and data collection methods are similar to previous studies by Nakagawa et al. (2013) and (Nakagawa et al., 2012).

Setting and Sample

The Queens Medical Center (QMC), located in Honolulu, is the largest tertiary center in the state of Hawaii; It is the top medical referral center in the Pacific Basin, which includes over 4,500,000 square miles of ocean containing Territories and Freely Associated States such as American Samoa, and Guam (Center, 2014; Consortium, 2002). QMC is the only facility in the state certified by The Joint Commission as a Primary Stroke Center (Center, 2014; Commission, 2014). A 505 acute care bed-facility that houses the state’s only neuroscience intensive care unit (NSICU), QMC is the preferred treatment center for ICH in Hawaii and admits approximately 80-100 patients with diagnosis of spontaneous ICH every year (Center, 2014; Morgenstern et al., 2010; Nakagawa et al., 2012; Nakagawa et al., 2013). Permission was received from the QMC Research and Institutional Review Committee to perform a retrospective study to determine racial differences in end-of-life decision-making and time to WOLS. Approval was given to
analyze data of all patients with diagnosis of spontaneous ICH who were admitted to QMC between January 1, 2006 and August 31, 2010. The study design, setting, sample and data collection methods are similar to previous studies by Nakagawa et al. (2012), and Nakagawa et al. (2013).

Patients were identified through use of QMC’s Get With The Guidelines-Stroke (GWTG-Stroke) database. GWTG-Stroke is a program created to improve stroke care and patient outcomes through hospital contribution of de-identified patient records to a national stroke database (AHA, 2014). Patients were previously added to this database by either prospective identification of patients with diagnosis of spontaneous ICH or retrospective identification of patients with International Classification of Diseases Ninth Edition (ICD-9) discharge codes (431 for ICH) by a trained reviewer. Cases were confirmed for spontaneous ICH by additional review of electronic medical records by a board-certified neurologist. This study sample consisted of adults ages 18 and older. To obtain information beyond the contents of the GWTG-Stroke database, chart reviews of all patients admitted between January 1, 2006 and August 31, 2010 with ICH were performed to assess differences between racial groups in time to withdrawal of life support after ICH.

**Inclusion criteria:** Patients 18 years and older with diagnosis of spontaneous ICH (ICD 9 code 431) at time of admission or discharge.

**Exclusion criteria:** Patients admitted to QMC previously with diagnosis of ICH, patients admitted with traumatic ICH, ICH related to cerebral aneurysm rupture or with ischemic stroke with hemorrhagic conversion.
Protection of Human Subjects

Approval for this research project was obtained from the Human Subjects Protection Program at the University of Arizona with deferral of IRB oversight to QMC’s Internal Review Board prior to data collection. Human subject information gathered was assigned to individual identification numbers and placed in a password protected electronic data file.

Data Collection

During retrospective chart analysis, collected data included: Patient demographic data, past medical history, substance abuse, GCS at time of admission, location and size of the ICH, presence of any intraventricular hemorrhage (IVH), length of stay (LOS) and if the patient was admitted to the neuroscience intensive care unit (NSICU), if they were admitted under the care of a neurointensivist or neurohospitalist, and if they had a pre-existing DNR order. Additional data collection included time of admission to hospital, as documented by time of admission orders, and time of withdrawal of life support, as documented by time of extubation or comfort care orders, or time of discontinuation of life-sustaining medications or by time of physician note indicating withdrawal of life-support. The difference between admission time and the time of withdrawal of life support orders (such as extubation or time of provider note) equals the total amount of time to withdrawal of life sustaining treatment.

Data Analysis Plan

Descriptive statistics were used to describe patient’s characteristics. Data was analyzed using statistical analysis software (SPSS version 22, IBM, Chicago, IL).
Aim 1: To determine if differences in the time to withdrawal of care (withdrawal of life-sustaining treatment) exist between NHOPIs and whites, a t-test was used to perform a univariate analysis of time to withdraw of care.

Aim 2: To determine confounding variables that may contribute to differences between NHOPI and Caucasians in time to withdrawal of care, a multivariate linear regression analysis was performed using co-variates. Results will be considered statistically significant with a level of $p < 0.05$.

Limitations

Limitations of this study included the limitations associated with retrospective studies, such as, limited control over what data was collected, the quality of the data collected, how the data was collected, and how the collected data was measured in the cohort of interest. Data may be limited, incomplete or inaccurate as some or all of it has been created and collected by others. In addition, this sample may not be representative of the population, which may decrease external validity.
CHAPTER FOUR MANUSCRIPT

Racial differences in withdrawal of life support after intracerebral hemorrhage

Kristen M. Shaw, DNP-candidate 1,2; Matthew J. Gallek, Ph.D 1; Kate G. Sheppard, Ph.D 1;
Leslie Ritter, Ph.D 1; Megan A. Vento, BS 2; Susan M. Asai, MSN 2; Kazuma Nakagawa, MD 2,3

1. The University of Arizona, College of Nursing, Tucson, AZ
2. The Queen’s Medical Center, Honolulu, HI
3. Department of Medicine, John A. Burns School of Medicine, University of Hawaii, Honolulu, HI

Cover title: Racial differences in withdrawal of life support after ICH

Corresponding Author:

Kristen Shaw
Neuroscience Institute
The Queen’s Medical Center
1301 Punchbowl Street
Honolulu, HI 96813
Phone: 513-550-1448
Email: kshaw0117@email.arizona.edu
Abstract

Background and Purpose: Differences in end-of-life decision-making among minorities after acute or chronic medical conditions have been well described in the literature. However, end-of-life decision-making among Native Hawaiian and Other Pacific Islanders (NHOPIs) has not been well studied.

Methods: A retrospective study was conducted on patients admitted to a primary stroke center in Honolulu with diagnosis of spontaneous intracerebral hemorrhage (ICH) between 2006 and 2010. Medical records were reviewed for occurrence of withdrawal of life support (WOLS) and time of WOLS. Unadjusted and multivariable logistic regression models were performed to determine associations between race and WOLS after ICH. Kaplan Meier analysis and Cox Regression were performed to estimate survival time to WOLS after ICH and to compare these results between racial groups.

Results: A total of 396 patients with diagnosis of spontaneous ICH were studied. Mean time to WOLS after ICH was found to be similar between non-Hispanic whites (NHWs) and NHOPIs (3 ± 5 vs. 3 ± 3, respectively, \( p = .925 \)). Prevalence of WOLS was significantly lower in NHOPIs in univariate analysis (odds ratio [OR] 0.35, 95% confidence interval [CI] 0.15, 0.80) and Kaplan Meier analysis predicted a significant difference in WOLS between NHOPI and NHWs within 30 days of ICH occurrence (\( p = <.01 \)). However, in multivariate analysis, race was no longer significant when adjusted for age (OR 0.59, 95% CI 0.25, 1.43) and when fully adjusted (OR 0.68, 95% CI 0.20, 2.39). NHOPIs were significantly younger at the time of spontaneous ICH when compared to their white counterparts (55 ± 16 vs. 68 ± 16, respectively, \( p = <.001 \)) although ICH severity and presentation such as initial Glasgow Coma Scale, presence
of intraventricular hemorrhage and ICH volume were similar (12 ± 4 vs. 11 ± 5, \( p = .241 \); 43% vs. 48% \( p = .604 \); 40 ± 60 vs. 41 ± 48, \( p = .901 \), respectively).

Conclusions: No difference in mean time to WOLS was noted between NHOPIs and NHWs after ICH. However, secondary analysis concluded that WOLS was less prevalent after ICH in the NHOPI population compared to NHWs, although the significance of this finding was attenuated by age. We conclude that NHOPIs in this population likely had a lower incidence of WOLS due to the fact that NHOPIs presented with ICH at a significantly younger age, although small sample size also may have resulted in difficulty detecting variances between populations.
Introduction

Intracerebral Hemorrhage and Withdrawal of Life Support

Stroke is one of the leading causes of both disability and death in the United States, afflicting approximately 800,000 people every year (Go et al., 2013). Up to 15% of strokes are of the hemorrhagic variety known as an intracerebral hemorrhage (ICH); These are devastating injuries, often resulting in a prognosis of disability and poor quality of life (Caplan, 1992; Christensen, Mayer, et al., 2009; Qureshi et al., 2001). Withdrawal of life support (WOLS) is the withdrawal of life-sustaining treatments; the choice to discontinue and further withhold life-sustaining therapies such as mechanical ventilation, blood pressure medications, antibiotics, or artificial hydration or nutrition (Curtis & Vincent, 2010). WOLS is frequently a consideration after ICH due to the high likelihood of decreased quality of life, and has been cited as the most frequent cause of death after ICH, commonly occurring soon after its onset (Becker et al., 2001; Christensen, Mayer, et al., 2009; Naidech et al., 2009; Zurasky et al., 2005).

The decision to WLS is a common occurrence and is the cause of death for the majority of patients in the adult intensive care units (Cooper et al., 2009; Sprung et al., 2003; Varelas et al., 2009). Doctorally prepared nurse practitioners (DNP) are prepared to provide healthcare for patients at a variety of care institutions and levels (AACN, 2006). This includes hospitalized patients who may be at the end of life due to acute illness. The needs and dynamics of the patient and their family must be known and recognized during this period of critical illness, and it must be understood that these needs may differ between various cultures (Kirchhoff & Faas, 2007). The DNP is prepared to diagnose, treat, educate and assist patients and families on their
healthcare journey, therefore they must also be knowledgeable about end-of-life decision-making and variations between populations that may occur in terms of WOLS preferences.

**Racial Differences in Withdrawal of Life Support**

Prior studies have shown differences in end-of-life decision-making by minority groups in the United States; Black and Hispanic individuals are known to desire more aggressive care, are less likely to withdraw life support (WLS) and take longer to come to the decision to WLS compared to non-Hispanic whites (NHWs) (Bardach et al., 2005; Cardenas-Turanzas et al., 2011; Cooper et al., 2012; Hopp & Duffy, 2000; Lu & Johantgen, 2011; Teno et al., 2007; Welch et al., 2005). However, little is known about the end-of-life care preferences and decision-making of Native Hawaiian and Other Pacific Islanders (NHOPIs).

**Native Hawaiian and Other Pacific Islanders**

The United States Census Bureau considers the group NHOPI to include Native Hawaiians, Guamanian/Chamorro, and others such as Samoans, Tongans, Micronesians and Fijians (Hixson et al., 2012). While currently accounting for less than 1% of the United States’ population, NHOPIs are one of the fastest growing groups in the country (Hixson et al., 2012).

Although there are many cultures within the NHOPI classification, such as Samoans and Micronesians, it is understood that one of the similarities among NHOPI populations is a sense of collectivism, versus the individualism often noted in white American culture (McLaughlin & Braun, 1998). Individualism, regarding the individual’s interests over that of the group’s, favors autonomy (McLaughlin & Braun, 1998). In regards to health care, individualism can explain a patient’s desire for information about their health and treatment options, self-determination, and the use of documents such as informed consent and advanced directives (McLaughlin & Braun,
Cultures such as NHOPI, who favor collectivism, tend to consider the collective needs of the group over the individual’s (McLaughlin & Braun, 1998). In this setting, an individual other than the patient may make health care decisions, and all family members are likely to know details such as the patient’s diagnosis and treatment options (McLaughlin & Braun, 1998).

Specifically in the Hawaiian culture, caring for an ill family member is considered very important and is valued spiritually (McLaughlin & Braun, 1998). The word ‘kokua’ is the Hawaiian term often used to describe this concept of support or assistance within the culture (McLaughlin & Braun, 1998). It is hypothesized that because this specific cultural group is known to care for one another, plans by an individual such as advanced directives are not needed, because they know they will be cared for unconditionally (McLaughlin & Braun, 1998).

Available studies on NHOPIs do not describe WOLS or aggressive treatment preferences but do indicate that NHOPIs have similar attitudes surrounding death and dying as other minority groups (Braun et al., 2006; Braun et al., 2001). Due to other similarities with minority groups such as increased health disparities and lack of advanced directives, it is reasonable to consider that NHOPIs may be similar to other minority groups in end-of-life care preferences and WOLS decision-making (Braun et al., 2006; Braun et al., 2001; Hopp & Duffy, 2000; Prevention, 2011; Teno et al., 2007; Welch et al., 2005).

Previous studies of minority populations and end-of-life decision-making minimally address time frames to WOLS decisions beyond the comparison of early orders, occurring within the first 24 hours, and all orders thereafter. Considering the frequent occurrence of WOLS after ICH and the lack of reporting on end-of-life decision-making in the NHOPI population, we wanted to investigate time to WOLS after ICH in the NHOPI population. Our objectives were to
determine if differences exist between NHOPI and NHWs in time to WOLS and to explore factors that may contribute to or explain these differences.

**Theoretical Framework**

A novel application of Madeline Leininger’s Culture Care Theory was used as a framework to support this study. This theory highlights the importance and influence of culture on health and healthcare; The main purpose of culture care theory being to reveal and describe “culturally based care factors influencing the health, well-being, illness or death of individuals or groups” (M. Leininger, 2002, p. 190). These discoveries can then be used to provide improved care that is culturally meaningful to patients from various cultural backgrounds and ethnicities (M. Leininger, 2002).

The presumptive reasoning for the need to conduct a statistical analysis focused on variations between racial groups can be explained through the Leininger’s Sunrise Model; the conceptual model of the culture care theory (Figure 1). In this study, differences in care patterns and practices among the NHOPI population will be seen as variations in WOLS after ICH. Additionally, based on the differences found in this study in end-of-life care preferences, Leiniger’s Sunrise Model can be used to guide the gathering of further information to explain the phenomena discovered in this research.

**Methods**

**Patients and Data Collection**

The Queens Medical Center (QMC), located in Honolulu, is the largest tertiary center in the state of Hawaii; It is the top medical referral center in the Pacific Basin, which includes over 4,500,000 square miles of ocean containing Territories and Freely Associated States such as
American Samoa, and Guam (Center, 2014; Consortium, 2002). QMC is the only facility in the state certified by The Joint Commission as a Primary Stroke Center (Center, 2014; Commission, 2014). A 505 acute care bed-facility that houses the state’s only neuroscience intensive care unit (NSICU), QMC is the preferred treatment center for ICH in Hawaii and admits approximately 80-100 patients with diagnosis of spontaneous ICH every year (Center, 2014; Morgenstern et al., 2010; Nakagawa et al., 2012; Nakagawa et al., 2013). Permission was received from the QMC Research and Institutional Review Committee to perform a retrospective study to determine racial differences in end-of-life decision-making and time to WOLS. Approval was given to analyze data of all patients with diagnosis of spontaneous ICH who were admitted to QMC between January 1, 2006 and August 31, 2010. The study design, setting, sample and data collection methods are similar to previous studies by Nakagawa et al. (2012), and Nakagawa et al. (2013).

Patients were identified through use of QMC’s Get With The Guidelines-Stroke (GWTG-Stroke) database. GWTG-Stroke is a program created to improve stroke care and patient outcomes through hospital contribution of de-identified patient records to a national stroke database (AHA, 2014). Patients were previously added to this database by either prospective identification of patients with diagnosis of spontaneous ICH or retrospective identification of patients with International Classification of Diseases Ninth Edition (ICD-9) discharge codes (431 for ICH) by a trained reviewer. Cases were confirmed for spontaneous ICH by additional review of electronic medical records by a board-certified neurologist. This study sample consisted of adults ages 18 and older. Patients admitted to QMC previously with
diagnosis of ICH, patients admitted with traumatic ICH, ICH related to cerebral aneurysm rupture or with ischemic stroke with hemorrhagic conversion were excluded from the study.

Data obtained from the GWTG-Stroke database included age, gender, race, past medical history, smoking and length of stay (LOS). Patients were classified as NHW, NHOPI, Asian or other. Chart reviews of electronic medical records for all patients admitted between January 1, 2006 and August 31, 2010 with spontaneous ICH were performed by trained reviewers to obtain marital status, methamphetamine use, and initial Glasgow Coma Scale (GCS). Admitting team was recorded as admission to neuro team if the admitting physician was a neurointensivist or neurohospitalist. All other admitting physicians were coded as other, as admission to a specialty service and unit may have an effect on when or how a discussion about WOLS takes place. Admission to NSICU was recorded, all other admissions to the floor or other ICUs were coded as other. The presence of a pre-existing do-not-resuscitate (DNR) order was noted as this often indicates desire for less aggressive care (Hemphill et al., 2004; Morgenstern et al., 2010). Patients who listed marital status as married were coded as such, all patients listed as unmarried, divorced, separated or widowed were considered unmarried. Patient’s initial head computed tomography (CT) scans were reviewed by a board-certified neurologist using a previously described standardized protocol blinded to patient identity and clinical data (Nakagawa et al., 2012; Nakagawa et al., 2013). Location of ICH was coded as basal ganglia, lobar, thalamus, brainstem, cerebellum and primary IVH. Presence of any intraventricular hemorrhage (IVH) was noted and ICH volume in mL was calculated using the ABC/2 method (Kothari et al., 1996).
Time to Withdrawal of Life Support

Data on WOLS was collected, and for patients with support withdrawn, time of withdrawal was noted. Data for time to WOLS was collected by a single reviewer through electronic medical record review of all patients and calculated by time of admission to time to WOLS. Admission time was noted as the time the admission order was placed. Any occurrence of WOLS was verified by description of plans to withdraw or actual WOLS in physician, nursing and other ancillary staff notes. Time of withdrawal was noted as the following items in descending order if the previous item was not present in the medical record: Time of extubation order placement, time of comfort measures order placement (such as specific comfort care order, order for morphine or other pain medication drip or discontinuation of life-sustaining medications, all with indications from notes that care was being withdrawn), time of physician, nursing, respiratory or other ancillary staff note that stated patient was extubated or had WOLS. Some patients were admitted to the hospital only to be supported until family or loved ones could arrive prior to WOLS. Patients whose charts had notes from physicians or other hospital staff before actual admission clearly stating the intent to WLS shortly after admission were coded to have 0 days to WOLS because, although actual withdrawal did not occur that day, the decision was made at the time of admission.

Analysis

Demographics and baseline characteristics of NHOPI and Asians were compared to NHWs as a reference group. A two-tailed t-test was used for analysis to compare continuous variables such as age, ICH volume and initial GCS. Categorical variables were analyzed using a chi-squared test. The same method was used to compare demographics and baseline
characteristics between patients who had WOLS and those who did not have WOLS. Primary analysis compared the overall prevalence and time differences of WOLS after ICH between NHOPIs and NHWs. Multivariable logistic regression analysis was performed to assess the relationships between race and WOLS. Three separate models were created; One model was adjusted for age, the second model was adjusted for age and sex, and the final model was adjusted for all of the variables with $p < 0.10$ in the univariate analysis comparing patients with and without WOLS. Secondary analysis included a Kaplan–Meier survival curve to analyze differences in time to WOLS between NHWs and NHOPIs over a 30-day period. A Cox proportional hazards regression analysis was also performed to assess survival curves with the same co-variates mentioned previously for the regression models. All analyses were performed using statistical software (SPSS version 22, IBM, Chicago, IL). The odds ratio (OR) and 95% confidence interval (CI) were calculated from the beta coefficients and their standard errors. Age was used as a continuous variable with a constant OR for each year. Hematoma volume was used as a continuous variable with a constant OR for each mL. Levels of $p < 0.05$ were considered statistically significant.

**Results**

Between January 2006 and August 2010 a total of 396 patients with spontaneous ICH were identified and all were included in this study. CT studies and subsequent data were available on all patients. Demographics and clinical characteristics in Table 1 reveal NHOPIs were younger ($p < .001$), more likely to have a history of diabetes ($p = .02$) had a longer LOS ($p = .008$) and were less likely to be married ($p = .02$) than their NHW counterparts. This unadjusted analysis also shows NHWS had a higher prevalence of WOLS when compared to
NHOPIs (31% vs. 14%, respectively, \( p = .02 \)), although no significant difference in the mean time to WOLS was noted between the groups (\( p = .93 \)).

As presented in Table 2, those who did have WOLS were older (\( p = <.001 \)), less likely to smoke (\( p = .03 \)), less likely to use methamphetamines (\( p = .01 \)), had a lower initial GCS (\( p = <.001 \)), a higher incidence of IVH (\( p = <.001 \)), had a higher ICH volume in mL (\( p = <.001 \)), were more often admitted to NSICU (\( p = .002 \)), had a higher prevalence of pre-existing DNR orders (\( p = <.001 \)) and had a shorter LOS (in days, \( p = .004 \)) when compared to patients who did not have WOLS.

The multivariable regression models' predicting factors that influenced the occurrence of WOLS are shown in Table 3. Co-variates for the regression model were based on criteria previously described in the results section. Racial categories, although not significant, were all forced into the model as this was the key point of interest; Additionally, LOS was left out, because although significant, LOS is not a predictor variable for WOLS, but rather it is likely the byproduct of deciding to pursue aggressive care or WLS. In model 1, unadjusted analysis indicates NHOPIs are about one third as likely to WLS when compared to NHWs. However, when age was added to the model, race was no longer a significant predictor for withdrawal of care for NHOPIs compared to NHWs. In the fully adjusted model race continued to be insignificant as a predictor of WOLS. Variables noted to be significantly associated with WOLS in the fully adjusted model included age, ICH volume, initial GCS, presence of IVH, and presence of a pre-existing DNR. A Kaplan–Meier survival analysis (Figure 2) was significant between NHWs and NHOPIs over a 30-day period (\( p = .01 \)). However, when the previously
described co- were used in a Cox proportional hazards regression between NHOPIs and NHWs over a 30-day period, the analysis showed race to be insignificant ($p = .95$).

**Discussion**

This study was performed with the hypothesis that time to WOLS after ICH would be different among NHOPIs when compared to NHWs, as previous studies have indicated for other minority groups such as blacks and Hispanics (Bardach et al., 2005; Cooper et al., 2012; Hopp & Duffy, 2000; R. W. Johnson et al., 2010; Shepardson et al., 1997; Zahuranec et al., 2009; Zurasky et al., 2005). The results of our study did not support the original intentions of concluding a difference in time to WOLS, although we did discover variances in prevalence of WOLS and survivorship estimates after ICH between NHOPIs and NHWs. The results of univariate analyses showed that NHOPIs are less likely to have WOLS compared to NHWs. Furthermore, Kaplan Meier analysis showed that after ICH, NHOPIs had higher survival rates than NHWs at 30-days. These results appear to be similar to other studies of minorities that have shown less likelihood for minorities to WLS after acute or chronic medical conditions (Bardach et al., 2005; Cooper et al., 2012; Hopp & Duffy, 2000; R. W. Johnson et al., 2010; Shepardson et al., 1997; Zahuranec et al., 2009; Zurasky et al., 2005). However, when fully adjusted in the multivariable models, race was no longer an independent predictor of WOLS and major clinical predictors for WOLS included older age, hematoma volume, presence of IVH, higher initial GCS and presence for pre-existing DNR.

Reviewing the demographic comparisons between NHWs and NHOPIs in the univariate analysis (Table 1), the NHPI patients in our study were, on average, more than a decade younger than NHWs. NHOPIs have been previously shown to have ICH at a younger age when
compared to NHWs and other studies have echoed this sentiment of the occurrence of ICH at a younger age in minority groups (Flaherty et al., 2005; Howard et al., 2013; Nakagawa et al., 2012; Zahuranec et al., 2009). Previous studies have also shown patients with older age to be independently associated with higher prevalence of WOLS or DNR orders, compared to younger patients (Cooper et al., 2009; Shepardson et al., 1997). Although our initial observation seemed to show a possible racial difference in the prevalence of WOLS after ICH, this was largely driven by the young age among the NHOPI compared to NHWs. We inferred that because the NHOPIs were generally younger they were considered to be more likely to survive or desire aggressive care and thereby were not as likely to have WOLS; However, when adjusted for age, there seems to not be any racial differences in the end-of-life decision-making between NHOPI and whites.

Additionally, many other variables that were noted to be significant in regards to the patients that had WOLS (Table 2), such as lower initial GCS, presence of IVH, higher ICH volume and a pre-existing DNR order, were not significantly different between NHOPIs and NHWs (Table 1). In the multivariable regression model, independent predictors of WOLS included lower initial GCS score, presence of IVH, higher ICH volume, a pre-existing DNR order and age. This implies that the difference in prevalence of WOLS between NHWs and NHOPIs is not due to race or a difference in clinical characteristics, but rather, based on age.

The presentation of ICH at a much younger age in NHOPIs when compared to NHWs and the other individuals in the study is highly alarming and speaks volumes for the health inequities facing this population. NHOPIs are known to have health disparities that are disproportionately high compared to other ethnic groups in the state of Hawaii and the United
States. NHOPIs are more likely to be obese, smoke, have diabetes and have hypertension when compared to NHWs and the rest of the United States (Aluli et al., 2007; Balabis et al., 2007; Look et al., 2013). The aforementioned are all risk factors for cardiovascular disease (CVD), and as a subcategory of CVD, stroke. In the state of Hawaii, CVD is the cause of over one-third of all deaths, and on average, NHOPIs die from CVD at an average age that is 7 years younger than NHWs and the rest of the state (Aluli et al., 2007; Balabis et al., 2007; Look et al., 2013).

As described by the AACN (2006) essentials, the DNP is meant not to simply apply new knowledge in health care, but to also create this knowledge. In the realm of population health, consideration and awareness of cultural diversity directs the DNP to advocate to create changes in health policy when disparities are noted (AACN, 2006). The literature available in the NHOPI population is greatly limited, and the DNP is prepared to identify gaps in knowledge and utilize research to identify community problems, including the topic examined here, racial differences in WOLS decisions.

Cultural Contemplations and Practice Recommendations

This study was created from an etic approach, as none of the authors are ourselves part of the culture of NHOPIs. Utilizing an etic perspective may diminish the observation bias associated with an emic approach, however, we realize this may also diminish our abilities to fully explain certain phenomena that occur in a culture outside of our own as we may not thoroughly understand the cultural nuances of the NHOPI population (Alegria et al., 2004).

The implications of research and knowledge generation and translation on NHOPIs are vast, especially in an area such as the city and county of Honolulu, where the NHOPI population is the highest in the nation (Look et al., 2013). Outcomes from this study indicate the presence of
severe health disparities among young NHOPIs, implying the need for investigation of potential services or policies to support this specific population to ensure equity and quality of health care. The small amount of literature available on the NHOPI population in regards to practice recommendations are limited. Although specific to the Samoan ethnicity, some literature that is available suggests that efforts to research and reduce health disparities in this population have largely been based in western perspective and medicine and may have created more distrust and fewer health benefits in the NHOPI population (Siaki, 2009). Suggestions for future research in this community cite the need for involvement of NHOPIs as researchers themselves and a higher level of general support and funding for culturally-centered research (Palafox, Buenconsejo-Lum, Riklon, & Waitzfelder, 2002)

The knowledge gained from the results of this study can assist the DNP and other practitioners in understanding nuances of health disparities and sensitivities in NHOPIs, and in the future development of population-specific quality improvement initiatives for health care equality. Specific recommendations based on the results of this study include the need for collaboration with primary care providers to address treatment of risk factors for ICH such as hypertension and diabetes in the NHOPI population. Also, based on the literature, there is a clear need for involvement of members of the NHOPI community to assist in determining the best courses of action for health promotion and quality initiatives for this population.

Limitations

Limitations of this study include those associated with retrospective studies, such as, limited control over how and what data was collected and the quality of the data collected. Data may be limited, incomplete or inaccurate as some had been created and collected by others
beyond the authors of this study. As the sample size for this study was pre-determined, prespecified power and sample calculations were not made. The small sample size likely limits the conclusions drawn from this study to preliminary observations. In addition, this sample consists of patients with a single diagnosis and from a single institution, which is a tertiary medical center and may have a selection bias toward accepting and admitting only severe cases of ICH from outlying hospitals. Thereby, the results of this study may not be representative of decision-making in the NHOPI community in the state of Hawaii, decreasing its external validity. Finally, end-of-life decision-making involves many factors, and often intangible nuances, involving the patient, their loved ones and the provider that cannot be characterized by retrospective studies. Due to the retrospective nature of this study it is impossible for us to make inferences about the appropriateness and timing of WOLS in these patients.

**Summary**

While our study did not find any differences between NHWs and NHOPIs in time to WOLS, the results suggest that NHOPIs are less likely than NHWs to have WOLS after ICH, although this association was attenuated by age and other confounders. The observed racial differences in WOLS were largely driven by the conclusion that NHOPIs are experiencing ICH at a much younger age than their white counterparts, which is reflective of the major health disparities noted in Hawaii.
REFERENCES


Siaki, L. (2009). *Perceived Risk for Cardiovascular Disease and Diabetes Type 2 Among Samoans With Metabolic Syndrome.* (Doctor of Philosophy), University of Arizona.


Table 1. Demographics and Baseline Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>NHW</th>
<th>NHOPI</th>
<th>p</th>
<th>Asian</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>Age, years</td>
<td>68 ± 16</td>
<td>55 ± 16</td>
<td>&lt;.001</td>
<td>67 ± 17</td>
<td>.66</td>
</tr>
<tr>
<td>Female</td>
<td>24 (39)</td>
<td>30 (42)</td>
<td>.79</td>
<td>118 (48)</td>
<td>.25</td>
</tr>
<tr>
<td>Married</td>
<td>39 (65)</td>
<td>33 (45)</td>
<td>.02</td>
<td>112 (45)</td>
<td>.006</td>
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<td>Diabetes</td>
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<td>26 (36)</td>
<td>.02</td>
<td>52 (21)</td>
<td>.61</td>
</tr>
<tr>
<td>Hypertension</td>
<td>38 (62)</td>
<td>53 (74)</td>
<td>.16</td>
<td>187 (75)</td>
<td>.04</td>
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<td>9 (13)</td>
<td>.37</td>
<td>25 (10)</td>
<td>.08</td>
</tr>
<tr>
<td>Smoking</td>
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<td>.83</td>
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<tr>
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<td>8 (11)</td>
<td>.09</td>
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<td>.40</td>
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<td>Initial GCS</td>
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<td>.38</td>
</tr>
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<td></td>
<td>.27</td>
<td></td>
<td>.11</td>
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<td>32 (44)</td>
<td></td>
<td>86 (35)</td>
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<td>Lobar</td>
<td>22 (36)</td>
<td>15 (21)</td>
<td></td>
<td>59 (24)</td>
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<td>Thalamus</td>
<td>7 (12)</td>
<td>12 (17)</td>
<td></td>
<td>51 (21)</td>
<td></td>
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<tr>
<td>Brainstem</td>
<td>2 (3)</td>
<td>5 (7)</td>
<td></td>
<td>16 (7)</td>
<td></td>
</tr>
<tr>
<td>Cerebellum</td>
<td>3 (5)</td>
<td>3 (4)</td>
<td></td>
<td>25 (10)</td>
<td></td>
</tr>
<tr>
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<td>5 (7)</td>
<td></td>
<td>11 (4)</td>
<td></td>
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<td>31 (43)</td>
<td>.60</td>
<td>121 (49)</td>
<td>.84</td>
</tr>
<tr>
<td>ICH Volume, mL</td>
<td>41 ± 48</td>
<td>40 ± 60</td>
<td>.90</td>
<td>37 ± 50</td>
<td>.64</td>
</tr>
<tr>
<td>Admit to NSICU</td>
<td>32 (53)</td>
<td>41 (57)</td>
<td>.60</td>
<td>127 (52)</td>
<td>.86</td>
</tr>
<tr>
<td>Admitted to neuro team</td>
<td>30 (49)</td>
<td>38 (53)</td>
<td>.68</td>
<td>116 (47)</td>
<td>.75</td>
</tr>
<tr>
<td>Pre-existing DNR order</td>
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<td>3 (4)</td>
<td>.54</td>
<td>16 (7)</td>
<td>.98</td>
</tr>
<tr>
<td>LOS</td>
<td>6 ± 7</td>
<td>14 ± 20</td>
<td>.008</td>
<td>11 ± 17</td>
<td>.03</td>
</tr>
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<td>WOLS</td>
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<td>10 (14)</td>
<td>.02</td>
<td>57 (23)</td>
<td>.19</td>
</tr>
<tr>
<td>Time to WOLS*</td>
<td>3 ± 5</td>
<td>3 ± 3</td>
<td>.93</td>
<td>4 ± 6</td>
<td>.38</td>
</tr>
</tbody>
</table>

NHW, Non-Hispanic whites; NHOPI, Native Hawaiian and Other Pacific Islanders; GCS, Glasgow Coma Scale; ICH, intracerebral hemorrhage; CT, computed tomography; IVH, intraventricular hemorrhage; mL, milliliter; NSICU, neuroscience intensive care unit; DNR, do-not-resuscitate; LOS, length of stay; WOLS, withdrawal of life support
NHW is the reference category
*Time to WOLS rounded up to nearest hospital day, up to 30 days
Table 2. Demographics and Baseline Characteristics of Patients With and Without WOLS

<table>
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<tr>
<th>Characteristic</th>
<th>WOLS</th>
<th>No WOLS</th>
<th>p</th>
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<tbody>
<tr>
<td></td>
<td>N (%) N= 89</td>
<td>N (%) N= 307</td>
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<tr>
<td>Age, years</td>
<td>75 ± 14</td>
<td>61 ± 17</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Female</td>
<td>48 (54)</td>
<td>130 (42)</td>
<td>.05</td>
</tr>
<tr>
<td>Race</td>
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<td></td>
<td>.12</td>
</tr>
<tr>
<td>NHW</td>
<td>19 (21)</td>
<td>42 (14)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>57 (64)</td>
<td>57 (64)</td>
<td></td>
</tr>
<tr>
<td>NHOPI</td>
<td>10 (11)</td>
<td>62 (20)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3 (3)</td>
<td>12 (4)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>42 (48)</td>
<td>144 (48)</td>
<td>.96</td>
</tr>
<tr>
<td>Diabetes</td>
<td>22 (25)</td>
<td>69 (23)</td>
<td>.66</td>
</tr>
<tr>
<td>Hypertension</td>
<td>70 (79)</td>
<td>215 (70)</td>
<td>.11</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>9 (10)</td>
<td>37 (12)</td>
<td>.62</td>
</tr>
<tr>
<td>Smoking</td>
<td>7 (8)</td>
<td>53 (17)</td>
<td>.03</td>
</tr>
<tr>
<td>Methamphetamine use</td>
<td>1 (1)</td>
<td>28 (9)</td>
<td>.01</td>
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<tr>
<td>Initial GCS</td>
<td>7 ± 4</td>
<td>12 ± 4</td>
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<tr>
<td>Location of ICH on CT</td>
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</tr>
<tr>
<td>Basal ganglia</td>
<td>37 (42)</td>
<td>114 (37)</td>
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<td>20 (23)</td>
<td>79 (26)</td>
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<td>4 (5)</td>
<td>15 (5)</td>
<td></td>
</tr>
<tr>
<td>Any IVH</td>
<td>70 (79)</td>
<td>119 (39)</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>ICH Volume, mL</td>
<td>78 ± 70</td>
<td>27 ± 38</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Admit to NSICU</td>
<td>60 (67)</td>
<td>149 (49)</td>
<td>.002</td>
</tr>
<tr>
<td>Admitted to neuro team</td>
<td>51 (57)</td>
<td>142 (46)</td>
<td>.07</td>
</tr>
<tr>
<td>Pre-existing DNR order</td>
<td>15 (17)</td>
<td>9 (3)</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>LOS</td>
<td>7 ± 11</td>
<td>12 ± 18</td>
<td>.004</td>
</tr>
</tbody>
</table>

WOLS, withdrawal of life support; NHW, Non-Hispanic whites; NHOPI, Native Hawaiian and Other Pacific Islanders; GCS, Glasgow Coma Scale; ICH, intracerebral hemorrhage; CT, computed tomography; IVH, intraventricular hemorrhage; mL, milliliter; NSICU, neuroscience intensive care unit; DNR, do-not-resuscitate; LOS, length of stay
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Model 1 Unadjusted OR (95% CI)</th>
<th>Model 2 Adjusted for age OR (95% CI)</th>
<th>Model 3 Adjusted for age and sex OR (95% CI)</th>
<th>Model 4 Fully adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asians</td>
<td>0.60 (0.33, 1.08)</td>
<td>0.55 (0.29, 1.05)</td>
<td>0.54 (0.28, 1.02)</td>
<td>0.65 (0.27, 1.59)</td>
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<tr>
<td>NHOPI</td>
<td>0.35 (0.15, 0.80)$^+$</td>
<td>0.59 (0.25, 1.43)</td>
<td>0.58 (0.24, 1.40)</td>
<td>0.68 (0.20, 2.39)</td>
</tr>
<tr>
<td>Others</td>
<td>0.46 (0.12, 1.80)</td>
<td>0.52 (0.12, 2.32)</td>
<td>0.52 (0.12, 2.31)</td>
<td>0.43 (0.05, 3.88)</td>
</tr>
<tr>
<td>Age</td>
<td>1.06 (1.04, 1.07)</td>
<td>1.05 (1.03, 1.07)</td>
<td>1.06 (1.03, 1.09)</td>
<td></td>
</tr>
<tr>
<td>Female sex</td>
<td>1.30 (0.78, 2.15)</td>
<td>1.38 (0.67, 1.84)</td>
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</tr>
<tr>
<td>ICH Volume, mL</td>
<td></td>
<td>1.01 (1.003-1.02)$^+$</td>
<td></td>
<td></td>
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<tr>
<td>Initial GCS</td>
<td>0.79 (0.72, 0.87)</td>
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<td></td>
</tr>
<tr>
<td>IVH</td>
<td></td>
<td>3.01 (1.44, 6.32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methamphetamine use</td>
<td>.19 (0.02, 1.77)</td>
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<td></td>
</tr>
<tr>
<td>NSICU admit</td>
<td>2.02 (0.68, 5.96)</td>
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<td></td>
</tr>
<tr>
<td>Pre-existing DNR</td>
<td>3.22 (1.03, 10.50)$^+$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>0.79 (0.24, 2.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted to neuro team</td>
<td>.44 (0.17, 1.17)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

WOLS, withdrawal of life support; NHOPI, Native Hawaiian and Other Pacific Islanders; ICH, intracerebral hemorrhage; mL, milliliter; GCS, Glasgow Coma Scale; IVH, intraventricular hemorrhage; NSICU, neuroscience intensive care unit; DNR, do-not-resuscitate;

*Reference group for race is NHW, non-Hispanic whites

$^+$p < .05
Figure 1. Leinenger’s Sunrise Model
Figure 2. Kaplan-Meier Curve, Univariate analysis of time to withdrawal of life support comparing Native Hawaiian and Other Pacific Islanders (NHOPIs) and non-Hispanic whites (NHWs) up to 30 days, $p = <.01$
Figure 3. Age stratification of all patients by percent of population
APPENDIX A

EMAIL GRANTING PERMISSION TO USE SUNRISE MODEL IMAGE
Kristen Shaw <kshaw0117@email.arizona.edu>

sunrise enabler

1 message

McFarland, Marilyn <mmcf@umflint.edu> To: "kshaw0117@email.arizona.edu" <kshaw0117@email.arizona.edu> Cc: "VANDERLAAN, JOHN" <jovander@umflint.edu>

Sat, Dec 14, 2013 at 10:55 AM

Dear Kristi,

Please cite source and use the Sunrise. Proceed with your work. This will suffice for now as details are worked out to give open permission with source citation. Thank you,

Marilyn McFarland

Marilyn McFarland, PhD, RN, FNP-BC, CTN-A Professor, Department of Nursing - School of Health Professions and Studies - The University of Michigan-Flint

303 East Kearsley Street - 2162 William S. White Building - Flint, MI 48502-1950 - Office Phone (810) 766-6777 Nursing Dept. Phone (810) 762-3420 Home phone (989) 684-7381 - Cell (989) 450 0967 - Fax (810) 766-6851 - E-mail: mmcf@umflint.edu
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