“El sueño de todos”: A Qualitative Study of Family/Caregiver Experience after an Acute Neurological Event in Argentina

by

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Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in the Duke Global Health Institute in the Graduate School of Duke University

2017
ABSTRACT

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Abstract

The family of patients hospitalized in an intensive care unit (ICU) after a neurological event often immediately assume the role of caregiver to an individual with significant health care needs. Family/caregivers act as patient advocates and members of the care team, yet their experiences accompanying neurocritical care patients in Argentina and assuming the caregiving role are not well understood. The purpose of this study is to investigate the experiences of family members/caregivers during the time in which they assume the caregiving role as a means to better understand the relationship between patient, family/caregiver, provider, and health system in the ICU to potentially inform the development of appropriate interventions.

This study explores the use of Bronfenbrenner’s Ecological Systems Theory to ethnographically investigate the perceptions and attitudes of family/caregivers regarding their experience and relationships and interactions between patient, family, provider, and health system after an acute neurological event in Argentina. Study implementation occurred over the course of eleven weeks and included direct observation and semi-structured interviews. The initial two-week direct observation period was used to determine study feasibility and provide contextual understanding. Family/caregiver experience was investigated using 9 qualitative, semi-structured interviews with family/caregivers. Participants were selected using purposive sampling
of family/caregivers of patients in a hospital ICU. Family/caregivers were unpaid family members, at least 18 years of age, and self-identified or elected by the family to speak on behalf of the family for the patient admitted to the ICU for an acute neurological event. Direct observation continued throughout the nine weeks of participant identification and interviewing after the initial two-week period to aid the investigator’s comprehensive understanding of patient and family/caregiver experience. Interviews were transcribed verbatim and translated line-by-line from Spanish to English. Iterative thematic analysis using a grounded theory approach was used to code and analyze interview transcripts. Thick description and comparison and categorization of themes were used to identify, explain, and verify patterns and develop broad themes.

Nine themes emerged based on iterative thematic analysis, including: adjusting to a changed life, managing emotions, changing role, relying on faith, redefining recovery, participating in patient care, depending on clinical experts, el trato humano, and finding unity in purpose. Patients, family/caregivers, and medical providers often interact in the ICU. While patients rely upon both providers and family/caregivers for care, family/caregivers also rely upon providers to explain prognosis and next steps, including plans for rehabilitation. Medical providers have the power to affect patient and family/caregiver experience through more than just medical care – family/caregivers perceive and place importance on interactions with providers.
Family members/caregivers form an integral part of the care team. The centrality of the patient to both family/caregiver and provider unites these two groups and emphasizes the need for recognition of the role that family/caregivers play in patient experience as a mediator between provider and patient. Exploration of family/caregiver experience can help improve patient- and family-centered care and mitigate disability and other negative health outcomes through deeper understanding of the needs and concerns of family/caregivers as they support the patient across the care continuum.
Dedication

This thesis project is dedicated to the patients of Hospital Italiano de Buenos Aires and their families.
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1. Background

The experience of patients as they transition through the health system is not well understood in Argentina. Additionally, the lack of a hospital to home transitional care strategy in Argentina represents a gap in services that threatens patients’ ability to heal after an acute injury or illness and unduly burdens their caregivers. This study explores the application of Urie Bronfenbrenner’s Ecological Systems Theory to healthcare systems as a means to understand patient and family/caregiver experience and perceptions after an acute neurological event. Of particular concern in this study is the immediate period after the neurological event during which the patient is hospitalized in the ICU and the family/caregiver is newly assuming the caregiving role (Brereton and Nolan 2002; Bronfenbrenner 1977). Ultimately, a deeper understanding of family/caregiver experience is necessary to develop culturally appropriate, family-centered transitional care strategies to improve patient and family outcomes, including quality of life, and foster supportive relationships between patient, family/caregiver, and medical provider.

1.1 Family/Caregiver

It is necessary to recognize the distinction between formal and informal caregivers. Schulz and Sherwood (2008) are careful to identify informal caregiving as “care that is provided by a family member or friend rather than by a professional who is
reimbursed for services” (105). In contrast, a formal caregiver is a provider associated with a formal service system, whether paid or volunteer (Family Caregiver Alliance 2014).

In this study, informal family caregivers are referred to as “family/caregiver” to distinguish them from medical providers as formal caregivers. “Family/caregiver” emphasizes that not all family members are necessarily assuming the caregiving role and that different family members act as caregivers to varying extents.

1.2 The Role of Family/Caregiver

While family members have cared for aging or ill relatives for thousands of years, the role of families as caregivers has emerged as a public health issue in the past twenty-five years (Barg et al. 2013; Shaji and Reddy 2012; Talley and Crews 2007). As the population of the United States continues to age, people living with disability or other loss of functionality increasingly rely upon family members to provide care. As of 2008, chronic conditions such as heart disease and stroke now kill more people than infectious disease (WHO 2008). This trend is likely to continue. The global shift of disease burden from infectious to noncommunicable disease accompanies an increased likelihood that people will live longer and with higher risk of acquiring disability from illness or injury (Singhal and Khadilkar 2014). Advances in medicine and technology have lengthened the life span and, thus, there is a growing need for long-term caregiving for many
individuals with health conditions (Shaji and Reddy 2012). Additionally, since the 1960s, caregiving in communities has become popular socially as medicine has pushed away from institutionalization (Talley and Crews 2007). Yet, despite the potential variety of specific caregiving experiences, caregiving is ubiquitous throughout society (Schulz and Sherwood 2008). It is important to understand the role of family members as caregivers in the context of the shift to family- and patient-centered care. Family members serving as informal caregivers are irreplaceable members of the care team (Shaji and Reddy 2012).

In the United States, the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) estimates that 43.5 million adults in the United States have provided care to an adult or child in the past 12 months (2015). It is estimated that family caregivers provide approximately 80 percent of homecare services in the United States (Thobaben 2006). The experiences of Americans serving as caregivers vary greatly in the intensity and duration and in the effects that caregiving has upon them (Talley and Crews 2007). In a national survey, 18.2 percent of respondents reported being caregivers on average for 24.4 hours per week. Nearly one-quarter of respondents provided more than 41 hours of care per week for a variety of conditions, including long- and short-term physical conditions, memory loss, or multiple conditions. Caregiving was found to be most time intensive for those caring for
a spouse or partner; on average, caregivers caring for a spouse or partner spent 44.6 hours per week as a caregiver (NAC and AARP Public Policy Institute 2015).

While data regarding the prevalence of family caregiving is available for some high income countries (HICs), such as the United States, United Kingdom, Canada, New Zealand, and others, extremely limited data is available regarding the burden of family caregiving in low and middle income countries (LMICs) (Bezrukov and Foigt 2002; Chao and Roth 2000; IACO n.d.).

The significance of the role of families as caregivers is emphasized by the principles of family- and patient-centered care. Family- and patient-centered care conceive of the role of family members as integral collaborative partners in patient care. Key principles include information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of the family and community. While there is limited evidence regarding the effect family-centered care has on patient health outcomes, family-centered care has been found to support health literacy and self-management, empowerment, efficient use of resources, and promote mental health and well-being (Kuo et al. 2012).

Recognizing caregiving as a public health issue is necessary to ensure the health of caregivers and those they are responsible for (Shaji and Reddy 2012; Talley and Crews 2007). Better understanding of family experience, knowledge, and perspective in the
patient medical experience is necessary as health systems move to a family-centered approach (Kuo et al. 2012). Framing family caregiving as a public health issue allows for surveillance and epidemiology, promotion of programs and services, and identification of solutions for problems faced by caregivers as a vulnerable group (Talley and Crews 2007). Caregiving responsibility must be shared among individuals, families, and governments to mitigate the burden of care and foster improved well-being (Shaji and Reddy 2012).

1.3 Experiences of Family/Caregiver

Caregiving is a lifespan experience. It is associated with aging and the shifting roles of parents, children, and other family members (Talley & Crews 2007). Caregivers often experience negative health effects that can impact the person they are caring for (Schrag et al. 2006; White et al. 2006). Due to these factors, caregiving is a major public health issue that bears real impact on health outcomes for caregivers and those they care for (Schulz and Sherwood 2008).

A common association in research regarding informal caregiving is that of distress, fatigue, or burden (Brown and Brown 2014; Schulz and Sherwood 2008). Negative effects of caregiving upon caregivers are prevalent in research literature, policy reports, and popular media (Brown and Brown 2014). Negative effects include feelings of burden, psychological stress, health disorders, and increased mortality (Brown and
Brown 2014; Schulz and Sherwood 2008). For instance, Epstein and Lubow (2009) found that almost half of new family members/caregivers experienced depressive symptoms soon after a family member suffered a stroke. However, family/caregiver experience is variable. Symptoms were more pronounced for women, family/caregivers with less education, and for family/caregivers with worse personal health. In general, depressive symptoms also correlated with caring for family members who are more functionally impaired, caring for a man, worse caregiver health, and poor family functioning. Caregivers of men were four times as likely to be depressed as caregivers of women (Epstein and Lubow 2009).

There exists a significant relationship between the health of a patient and the health of his or her caregiver. White et al. (2006) found significant negative impacts on caregiver’s health-related quality of life even 2 years post-stroke, emphasizing the need for longitudinal assessment of caregiver experience. A study of long-term family/caregivers after stroke found that there is a significant positive association between the stroke survivor’s social participation in family and the family/caregiver’s quality of life (White et al. 2006). Greater attention to family/caregiver emotional and physical health is needed to improve health outcomes for both family/caregivers and people living with disability after an illness or medical event (Schrag et al. 2006).

Not all family members/caregivers have the same experience; there exists variety
in experience based on patient pathology and caregiving duration. Acting as
family/caregiver can be particularly strenuous for chronic conditions or acute events
with lasting impact, such as stroke (White et al. 2006). Additionally, Brereton and Nolan
(2002) identify family caregiving as a process. There are three distinct periods for study
in regards to family/caregiver experience: taking up the caregiving role, continuing in
the role, and relinquishing the role. Each time period accompanies unique challenges
and varying burden (Brereton and Nolan 2002). Experience differs over the course of the
caregiving experience even for a single family/caregiver (White et al. 2006). In a
longitudinal study exploring the relationship between patient characteristics,
characteristics of the caregiver, and caregiver coping resources with caregiver physical
and mental health outcomes, Teel et al. (2001) found that caregiver functioning is not
static, although there does appear to be overall stability of caregivers’ perceptions after
the first few months post-stroke.

Many studies do not explore the experiences of family/caregivers in regards to
patient experience or their own roles, despite the significant role that family
members/caregivers often play in patient experience. Better understanding of
family/caregiver experience and burden can be used to improve the lives of both patient
and family/caregiver (Schrag et al. 2006). Greenfield and Jensen (2010) recommend
recognition and consideration of all individuals involved in care and patient medical
experience, including family/caregiver, involved in the patient’s life and care experience. Family/caregivers also act as partners in decision-making based on the principles of family-centered care, especially in pediatric settings and settings where the patient is unable to consent, such as neurological critical care (Kuo et al. 2012). Many studies of patient experience and quality of life do not include caregiver experience, despite the ethical and practical implications of the inclusion of family/caregivers and the link between family/caregiver and patient quality of life (Schrag et al. 2006).

1.4 Theories of Family Caregiving

The caregiver strain theory, healthy caregiver theory, and alternative approach are commonly used to understand family/caregiver experience (Brown and Brown 2014). These three theories encapsulate debates within the field of family/caregiver research regarding the utility of different models as the basis for understanding and synthesizing family/caregiver experience.

Traditionally, studies of family/caregiver experience focus on the negative effects of caregiving based on the chronic stress model of informal caregiving. In these studies, family/caregiver experience is related to depression, anxiety, and distress (Schulz and Sherwood 2014). Yet, there remains tension among scholars regarding whether caregiving is an inherently negative experience and which theory regarding
family/caregiving experience is most appropriate (Brown and Brown 2014; Schulz and Sherwood 2008).

### 1.4.1 The Caregiver Strain Theory

The caregiver strain theory, also referred to as the “wear and tear” theory, originated from the work of Hans Selye (Brown and Brown 2014). Selye, a biologist and endocrinologist, first identified and classified steroid hormones. Selye’s work led to the recognition of the “stress response.” Through Selye’s work, stress became a meaningful construct in health and medicine, particularly as researchers began to study the health effects of stress and the stress response (Szabo et al. 2012).

Schulz and Sherwood (2008) use the chronic stress model to understand caregiver experience. Features of the chronic stress model applicable to the family/caregiver include extended physical and psychological strain, high levels of unpredictability and uncontrollability, creation of secondary stress in other areas of life due to caregiving, and high levels of vigilance. Objective stressors such as physical disability, cognitive impairment, problem behaviors, and type and intensity of care cause psychological distress and physiological responses contributing to caregiver illness and mortality. Moderating factors include the caregiver’s access to resources, socioeconomic status, prior health status, and level of social support (Schulz and Sherwood 2008). The caregiver strain theory is often used as a means to explain and
examine the negative health outcomes family/caregivers experience (Brown and Brown 2014).

1.4.2 Criticism of the Caregiver Strain Theory

Brown and Brown (2014) criticize the use of the chronic stress model to explain family/caregiving experience and believe that the prevalence of caregiver burden causing negative health outcomes is overstated. In spite of the stress often associated with the family/caregiver role, approximately one-third of caregivers do not report negative effects and even identify positive outcomes, including new skills, feeling purposeful or needed, strengthened relationships, and feeling good about oneself (Schulz and Sherwood 2008). This is somewhat attributed to variations in intensity and duration of caregiving. Effects of caregiving on health are perceived to be greatest when there is long duration or high intensity (Brown and Brown 2014). Level of patient suffering is also an important aspect for consideration in relation to patient and family/caregiver experience (Schulz and Sherwood 2008).

When investigating family/caregiver experience, researchers often are biased based on preconceived notions of family/caregiver burden. Brown and Brown (2014) also identify methodological limitations. In studies of family/caregivers, burden is often attributed to family/caregiver experience without considering potential confounding variables that can also contribute to negative health outcomes – such as age,
socioeconomic status, previous health status, and assortative mating – selection bias, or skewed interpretation.

Brown and Brown (2014) believe that the chronic stress model is not appropriate as a means to encapsulate family/caregiver experience and is in great need of revision based on the biological and evolutionary adaptive value of caregiving. This critique is based on data demonstrating the health benefits and positive well-being associated with caregiving and the ways in which non-human animals also care for one another (Brown and Brown 2014).

1.4.3 The Healthy Caregiver Theory

Some scholars attribute positive caregiver outcomes to the nature of those individuals who tend to assume the family/caregiver role (Bertrand et al. 2011; Brown and Brown 2014; Fredman et al. 2010). The healthy caregiver theory is predicated on the notion that physically healthier individuals are more likely to assume the family/caregiver role. Activity level based on the assumption of the family/caregiver role contributes to the family/caregiver’s personal health maintenance, strengthening the caregiver health advantage (Brown and Brown 2014).

1.4.4 Criticism of the Healthy Caregiver Theory

Though the healthy caregiver theory has logical appeal, little evidence exists to support this theory. Additional studies regarding how families select the individual
family member/caregiver primarily responsible for care are needed to examine the applicability of the healthy caregiver theory. (Brown and Brown 2014).

1.4.5 Alternative Approach

Brown and Brown (2014) developed the alternative approach to challenge both the caregiver strain and the healthy caregiver theory. The alternative approach cautions against sweeping causal generalizations and potential misleading overstatements regarding associations between negative health outcomes and the informal family/caregiver role. Brown and Brown (2014) situate family caregiving in the context of evolution in which caregiving guides behavioral changes along adaptive lines. Caregiving is conceived of as an adaptive response contributing to survival for family/caregivers based on motivational conflicts and tradeoffs. Negative family/caregiver emotions are not perceived as dysfunctional responses, but as part of a larger biological sensitivity to context. There are also positive feelings associated with caregiving, including closeness, sympathy, compassion, and love. Positive emotions function to increase or encourage caregiving behaviors, though caregiving behaviors may also have negative effects (Brown and Brown 2014).

Brown and Brown (2014) encourage application of the alternative approach to research and theory, family/caregiver assessment and intervention, and public policy. This alternative approach provides a more balanced view of caregiving incorporating
biological principles and both positive and negative effects of caregiving on the
family/caregiver (Brown and Brown 2014). Applying the lens of the alternative approach
provides a means to recognize both positive and negative family/caregiver experiences,
at times within the same individual family member/caregiver experience (Brown and
Brown 2014).

1.5 Disease Burden: Neurological Disorders and Disability

It is also necessary to contextualize the experiences of patients and their
family/caregivers within the context of the patient’s pathology. Although many
neurological disorders have acute onset, they are often associated with chronic sequelae
and long-term disability. Patients with neurological disorders or disability often require
significant support from family members/caregivers due to associated physical,
cognitive, and psychosocial limitations (Picenna et al. 2016; WHO 2006).

1.5.1 Neurological Disorders: Global Burden and Issues

According to the Global Burden of Disease 2010 Study, stroke is the second
leading cause of death globally and the third leading cause of death and disability
(Murray et al. 2012). Nervous system disorders are major causes of death and disability
globally and have emerged as a global health priority (Chin and Vora 2014; Silberberg et
al. 2015). Neurological disease or disability may result from neurological disorder,
cognitive dysfunction from malnutrition, poor sanitation, or as an effect of HIV-acquired
immunodeficiency syndrome (HIV-AIDS), or intracranial, spinal, or nerve injuries due to road traffic injury, war, falls, or other violent injury (Chin and Vora 2014).

A variety of conditions and diseases cause or contribute to neurological disease or disability; due to this, it is necessary to delineate a definition of neurological disease as operationalized globally. The Global Burden of Disease includes neurological disorders in the neuropsychiatric category and disorders/injuries with neurological sequelae in other categories. Neurological disorders in the neuropsychiatric category include epilepsy, Alzheimer and other dementias, Parkinson’s disease, Multiple Sclerosis, and migraines for both years lived with disability (YLDs) and disability-adjusted life years (DALYs). For YLDs, disorders/injuries with neurological sequelae in other categories include cerebrovascular disease (CVD), neuroinfections, nutritional deficiencies and neuropathies, and neurological injuries, while for DALYs and deaths disorders/injuries include CVD, poliomyelitis, tetanus, meningitis, and Japanese encephalitis (WHO 2006).

Neurological disorders and CVD represent 7.1 percent of the global DALY burden for all causes and ages (Chin and Vora 2014). By 2010, neurological, mental, developmental, and substance-use disorders were estimated to account for more than 29 percent of the global burden of disease (Silberberg et al. 2015). CVD has the highest disability-adjusted life year (DALY) burden for neurological disorders at 58.1 percent of
the total neurological burden and 4.1 percent of the total global DALY burden (Chin and Vora 2014). Traumatic brain injury (TBI) – not counted by the Global Burden of Disease within neurological and mental disorders, but within injury – represents 11.2 percent of the global DALY burden (Chin and Vora 2014).

While some neurological disorders are congenital, others are acquired over the life course and have chronic sequelae leading to disability. For instance, neurological disorders, such as stroke, have considerable long-term impact regardless of age at first incident. Patel et al. (2006) estimated that 26 percent of study participants were moderately or severely disabled three years post-stroke. TBI also impacts individuals regardless of age. TBI is the leading cause of disability of people under 40. Most recovery occurs in the first two years post-TBI. Individuals who survive the initial two years post-TBI often have good outcomes, though they may experience issues with memory, attention, executive function, behavioral control, and regulation of mood (Fleminger and Ponsford 2005). Among individuals who have survived TBI, approximately three-quarters report no TBI-related problems decades later; however, some still suffer from problems with memory, thinking, and physical and emotional health. Increased TBI severity is also associated with heightened risk of TBI-related sequelae (Brown et al. 2011). Though neurological disorders, such as stroke or TBI, may
be acute onset they also often lead to complex chronic disabilities that patients and family/caregivers must address for the duration of the patient’s life.

Neurological disorders impact not only the individual patient, but also the patient’s family and community. The nature of neurological diagnoses often causes uncertainty and fear for patients and their family. Potential physical concerns include memory loss, incontinence, pain, change in appearance, effects on sexual and reproductive health, ability to communicate, or even severe disability and dependency. Socioeconomic concerns for patients and family/caregivers include dependency on other family members, change in family role, loss of employment, financial burden, loss of independence, changes in ability to participate in activities, and other effects on family and caregiver (Hewer 1997).

Neurological events can also have social and psychological impact on both patient and family/caregiver. The most frequent psychiatric problem associated with stroke is depression; as many as 31 percent of individuals develop depression post-stroke (Hackett and Pickles 2014). Patients who have suffered a neurological event often have new disability causing role change within the family due to new or increased dependence on family/caregiver. Because of the ways in which neurological disorders and new disability can change preexisting social systems, neurological illness can strain or strengthen the relationships between family/caregiver and patient. Patient role
change can also lead to boredom and/or depression. Both patients and family/caregivers may experience frustration with patient reliance upon family/caregiver. Loss of speech is a common consequence of stroke and other neurological disorders. Additionally, limited ability to communicate is identified by both patients and family/caregivers as an emotional trigger related to dependence (Lynch et al. 2008).

Social and economic difficulties are compounded in low- and middle-income countries (LMICs) by the limited availability of neurological care and the lack of effective integrated care pathways to ensure appropriate rehabilitation post-treatment (Singhal and Khadilkar 2014). LMICs have a smaller proportional burden of neurological disorders and cardiovascular disease when compared to the high burden in LMICs of communicable disease. However, people living in LMICs are also more likely to experience long-term effects from early life trauma, infectious disease, and malnutrition, which can contribute to the development of neurological disease or disability (Silberberg et al. 2015). The absolute burden of neurological disorders and cardiovascular disease is six times higher in LMICs as compared to high income countries (Chin and Vora 2014). Age-adjusted mortality rates for stroke alone are three to four times higher in LMICs than in high income countries. High burden of neurological disorder and disability in LMICs is further compounded by lack the
resources and infrastructure to provide care for neurological patients (Chin and Vora 2014).

Importantly, though, the negative impact of most neurological disorders and diseases can be prevented or treated with appropriate care and rehabilitation. The potential to mitigate neurological disability through improved care systems emphasizing family- and patient-centered approaches is vital in confronting the global burden of neurological disease and disability.

1.5.2 Disability from Neurological Disease: Global Burden and Issues

Nervous systems disorders are major causes of disability. While many neurological disorders are acute, they often have chronic sequelae that heavily impact the life of the patient and family/caregiver, including potential changes in cognitive, physical, and social functioning (Hewer 1997). The World Health Organization (WHO) estimates that 15 percent of the world’s population has some form of disability. Of these approximately 1 billion people living with disability, between 110 and 190 million suffer severe functional impairment (WHO 2016). Many people with disability suffer acutely from loss of functionality and drastic change in social role, including those suffering new mental, cognitive, and physical limitations after an acute neurological event (WHO 2016).
The WHO’s International Classification of Functioning, Disability, and Health (ICF), the international standard to describe and measure health and disability, includes six domains of functioning: cognition, mobility, self-care, getting along (social interactions), life activities, and participation. Functioning and disability are conceptualized as a “dynamic interaction between a person’s health condition, environmental factors, and personal factors,” in which disability is represented through bio-psycho-social synthesis of both the medical and social models (WHO 2013:4). Disability represents negative aspects or limitations of physical and social functioning based on the six domains of functioning (WHO 2002).

New disability can arise as the result of an acute injury or illness, hospitalization, or poor post-hospital care (Covinsky et al. 2011). The risk for disability is based on an individual patient’s functional reserve, or his or her vulnerability and ability to recover, and compounded by the severity of acute illness and hospitalization and post-hospitalization factors. Preillness determinants that influence functional reserve include age, mobility, cognitive function, preexisting limitations on activities of daily living or instrumental activities of daily living, geriatric syndromes, social functioning, and depression. Even during hospitalization, the environment, restricted mobility, dependence, and changes in nutrition can lead to hospitalization-associated disability.
(HAD). Then, post-hospitalization, the environment, resources, community support, and nature of discharge can lead to new disability (Covinsky et al. 2011).

Family members/caregivers often assume the caregiving role at disease onset and continue to care for the patient during hospitalization and throughout post-hospitalization rehabilitation (Brereton and Nolan 2002). Family/caregivers are important care providers for neurological patients who often have complicated chronic sequelae and care needs post-hospitalization and even post-rehabilitation (Shaji and Reddy 2012). The importance of post-hospital care in promoting recovery and preventing new disability after a neurological event emphasizes the importance of family/caregivers as collaborative members of the care team providing long-term care to patients after a neurological event (Naylor and Keating 2008).

1.5.3 Disease and Disability in Argentina

In Argentina specifically, the burden of disease is largely attributable to noncommunicable diseases. Premature deaths from noncommunicable diseases account for 20.8 percent of all deaths in people less than seventy years old (PAHO 2012). The leading causes of Years of Life Lost (YLLs) to premature death include ischemic heart disease, lower respiratory infections, CVD, and road injury (IHME 2013). The burden of noncommunicable disease in Argentina is also rising. Between 1990 and 2010, the
percentage of DALYs attributable to stroke in Argentina increased by more than one-third (IHME 2010).

According to the National Registry of People with Disability (based on the Certificate of Disability), 731,745 Argentineans were living with disability in 2015. Of those living with disability, 32 percent reported mental disability, 29 percent motor, 8 percent visceral, 8 percent auditory, and 5 percent visual. An additional 14 percent of people living with disability in Argentina are certified as experiencing multiple disabilities (SNR 2015). In Argentina, 46.9 percent of all disability is attributed to neurological disease (Somoza and Melcon 2015). Almost all of neurological disability in Argentina is due to three groups of conditions: 43.4 percent is due to dementias, 37.6 percent to CVD, and 14.1 percent to epilepsy (Somoza and Melcon 2015). Neurological disability in Argentina has a high burden.

Disability in Argentina is perceived as a medical problem (Schrader and Chavez Penillas 2012). Legally, Argentina has a national policy defining disability and governing the administration of services to people certified as living with disability (Ley No. 25.504). In its national disability policy, Argentina recognizes the ICF conception of functioning and disability with the bio-psycho-social synthesis of health, environment, and personal factors, suggesting a legal shift in the way disability is perceived in Argentina with the potential for a sociocultural shift (Ley No. 25.504; SNR 2015).
Disability in Argentina is categorized into five specific groups: motor, visceral, mental, auditory, and visual disability (SNR 2015). These five categories (and their combinations) are used to determine citizen eligibility for Argentina’s national Certificado Único de Discapacidad (Certificate of Disability) under the national disability policy. Argentina’s Certificate of Disability allows people living with disability guaranteed benefits, including government-provided healthcare and free public transportation. Eligibility is determined by health status (as certified by a medical professional), demographic variables, and review by an interdisciplinary board (SNR 2015). While a comprehensive national disability law does exist in Argentina, provincial implementation is varied (Reed 2015). Limited implementation has led to a shortage of services for people living with disabilities, low labor force participation, and poor housing (Schiappacasse et al. 2014).

CVD is preventable and treatable. The impact of stroke and other neurological diseases on DALY burden can be mitigated through recognition of the necessity of transitional care strategies and the implementation of integrated care to prevent the new disability and mitigate severity of existing disability post-neurological event.
1.6 Healthcare Delivery

1.6.1 Argentina: Sociodemographic Context and Health System

Argentina is an upper-middle income country with a population of 43,886,748 people (CIA 2017; World Bank 2017). About 12 percent of the population is over the age of 65 (World Bank 2014). More than 90 percent of the population is urban (World Bank 2014). Approximately one-third of the population lives below the poverty line (CIA 2017).

Argentina spends 605 USD per capita on health or 4.8 percent of its gross domestic product (World Bank 2014). Argentinean health statistics are similar to that of Chile and Uruguay, though on some measures Argentina fairs worse than its economically similar neighbors. Life expectancy at birth is 76.3 years in Argentina as compared to 78.8 years in Chile and 77 years in Uruguay (World Bank 2014). In regards to maternal mortality, Argentina has 52 maternal deaths per 100,000 live births, while Chile has only 22 and Uruguay 15. Argentina is predicted to have limited success resolving national health issues and improving key indicators without addressing the provincial delivery of healthcare (Belló and Becerril-Montekio 2011).

Argentina is a presidential republic that has had peaceful transfers of power since 1989. The Ministry of Health has national treatment guidelines (updated in 2010) for primary care, secondary care, and pediatric conditions (WHO 2010). Argentina went
through a health sector reform in the 1990s as part of a wider economic and social restructuring. The aim of healthcare reform was to decentralize services and restructure the health insurance system (Belló and Becerril-Montekio 2011).

Argentina’s national health policy is administered by the Ministry of Health. The government is the responsible-garante with the duty of protecting health as a right for all citizens. Healthcare in Argentina is organized around three main insurance schemes: public, **Obra Social** (Social Security), and private. Public insurance is financed by taxes, Social Security by compulsory payroll contributions, and private insurance from out of pocket contributions (Belló and Becerril-Montekio 2011). In Argentina, 63.92 percent of Argentineans are insured, meaning that slightly more than one-third (36.08 percent) of all Argentineans have no health insurance (INDEC 2010). Of those insured, 46 percent have Social Security, 11 percent have prepaid Social Security, and less than 2 percent are on a state health program or plan. Only 5 percent of Argentineans have private health insurance (INDEC 2010). 30.7 percent of health expenditure is out of pocket (World Bank 2014).

Recently, Argentina’s Ministry of Health has created a Plan for Universal Health Care. This decree, issued in 2016, demonstrates Argentina’s commitment to improve the quality of primary care, develop and modernize Integrated Networks of Health Care Services through technological advances in the public health system, and promote
preventive care (Decreto 908). Argentina’s PUHC is expected to provide care for 15 million Argentineans currently receiving care from public hospitals. The Argentinean Plan for Universal Health Care will also provide care for people living with disability (Rodriguez-Ferrand 2016).

### 1.6.2 Risk of Disability and Disease Burden from Fragmentation of Care

Currently, the experience of newly disabled patients, and especially the experience of family/caregivers, as they transition home from the hospital in Argentina is not well understood. Burden as defined by hospital readmissions does not consider the quality of life or functional status patients’ experience post-hospitalization; furthermore, it does not accurately reflect the challenges patients, caregivers, family, communities, and health systems confront in regards to transitioning home from the hospital and navigating newly acquired disability (Naylor and Keating 2008).

Disability after an acute injury or illness can best be mitigated with appropriate care that begins early in the hospital and is planned to continue when a hospitalized patient transitions to post-hospital services and then home. Fragmentation in care can complicate these care transitions, threaten patient safety, and potentially compromise recovery (Chen et al. 2015). The hospital to home transition is a critical intervention point independent of patient age, cultural values, country, or other available resources. In the United States, the care continuum is delineated by a range of services on a scale
from higher to lower intensity. In the U.S., potential locations of care include short-term and long-term acute hospitals, inpatient rehabilitation facilities, skilled nursing facilities, outpatient clinics and rehabilitation, homecare, and hospice. In Argentina, the availability of these services varies dramatically by geographic region. Furthermore, the care continuum for neurological disorders is complicated by the common need for post-hospital rehabilitation and care (Wissel et al. 2013); yet, limited by access and availability. Patient transitions can be difficult for patients and their family/caregivers as they try to adapt to changing roles and locations of care (Chen et al. 2015).

The care continuum is less understood in LMICs and yet simpler in many aspects due to the limitation on service availability for different levels of patient acuity. The predominant care pathway for patients with acute illness or injury includes one major transition: hospital to home and community. Evidence suggests that during the hospital-to-home care transition patients are particularly vulnerable to fragmentation and breakdowns in care that may lead to adverse health events, low satisfaction with care, and high rates of rehospitalization (Naylor and Keating 2008).

Implementation of effective transitional care strategies has the potential to prevent new disability and mitigate existing disability. Transitional care is a “set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location”
(Coleman and Boult 2003:556). Transitional care refers to a broad range of services. The purpose of transitional care is to use time-limited approaches to ensure continuity of care, prevent poor health outcomes, and promote safe transfer of patients between settings. Transitional care differs from primary care, discharge planning, care coordination, and disease management (though it may share characteristics with these forms of care) in that it is time-limited, focuses on highly vulnerable or chronically ill patients, and emphasizes the role of family/caregivers. In transitional care, family/caregiver education and empowerment as members of the care team is essential to the continuity of care as a means to prevent rehospitalization and mitigate disability (Naylor et al. 2011).

Scholars and national organizations have difficulty agreeing upon a singular definition of best practice for transitional care. Scholars are unified in calling for comprehensive discharge planning, though other components identified vary. Components identified as essential in ideal transitional care models include: communication, such as transition records/care plans; availability, timeliness, clarity, and organization of information; medication safety; educating patients and promoting self-management; a tool for plan of care; enlisting the help of social and community supports; advanced care planning; coordinating care among team members; monitoring and managing symptoms post-discharge; follow-up with outpatient providers; and,
monitoring and improving transitions (Rochester-Eyguokan et al. 2016). Based on a review of 188 articles describing transitional care models, Rochester-Eyguokan et al. (2016) identified multimodal (occurring across multiple care transitions), multidisciplinary interventions focused on strengthening communication as best practice in transitional care. Though Rochester-Eyguokan et al. (2016) did identify multimodal, multidisciplinary models as best practice in transitional care, the authors also recognized the need for transitional care models to be tailored to the care context based on patient population and specific setting.

Currently, the lack of a transitional care strategy in many countries, including Argentina and many other LMICs, represents a key gap in services that hinders patients’ ability to more fully heal after an acute injury or illness. Lack of transitional care can also unduly burden family/caregivers economically, physically, and emotionally. Stroke and other acute neurological conditions with high survivorship associated with chronic physical, cognitive, and emotional sequelae heavily impact the quality of life of survivors and their family/caregivers (Wissel et al. 2013). Fragmentation of care threatens the ability of patients to recover optimally and family/caregivers to support progress. Patients and family/caregivers often report fragmented or limited support as patient’s transition home from the hospital (Piccenna et al. 2016). Key contributors to unsatisfactory experience and less favorable outcomes include poor communication,
limited opportunity to participate in care, and disorganized social support services (Piccenna et al. 2016).

Although family/caregivers play an important role during hospitalization and after discharge, they tend to rate their level of engagement in decision-making and preparedness for the patient’s transitions as low (Naylor and Keating 2008). Family/caregivers represent key members of patient medical experience and are particularly important as a patient transitions to a rehabilitative or home setting in which family/caregivers assume a greater role for direct care (Naylor and Keating 2008). This is particularly relevant in LMICs where services post-hospitalization are limited. Understanding the experiences of caregivers provides valuable information to form appropriate interventions to assist caregivers and increase quality of life for caregivers and people living with disability. Currently, the dearth of proven, effective strategies to aid caregivers in their role represents a key gap in services that threatens the health of those living with a disability and their ability to recover, as well as burdens caregivers economically, physically, and emotionally. Aiding family/caregivers, especially during care transitions, can help to minimize burden and support the ability of family/caregivers to care for a loved one after an acute neurological event (Naylor and Keating 2008).

There exists a clear and compelling need to investigate and address caregiver
experience across an episode of care. Understanding how patients and family/caregivers experience illness and recovery is essential to the development of appropriate and effective health systems to promote rehabilitation, recovery, and quality of life (Burton 2000; Schrag 2010). Understanding experience can help shape health system change towards integrated care pathways and person-centered care (WHO 2002; WHO 2013; Wissel et al. 2008). Ultimately, health systems strengthening should include strategies to support care transition as an essential component to healthcare delivery, as well as the recognition that informal family caregivers are vital providers of health care who also have specific health needs deserving attention.

1.7 Study Purpose

Family members/caregivers often assume the caregiving role after an acute neurological event and work with medical providers to provide care and support the patient. This study explores the experiences of family/caregivers in Buenos Aires, Argentina, as members of the care team after a family member experiences an acute neurological event and the family/caregiver is newly assuming the caregiving role. Bronfenbrenner’s Ecological Systems Theory is applied to ethnographically explore the interaction and reciprocity between patient, family/caregiver, medical provider, and health system in the ICU from the family member/caregiver’s perspective. Findings can highlight the role that family/caregivers play as members of the care team. Findings can
also inform development and improvement of patient- and family-centered care across the care continuum.
2. Methods

2.1 Project Design

This study is part of a larger study in Buenos Aires, Argentina. The objective of the larger study is to improve the relationship between patients, families, and medical providers through the use of educational videos to teach and train family members in the daily handling of the patient in regard to nutrition and basic rehabilitation. This study investigates the experiences of family/caregivers to better understand potential needs in regards to patient care.

The purpose of this sub-study is to improve knowledge regarding the experiences of patients and their family after an acute neurological event as the patient transitions through the health system. This study was approved by Hospital Italiano de Buenos Aires’s Comité de Ética y Protocolos de Investigación (Committee of Ethics and Investigative Protocols), the equivalent of an Institutional Review Board. Study design and data collection were completed at Hospital Italiano de Buenos Aires. All participants provided written informed consent.

Interview transcription, translation, and data analysis were completed at Duke University. This study was also approved by the Duke University Health System Institutional Review Board. Interviews were transcribed verbatim by the lead investigator. To protect confidentiality, all identifying information and protected health
information was removed from interview transcripts. Interviews were then translated by
the lead investigator. Interviews were translated from Spanish to English line-by-line
with minimal edits and/or interpretation to preserve the participants’ original meaning
as much as possible. Interviews were then coded thematically using NVivo 11.4.0 for
Mac. Coded transcripts were analyzed using thick description and comparison and
categorization of codes. Illustrative quotations incorporated in the results section were
edited for clarity and grammar so as to best represent the meaning and voice of
participants.

2.2 Theoretical Framework

The previously discussed theories of caregiver experience, including the
caregiver strain theory, healthy caregiver theory, and alternative approach, provide a
means to understand family/caregiver experience. Family/caregiver theories are useful
and necessary to understand the potential positive and negative effects on health and
well-being an individual may experience as he or she assumes the caregiving role
(Brown and Brown 2014; Schulz and Sherwood 2008). The primary focus of
family/caregiver theories is the effect of caregiving on the individual family/caregiver.

In this study, family/caregiver experience is understood in relationship to other
actors in the ICU setting, including patients, healthcare providers, and the health system
generally. Due to this, Bronfenbrenner’s Ecological Systems Theory primarily informed
study design in lieu of more traditional family/caregiver theories. A patient-centered systems approach provides a means to understand not only family/caregiver experience as an isolated group, but also family/caregiver interactions and relationships with other groups in the ICU. In doing so, it provides a more holistic representation of family/caregiver experience assuming the caregiving role and participating as members of the care team in the ICU. Individual family/caregiver theories recognizing the mental, emotional, and physical impact on family/caregiver still form the foundation of family/caregiver experience as incorporated with other actors.

2.2.1. Critical Medical Anthropology and Bronfenbrenner’s Ecological Systems Theory

Merrill Singer identifies key issues with conventional medical anthropology, in which there is, “a narrow understanding of social relations; inattention to the political structuring of meaning in the clinical setting; a desocialized approach to the human/environment relationship; and far-reaching medicalization” (1990:179). To correct these issues, Singer calls for the use of critical medical anthropology (CMA) (Singer 1990). Key elements of CMA integrated in study design include recognition of: 1) the role of power within relationships in health care systems and how this may affect medical experience, and 2) the importance of sufferer experience, also known as the lived experience of individuals dealing with illness, suffering, and healing, and the social relationships of those who are ill.
Urie Bronfenbrenner’s Ecological Systems Theory provides the basis for study design as a means to explore the interactions, experiences, and relationships between those who are ill, family members/caregivers, medical providers, and the health system broadly in line with CMA theory (Bronfenbrenner 1977). Systems theories have had broad application in a variety of disciplines, including physical, biological, and social sciences, such as anthropology. Historically, systems analysis in anthropology has applied mathematical methods to understand physical, biological, or social phenomena to display human adaptation in webs of mutual causality. Modern systems theory provides a means to explore relationships and interactions between variables. In this sense, systems theory provides a framework for analysis incorporating the traditional anthropological holism. Modern anthropological systems theory differs from anthropological holism in that it specifies units within relationships. Systems analysis can be static or dynamic; regardless, systems theory provides a means to model multiple relationships in a variety of ways. Anthropology recognizes that there is no single systems theory; rather, there exist many ways to examine dynamic relationships between salient units (Rodin et al. 1978).

Originally, Bronfenbrenner developed Ecological Systems Theory to apply to the psychology of human development (Bronfenbrenner 1977). Ecological Systems Theory conceives of the environment as a “nested arrangement of structures, each within the
next” (Bronfenbrenner 1977:514), in which there are reciprocal interactions within and between these nested structures. Moreover, each level is most influenced by the two layers surrounding it. In Bronfenbrenner’s Theory, there are four levels radiating out from the individual: the microsystem (immediate setting, including, family, school, or peers), the mesosystem (interconnections between the micro and exosystems), the exosystem (specific social structures, including major societal institutions such as community and government, and the macrosystem (social system, including economics, culture, and politics) (Bronfenbrenner 1977).

The use of Ecological Systems Theory provides a framework by which to understand reality regardless of discipline (Rodin et al. 1978). Systems approaches are used in public health to examine how change occurs within and across institutions or organizations (Glanz et al. 2008). Additionally, Ecological Systems Theory has been widely used to understand health behavior and promotion and community health research (Glanz et al. 2008; Gregson et al. 2001; Lounsbury and Mitchell 2009; McLeroy et al. 1988).

Challenges with applying ecological theories and models to health behavior and promotion include the need for further assessment and development of data collection methods within and between each level of the model (Gregson et al. 2001). A subsequent challenge of using social-ecological models in research is the potential need for
significant investment in formative research as a means to understand roles and
structures between and within levels. For instance, there currently exists little empirical
evidence to inform application of systems theories to a variety of systems, including
community health organizations, workplaces, or communities. There is also limited
evidence regarding appropriate outcomes and control variables to explain systems
models as complex data sets (Glanz et al. 2008). Due to this, qualitative methods can
provide a formative means to better conceptualize dynamics within social-ecological
systems before the implementation of further research (Lounsbury and Mitchell 2009).

While some critics maintain that systems theory is limited to a static
representation of reality, other scholars argue that systems theory can be used to
understand dynamic systems of change or static environments (Rodin et al. 1978).
Social-ecological models provide a means to understand dynamic and complex
interactions within environments across time and space within a bounded set of
individuals (Lounsbury and Mitchell 2009; Rodin et al. 1978). Additionally, critics of
systems theory argue that a system cannot accurately capture the variability of human
experience. While it is true that it can be difficult to capture flexible, varied, human
experience in a single model, anthropologists also recognize the value of systems
theories as heuristic devices for understanding cultural processes while simultaneously
considering the limitations of systems theory as a means to fully capture a wide range of human experiences.

When applying social ecological systems and/or models to health events, caution must be taken to avoid overgeneralization beyond the specific context. Identifying the appropriate level of analysis in systems models can help avoid overgeneralization and better understand interconnections and influence between levels based on the specific problem studied. Yet, an additional challenge of applying socio-ecological theory can be choosing a more specific, contextually appropriate model while questioning the imposition of one’s own biases. When applying a socioecological model it can be easy to identify the relationships already present in the model, regardless of reality, because the model forecasts those relationships (Rodin et al. 1978). In using and applying ecological systems theory it is necessary to recognize and attempt to mitigate bias.

Ultimately, ecological systems models recognize that behavior and experience is affected by an individual’s social environment. Ecological systems and/or models move beyond the individual to recognize the various forces that affect and influence experience and health (McLeroy et al. 1988). Division of social environment into analytic levels assists in the delineation of different types of interactions and social influences as a means to develop appropriate, targeted interventions through investigation of patterned behavior by individuals or in groups as the salient outcomes (McLeroy et al.
A common criticism of ecological models is that they lack specificity to guide interventions. To avoid this issue, study design uses a context-specific representation of Bronfenbrenner’s Ecological Systems Theory to be discussed in greater detail below (Bronfenbrenner 1977).

### 2.2.2 Patient-Centered Care

Study design is also rooted in the principles of patient- and family-centered care. A major proposition of this study is the importance of addressing patient and family/caregiver experience as a means to improve care, acknowledging patients as autonomous, complex human beings with varied needs and perceptions, and recognizing the significant role that family members/caregivers play as integral members of the care team.

Patient-centered care, also known as family-centered care in primarily pediatric settings, emphasizes the need for respect for patients as individual human beings as imperative, thus placing importance on patient and family/caregiver perspectives and decisions regarding medical care (Epstein and Street 2011).

Most patients in Intensive Care settings who have suffered an acute neurological event are unable to participate in qualitative studies due to their health status. Because the family has a central role in patient care both in and outside of the hospital (Bowen et
al. 2001; Li et al. 2003), family members/caregivers are the focus of data collection to better understand patient and family/caregiver experience.

### 2.2.3 Integrating and Applying Ecological Systems Theory and Patient-Centered Care

Patient-centered care and Ecological Systems Theory are integrated as the foundation of study design. Additionally, ecological principles can be applied to health systems to understand stakeholder experiences, including the patient’s relationship with family, medical providers and the hospital environment, and the health system at large (Glanz et al. 2008; Lounsbury and Mitchell 2009; McLaren and Hawe 2005).

In applying Ecological Systems Theory principles to health in this study, a simplified patient-centered model developed by the lead investigator and research team based on systems theory and health promotion literature with four salient levels is used: patient, family/caregiver, provider, and health system (Figure 1) (Bronfenbrenner 1977; Gregson et al. 2001). Bronfenbrenner’s microsystem and the common “interpersonal” level (encompassing family, peers, social network, and associations) used in health behavior and promotion literature is divided here to better differentiate between family/caregiver and health provider (Bronfenbrenner 1977; Gregson et al. 2001).
Figure 1: Model of patient-centered study design based on Bronfenbrenner’s Ecological Systems Theory and the principles of CMA (Bronfenbrenner 1977).

1Based on the principles of patient- and family-centered care the patient is the center of the model, the individual level of Bronfenbrenner’s Ecological Systems Theory.

2In Bronfenbrenner’s theory, Family/Caregiver and Health Provider both form part of the microsystem, the immediate setting of the individual at the center of the theory. In this model, Family/Caregiver and Health Provider have been separated to distinguish the relationships and interactions each has with the patient and other levels.

3The Family/Caregiver and Family form the same layer of the microsystem, the immediate setting of the patient. However, Family/Caregiver and Family are separated so as to delineate differences in relationships between Family members who do not assume the Caregiver role and Family who become Family/Caregiver and assume the Caregiver role.
2.3 Setting

Data collection occurred in Buenos Aires, Argentina, in the adult ICU of Hospital Italiano de Buenos Aires, a private, Joint Commission-certified teaching hospital. The ICU of Hospital Italiano is “open” in that there are no visiting hours – family/caregivers are allowed to remain with their loved ones at all times. Patients are assigned an attending physician. Family/caregivers attend daily conferences around midday with the attending physician to receive a report on the patient’s health status and ask any questions they may have. Patients are also cared for by teams of specialists in addition to the attending team. The neurocritical care team consisted of a lead neurologist, neurological fellows, a neurocritical care nurse, and various residents rotating between teams in the ICU. The neurological critical care team is unique in this ICU in that the team has a nurse dedicated to neurological patients. No other specialist team in this ICU had a specialized nurse assigned to the team.

2.4 Participant Population

Participants were the primary family/caregivers of patients who had been hospitalized in the ICU. All patients had suffered an acute neurological event and were under the care of the neurocritical care team. We targeted family/caregivers of patients after a neurological event based on these criteria: (a) at least 18 years of age, (b) caring for someone newly disabled (as defined by self-report of new physical limitations), (c)
caring for someone recently hospitalized for a neurological injury or illness who will transition home or to a rehabilitation center from the hospital, (d) cognitively able to provide informed consent, and (d) Spanish or English speaking. Family/caregivers of patients not in the ICU for sufficient time (24-48 hours) to be approached and interviewed or patients without family/caregivers present and identifiable in the ICU were excluded.

2.5 Procedures

Study implementation occurred over the course of eleven weeks. This included direct observation and semi-structured interviews. The lead investigator remained in the presence of a neurocritical care team member during all observations and patient interactions. An a priori interview guide was developed outside of the care environment based on Bronfenbrenner’s Ecological Systems Theory and relevant transitional care, family/caregiver burden, neurological disorder, and rehabilitation literature (Bronfenbrenner 1977; Coleman and Boult 2003; Covinsky 2011; Martinsen et al. 2015; Naylor and Keating 2008; Rochester-Eyeguokan et al. 2016).

2.5.1 Direct Observation

Direct observation is useful when trying to understand ongoing behaviors, processes, or unfolding situations or events (Taylor-Powell and Steele 1996). The first two weeks of study implementation consisted entirely of direct observation to
familiarize the investigator with the setting. Based on Bronfenbrenner’s Ecological Systems Theory, observations focused on relationships and interactions between family members/caregivers, patients, and medical providers through body language, speech, and other gestures, as well as general patient and family/caregiver experience to better understand behaviors, processes, and relationships across ecological levels. During these two weeks, direct observations occurred daily during the rounds of the neurocritical care team and the separate rounds of the neurocritical care nurse.

Written consent was not necessary since observations occurred during a time when patients and families were aware they were being monitored, no protected health information was recorded, and only written notes were taken during observations. Oral consent was obtained. To obtain oral consent, a medical provider briefly explained the purpose of the study was to better understand patient and family/caregiver experience and that the investigator was observing interactions between patient, family/caregiver, and provider and recording observations using written notes. Family/caregivers were then asked if the lead investigator could observe as part of the medical team. Participant reactivity to observation was limited since observations occurred in the course of regular hospital procedure and the lead investigator was one observer embedded among a group of medical providers (Bernard 2011a). Individual patient observations lasted between five and thirty minutes, though the length of data collection was longer as it
often included multiple patients (all current neurocritical patients). The exact number observed on any one day was variable.

Direct observation in the first two weeks served two purposes: 1) to familiarize the lead investigator with the setting, and 2) to inform the revision of study design to be appropriate to family/caregiver and patient experience and to be feasible within the environment. Observation of patient, family, and medical providers helped to determine the feasibility regarding number of interviews per family/caregiver, sample size, and site of interviews. Because of the extended length of time patients remain in the ICU, the most feasible study design was determined to be a single interview of a family member/caregiver several days after patient admission to the ICU. This ensured that the lead investigator and family/caregiver (participant) had a chance to become familiar before the interview. Projected sample size was kept low to account for the limited, and somewhat unpredictable, number of patients admitted with a neurological diagnosis. Additionally, each participant was interviewed once because of overwhelming difficulty with tracking family/caregivers after the patient left the ICU. ICU physicians were not involved in post-hospitalization follow-up and had limited involvement in patient care in-hospital after the patient left the ICU. These factors made a second interview of a participant after the patient had experienced a care transition prohibitively difficult.
Direct observation continued throughout the nine weeks of participant identification and interviewing after the initial two-week period to aid the investigator’s comprehensive understanding of patient and family/caregiver experience. Observations continued during the daily rounds of the neurocritical care team and the rounds of the neurocritical care nurse. Additional observations during the rounds of the hospital’s Unidad de Planificación de Alta (Discharge Planning Unit) and family conferences between family/caregiver and the attending physician in the ICU were completed. The lead investigator observed the Discharge Planning Unit rounds two times, family conferences with providers three times, and the neurocritical care team and nurse rounds several times each week over the course of the nine weeks in order to have robust observations and remain familiar with current patients and family members/caregivers before they were approached for interviews.

Both observations and researcher reflections were recorded during direct observation, though observations and reflections were kept separate to maintain more objective observation data with reflective reactions to note potential bias. More objective observations and subjective reflections were recorded separately to enable the lead investigator to better recognize inherent bias (Taylor-Powell and Steele 1996). While observations provided a more objective account of events and experiences, reflections helped the investigator to revisit subjective reactions, recognize bias, empathize with
patients and family/caregivers, and immerse herself in the ICU environment as much as possible. After each observation, notes were used to create a narrative account of the observation.

2.5.2 Interview Guide

An a priori interview guide was developed based on relevant family/caregiver, critical care, transitional care, and neurological disease and disability literature before the lead investigator arrived at the research site. The a priori-developed interview guide was revised based on discussions with the neurocritical care team and observation notes after the initial two-week observation period. The interview guide was translated from English to Spanish by the lead investigator and back-translated by a native Spanish speaker to ensure validity. Interview guide themes include family/caregiver experience, patient experience, challenges, coping, anticipated outcome, and obstacles.

2.5.3 Participant Recruitment

Participant identification and recruitment for interviews began after the initial two-week observation period. The neurocritical care team physicians and nurse identified the patients with family members/caregivers who met eligibility criteria. No recruitment materials were used. The specific family/caregiver to interview was identified at the discretion of the patient’s family after the nature of the study was described. Purposive sampling was used.
In order to facilitate more open and trusting relationships between researchers and participants, the lead investigator accompanied the neurocritical care team on its daily rounds to meet and become familiar with current neurological patients and their family/caregivers. After the lead investigator had met the family/caregivers during clinical rounds, family/caregivers who met eligibility criteria were approached by a nurse from the neurocritical care team and invited to participate in an interview. The lead investigator accompanied the nurse. If the caregiver agreed to learn more, the study and the informed consent process were explained. It was explained that she or he could choose to complete an interview, withdraw at any time, and stop an interview in progress without the requirement of having to continue later. No compensation was provided. Recruitment continued until thematic saturation was reached on the family/caregiver’s ability to define successful recovery post-neurological event (Francis et al. 2010; Guest et al. 2006).

Family/caregivers initially agreed to participate based on a brief summary of the research purpose, methods, and approximate length of interview. Once family/caregivers provided initial agreement, the family member/caregiver and lead investigator worked together to arrange a mutually convenient day and time to hold the interview. Some family members/caregivers were interviewed at the same time of their initial approach if they consented and the time was convenient. Informed consent was
then obtained by paraphrasing the informed consent document to the family/caregiver in Spanish and presenting the written document to review. Family/caregivers were given time to consider the decision to participate and did not need to decide on the same day of the invitation to participate; but, all family/caregivers agreed upon the initial request and decided to participate during the formal informed consent process at the beginning of the interview. All participants consented prior to data collection. Consent included the approval to audio record the interviews. A copy of the signed informed consent form in Spanish was provided for the family/caregiver. This included information on how to contact the study team at any time after the interview. Family/caregivers were also asked if they would be willing to share personal contact information (phone number or email) to be contacted after the interview regarding their continued transitions of care, with the potential for follow-up interviews. In this sample, no patients of family/caregivers willing to provide contact information transitioned to rehabilitation or home for a sufficient period of time to schedule an interview before the end of the data collection period.

2.5.4 Interviews

Semi-structured interviews were used to better understand patient and family/caregiver experience. Semi-structured interviews permitted some of the same flexibility of unstructured interviews, but with the use of an interview guide to ensure
comparability (Bernard 2011b). Informed consent was obtained prior to each interview. Family caregivers were reminded of the option to discontinue the interview at any time throughout the interview.

The interview team consisted of 1-2 people. Each family/caregiver interview was in Spanish, led by the lead investigator who is fluent in Spanish. A native Spanish speaker, either a fellow or the nurse from the neurocritical care team, was also present at initial interviews though eventually determined to not be necessary based on the investigator’s Spanish proficiency and ability to interview alone. Interviews focused on the patient and family experience, transitions of care, burden, and major life changes.

Interviews lasted between approximately 20 and 60 minutes. Interviews were recorded and transcribed verbatim in Spanish. Interviews were then translated by the original interviewer into English. One-third of all transcripts and translations were validated by a native Spanish speaker. In cases where transcriber/translator and validator disagreed, audio recordings were referenced and discussed to reach consensus. Any family/caregiver or patient identifiers self-disclosed by participants were not transcribed.

2.6 Trustworthiness

Although the study aim – patient and caregiver experience after a neurological event – is broad, based on the specificity of the sample, use of established theory, strong
quality of dialogue, and the case-based analysis strategy to present a patterns of family/caregiver and patient experience, the sample is deemed to have sufficient information power to answer the research question (Guest et al. 2006; Malterud et al. 2015).

### 2.7 Thematic Analysis

Iterative thematic analysis was used to analyze interview transcripts based on a priori themes from the interview guide and Bronfenbrenner’s Ecological Systems Theory and inductive themes arising from the data (Bradley et al. 2007; Smith and Firth 2011). Identified themes ultimately include inductive themes based on similarities and differences, repetitions, and transitions and a priori, theory-related themes (DeCuir-Gunby et al. 2011; Ryan and Bernard 2003). This approach helped to capture themes important to both theory and participants.

The qualitative codebook was developed by first creating a codebook based on Ecological Systems Theory and familiarity with the data. Then, one interview was coded inductively using a line by line grounded theory approach (Bradley et al. 2007). The codes from the a priori, theory-based codebook and the codes that emerged from the grounded theory approach were compared and were similar (DeCuir-Gunby et al. 2011). Thus, a combination of conventional and directed content analysis approaches was ultimately used to create a codebook of 27 codes to apply to all interviews (Hsieh and...
Shannon 2005). In keeping with the grounded theory approach, after coding two-thirds of all interview transcripts, the lead investigator met with committee members to discuss current findings, potential implications, and future directions in order to refine analysis and confirm current work. After the first round of coding, new codes were identified and incorporated. All interviews then underwent a second iteration of coding with three newly identified codes (Bradley et al. 2007). Newly identified codes were more specific areas within first rounds codes meant to better encapsulate salient ideas.

After all transcripts were coded twice, thick description and comparison and categorization of themes were used to identify, explain, and verify patterns and develop broad themes (Geertz 1973). Codes were categorized based on content analysis and Bronfenbrenner’s Ecological Systems Theory to create a hierarchical structure to better understand family/caregiver perception of the family’s and patient’s experiences, concerns, and attitudes after a neurological event (Bronfenbrenner 1977). Categorization of salient themes employed the principles of thematic network analysis. (Attride-Stirling 2001). Thematic network analysis is used to find explicit rationalizations and connect them with implicit associations. The thematic network provides a means to readily identify key areas regarding participant perception of family/caregiver and patient experience.
In this hierarchy, relevant themes are attributed to the ecological levels of the patient-centered systems model used in this study and adapted from Bronfenbrenner’s Theory. Broad themes were further analyzed for similarities and differences with particular emphasis on between- and within-level interactions based on Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner 1977). From this process, 9 unique themes emerged to capture patient and family/caregiver experience after a neurological event. These themes are discussed below.
3. Results

3.1 Participant Characteristics

Nine family members/caregivers were interviewed. Seven family members/caregivers were interviewed in the ICU and two family members/caregivers were interviewed after patients were transferred from the ICU to the general floor. Eight family members/caregivers were met first in the ICU, while one family member/caregiver was met on the general floor. That patient had also first been an ICU patient. All patients of the family members/caregivers had suffered an acute neurological event or were post-operative following a neurological disorder. Four patients of those family/caregivers presented with hemorrhagic or ischemic stroke, two with traumatic brain injury (TBI), one with Guillain-Barré, one with a spinal lesion, and one with hydrocephalus (post-operative). In relation to the patient, family/caregivers interviewed included three parents, two spouses, one partner, one sibling, one cousin, and one child (Table 1).
### Table 1: Family/Caregiver and Patient Characteristics

<table>
<thead>
<tr>
<th>Family/Caregiver Name</th>
<th>Family/Caregiver Sex</th>
<th>Relationship to Patient</th>
<th>Patient Admitting Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Juan</td>
<td>Male</td>
<td>Husband</td>
<td>Subarachnoid Hemorrhage</td>
</tr>
<tr>
<td>Maria</td>
<td>Female</td>
<td>Cousin</td>
<td>Multiple traumas including TBI</td>
</tr>
<tr>
<td>Carolina</td>
<td>Female</td>
<td>Sister</td>
<td>Multiple traumas, potential TBI</td>
</tr>
<tr>
<td>Ana</td>
<td>Female</td>
<td>Wife</td>
<td>Guillain-Barré</td>
</tr>
<tr>
<td>Carlos</td>
<td>Male</td>
<td>Partner</td>
<td>Stroke</td>
</tr>
<tr>
<td>Felipe</td>
<td>Male</td>
<td>Father</td>
<td>Stroke</td>
</tr>
<tr>
<td>Sofia</td>
<td>Female</td>
<td>Mother</td>
<td>Spinal lesion</td>
</tr>
<tr>
<td>Lucía</td>
<td>Female</td>
<td>Daughter</td>
<td>Stroke</td>
</tr>
<tr>
<td>Valentina</td>
<td>Female</td>
<td>Mother</td>
<td>Hydrocephalus</td>
</tr>
</tbody>
</table>

#### 3.2 Themes

Overarching themes and dimensions of distinction are used to describe family/caregivers experience. Although all family/caregivers in this study are in the same neurocritical care environment, there exists diversity of experience based on patient pathology and prognosis and individual family and caregiver characteristics. Differences in family member experience create distinctions within the family that may affect interactions with the patient, provider, and health system. Analysis included categorization of salient codes attributed to appropriate level of the patient-centered model employed (Figure 2).
Figure 2: Hierarchy of codes for content analysis based on a simplified, patient-centered systems model adapted from Bronfenbrenner’s Ecological Systems Theory and incorporating inductively developed codes based on family/caregiver experiences and perceptions (Bronfenbrenner 1977).
It is important to note that all data in this study are from the family/caregiver perspective. The 27 codes developed from the iterative coding approach were applied to 9 family/caregiver interview transcripts. From these 27 codes, 9 cohesive themes, some occurring within levels and some occurring across levels, were identified to describe family/caregiver experience after an acute neurological event in the ICU. To illustrate identified themes, excerpts from the transcripts are included below.

3.2.1 Theme 1—Adjusting to a Changed Life: “And, it changed, it changed a lot. At this moment it has changed a lot.”

*Sudden life change for family members/caregivers post-neurological event.* A critical illness often represents totalizing life change for both patients and their family/caregivers with subsequent mental and emotional burden. Lucía says about her father’s stroke. “[I]t changed your perspective on everything, on everything. […] He had been hypertensive since he was 60 years old, and, because of this I thought it was the end.” Ana also believes that her life and her husband’s life have changed completely since being diagnosed with both cancer and then Guillain-Barré. Ana said, “And, it [life] has changed completely […] [W]e had something in common, we went out together you see, I don’t know, we went out in the boat, we went out, that was our life, our refuge. This, and now, he doesn’t like everything [the same].”

The extent to which family/caregivers identify life change varies. Maria, when asked how the life of her cousin has changed says, “And, it changed, it changed a lot. At
this moment it has changed a lot. The theme is going to be how it is going to change after with the conditions that remain.” In Maria’s response she identifies a high degree of present change and an unknown degree of future change.

Other family/caregivers perceive the neurological event their loved one experienced as completely changing the patient’s life, regardless of specific pathology. Carlos says, regarding his partner, “[Patient’s name]’s life has changed forever. The life of [patient name], only of [patient name], will change forever.”

Family/caregivers were also emotional regarding patient health status and expected recovery. Of particular concern was the uncertainty surrounding prognosis. For instance, Ana, whose husband suffered from Guillian-Barre, said, “Right now I can’t tell you everything that is going to happen,” and “I can’t tell what our future will be.”

Another characteristic of the change experienced by family/caregivers and patients is the suddenness in which the change occurred. Carlos said that his partner’s stroke occurred without warning. “It happened without warning. It happened without anything previous, without a symptom. […] It happened one morning, any morning, a common day.”

Additionally, when asked what was most difficult, Ana remarked, “Very difficult because all of a sudden, look at this change, like the difference in being in a place where a hit can condemn them [the patient] to die.” Ana perceived that the
suddenness of the transition in her husband’s health status made the experience even more difficult.

3.2.2 Theme 2—Managing Emotions: “I am emotional enough, and, then, I don’t want to cry here, and not outside of here in front of my children.”

*Mental and emotional impact of the family/caregiver role.* Family/caregivers experience varied burden in their role as caregivers and perceive their experience differently. Family/caregivers also process and react to the difficult parts of their experience in different ways. Lucía comments about each family member’s individual experience, “We don’t know that, we don’t know the progress he will have, but, each is going to feel pain in a distinct way.” Personally, Lucía is “studying to be a teacher, I have to do an internship, I have children I am in charge of, I can’t do my classes, I can’t do anything, I am living like I’m in a novel of terror.” Carolina identified the emotional experience as the most difficult part of the ICU. When asked what is most difficult for her, Carolina described her struggle to control her feelings:

Um, to control my emotions. [...] I am emotional enough, and, then, I don’t want to cry here, and not outside of here in front of my children, look, actually, the first and second day, I arrived at my house, opened the door, and immediately cried there. But, what is the most difficult for me, it isn’t difficult to be with her. It is difficult to not falter or feel bad for others. This is difficult for me. I am trying, and I am overcoming it enough, but, well, this is difficult for me. And, obviously, she is my sister and I love her, and this kills me. But, it is, why, okay. It is what happened and I have to keep moving forward, you see, from this. There, okay. This is what I am living now, you see. Don’t give me - I don’t stop, moreover,
right? I get up a quarter before six and I don’t stop all day, and at night I stop to rest.

Felipe also identified controlling his emotions as a difficult part of his experience as family/caregiver. Felipe stated:

But, well, I have to be calm so something else doesn’t come up. But there is that worry. There are moments there that I feel down or that make me, and I don’t, I tell you, there are levels like this, because [if] I decline in bed it will be worse. And, she if sees us well, the other family members, she is going to believe that the family will help her more if she doesn’t see me bad.

Felipe perceived maintenance of his emotional state as a means of preventing his own health decline. He is concerned that if he were to give in to his emotions he would fall ill, be unable to care for his daughter, and make everything worse.

Some family/caregivers identify solitude, the new silence caused by the absence of the patient’s voice, and bearing the family/caregiver burden alone as what is most difficult. While, in some ways, new silence may be identified as a life change due to neurological event, silence and solitude are more significant for family/caregivers due to the emotional impact. Ana, for instance, when asked to describe the most difficult part of her experience, said, “To go home.” Ana perceived going home as difficult because she was alone. Many of her friends and neighbors had died in the past year. Similarly, Carlos identifies the silence he lives in as a result of his partner’s stroke and inability to
communicate as the most difficult thing for him. Carlos calls the silence “unbearable,” and said:

The silence. Above everything else, that I would change, if I could change anything for one hour, thirty minutes, I would speak with him. [...] To ask him questions or to tell him one more time that he is the most important thing I have in my life. The silence above anything else. It’s an absolute vacuum. [Patient’s name], from when he had the stroke couldn’t speak. Never again can I hear his sound. [...] I can see his eyes, I can see his body, his hands, his face. But I can’t hear his voice. [...] This is the most painful of everything. No. And to know that I will never again.

Silence and feeling alone, whether because a family/caregiver is physically alone or because the mental and cognitive effects of the neurological event affect the family/caregiver’s ability to communicate with the patient, affect the family/caregiver’s emotional state by causing additional strain and as a source of grief.

Family/caregivers described the patient’s medical experience as emotionally impacting not only the family member/caregiver interviewed, but also children of the family/caregiver and/or patient. Adolescent children have different experiences as family/caregivers as compared to adult children or other adult relatives of the patient. Although adolescent children are often kept separate from the medical environment and provided limited information regarding family member health status by the other family/caregivers as a means to limit the emotional impact on children. Family/caregivers observe and describe both the impact on themselves as family members/caregivers attempting to distance their own children from the patient’s
situation and the impact on patients’ children.

Juan described the experience of his three children with his wife’s hospitalization and the reason they do not visit their hospitalized mother:

They [the kids] never come here. One came with my sister-in-law and one came here the first day and never again. After, [child’s name] yesterday. I wouldn’t like to see her either. I don’t know if they will come with how she is now. She is intubated, to see your mother like that, you see? I speak with her and that is okay, but if she were your mother? There is no doubt she will improve, so what point does it serve?

Juan references the difficulty in seeing his wife hospitalized has on himself as the patient’s spouse, but shields his children from the same experience. Juan distances his children from the hospital as a means to mitigate the emotional burden he experiences.

Similarly, the two children of a patient who had a stroke also had restricted visitation of their father than other family/caregivers of that patient. Maria, the patient’s cousin, describes the children’s experience:

Well, the little girl still hasn’t seen him. We talk, okay, and we talk with a psychologist, and she recommends for him to be more disconnected from the machines [before she sees him]. And the little boy sees him. He can for three days. And yes he came to see. He is 16 years old, it seems to be that he is aware and at the same time, because of his age, doesn’t realize the gravity, you see? […] The little boy talks with a psychologist here. But… […] And, I…he says that he doesn’t need to, but I think he does, it helps, I see it, yes.

The patient’s children are also kept separate from the patient, though the children did visit initially. Furthermore, the experience between the children is differentiated based
on the children’s ages; the older child does visit his hospitalized father, though he also speaks with a psychologist to presumably handle the emotional burden, as Maria says visits with the psychologist “help,” despite what the patient’s son may think. Additionally, Maria perceives that while the patient’s son does visit his father, he may not fully grasp the situation. This is also suggests a differentiation in emotional burden between adult family/caregivers and adolescent children.

Carolina described the experience of her sister’s children, “The young man, he’s little, he is 16 years old and this boy hasn’t shed a tear. And he hasn’t spoken to me, he is still very affected. But, look, it’s an age where they want to show that they are little men, by doing this, okay.” In this case, the patient’s children are also emotionally impacted by the patient’s experience.

Family/caregivers also caring for their own children may feel burdened in different ways. Maria, the cousin of a patient, describes her experience with her own children and how she attempts to limit how affected they are emotionally by the situation:

I am emotional enough, and, then, I don’t want to cry here, and not outside of here in front of my children, look, actually, the first and second day, I arrived at my house, opened the door, and immediately cried there. [...] I am trying to keep her husband and children company. Her children are going home to sleep during this time, okay?
Maria attempts to limit the impact of her cousin’s illness on his children and on her own children. In doing so, she takes more burden upon herself. Lucía also describes the impact on her own children as they attempt to understand the experience, “I have small children, so they cry for us, they guess what has happened.” María’s and Lucía’s children, though not fully involved in the patient’s experience, still experience emotional burden due of it.

As Carolina discussed what was most difficult for her, she also identified her coping strategy – to keep moving forward. Family/caregivers identify various coping strategies employed to handle the emotional experience of a loved one’s hospitalization. Lucía coped with her father’s hospitalization by maintaining a distanced with her sisters. Lucía said:

I maintained a distance with my sisters. In the moment that my sister came to hug me, I put a distance, in another moment that my youngest sister that I was going to curse, […] To take that we all were bleeding emotionally, we were calm, but we were very distressed, but waiting, but I personally maintained, eh, […] I put a distance between myself.

### 3.2.3 Theme 3—Changing Roles: “I am put in the role of the older sister, to be at the side of my mother. […] I tell you each one [of us] has an important role.”

*Role change and the assumption of new roles.* Family/caregivers assume the role of caregiver after a patient’s neurological event. Family/caregivers within one family may also assume different roles. Not all family members have the...
same experience with role change and not all family members assume the role of primary family caregiver.

Lucía identifies her family members as assuming different roles and perceiving and processing the medical experience in different ways. Lucía said:

I am put in the role of the older sister, to be at the side of my mother. […] I tell you each one [of us] has an important role. NAME was very important, the nurse, was very, very important with the physical, at first. And, I believe the other effective connection with him, and, well, for me his treatment is very important, with my mother, his spouse, it seems to be that both, the health is going to come from this, for the physical, and, I, at the same time, if they come together, and well, no one big thing.

Lucía perceives each member of her family as playing a distinct role in the care and recovery of her father, “[W]e each try to have appropriate, each one has a way with him, […] Each one is going to have a different manner. It is good that he understood, that no one is closed to this, but the most painful is, eh, how much we lost.”

Some family are very involved in care. In Lucía’s family the adult children and spouse of the patient, Lucía’s father, seem to act in concert as family/caregivers. Lucía describes her family, “But, I, I looked for him to be better, thanks to God, fortunately we are very united, we are very good, we go on sharing with others that aren’t here.” In the case of Lucía’s family each was described as serving a necessary role in patient care without one family member seeming to be the primary family/caregiver.
However, other adult children rely upon a parent or other family/caregiver to serve as the primary caregiver, Ana describes this to be true of her family:

On the other side, eh, [I have] all of the responsibilities, or, I have some marvelous children that come and visit and everything, but, imagine, they work, they have their things, and I do everything. You understand me? You understand? I’m not complaining, but this is change is deeply part of us.

At times, family/caregivers assume different roles in relation to the patient. Assumption of family/caregiver role by the family also varies based on the patient’s health status. The experiences of family/caregivers whose family members are conscious and able to participate, such as Sofia’s daughter, vary significantly from the experiences of family/caregivers whose loved ones have not regained consciousness, such as Carlos’s partner or Lucía’s father.

3.2.4 Theme 4—Relying on Faith: “I am dealing with God to give me clarity, understanding, to see in what I can help.”

Importance of faith and fate. Faith and fate were described by family/caregivers as the foundation for coping and as a means to explain what happened and what is currently happening to patients. Family/caregivers describe patient faith as a means for patients to fortify their recovery.

Maria describes her cousin:

So, I think that, he is very much a believer. He believes more than anyone, than any of us. So, this, I think, that, it is a plus, for him. It helps him to feel like he can win. He isn’t going to stay like others in his room, in this.
He is going to be able to win for his children, okay. This is what we believe, I tell you.

Ana also describes her husband as a believer:

But, I, but, that he has a separate resistance very much from inside, you see, he is a believer as well, and that helps us. I believe that the important thing is that you believe, eh? In a name, form, a plant, a flower, [...] but that, for me, is fundamental, fundamental. Or if, that is the whole part of being human.

Family/caregivers who identify faith as an important patient belief also perceive that patient recovery will be enhanced or strengthened by patient faith.

Family/caregivers also discuss faith in terms of their own beliefs. Family/caregivers describe their faith in some inevitable force as a means of explaining or justifying patient illness. Reliance upon faith in this regard presents patient illness as inevitable.

Carolina speaks of the role of fate in her sister’s car accident:

And my mom just told me the other day that she had a chat [with the patient] and had coffee, and, well, she [the patient] said she was so happy, with everything, see, because she had just restored her house and the study. She is a lawyer and her husband is too, they had restored/renovated the study. She said she was so happy, so happy, she said to my other sister. Because of this, I said, in this life, a piece of advice, we cannot say, never can we say that we have everything figured out, because something will go “Ping!” I am very Catholic and I don’t think God is vengeful, but something happened in the universe that said no, you have everything going well, “ping!” I don’t know. It makes me a little afraid. And she said she was afraid, I don’t know. And, everything at work was going well, she was doing what she liked, the kids were good. And, well.
Carolina perceives her sister’s road traffic injury as inevitable, a consequence of fate. Additionally, Carolina presents faith as a coping mechanism. Carolina said, “You have to have faith in good, that in some moment there is, there could be [...] Right now I can’t tell you everything that is going to happen.” In this way Carolina presents fate and faith as related concepts that can both justify an illness and help family/caregivers to cope with illness.

Sofia also cites faith and fate as part of her experience as family/caregiver. Sofia talks about faith in terms of providing for the good in her daughter’s experience. Throughout the interview, Sofia thanks God. For instance, she stated, “But, thanks to God, nothing is wrong right now, everything is perfect, everything good.” Sofia also referenced faith as a means of coping:

[B]ut the shadow will go from us, okay. We always have the idea that this is going to happen and we will put it all with the idea that... [...] We never operated like this, the problem is this, you keep moving forward. We always move in this way. Because, why poor me, no? Because I, no, no, we maintain it there. Always asking for God to help us, right? I always ask God to give me strength to face problems, but everyone has problems, but...

Thus, faith and the inevitability of fate are key components of Carolina’s perception of family/caregiver experience. Carlos also notes the importance of faith as a form of coping, particularly when family/caregivers have to wait, “To have faith, for those that believe. And those that don’t have faith, that they have patience. It could be
you don’t have faith, because it is of religion. But, you could have, you have to strive to have patience because all medical things end by saying, they end saying that you have to wait.”

3.2.5 Theme 5—Redefining Recovery: “[S]he will not be the same person as before, but, it torments me to say this now.”

*Definition of successful recovery dependent on patient experience and prognosis.*

Definitions of successful recovery by family/caregivers varied greatly. Some family/caregivers had straightforward goals for recovery unrelated to health outcomes. For instance, Ana’s husband has both cancer and Guillain-Barré. Rather than focusing on health outcomes, Ana defined her husband’s successful recovery as being able to return home, “to be with me.” In contrast, other family/caregivers had more specific hopes regarding physical, mental, and cognitive recovery.

Family/caregivers whose family members had a brain injury, in these cases either from stroke or subarachnoid hemorrhage, were more concerned with mental and cognitive recovery than physical recovery, particularly if those patients had not regained consciousness or had regained limited consciousness and recovery was still uncertain. Emphasis of mental and cognitive recovery is congruent with patient pathology in these cases.

For example, Juan hoped that his wife would be able to, “At least to listen as she could before, to be in good condition, to be able to touch me […] Because in fifteen days
she hasn’t opened an eye, not moved her hands, I chat with her and she says nothing to me.” Juan’s wife has not regained consciousness since she had experienced a subarachnoid hemorrhage.

Felipe, whose daughter had already regained consciousness, though intermittently, hoped she would be able to regain some of her memory. He accepted to some extent that she may never recover fully, though he had difficulty accepting this.

Felipe defined successful recovery for his daughter:

[S]he will not be the same person as before, but, it torments me to say this now. I don’t agree. Or that she will see the photo of a friend, in order to say something, and doesn’t remember the name and it makes her feel bad and cry, it makes her sad. That is what I would not like. [I would like] [t]hat she sees a photo and says to you, “Ah, this is my friend, Carlos.”

Felipe perceived that memory loss distressed his daughter and hoped her distress would be alleviated if she could regain her memory regardless of other physical recovery. Lucía also emphasized the importance to her for her father to recovery mental and cognitive ability, specifically highlighting the ability to communicate and retain his intelligence and her acceptance of the loss of physical functioning as long as he retained some cognitive functioning:

[O]bviously you want your dad to walk, eh, that he is the same, right? But, in this, we know that from the beginning with all that he has lost he isn’t going to recuperate. So, I prefer that he loses the physical. […] From the beginning I have said to the doctors, I prefer, my attention isn’t on the physical, but the mental, on the cognitive, this is it.
In contrast to the mental and cognitive focus of family/caregivers of patients who had experienced a stroke or other hemorrhage, family/caregivers of patients who had road traffic injury resulting in TBI were more focused on the patient’s physical recovery and return to previous lifestyle. For instance, Maria defined her cousin’s successful recovery as the ability to keep working post-discharge and return to his normal life.

Carolina also focused on the physical and cognitive recovery of her sister, emphasizing her sister’s ability to cope with new functional disability. In describing what successful recovery would be for her sister, Carolina said:

For me, it is that everything is normal – relatively normal, at least aesthetically. Second, to not stay here, I think she will not, but it was a possibility. [...] I will be happy if she doesn’t lose anything, with all of this, and okay, and after to see a psychiatrist and to have mobility, to have general movement and, after the [intracranial] pressure is fine, all of these things. I don’t know. It seems to me, she can brush her teeth with her left arm and it will be fine.

In some cases, there was no need to redefine successful recovery due to patient’s treatment stage and disease course. In this case of Sofia’s daughter, the definition of successful recovery was in the context of an already complete, successful operation to remove a spinal lesion. Sofia perceived that full recovery was possible. When asked to define successful recovery for her daughter, Sofia answered in terms of the operation’s success, “What I see, it didn’t touch any nerve that can cause a disability, because she
talks, speaks, and thinks. I give this part a ten. The operation has been successful to the maximum.” In this case, the largest barrier to patient recovery, the risk of operation, had already been overcome and full recovery was in sight. There was no need to redefine successful recovery.

One family/caregiver was unable to forecast what a successful recovery would be for his family member. When asked what a successful recovery would look like for his partner, Carlos responded:

He has very […] very, very few possibilities. […] I will never know. I wish I could respond to you, but no, but [patient name] isn’t a patient that has a high probability of recuperation. Eh, the other day the doctor told me, if [patient name] is able to leave the hospital, if he gets to leave the hospital, he will die before me, he will die before his mother and his brother, unfailingly. There is no hope of recovery. […] I don’t have an answer.

In this case, Carlos recognized his partner would never recover fully. This case is unusual in comparison to others in this sample in that the patient’s prognosis was so poor that no recovery was expected and the family/caregiver was in the process making end of life decisions. Carlos’ inability to forecast recovery is in part due to the very poor prognosis of his partner after having suffered two strokes. The uncertainty or inability to know what will happen next can also be a function of the patient’s current pathology. Family/caregiver definition of successful recovery is tempered by patient diagnosis by a medical provider.
3.2.6 Theme 6—Participating in Patient Care: “To be here is good because I am at her side.”

*Importance of relationship with patient.* Unsurprisingly, family/caregivers emphasize the centrality of the patient to their experience. Of particular importance is the relationship between family/caregiver and patient.

Family/caregivers emphasize the importance of accompanying their sick family member in the ICU and perceive it as beneficial to both family/caregiver and patient. In this context, Carlos remarked:

They told me to be with all the time with the person that you want to the most. All the time that I want I can stay there. I can kiss him, I can hug him, I can touch him. [...] I feel free, all the time, to be with [patient’s name].

Family/caregivers recognize the importance of an ICU without visiting hours in which family/caregivers are allowed to stay with patients at all times, referred to as “open intensive care.”

Juan, the husband of a woman who had suffered a subarachnoid hemorrhage, remarked:

To be here is good because I am at her side. And another thing, that you can enter at the hour you want. I can see her. In other places, they don’t have that, they have a half hour in the morning and a half hour in the afternoon, and they don’t have anything else. Here I can come whenever.

Increased participation in care due to the hospital’s “open Intensive Care” policy also allowed family/caregivers to feel more “united” with sick family members, making
family/caregivers feel calmer, more relieved, and strengthening the relationship between the hospitalized family member and other family/caregivers. Juan said that being at his wife’s side is what helped him the most during the intensive care experience. Maria, the cousin of a man who had suffered a road traffic injury with multiple traumas, including traumatic brain injury (TBI), said that her experience was better with an open Intensive Care, “But, so, here I find that it goes a little better because I can enter, I can leave...I can be with him more. [...] Here I feel a little calmer.” In this way, the clearance of the family/caregiver to remain with the patient, afforded by the hospital policy, strengthened the relationship between the family/caregiver and hospitalized patient.

Most family/caregivers emphasized that “open Intensive Care” was a positive, helpful part of their experience, particularly in contrast with previous experiences with hospitalization in which visits with patients were limited by visiting hours. Increased access to patients also provided a means by which family/caregivers could be more involved with patient care, such as bathing, feeding, placing towels on a patient’s head or other stimulation. Methods of stimulation cited included passive mobilization, talking or reading to the patient, or playing music.

Family/caregivers also perceived that patient experience was better because of the open Intensive Care policy. Carolina, the sister of a woman who had a car accident
resulting in multiple traumas and potential TBI, said, “And, truthfully, that she can wake up and see a face she knows is great. This system is very good.”

In general, family/caregivers perceived a close relationship between patient and family/caregiver as good, and found that increased times spent together in the ICU meant increased opportunity to participate in care. Constant access was a source of relief that allowed family/caregivers to feel more united with hospitalized family members.

3.2.7 Theme 7—Depending on Clinical Experts: “I calculate, I don’t know [what’s next], the doctors haven’t told us.”

Reliance on medical providers. Family/caregivers rely on medical providers to explain current care and next steps. Most family/caregivers express limited knowledge about the next steps in the patient’s care trajectory, including rehabilitation, expected recovery and goal setting, and what the patient’s life will be like post-hospitalization beyond what has been discussed with a medical provider.

Lack of surety increases when family/caregivers don’t know the patient’s current state, ability to recover, and to what extent he or she can recover. Lucía, the daughter of a man who had a stroke, said, “[W]e don’t know what he is going to respond to, if he is going to advance, if he understood us the other day, or if he going to move backwards. Thanks to God, we are seeing the advance, I believe that he surprises the doctors.”

When asked what is likely to happen to her cousin post-discharge, Maria said “I already told you, I don’t know.” Similarly, Lucía said, “[W]e don’t know the progress he
Some family/caregivers are uncertain about what happened preceding a patient’s hospitalization and what is currently happening in the ICU, though this is uncommon. Maria said that her family still doesn’t know what happened to her cousin because he has been unconscious since his car accident:

We don’t, don’t know because he entered Intensive Care, he went to a hospital directly because it was closer. They attended this there, the first efforts, of the...they did there in a regional hospital. [...] And he entered unconscious. We don’t know. [...] He is sleeping, you see, every day, he is in a coma since the accident, so. No. It can’t be.

Even those family/caregivers who expressed uncertainty were often able to imagine potential future scenarios. Juan, speaking about his wife, said:

I don’t know how her life has changed, when she leaves here we will know. And, I don’t know. I don’t know what to tell you, when we leave here...the truth is, I don’t know. Because when we leave here, we have to be together more because she is intubated. Or, when this passes, at least for the moment. It [the intubation] might stay, I’m afraid, if it’s necessary.

Yet, even when family/caregivers project what a patient’s future may be like, there still exists significant uncertainty.

Throughout family/caregiver descriptions of what will happen post-discharge, how patients’ lives will change, and what recovery will be like, family/caregivers reference what medical providers have and have not told them. Juan, in describing his experience with the family conferences with medical providers, said: “[W]e ask about
the things in the future, and, well, they [medical providers] tell us that we have to wait, they explain to us why, and it is because we have to wait for the progression, right?”

Similarly, Carolina described the probable care trajectory of her sister post-discharge:

I calculate, I don’t know [what’s next], the doctors haven’t told us, but she will pass to another room until they can finish with all the first operations, and after, she will go to rehabilitation, and with some rehabilitation at home. She will have to travel, I suppose, to rehabilitation as part of her recovery, and yes, okay, enter into a second age of rehabilitation. This is what I imagine, still they [the doctors] haven’t told us anything, but this is what I imagine.

Family/caregivers frequently separate their predictions of what will happen to patients from what doctors and other medical providers tell them. In doing so, family/caregivers assign a higher degree of surety to what medical providers have told them and defer to the judgment of the medical team. This is true even when family/caregivers do not know what that judgment may be. Family members/caregivers often speak of patient trajectory in terms of broad, long-term goals. Family/caregivers show a high degree of willingness to wait for and follow the orders of medical providers in most cases. Sofia, when asked what will happen to her daughter post-discharge, illustrates this point. She said:

And, the idea is that she will stay, even though she was to be discharged yesterday morning, but she will stay, the surgeon hasn’t said how long, but maybe about fifteen days here. Then, we have already equipped an apartment in front [of the hospital], so she can be very close. After this I
don’t know what will happen. […] They [providers] will tell us, okay. Until now they haven’t told us, but we will do it.

In this case, Sofia demonstrates her reliance on medical providers; though she is unaware what the next step will be for her daughter, she demonstrated complete commitment and willingness to follow the advice of medical providers and do whatever the patient needs to recover regardless of what it may be. Reliance on medical provider is not identified as bad, simply as a facet of family/caregiver experience.

Family/caregivers continue to express limited knowledge even when a medical provider has indicated potential patient trajectory. Juan, speaking about what his wife, said:

The doctor commented to us he supposes that from here he will pass to Intermediate care or the general floor, I don’t know. […] And, after he will have to go to a rehabilitation center. This plan should happen perfectly. Eh, maybe not, only because, I think of the problems with musculature, with walking. I don’t know about eating. Intensive Care wearies you doesn’t it? […] Moreover, we still don’t know.

In this case, Juan seems not necessarily to express doubt regarding provider recommendation, but to express continual uncertainty based on the precariousness and complexity of his wife’s situation tempered by medical advice.

Family/caregivers rely on medical providers to explain current care and next steps, in addition to providing care. Lucia relied upon medical providers to help her family find and choose a rehabilitation center and what to do next, “Or if they suggest a
rehabilitation center, I believe there are various, they tell us, we will understand then. How to go to a center, and we are going to achieve it. This will come to us in time.”

Family/caregivers also rely on medical providers to make the medical environment more familiar. Carlos described the care his partner received:

They enter, measure you, greet you, and they say to you, I am going to put this thing, this remedy, I am going to do this thing, explaining all the time, communicating what is happening. [...] Then, to know [what is happening], it removes fears. It [the ICU] isn’t a different world, it is a world very, very...it is, everything scares you, it all makes you afraid because you aren’t familiar with anything [...] All the sound sounds and parameters and numbers and alarms all the time making noise.

Then, Carlos explains the difference he felt after a medical provider explained the purpose of the medical equipment and the meaning of the alarms:

You know there are sounds that aren’t urgent, and there are urgent sounds [...] It helps you when they talk, they explain, then, you don’t feel like you are bothering a nurse because you don’t have to leave to ask a nurse something every moment, nurse, nurse, no. You tell the nurse when the alarm goes off, and the noise is very loud. And, then, sometimes you need a nurse, but sometimes you don’t. So, this helps you. [...] That they speak to you, that they explain.

In this case, medical providers were able to alleviate Carlos’s fears by explaining previously unfamiliar medical equipment and sounds. The trust and reliance that family/caregivers have in medical providers may alleviate uncertainty at times, but it also means that transmission of incorrect or unclear information is particularly
distressful. Lucía reported being initially very emotional during a medical report from a doctor:

The doctor told me he [the patient] was dying, my father, because we saw that, there are those here, that are very, very grave and that can die at any moment […] Then, what the doctor told me was wrong. The diagnosis he gave me was wrong, it wasn’t so grave like, like the diagnosis when we entered

Some participants noted that family/caregiver reliance upon medical providers to explain patient health status meant providers must be completely honest patient status and prognosis. Carlos, the partner of a man who had suffered two strokes, observed that the medical team would sometimes explain things in a way that would “guard false hopes”:

I prefer that they [providers] tell me 100 percent the truth. […] Also, because, in this place, there is the opportunity to always be with [patient name]. So, their words have to correspond, they have to be in harmony, if Intensive Care is open, when they have to tell you something, they also have to be sincere. They have to be on par with you.

Carlos emphasized the need of family/caregivers to be able to trust that medical providers were not trying to soften the reality of the patient’s situation. Carlos said, “It is never negative to know the truth. Never. It is painful. But it isn’t negative, it isn’t bad to know the truth.”

Family/caregivers emphasize the comfort and security that can come from interactions with medical providers. From these interactions, caregivers gain
understanding regarding current medical care and potential future trajectories for their loved one and are better able to participate in care. Yet, regardless of provider care, family/caregivers often experience uncertainty regarding many aspects of care.

Family/caregivers also rely on medical providers to explain patient trajectory in terms of rehabilitative potential in addition to future location of care. Family/caregivers understood and acknowledged when patients would not return to previous functionality and were able to redefine successful recovery when necessary based on patient diagnosis and prognosis.

3.2.8 Theme 8—*El trato humano*: “To me it seems the doctors, the nurses, the girls, eh…, *el trato humano*, [has helped the most] for me.”

*El trato humano.* Family/caregivers perceive differences in their experience with care from medical providers based on *el trato humano*, the human treatment family/caregivers and patients receive within the hospital environment, in addition to relying on medical providers to provide and explain care and patient trajectory. Caregivers commonly speak of care by medical providers in terms of how family/caregivers and patients are treated as people rather than in technical biomedical terms (which may be a function of family/caregiver understanding of medical care).

Ana described her interactions with medical providers and the impact this has had on her experience:
To me it seems the doctors, the nurses, the girls, eh..., *el trato humano*, [has helped the most] for me, because look, you can be in a wonderful place, but they don’t notice what’s going on. […] obviously, [it’s important] that they care for the body, but also their mind, their spirit, that they are accompanying me.

Family/caregivers emphasize the importance that the disposition of medical providers has on perception of care. Family/caregivers found it helpful when doctors, nurses, and other providers show respect for patients. Carlos, recounting what has helped him, said:

> It is that they [medical providers] explain. They explain it all to him [the patient]. The respect for [patient name] – because when [patient name] was in a coma, and now he is in a coma, they enter with a syringe to poke, they say, ‘Hello [patient name], I am going to give you a little pinch.’ Why, ‘Hello [patient name],’ if [patient name] can’t hear? Well, due to respect.

Carlos was pleased that providers caring for his partner didn’t enter in silence, do their job, and leave. He appreciated the respect that medical staff showed his loved one, even though his partner was unconscious.

Moreover, this respect and humane treatment extended not only to patients, but also to family/caregivers. Carolina appreciated the “patience of everyone with us, with her, they treat everyone with care, until she awakens.” Lucía also remarked upon her family’s treatment by medical providers. Lucía said, “[T]he attention is valuable, the human attention, the medical attention, how they have treated us, how they have allowed us to be with him, each one.” In the case of Lucía’s family, Lucía perceived that
each family member appreciated the attention she received by medical providers and the support the family received from medical staff in attending their family member.

Carlos commented that if he were ever to be hospitalized, he would hope to be treated by medical providers as his partner had been. Carlos was emotional as he said:

If something happens to me one day, I would want to be in this place. I would want them to enter and tell me “hello” even though I couldn’t hear, the same as [patient name]. Even though he can’t hear, just the same, they greet him and say hello. I would want the same for me.

Caregivers seemed to feel their family members were better cared for by providers who cared beyond the physical. Maria, describing the care her cousin received, said, “It seems great to me. It seems good to me. I don’t know. I think that in the job, if you do a job you have to like it. If not, you won’t do it well, this is another thing,” as she described the attention she and her cousin received from a member of the neurointensive team.

Family/caregivers often indicated that what was most helpful to them in the ICU was *el trato humano*. Carolina described what was most helpful to her as family/caregiver accompanying a patient in the ICU experience. Carolina cited, “The medical attention, I think. And, human attention. The human attention, without a doubt. The quality of the doctors, and of the nurses and the general attention she has received.”

Interactions with medical providers are able to give family/caregivers comfort, particularly when medical providers provide emotional support or are able to
empathize with patient or family/caregiver experience. For instance, Carlos described an interaction with the surgeon that operated on his partner:

The surgeon that operated on [patient name] had a wife here [the ICU] and she died. She died from a problem in her brain. And he was a brain surgeon. It is ironic. It is the biggest irony of life. And many times he told me that he had been in my shoes. [...] And that is it, with this I have had luck here [in the ICU] to have a surgeon that had a problem with a family member, the same problem as mine. This empathy, this thing in common, it made me think that I could continue. Sometimes, I didn’t believe I could. But sometimes, also, I believe that I can continue.

For Carlos, and other family/caregivers, the human attention received from medical providers heavily impacted family/caregiver experience and their perception of patient experience. However, family/caregivers were also able to recognize when medical providers did not seem to care about patients as individuals. One family/caregiver interviewed emphasized that some medical providers do not care and that medical providers “are forgetting that the patients are people.”

Valentina described the experience of her son. Valentina perceived the medical providers to rely upon protocol and biomedical processes without regard for individual needs. Valentina said about her son and his experience:

This child is not a protocol, he is a person. So, they [medical providers] come to take blood and another at 12:30AM at night, at 1:30AM another to take blood, and then another. Every four hours another vampire appeared, looking for more blood. After the operation, the child already had blood taken. They [medical providers] said, “No, this is the routine.” No, enough routine, I am going to say, enough routine. What is this routine? [...] They did this seven times.
Valentina was highly distressed by her experience with medical providers. She perceived providers to dehumanize her son during the course of treatment. She continued, “I came looking for excellence. And I didn’t find excellence. I am finding a lot of technology, a lot the patient doesn’t wish. I haven’t liked this. Because of this, I will go.” In this case, the family/caregiver perceived that medical providers lacked empathy and that the lack of empathy affected the care the patient received.

3.2.9 Theme 9—Finding Unity in Purpose: “I believe that family and love, you can really see the effect.”

*Family unity.* Family/caregivers as groups experience varying degrees of unity as they assume and act in the caregiver role. Some family/caregivers perceived that family unity is supportive to patients and improves patient and family/caregiver experience. Two main patterns emerged regarding the importance of family unity in coping with neurological events.

Felipe, as the father of a young woman who had a stroke, felt the need to “to remain calm all the time for her [the patient].” Felipe recognized he was fortunate to have a job that allowed him time off to care for his hospitalized daughter. However, Felipe’s wife was in a different province. His family experienced fragmentation due to the need for some family members need to travel to care for the patient. Felipe served as the primary family/caregiver present with his daughter. Felipe said:
But I feel bad to see that, that I am here, my wife is 2,000 kilometers away. In the coming week, I will go to work. Now, I have taken some vacation days. I will go and I will stay at home alone because my wife will come until she sleeps and I don’t know for how long. […] No, we talk about the disruption between my four children and my wife. I have a sister in another province, [location], 1000 kilometers away as well. She uses her time, she comes to stay somedays and we return home. It is complicated enough.

Felipe’s family experienced fragmentation even as they came together as a family to care for the patient. Felipe’s grandchild was also hospitalized for cancer during this time.

While unified in mission, Felipe’s family was geographically divided and divided by its need to care for two hospitalized individuals.

In contrast, other family experienced greater geographic unity and unity of purpose with multiple family members assuming the role of primary family/caregiver for one patient. Throughout Lucía’s interview, she emphasized the unity of her family and the effect she believed this had on her father’s recovery:

I believe that family and love, you can really see the effect, it’s a lot to see it in everything, because from the first moment that we knew we were here, we said, very well, the first thing has to b, that we all call ourselves a family. We are a very big family, we have differences, we are erratic, we say things, but we speak well of each other, without mistreatment, […] And, each one of us has a very important role.

Lucía’s family was able to provide unified support from a single location. When family members did have to travel home or to another province, the remaining family members sent video updates of their father’s progress.
Important distinctions exist between family/caregivers as groups in the ICU. While both Felipe and Lucía’s family had multiple individuals acting as family/caregiver for a patient, geographic variability changed the experience of who family/caregivers were able to rely upon. The level of integration of family members with one another varies, affecting family/caregiver experience and potentially patient experience. While family/caregivers are similar in many ways, there are important group-level distinctions in family experience.

Regardless of differing degrees and forms of family unity, all family members/caregivers interviewed revealed dedication to the patient’s recovery as the catalyst for family unity. Carlos described the central dedication or hope of family members. Carlos identified the fundamental similarity uniting family/caregivers, “We all say the same of our family member, of our patient, ‘He/she is always good, he/she is always kind.’ It doesn’t matter if you are 39 years old or 20 years old or a grandmother of 80 years, we all want our family member to live.” Carlos called the hope of family members/caregivers that a patient would recover and go home “el sueño de todos,” or “the dream of everyone”. Family members/caregivers consistently demonstrated commitment to the patient and a shared hope for patient recovery and return to a life as “normal” as possible. Family/caregivers demonstrated the importance of the
relationship between family/caregiver and patient and within the family to achieve the
dream of recovery.

3.3 Integrating Thematic Analysis and Patient-Centered Systems Theory

The 9 themes identified above based on thematic content analysis are centered on
family/caregiver due to the nature of study design: all participants self-identified as
family members/caregivers. The identified themes fit within and across the levels of the
patient-centered systems model used (Figure 1). Six themes, adjusting to a changed life,
managing emotions, changing role, relying on faith, redefining recovery, and finding
unity in purpose, fit within the experiences of family members/caregivers in the ICU.
Depending on clinical experts occurs across health provider and family and caregiver.
Participating in patient care occurs across family and caregiver and patient. El trato
humano occurs across health provider, family and caregiver, and patient (Figure 3).
Figure 3: Attribution of themes across the four levels (health system, health provider, family & caregiver, patient) of a simplified, patient-centered systems model adapted based on the principles of Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner 1977)
4. Discussion

Understanding family/caregiver experience as family/caregivers newly assume the caregiving role provides a means to also understand and potentially improve patient experience, family/caregiver inclusion in care, and healthcare delivery. The purpose of this study is to explore patient, family/caregiver, and provider interactions and the effects of those interactions and relationships on family/caregiver perception of experience after an acute neurological event. A patient-centered ecological systems model, based on Ecological Systems Theory, is applicable as a framework to understand these interactions. After a loved one experiences an acute neurological event, family/caregivers describe adjusting to a changed life, managing emotions, changing role, relying on faith, redefining recovery, participating in patient care, depending on clinical experts, el trato humano, and finding unity in purpose. Family/caregivers value participating in patient care and depend upon clinical experts to explain current patient care and future patient trajectory. The centrality of the patient to both family/caregiver and provider unites family/caregiver and provider in purpose and emphasizes the need for recognition of the role that family/caregivers play in patient experience as a mediator between provider and patient. Family/caregiver and patient experience are fundamentally entwined. Exploration of family/caregiver experience can help improve care and mitigate disability and other negative health outcomes through deeper
understanding of the needs and concerns of family/caregivers as they support the patient throughout the continuum of care.

4.1 Bronfenbrenner’s Ecological Systems Theory as a Model for Neurocritical Patient and Family/Caregiver Experience

This study explores the application of Bronfenbrenner’s Ecological Systems Theory to understand patient and family/caregiver experience after an acute neurological event. Bronfenbrenner’s theory is useful in understanding patient and family/caregiver experience in the ICU setting, particularly in regards to neurological patients due to the nature and criticality of their pathology in the ICU. Family/caregiver serves as a mediator between patient and medical provider. While it is common for a family member/caregiver to act as a legal mediator regarding decision-making for critical patients, this study found that family members/caregivers also serve as social mediators.

Ecological Systems Theory is typically used in psychology to apply to child development, though it has also been used to understand the experiences of children in healthcare settings (Bronfenbrenner 1977). In some ways, neurocritical patients share important characteristics with children, such as dependency on family/caregiver and compromised ability to make decisions. Due to patient dependency after an acute neurological event, a simplified, patient-centered model does apply to patient and family/caregiver experience in most cases. Anomalous cases include when the patient is
post-operative, has a short ICU stay, or retains higher levels of cognizance during the ICU stay, such as in the case of Sofia’s daughter after she has surgery to remove a spinal lesion. However, in this case, the exception proves the applicability of ecological systems to neurocritical patients – a patient-centered ecological model in which family/caregiver serves as mediator between patient and medical provider applies better when the patient is critical, unconscious, or has neurological deficits.

In this study, salient themes capture family/caregiver perspective on patient and provider experience in accordance with Ecological Systems Theory. Within family/caregiver experience, salient themes include redefining recovery, finding unity in purpose, managing emotions, adjusting to a changed life, relying on faith, and changing role. Each of these themes involves family/caregiver relationship to patient to some extent; this is expected in this situation because the identity of an individual as the family/caregiver is salient only in relation to the patient. Nevertheless, these themes occur within and across family/caregiver as a level of the simplified, patient-centered model.

Other identified themes also occur within the scope of the simplified patient-centered ecological model. Participating in patient care occurs between proximal levels – family/caregiver and patient. Similarly, depending on clinical experts occurs between proximal levels – family/caregiver and provider. In the case of el trato humano, the theme
occurs between three consecutive levels, provider, family/caregiver and patient. Perception of *el trato humano* between provider and patient is mediated by family/caregiver. Family/caregiver rarely mention interactions with the health system beyond their experiences with hospital policy in their immediate environment. At times, family members/caregivers do reference interactions with health insurance, particularly in regards to coordinating patient transition to rehabilitation, though these references were limited and mentioned only in passing.

### 4.2 Family/Caregiver Experience

Family/caregiver experience in the ICU post-acute neurological event is characterized by managing emotions, adjusting to a changed life, changing role, and relying on faith. Family/caregivers often experience high levels of burden that can impact family/caregiver physical and mental health status and quality of life with a subsequent need to manage emotions (Luker et al. 2015; Talley and Crews 2007; Teel et al. 1999; Thobaben 2006; White et al. 2006).

Family/caregivers experience mental and emotional burden after a patient suffers an acute neurological event (Brereton and Nolan 2002; Epstein-Lubow et al. 2009; Schulz and Sherwood 2008; Schrag et al. 2006; Thobaben 2006; Teel et al. 2001; White et al. 2006). Additionally, family members/caregivers often have little time to prepare to assume the caregiving role due to the sudden nature of acute neurological events and
commonly experience uncertainty and lack of confidence, though this experience is most
often associated with individuals newly assuming the caregiving role and is not
necessarily characteristic across family/caregiver experience (Brereton and Nolan 2002).

Family/caregiver experience must be understood in context in order to recognize
the diversity and mutability of family/caregiver needs and provide appropriate support.
Family/caregiver experience can differ based on patient pathology and severity,
prognosis, and past experiences with critical care and hospitalized family members
(Epstein and Lubow 2009; Thommessen et al. 2001). In a study of the perceptions of
stroke survivors and family/caregiver’s perceptions regarding engagement in
rehabilitation, Chen et al. (2015) found that the needs of both patients and
family/caregivers differ depending on stage of recovery, pre-existing health conditions,
and goals and expectations of rehabilitation.

Faith in a higher power or an illness for a great purpose was often described by
family/caregivers. Family/caregivers commonly assign spiritual or religious
explanations and rely upon faith to understand or rationalize patient illness and the
assumption of the family/caregiver role (Zhang and Lee 2017). Faith or spirituality is
commonly identified as a beneficial coping mechanism for family member/caregiver
(Parekh et al. 2017).
4.3 Relationship Between Family/Caregiver and Patient

While it is important to recognize distinctions between family/caregivers based on individual experience, there also exist commonalities across family members/caregivers. Fleming et al. (2012) find that having supportive family and friends was perceived to improve patient well-being. Family/caregivers emphasize their concern and demonstrate their commitment to the patient. Family/caregivers commonly identify their primary role as supporting the patient (Fleming et al. 2012). As was the case in this study, family/caregivers often prioritize their relationship with the patient and find unity in this purpose. The recovery of a loved one is el sueño de todos, the fondest hope or dream for any family member.

The importance of family unity as perceived by family/caregivers signifies the central relationship within families as family members unite to care for the patient. A previously identified link exists between family members/caregivers who experience depressive symptoms and poor family functioning (Epstein-Lubow et al. 2009). The significance of family unity also emphasizes the centrality of the patient – families perceive their ability to unify around the patient and support care and recovery as providing a better experience for the patient in the present and aiding future recovery. Family members/caregivers are able to join together as a cohesive unit as a means of better supporting the patient. Though finding unity in purpose is predicated on the
centrality of the family/caregiver’s relationship to the patient, finding unity in purpose is a within-family phenomenon.

Family/caregivers often participate heavily in care. In some cases, they act as the colleagues of health professionals and share in decision-making and care to varying extents. Stroke and other neurological rehabilitation often takes place in the context of family members who often provide direct assistance to the patient (Epstein-Lubow et al. 2009). Family-centered interventions are needed to alleviate family/caregiver burden and promote patient recovery. Family-centered interventions are particularly importance based on the impact family functioning and unity has on family/caregiver and the perceived relationship between familial support and patient recovery.

4.4 Relationship Between Family/Caregiver and Provider

Family/caregivers depend on clinical experts to provide education and support in addition to patient care. While family/caregivers may identify some plan regarding patient care post-hospitalization, they often display limited awareness about what will happen next beyond what has been discussed with medical providers. Family/caregivers rely upon providers to explain past, present, and future care trajectory, including potential care transitions. For example, stroke survivors and their families often need additional education and support beyond what is commonly provided in care settings (Loupis and Faux 2013). Additionally, family/caregiver and provider collaboration and
communication provides a means to aid provider understanding and response to changing caregiver needs and experience (Brereton and Nolan 2002). Provider uncertainty is reflected in family/caregiver uncertainty. Incorrect information or deviation from information provided by medical provider may cause additional uncertainty and distress to the family/caregivers and patient.

One venue for providers to communicate current patient health status and future steps for recovery is at family conferences. In this study, family conferences are identified by family/caregivers as the main form in which the family receives information regarding the patient’s health status. Conferences between family/caregiver and medical provider have also been identified as the standard of care for stroke rehabilitation (Loupis and Faux 2013). In this study, family members/caregiver describe providers’ patience and willingness to answer questions at family conferences as key aspects contributing to positive and helpful communication. Loupis and Faux (2013) identify hospital family conferences as beneficial to communicate progress, discuss findings, and plan discharge, especially since family conferences provide a time for family/caregivers to communicate concerns regarding care. Family/caregivers interviewed describe family conferences positively, emphasizing their appreciation for providers remaining attentive to family/caregiver concerns and feeling listened to and supported throughout the interaction. In the literature, successful family conferences are
those in which both patient and family/caregiver are involved in decision-making and planning (Loupis and Faux 2013).

Family/caregivers rely upon providers particularly to explain prognosis and next steps, including plans for rehabilitation. Family/caregiver reliance on medical providers for information, education, and support makes it necessary for medical providers to convey accurate and sincere information to family/caregivers. Moreover, improving patient and family/caregiver understanding can support the uptake of behaviors that promote recovery (Danzl et al. 2016). However, family/caregivers often recognize when medical providers are not completely honest, particularly when providers present a gentler, rose-tinted view of patient prognosis.

When family/caregivers perceive they cannot rely upon providers to 1) present health status objectively without softening difficult news or 2) correctly predict patient trajectory, family members/caregivers experience increased uncertainty and distress.

The continuum of care is often presented by providers as a linear or hierarchical experience in the literature, though the actual experience of patients often differs based on a variety of characteristics (Wissel et al. 2013). Family/caregivers perceive patient readmission or delay in transition to rehabilitation as a cause for concern, or even a failure in patient recovery. Loupis and Faux (2013) acknowledge the difficulty of accurately conveying long-term prognosis at the beginning of a patient’s rehabilitation.
At this stage, prognoses as given by providers are often inaccurate. Medical providers must recognize both their limited ability to forecast patient recovery and rehabilitation while patients are still in the ICU and the reliance family members/caregivers have upon the information medical providers do give in considering the appropriate time and manner in which to disclose any determination of patient trajectory and rehabilitation.

Medical providers have the power to affect patient and family/caregiver experience through more than just medical care – family/caregivers perceive and place importance on interpersonal interactions with providers. *El trato humano*, or the human treatment, providers give to family/caregivers and patients is of fundamental importance to families in the ICU. Family/caregivers perceive medical providers taking the time to educate and support family/caregivers as positive in both this study and the literature. Fleming et al. (2012) emphasize the importance that patients and family members/caregivers place on positive interactions with providers.

Family/caregivers perceive knowledge regarding the patient as essential to their ability to support the patient and perceived lacking information as compromising their ability to support the patient. Family/caregiver perception of *el trato humano* was a key theme in previously discussed family/caregiver conferences with providers. Patient and family/caregivers are also able to identify perceived disrespect or dehumanization of the patient as a disease or medical condition to be treated rather than a person.
Family/caregivers have been found to report feelings of isolation when medical providers do not recognize and encourage their attempts to assume the caregiver role and participate in care (Brereton and Nolan 2002). Positive provider support is perceived to contribute to positive health outcomes. Additionally, medical provider support and education of family members may have other benefits. Kebede (2016) reports that patients’ perception of high quality interactions with providers correlates with higher satisfaction and increased patient adherence to treatment recommendations. Medical providers ought to recognize the role that empathy can play in fostering relationships between family/caregiver and providers for the perceived benefit of the patient.

4.5 “What Matters to You?”

The self-identified needs and concerns of patients and family/caregivers are often neglected. Patients and family/caregivers are often not included in planning and decision-making or goal-setting. Family/caregivers concerns are often given limited consideration by medical staff in decisions regarding care and treatment, discharge arrangements, and time of patient discharge (O’Brien et al. 2014; Perry and Middleton 2011; Piccenna et al. 2016).

In this study, family/caregivers were able to redefine recovery goals for their family members. While patient goals are often long-term and broad, medical provider
goals tend to be short-term and specific. Differences between staff and patient perspectives can be a major barrier to goal setting (Plant et al. 2016). Medical provider goals commonly take priority over patient and family/caregiver goals, causing tension for some patients and family/caregivers, while other patients and family/caregivers expect prioritization of provider goals (Plant et al. 2016). Plant et al. (2016) ultimately suggests that current methods of goal-setting in inpatient settings soon after the health event are not appropriate based on systemic barriers. There also exists benefit to early goal setting as a means to motivate recovery (Plant et al. 2016). Regardless, it is necessary to recognize the common disconnect between patient of family/caregiver and provider expectations and potential causes and remedies.

Patient and family/caregiver expectations of recovery must be recognized in line with the principles of autonomy and empathy enshrined in a patient- and family-centered approach to care. Failure to engage patients and their family/caregivers in decision-making dehumanizes patients and disempowers those responsible for their care. Kebede (2016) emphasizes the need to ask “What matters to you?” instead of, “What is the matter?,” as a means to reframe patient interactions and allow patients and/or family/caregivers to disclose interests, values, and preferences in a manner respectful of the patient as an individual, rather than a diagnosis. Though the optimal way to engage patients and family/caregivers has not yet been identified, patient-
centered approaches are gaining in popularity. Patient-centered attempts to shift medical practice from “What is the matter?,” to “What matters to you?,” emphasize the importance of recognizing and confronting provider and patient/family expectations and perceptions.

Disparate levels of medical knowledge between providers and family/caregivers likely contribute to some goal-setting disconnect. Plant et al. (2016) reports patient and family/caregiver lack of medical knowledge and understanding of treatment, rehabilitation, and potential for recovery as a barrier to patient goal setting. Because patients and family/caregivers usually have limited medical knowledge and do not know what is recovery is possible, goal-setting can be challenging.

Decision-making and goal-setting must take into account competing values, expectations, and different conceptions of the nature of the problem and acceptable outcomes (Loupis and Faux 2013). Decisions cannot be made without negotiation between invested groups, including patient, family/caregiver, and provider. Goals can be tailored to individual patients’ needs and preferences as a facilitator to goal setting (e.g., working within a patient’s preference for long-term goals, rather than imposing specific goals). Therapist-led individualized goal setting approaches can facilitate the establishment of personally significant goals (Plant et al. 2016).


4.6 **Strengths and Limitations**

A key limitation of this study is that it is cross-sectional and only captures family/caregiver and patient experience immediately after a neurological event.

Family/caregiver experience and burden change over time throughout the course of caregiving (Brereton and Nolan 2002; Teel et al. 2001). This study captures only a single time point in which family members/caregivers have recently assumed the caregiver role. Ideally, family/caregivers would be interviewed at least at two time points, hospital and home, to better understand changes in experience and issues related to transitional care. Additionally, this study has a specific sample with limited size. While the sample specificity may affect applicability of results to other critical care settings, the specificity makes results as applied to this setting, a neurological ICU in Argentina, more robust. Furthermore, the similarity of medical procedures and care trajectory among patients and family/caregivers after an acute neurological makes it likely that results are applicable to other settings, though additional studies are necessary to confirm this conjecture. There is likely to be variability across ICUs caring for different patient populations with different providers. There is also likely to be variation across hospitals if additional sites were to be studied. Another study limitation is that this study does not encompass the experience of patients from the patient’s perspective. Provider perspective is also not currently considered.
4.7 Future Research

Family members as caregivers is a growing area of health systems research (Talley and Crews 2007). As the elderly population continues to increase and the burden of noncommunicable diseases rises as national disease burden shifts away from infectious and maternal disease, more and more family members will be thrust into the caregiving role (Barg et al. 2013; Talley and Crews 2007; Singhal and Khadilkar 2014). Future research of interest is integration of multiple perspectives, particularly patient, medical provider, and caregivers in other settings and at other time points, into Bronfenbrenner’s theory to explore wider applicability of a patient-centered ecological systems model as a means to conceptualize experience and relationships. Also of interest is the extent to which family/caregivers rely upon medical provider advice and prognosis and the effect this may have on family/caregiver and patient. While the focus of this study was the relationships and interactions between levels of the patient-centered model (patient, family/caregiver, provider, health system), there also exist important within-groups distinctions. For instance, there exist important distinctions between the ways in which family members assume distinct caregiving roles and experience caregiver burden. Future research is necessary to investigate family/caregiver characteristics that may result in different family/caregiver experience.
4.8 Conclusion

Family members/caregivers form an integral part of the care team. Providers must understand the ways in which family/caregivers assume and experience the caregiving role in order to respond appropriately to caregiver needs and ensure patients recover successfully in a supportive environment.

The purpose of this research is to improve care, particularly transitional care, through increased knowledge regarding the experiences and perceptions of patients and their families. Family/caregivers perceive that their experience and, consequently, their care is better when they work in concert with medical providers with the focus on the patient. Family/caregivers identify the importance of sincere communication, patient support, and el trato humano as part of the care experience.

Family members/caregivers must be recognized as members of the care team. Medical providers and family/caregivers have the same fundamental goal: to provide the best care possible for the patient and achieve successful recovery (Brereton and Nolan 2002). Both medical providers and family members/caregivers ought to work in concert to support one another for the benefit of the patient. Leveraging the relationship between providers and family/caregiver can lead to improved patient care and better support in response to family/caregiver experiences, perspective, and potential concerns. Ultimately, a more thorough understanding of care trajectory provides the opportunity
to realize systemic change to improve patient, family/caregiver, and provider experience, strengthen continuity of care and prevent new disability, and better support patients and families when they need it most.
Appendix A: Interview Guide

Opening: Hola, soy Michelle Roberts. Soy antropóloga estudiando a la Universidad de Duke en los Estados Unidos. Estoy trabajando con Hospital Italiano de Buenos Aires y Hospital Universitario Austral por tres meses para entender mejor las experiencias de pacientes con condiciones neurológicas y sus familias con las discapacidades nuevas.

Tengo algunas preguntas para preguntarle de su experiencia dentro del hospital y el centro de rehabilitación.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Question (English)</th>
<th>#</th>
<th>Question (Spanish)</th>
<th>Probe</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction &amp; General Experience</td>
<td>How are you?</td>
<td>1</td>
<td>¿Cómo está usted?</td>
<td></td>
<td>Físicamente? Emocionalmente?</td>
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<tr>
<td></td>
<td>How do you receive health information about your family member?</td>
<td>2</td>
<td>¿Qué pasó con su familiar?</td>
<td>¿Cómo es un día típico por su familiar ahora? ¿Describe porque está acá? Como están relacionados?</td>
<td></td>
</tr>
<tr>
<td>Patient Experience</td>
<td>How do you receive health information about your family member?</td>
<td>3</td>
<td>¿Cómo recibe información de la salud de su familiar?</td>
<td>¿Quién le dijo como era su familiar?</td>
<td>En el hospital? En terapia intensiva? En el piso general? En el centro de</td>
</tr>
</tbody>
</table>
| How has your family member’s life changed? (up to this point) | 4 | ¿Cómo ha cambiado la vida de su familiar? | - En la terapia intensiva?  
- Dentro del centro de rehabilitación?  
- A casa después de la hospitalización? | Físicamente?  
Emocionalmente? |
|---|---|---|---|---|
| Describe your experience as a caregiver | 5 | Describa su experiencia como familiar de una persona con problemas de salud. | - ¿Qué cosas han cambiado en su familia ahora?  
- ¿Cómo siente usted?  
- Responsabilidad es nuevas?  
- La familia? | Físicamente?  
Emocionalmente? |
| What was a typical day like for you before your family member’s hospitalization? | 6 | ¿Cómo era un día típico antes de la hospitalización de su familiar? | (specify if his/her day or the sick person) | 
| Challenges | 7 | ¿Cuáles son las cosas más difíciles para su familiar? | Fiscalmente?  
Emocionalmente? |
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</thead>
<tbody>
<tr>
<td><strong>What challenges do you have as a caregiver?</strong></td>
<td><strong>¿Cuales son las cosas más difíciles para su?</strong></td>
<td><strong>¿Cual el la única cosa más difícil?</strong></td>
<td><strong>Individual? Community? Family? Health Care? Health System?</strong></td>
</tr>
<tr>
<td><strong>What do you do to manage those challenges?</strong></td>
<td><strong>¿Qué hace para evitar estas cosas difíciles?</strong></td>
<td>[Coping]</td>
<td>Family? Community? Health Services? Religion?</td>
</tr>
<tr>
<td><strong>What has been helpful?</strong></td>
<td><strong>¿Qué le ha ayudado?</strong></td>
<td>[Coping]</td>
<td></td>
</tr>
<tr>
<td><strong>What hasn’t been helpful?</strong></td>
<td><strong>¿Qué no le ha ayudado?</strong></td>
<td>[Coping]</td>
<td></td>
</tr>
<tr>
<td><strong>What would have been helpful?</strong></td>
<td><strong>¿Qué podría haberle ayudado que no tenía?</strong></td>
<td></td>
<td>Que necesita?</td>
</tr>
<tr>
<td><strong>What support could have been provided</strong></td>
<td><strong>¿Qué puede hacer el hospital después de dar de alta a o en el hospital?</strong></td>
<td></td>
<td>Individuo Familia Comunidad Hospital</td>
</tr>
<tr>
<td>after you left the hospital?</td>
<td>su familiar para ayudarles más?</td>
<td>Sistema Sanitario</td>
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<tr>
<td>How would you define success with the recuperation of your family member?</td>
<td>¿Cómo define el éxito con la recuperación de su familiar?</td>
<td>¿Qué le gustaría poder hacer a su familiar? (What would your family member like to be able to do?)</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>¿Qué le gustaría poder hacer a su familiar? (What would your family member like to be able to do?)</td>
<td>Físicamente? Emocionalmente?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Conclusion</th>
<th>Are there any questions you would like to add?</th>
<th>15</th>
<th>¿Hay alguna otra pregunta que desea añadir a la entrevista?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there any questions you would like to ask me?</td>
<td>16</td>
<td>¿Tiene alguna pregunta que le gustaría hacerme?</td>
<td></td>
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Bibliography


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