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UNIVERSITY OF CALIFORNIA,
IRVINE

Stroke Survivor and Family Caregiver Support Utilizing a Caregiver Assessment Tool

DNP Scholarly Project Paper

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF NURSING PRACTICE

in Nursing Science

by

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2022

DEDICATION

To

my parents and family

in recognition of the path they've paved to create a brighter future

Do not let anyone look down on you because you are young, but set an example for the believers in speech, in conduct, in love, in faith and in purity.

1 Timothy 4:12

and in thanksgiving and gratitude for His guidance and faith in me

I can do all things through Him who gives me strength.

Philippians 4:13

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Thank you, especially, to our stroke patients and their families for allowing us, complete strangers, to enter their lives in the most vulnerable of times.

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VITA

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Doctor of Nursing Practice, Family Nurse Practitioner in Nursing Science

ABSTRACT OF DNP PROJECT SCHOLARLY PAPER

Stroke Survivor and Family Caregiver Support Utilizing a Caregiver Assessment Tool

by

Abigail Tabug Edilloran

Doctor of Nursing Practice, Family Nurse Practitioner in Nursing Science

University of California, Irvine, 2022

Assistant Professor Jung In Park, Chair

Purpose: This Quality Improvement project aimed to improve family caregiver support by individualizing support services and education guided by a caregiver preparedness assessment tool.

Background: The caregiver's mental health and well-being are intimately linked with stroke survivors' health outcomes and quality of life (Sutter-Leve et al., 2021). However, a systematic review of the literature has revealed that caregiver support interventions are small and inconsistent, despite the positive effects on caregiver efficacy, wellness, and health outcomes (Lopez-Hartmann et al., 2012).

Design: The design of this project was a single-site, evidence-based project integrating recommendations from the literature and the American Heart Association's Clinical Practice Guidelines for Adult Stroke Rehabilitation and Recovery (Winstein et al., 2016).

PICO Question: Among stroke survivors and family caregivers discharging from a comprehensive stroke center, how can caregiver preparedness assessment in conjunction with a stroke survivor and caregiver support program, compared to usual care, influence discharge readiness and address gaps in caregiver readiness?

Methods: Family caregivers of stroke survivors admitted to a 12-bed Neuro Intensive Care Unit or a 12-bed Neuro Progressive Care Unit at an academic medical center were given a caregiver assessment at hospital admission and discharge. Family caregivers were assessed utilizing the Preparedness for

Caregiving Scale (PCS) of the Family Care Inventory. Family caregivers were given individualized interventions guided by their admission PCS scores. Throughout hospitalization, domains of need were communicated to the interdisciplinary care team via electronic medical record and displayed signs in the patient's room. Discharge PCS scores were evaluated for efficacy of the intervention. Secondary outcome measures include care team surveys, anecdotal patient and family feedback, patient satisfaction scores, daily stroke education audits, and MyChart activation rates (patient portal).

Results: PCS scores demonstrated improved caregiver readiness ($p=0.00258$). Dominant themes of mobility, communication, coping, caregiver stress, and help from the healthcare system continue to be areas of need, as reflected in the care team surveys and family caregivers' responses. Patient satisfaction scores in communication, discharge, and care transitions were positively impacted during the project time frame.

Conclusions: The interdisciplinary stroke team effectively identified family caregivers' unmet needs and were addressed appropriately. This project highlighted the importance of family caregiver involvement in early education during a stroke survivors' diagnosis and care. Future studies include refining how to operationalize a caregiver assessment tool within existing workflows to optimize resources, time allocation, and care coordination.

CHAPTER I: INTRODUCTION

Stroke Survivor and Family Caregiver Support

The caregiver's mental health and well-being are intimately linked with the stroke survivor's health outcomes and quality of life (Sutter-Leve et al., 2021). Furthermore, the COVID-19 pandemic poses a unique challenge to family caregivers facing limited visitation in healthcare institutions, transitioning to telehealth, and managing the complex chronic disease at home. The pandemic has affected family caregivers of stroke survivors as they fear the impact of COVID-19 on the caregiver and the patient, lack understanding in their competency of care, feel unprepared for discharge, and experience communication challenges (Sutter-Leve et al., 2021). There is an increased reliance on family caregivers to support those with chronic disease at home; however, there are limited processes in place to do so. Caregiver support interventions are small and inconsistent, despite knowing caregiver support has positive effects on caregiver efficacy, wellness, and health outcomes (Lopez-Hartmann et al., 2012). If not addressed, the caregiver burden has negative consequences for the caregiver and the individuals they care for.

Background

Family Caregivers and Caregiver Burnout

With the dramatic aging of the population and the increased number of individuals living with chronic disease, family members increasingly serve as family caregivers for their parents, relatives, and friends. Informal family caregiving, defined as an unpaid family caregiver involved in assisting with daily living activities or medical tasks, is the most common form of long-term care provided in the United States (Frederick, 2018). A survey by the American Association of Retired People (AARP) conducted in 2018 revealed that 44% of California voters aged 40 years or older are current or former caregivers, and 51% of respondents will likely be family caregivers in the future (AARP, 2018).

While caring for the older adult will continue to be a global priority as the baby-boom population ages, there are enormous pressures and burdens of family caregiving, such as burnout, compromised health, depression, and depletion of financial resources – all of which are the realities of daily life for millions of American families (Campbell et al., 2014). These caregiver burdens have become a significant social problem, affecting the quality of life; yet family caregivers still prioritize caring for their loved ones to live independently at home (Campbell et al., 2014). Family caregivers report that they need to use their own money to help, are emotionally stressed because of caregiving responsibilities and trying to maintain a life-work balance, and often find it challenging to get enough rest (AARP, 2018). Changes in the caregiver's quality of life, such as anxiety and depression, have been associated with the deterioration of the physical and cognitive functions of the individuals they care for (Pucciarelli et al., 2018).

The Stroke Survivor and The Family Caregiver

Stroke is the leading cause of significant disability globally and in the U.S (Benjamin et al., 2019). Compared to other caregiving situations, the impact of a stroke, including disability, suddenly hits families with an abrupt onset of complex demands, often with no time to adjust to their new reality. As a result, they do not have a firm grasp on the new role they are undertaking and are underprepared to take on the required knowledge and skills to meet stroke patients' needs post-hospital discharge (Camicia et al., 2019). However, it is important to understand that the stroke survivor's physical and cognitive status at hospital discharge and the existing state of the caregiver's responsibilities, health concerns, and relationship with the stroke survivor influence how a family caregiver can successfully assume the caregiver role (Camicia et al., 2019).

Stroke's lasting effects on the individual and their support system are devastating, both physically and psychosocially, far beyond their stay in the hospital. Stroke survivors frequently require assistance with basic activities of daily living (ADLs), which family members will usually provide as they rehabilitate and recover at home. Thus, the caregiver stress associated with caring for a stroke survivor

can interfere with stroke rehabilitation and negatively impact caregivers through social isolation, declining health, and increasing their risk for mortality (Camak, 2015; Gaio et al., 2019; Minshall et al., 2019). Moreover, depression is prevalent among stroke family caregivers, with some studies reporting higher rates of depression in caregivers than those they care for (Camak, 2015; Gaio et al., 2019). Family caregiver stress is also commonly associated with the long-term institutionalization of stroke survivors, leading to high healthcare costs (Tseung et al., 2019).

Significance

A Growing Aging Population

Caregiver burden will continue to grow into a more significant chronic problem, as the population of California's older adults over 60 years old continues to multiply. Between 1970 and 2016, the number of older adults in California grew from 2.5 million to 7.8 million, a 212% increase (Brown Jr. et al., 2017). Moreover, by 2030, it is projected that there will be an estimated 10.9 million older Californians, with over 1 million individuals being 85 years or older (Brown Jr. et al., 2017). This increase in population, coupled with complex chronic disease management, will further necessitate appropriate preparation for family caregivers and increased reliance on the healthcare system for support. Also, families will need information and support services to preserve their critical role as caregivers for the aged population.

Quality of Care Factors

Many caregivers often feel unprepared and report insufficient assistance or education from healthcare professionals (CDC, 2017; NAC & AARP, 2020; Reinhard et al., 2019). The AARP 2012 report *Home Alone: Family Caregivers Providing Complex Chronic Care* revealed that family caregivers perform complex medical and nursing tasks, once considered the responsibility of trained healthcare professionals, with little guidance or support (Reinhard et al., 2019). With the shift in healthcare to

community settings versus the traditional residential care settings, many family caregivers (55%) rely on healthcare professionals to be their only source of information for providing care, yet have few conversations about what they need to care for their family member at home or how to support themselves (NAC & AARP, 2020). As such, more than a quarter of family caregivers are afraid to make mistakes in managing medications, using meters and monitors, and performing wound care (Reinhard et al., 2019). Family caregivers are unable to provide the quality care at home if they are inadequately prepared by the health system.

Furthermore, the National Alliance for Caregiving (NAC) and AARP's 2020 report on caregiving in the U.S demonstrate the increasing strain on family caregivers. Compared to their 2015 report, more family caregivers have difficulty coordinating care, are caring for more than one person, and 23% of Americans report that caregiving has made their health worse (NAC & AARP, 2020). The CDC parallels this report with data revealing that caregivers often neglect their own health needs and are at increased risk for having multiple chronic diseases. According to the CDC, 92.2% of caregivers aged 45 years and older have some form of health coverage but only 79.3% had a routine checkup in the past year (CDC, 2017). Coupled with this, 40.7% of caregivers report having two or more chronic diseases, 33% report having a disability, and 14.1% of caregivers have coronary heart disease and/or stroke limiting their ability to care for a loved one (CDC, 2017). With these growing issues, of critical concern is the increasing prevalence in these quality-of-care factors and the quality-of-life factors for family caregivers themselves, as more individuals will need care with fewer potential family members available to provide everyday help.

Hospital Discharge & Caregiver Readiness

Adding to the complexity of family caregiving is the transition from hospital to home. Transitions of care across different care settings, such as a hospital to home, represent a vulnerable and critical period for patients and their families. Almost one-fifth of Medicare beneficiaries discharged from an acute care

hospital are readmitted within 30 days, with high readmission rates attributed to inadequate discharge preparation, lack of patient and family caregiver readiness, poor discharge coordination, and ineffective coping (Bobay et al., 2010). Older adults and stroke survivors have unique discharge needs because of their increased likelihood of multiple comorbidities and the physical and psychosocial limitations associated with their disease process and older age (Bobay et al., 2010). Despite the known adverse effects of caregiver burden and the vital role of family caregivers in stroke survivors' ongoing care, support for caregivers is limited. Those who care for their loved ones at home assume the many functions of a healthcare provider, nursing assistant, social worker, and more, often lacking knowledge, training, and resources (Lopez-Hartmann et al., 2012).

Problem Statement

As a Comprehensive Stroke Center, the Joint Commission supported University of California (UC) San Diego Health in their 2017 redesignation survey to improve patient/family education delivery and their coordination of care across the care continuum. Furthermore, a needs assessment conducted among the stroke interdisciplinary team (n=27) revealed that the stroke patients' most significant needs upon hospital discharge include education about mobility (85.18%), communication (62.97%), activities of daily living (66.67%), and information about depression, anxiety, and coping skills (74.08%). The care team also identified a lack of knowledge regarding community resources and support to assist long-term care provision. A geographical survey of comparable local health organizations also revealed gaps in practice in the organization's current state compared to evidence-based recommendations and community standards of care regarding stroke caregiver support during their transition between hospital and discharge. Therefore, there is opportunity for improvement in the caregiver support services that the organization provides, as well as the tools used by the care team to identify how to best address patients' and families' needs across the stroke continuum.

This initiative proposes to address caregiver support during transitions of care for stroke survivors and their caregivers after hospital discharge. This will be addressed within the context of the following PICO question: Among stroke survivors and family caregivers discharging from a comprehensive stroke center, how can caregiver preparedness assessment in conjunction with a stroke survivor and caregiver support program, compared to usual care, influence discharge readiness and address gaps in caregiver readiness?

CHAPTER II: BODY OF EVIDENCE

Review of the Literature

Search Process

A systematic review of the literature was conducted concerning the efficacy of hospital support programs and caregiver preparedness for stroke survivors upon hospital discharge. Relevant articles published within the past five years were identified through CINAHL and PubMed databases, utilizing a combination of the following search terms: stroke patients, post-stroke, patient-family relations, families, caregivers, caregiver burden, caregiver support, family caregiver status, caregiver role strain, discharge planning, discharge, transitional care, transition, readiness, discharge, and support group. In addition, this review included articles about the lived experiences of stroke survivors and their family caregivers after hospital discharge, utilization of caregiver assessment methodologies, and hospital-based support programs. Among this search, 71 articles were retrieved. of which 31 articles were duplicates, and 51 articles met inclusion criteria (see Appendix A). Non-English and non-peer-reviewed studies were excluded from this analysis. Seventeen abstracts were included in the screening process, in which nine articles met eligibility for full-text review. Six studies were qualitative, and three studies were quantitative. Furthermore, the DNP student reviewed reference sections of published studies to identify critical contextual interventions to the project population, yielding ten relevant articles. Studies were included to evaluate predictors of caregiver needs and support services initiated during the early post-

stroke period. A total of 19 articles and one clinical practice guideline were reviewed within this literature analysis (see Appendix B and Appendix C).

Appraisal of Evidence

As one of the leading causes of significant disabilities in the U.S, there is an estimated 6.6 million stroke survivors, with approximately more than 4.5 million living with some level of disability following stroke (Benjamin et al., 2019). Subsequently, stroke survivors often require family caregivers to assist with rehabilitation, and in turn, family caregiving has become the most common form of long-term care in the U.S (Frederick, 2018). Nevertheless, the AARP reports that many caregivers feel unprepared and have insufficient assistance or education from healthcare professionals (Reinhard et al., 2019). This systematic review explores the studies surrounding the approaches to family caregiver assessment and the support programs utilized to address caregiver and discharge readiness when transitioning from hospital to home.

Comprehensive Synthesis of Evidence

Phases of Stroke Recovery and the Evolving Needs

Stroke patients' challenges and support needs of their family caregivers often evolve as they transition through the stroke care continuum. Among four qualitative studies surrounding stroke caregiver readiness, stroke recovery was categorized in phases associated with different sets of challenges, and therefore different support needs (Lou et al., 2015; Lutz et al., 2015; Lutz et al., 2016; Pesantes et al., 2017). In a grounded theory study interviewing stroke patients and family caregivers six months post-discharge (n=38), Lutz et al. (2016) identified three phases of the stroke trajectory: the stroke crisis, expectations for recovery, and the crisis of discharge. At each stage of the trajectory, caregivers demonstrated that they did not understand their role well and were often underprepared. In the stroke crisis phase, patients and families were focused on patient survival and decisions about rehabilitation, which then progressed to recovery and overwhelming feelings of discharge preparation among multiple

competing demands. Eventually, realizing the normality of the caregiver role and their increased risk for injury, poor health, financial impact, and change in plans became the focus for caregivers during the crisis of discharge (Lutz et al., 2016).

Similarly, patients' and families' evolving needs were described as related to illness duration (Lou et al., 2015). However, health information, professional support, and community networks were the leading needs domains in all stages, from their time spent in the intensive care unit, before hospital discharge, two weeks post-hospitalization, and at 3-months post-hospitalization (Lou et al., 2015). Interviews with stroke caregivers (n=12) also revealed that emotional distress was most intense immediately after the stroke event, affecting their ability to care for their family member, which lessened as they became more confident in their caregiving ability (Pesantes et al., 2017).

As stroke survivors progress through their recovery, the literature demonstrated the necessity to identify their contextual factors on the stroke recovery continuum. However, it is also important to note the limitations of the existing evidence when considering these findings. Studies were limited to small convenient sample sizes, lack of specificity regarding the severity of the post-stroke disability, or the patient's discharge disposition directly to home versus rehab facility. These factors might have an important impact on the family caregiver's role and preparedness.

Despite this, these studies are valuable as they allow a glimpse into the lived experiences of a stroke caregiver and survivor as they transition from the acute care setting back to the community. They reveal consistent themes regarding the phases of stroke recovery and its impact on learning, caregiving, and coping. The severity of the disease process affects the survivor's and caregiver's ability to process the required knowledge and training to adjust to their new normal. Therefore, healthcare professionals must tailor interventions for stroke survivors and their caregivers to their readiness utilizing anticipatory guidance strategies.

Efficacy of Caregiver Assessment Tools

Of the 19 articles reviewed, 17 articles discussed the impact of caregiver assessment on caregiver support programs and their readiness. Caregiver assessment tools allow for an individualized, person-centered approach in identifying educational support and resources needed. Several conditions were described by patients and caregivers, influencing their ability to cope with the transition from hospital discharge to home (Camicia et al., 2021; Hagedoorn et al., 2020). The conditions included the following: the caregiver's pre-stroke caregiving experience, the strength of the patient/caregiver relationship, family responsibilities, financial impact, access to resources, and caregiver's perceived needs were all contributory factors to their caregiving ability (Camicia et al., 2021; Hagedoorn et al., 2020; Pesantes et al., 2017; Rath et al., 2020). In a prospective multi-center randomized controlled trial, Cheng (2018) used a caregiver assessment tool at varying time points in the stroke patient's recovery to better understand caregiver competence and create a psychoeducational program that best fits their needs. Additionally, National Institutes of Health Stroke Scale (NIHSS) scores on admission and the requirements of family caregivers correlated significantly with those who had more significant care needs, and NIHSS was a good predictor of physical function of stroke patients (Lou et al., 2015). Furthermore, Lou et al. (2015) recommended that the first two stages during hospitalization (before transfer from intensive care to the neurological unit and before hospital discharge) may be a critical time for healthcare providers to perform needs assessments.

Among this discussion, it is essential to note various existing caregiver assessment tools in the literature. Specific tools include the Preparedness Assessment for the Transition Home after Stroke (PATH-s) assessment tool, the Preparedness for Caregiving Scale (PCS) of the Family Care Inventory, the Family Collaboration Scale (FCS), the Family Strain Questionnaire-Short Form (FSQ-SF), and the Family Caregiver Activation in Transitions (FCAT) tool. The PCS, an 8-item questionnaire, was identified as the most widely used tool in assessing family readiness, measuring the perceptions of the role of family preparedness (Abu et al., 2020). Two articles emphasized that the PCS can significantly increase family readiness for stroke care (Abu et al., 2020; Hagedoorn et al., 2020). Furthermore, the

PATH-s instrument, consisting of 25 question domains, measured family commitment and capacity, provoking cues to action to address specific concerns post-discharge regarding long-term complications of stroke and their caregiving role (Camicia et al., 2021).

Similarly, the FCAT tool can guide the care team in understanding what areas family caregivers need additional support in and match the patient and their caregiver with appropriate resources (Coleman, 2016). The PATH-s was the only existing caregiver assessment tool tailed to stroke care. However, it was the lengthiest questionnaire for caregivers to fill out, which may be a potential barrier.

Assessment of family caregiver readiness has elicited concerns that may not have been identified without proper assessment. These qualitative research articles suggest factors that influence family readiness are significant indicators for healthcare professionals when preparing stroke patients for discharge. However, careful consideration is needed regarding what specific assessment tool is used to respect the time and workload of the frontline staff performing these assessments. With the implementation of a standardized caregiver assessment, an individualized care plan can be developed, and services for caregivers and patients can be tailored to their specific needs. Furthermore, it allows information to be compared across organizations, hospitals, and various settings to ensure equitable distribution of resources.

Caregiver Education and Support Programs

Throughout the stroke continuum, a support group or training session for caregivers demonstrated increased empowerment and readiness for post-stroke care (Araujo et al., 2017; Cameron et al., 2015; Camak, 2015; Gaio et al., 2019; Hartford, Lear, & Nimmon, 2019; Smith et al., 2019; Sumeet & George, 2017). For example, in the Timing it Right Stroke Family Support Program, stroke caregivers spent a median of five sessions and 123 minutes in the stroke support intervention. Results of this single-blind explanatory mixed-method randomized control trial illustrated that caregivers enrolled in the intervention

stated improvement in perceived support (P=0.04) and sense of mastery (P=0.06), compared to standard care (Cameron et al., 2015).

Additionally, caregiver support groups or training sessions demonstrated positive outcomes with the following themes: shared experiences of managing stroke, providing and navigating resources, and addressing the psychological impact of caregiving (Camak, 2015; Danzi et al., 2016; Gaio et al., 2019; Hartford et al., 2019; Minshall et al., 2019). Most notably, stroke caregiver support interventions can be cost-effective by reducing emergency room visits, readmissions to the hospital, and fewer illnesses because the survivor has better support at home (Tseung et al., 2019). Thus, the evidence supports the need for caregiver and family support in a support group or educational program.

Despite the evidence regarding the detrimental effects of caregiver burden and transitional stroke support programs' efficacy, and just as caregiver readiness is essential for the successful delivery of patient and family education, organizational readiness is crucial for formulating an implementation plan for caregiver and family support. (Forster et al., 2015; Lutz et al., 2020). For example, the Training Caregivers after Stroke (TRACS) trial was conducted across a range of inpatient stroke units to equip multidisciplinary team members with the skills to identify the knowledge and skills that family caregivers would need to care for stroke patients after hospital discharge (Forster et al., 2015). However, despite high attendance during training and positive feedback from staff members, training was not consistently disseminated to other care team members and was not always implemented into practice (Forster et al., 2015). Comparably, the Comprehensive Post-Acute Stroke Service-Transitional Care (COMPASS-TC) study evaluated real-world successes and challenges with integrating a multifaceted transitional program into clinical workflow across 19 hospitals (Lutz et al., 2020). The COMPASS-TC study reinforced the need for organizational commitment and capacity, prioritization, and resource allocation, in addition to autonomy and support for clinicians (Lutz et al., 2020).

Limitations and Conclusions

There is a lack of specificity regarding the appropriate education and training for caregivers, contributing to an environment where caregivers often receive minimal information and knowledge because hospitals have little direction over providing education and training to caregivers. While recommendations to utilize a caregiver assessment tool demonstrate improved caregiver readiness outcomes, there is no existing universal reference instrument to give a global overview of caregiver needs. Other considerations when critiquing the studies' findings are that most of the articles published are qualitative, with limited evidence demonstrating patient outcomes or quantifiable improvement in the stroke survivor's and caregiver's quality of life. Additionally, consideration regarding the timing of support services concerning the stroke continuum should be anticipated when implementing a support program.

The survivor's and caregiver's psychosocial readiness to engage in learning and the specific support services must be tailored to their needs during each recovery phase. Healthcare providers must also assess organizational readiness for a sustainable, successful support program and active involvement of the multidisciplinary team. Lastly, further research is needed on its efficacy on patient and caregiver outcomes and the most operational standardized tool to assess caregiver needs at hospital discharge.

Clinical Practice Guidelines Appraisal

The American Heart Association (AHA) and the American Stroke Association (ASA) have published guidelines recommending the inclusion of family education programs as part of clinical care to reduce anxiety, depression, post-traumatic stress, and generalized stress while improving family satisfaction. The AHA/ASA published the Guidelines for Adult Stroke Rehabilitation and Recovery (2016), including Class IIA recommendations for individualized discharge planning in the transition from hospital to home, providing regular family caregiver support regarding education, training, counseling, and support structure and financial assistance. Furthermore, AHA/ASA makes Class I recommendations for acute care hospitals to maintain up-to-date inventories of community resources, providing information

about local resources to patients and families while considering their specific preferences with appropriate follow-up (Winstein et al., 2016).

Recommendations that outline specific rehabilitative support systems provided by the acute care system are described and appraised in the AGREE II instrument (Appendix D). The guidelines do not specify their criteria for selecting the evidence included in their recommendations. However, the guidelines have been through extensive internal and external peer review, Stroke Council Leadership review, and the Scientific Statements Oversight Committee review of the AHA. In addition, the American Academy of Neurology and the American Congress of Rehabilitation Medicine affirm the value of the content of these guidelines. However, it is also important to note that there are few large-scale rigorous clinical trials in this field, and the only available data to drive the recommendations were those in smaller trials.

Nonetheless, these guidelines can guide the proposed project for a stroke support program in creating a comprehensive resource guide to local community resources through agencies such as the local chapter of the AHA and the organization's Comprehensive Stroke Program. This can be integrated within discharge order sets and discharge education provided by the discharging nurse and social worker, carried through during the patient's initial outpatient visits with the stroke clinic post-discharge. Furthermore, the integration of a caregiver needs assessment tool during their hospital stay can reinforce the recommendation for family caregiver involvement in decision making and treatment planning as early as possible (class IIb, level of evidence B) and individualize resources to the patient/caregiver's preference (class I, level of evidence C).

Evidence-Based Recommendations

The literature recommends the integration of a standardized caregiver needs assessment tool before hospital discharge as an impactful and cost-effect intervention to guide a tailored stroke survivor and family caregiver support program. Family caregivers often do not realize what they need or what

skills and training are lacking when transitioning home after hospital discharge. Thus, understanding the stroke crisis trajectory and the unique needs that each phase brings can aid in designing support and education programs for patients and families. Healthcare professionals can create a bundled approach with resources and training materials upon hospital discharge. Furthermore, a caregiver assessment tool can individualize these resources and realize unmet needs before transitioning patients and their families to the next phase in their recovery.

It is also evident that organizational commitment and stakeholder buy-in are crucial in successfully implementing a caregiver support program across care transitions from hospital to home. Caregiver support requires the refined coordination of an interdisciplinary team across the different phases of stroke recovery. Healthcare professionals must be mindful of the intensive mobilization efforts to take on such an endeavor to ensure sustainability and efficacy and be sensitive to organizational readiness and willingness to adopt change. Thus, this author recommends small initial changes such as a caregiver assessment tool integrated within the electronic medical record. This assessment can be integrated upon discharge teaching, daily stroke education, or routine case management assessment to not heavily disrupt an already hectic workflow. Family caregivers and stroke patients can be stratified into categories based on the results of their assessments. The hospital care team can appropriately provide patient-family-centered training and education and tailored resources for patients and families after their hospital stay. Ultimately, the proposal from this literature offers a real-world strategy to integrate simple interventions for family caregiver assessment and support into clinical workflow in the hospital setting.

CHAPTER III: PROJECT FRAMEWORK

Evidence-Based Practice Model

The conceptual framework for this project is the Iowa Model Revised, an evidence-based practice (EBP) model promoting quality care by incorporating the patient, provider, and the social system (Appendix E) (Moran et al., 2020). The Iowa Model Revised guides clinical decision-making and EBP

implementation from both the practitioner and organizational perspectives. Linking practice changes within the system, the Iowa Model Revised is an application-oriented guide for the EBP process that involves expanding piloting the practice change, implementation, patient engagement, and sustaining change (Buckwalter et al., 2017).

The Iowa Model Revised was applied to this initiative to pilot the family caregiver assessment tool among family caregivers of stroke survivors before hospital discharge to determine its efficacy in meeting their caregiving needs. This model was selected because of how its components seamlessly integrates the proposed project elements. With its emphasis on the organizational infrastructure, the proposed change project requires coordination across interdisciplinary team members and organizational investment in enhancing stroke survivor support. Additionally, it allows for feedback loops to guide change processes when trialing the practice change before widespread implementation across the system (Schaffer et al., 2012). For example, the project team was engaged to evaluate effectiveness throughout the pilot and minor adjustments in workflow was made. In a fluid environment such as a stroke unit working with stroke survivors and families of varying needs, this model addresses decision points throughout the implementation process and how to adjust accordingly when translating into practice. The Iowa Model Revised also emphasizes a pilot study to evaluate the implementation plan, considering the availability of time and resources and patient-family engagement and feedback.

Logic Model

To aid in program evaluation, the logic model (Appendix F) outlines the flow of materials and processes to produce the outcomes of this proposal. With the understanding that clinicians and involved staff will have adequate motivation and time to implement this new initiative, this project will require time, training, and interdisciplinary care coordination invested in initiating the project. The time and care coordination will assist in creating the tools and methods to reach patients and family caregivers in a coordinated and individualized effort to deliver support services unique to their needs.

Furthermore, the logic model outlines the potential impact of these efforts. This includes improved patient and family caregiver support, patient satisfaction, and refined staff knowledge of patient/family caregiver needs before hospital discharge. Moreover, these efforts can have long-term impacts to expanding the stroke support services offered by the organization's stroke program and promoting its ongoing comprehensive stroke center designation by The Joint Commission by upholding evidence-based practices and enhancing the services provided to patients and families.

In this discussion, it is also essential to note potential external factors that may affect the success of this pilot study. For example, the outcome of this project is contingent upon stroke patient volume, the dynamic changes to the hospital patient visitation policy due to the ongoing pandemic, and the staffing factors that may affect the care team's ability to implement patient and family assessment and education. The logic model in Appendix F outlines this program evaluation and process flow in detail.

CHAPTER IV: METHODS

Project Goals

This project aimed to improve family caregiver support by individualizing support services and patient-family education as identified through a caregiver preparedness assessment tool. This initiative was conducted within dedicated neuro units, facilitated by specialty-trained neuro nurses to administer the caregiver preparedness assessment tool twice in the patient's hospitalization, upon admission and discharge. Participant scores on the caregiver assessment tool measured family caregiver readiness and was monitored before and after initiating the caregiver support bundle and individualized interventions. Secondary outcomes also include the following as process measures:

- HCAHPS scores in the domains of “communication with nurses”, “discharge information”, and “care transitions”

- Increased compliance with patient education measured by Electronic Medical Records (EMR) documentation
- MyChart (patient portal) activation rates before and after the pilot
- Interdisciplinary stroke care team needs assessment pre- and post-pilot

Project Description

Project Type/Design

This project is evidence-based, integrating recommendations from the literature and clinical practice guidelines published by the AHA and ASA.

Project Setting/Population

This pilot project was conducted at UC San Diego Health System's Jacobs Medical Center, a Comprehensive Stroke Center designated by The Joint Commission since 2017. UC San Diego Health was the first to receive Comprehensive Stroke Center certification in San Diego and remains the only health system in the county to have the certification at two hospitals. Its organization has a dedicated 12-bed Neuro Stroke Progressive Care Unit (PCU) and 12-bed Neurocritical Care Intensive Care Unit (ICU), staffed by a multidisciplinary team of experts of neurologists, neurointensivists, neurosurgeons, rehabilitation therapists, and neuro nurses.

Nursing staff, directly responsible for facilitating the PCS tool to family caregivers, are specialty trained neuro-stroke nurses caring for a complex population of stroke patients. A letter of support from the project site has been obtained and is referenced in Appendix H.

Participants and Recruitment

Participants in this pilot project include family caregivers of stroke survivors with a primary diagnosis of ischemic stroke, hemorrhagic stroke (intracranial hemorrhage, subarachnoid), or transient

ischemic attack (TIA) admitted to the Neuro ICU or PCU within the pilot time frame, January to March 2022. They were recruited to take the PCS tool within 24 hours of admission to the neuro unit or identification of a family caregiver. Patients who were transferred out of the selected stroke units during their hospital stay were no longer included in the project. Further inclusion criteria include English or Spanish speaking, stroke survivors with a designated family caregiver identified during their stay in the neuro unit, and family caregivers of patients discharged to home or nursing facility. Exclusion criteria include patients without family caregivers identified, non-English/Spanish speaking, family caregivers of deceased patients, and family caregivers of patients without stroke as the primary diagnosis for their hospitalization.

Description of Intervention

The DNP student and project committee facilitated care team education regarding implementing the stroke survivor and caregiver support bundle via an online education module, staff meetings, and on-unit in-services. Upon introducing the discharge bundle, family caregivers were asked to complete the PCS of the Family Care Inventory tool to establish their baseline readiness for caregiving. Throughout hospitalization, family caregivers had an opportunity to review the resources provided and ask questions to the care team utilizing the "Your Stroke Discharge Checklist" included within the bundle (Appendix I). Based on the family caregivers' response to the PCS tool, the care team initiated additional individualized interventions based on the domains identified as their greatest need (Appendix I). These individualized interventions were communicated to the entire care team by updating the "yellow sticky note" in the patient's EMR and with educational posters displayed in the patient's room. This signaled any care team member who accesses the patients' chart to focus on these individualized needs when providing education, therapy, or addressing any family caregiver questions at the bedside. Lastly, after ongoing education and support from the care team during their hospitalization, family caregivers were reassessed via the PCS tool on the day of discharge.

Measures/Instruments

Outcome measures were defined through an assessment of caregiver and discharge readiness as assessed through the PCS of the Family Care Inventory tool (Appendix J). The PCS is a caregiver self-rated instrument that consists of 8-items. It examines perceived readiness in the domains of the caregiving role: providing physical care, emotional support, setting up in-home support services, and coping with the stress of caregiving (Abu et al., 2020; Hagedoorn et al., 2020). The DNP student chose this tool because it has been the most widely used tool assessing family readiness and has been demonstrated to be a reliable and valid tool in caregivers of stroke survivors (Abu et al., 2020; Pucciarelli et al., 2018). This assessment was conducted before and after implementing the stroke-specific discharge bundle to determine the effectiveness of the current systems for caregiver support with transitions in care and then again post-intervention.

Data Collection Procedures

Each participant (family caregiver) was requested to complete the PCS upon the stroke survivor's admission to the neuro unit and upon discharge from the hospital. In addition, the patient's stroke diagnosis, hospital length of stay, and family caregiver demographics was also collected. Furthermore, in order to understand care team perception of support services provided, an interdisciplinary stroke care team needs assessment was conducted before and after this project. The care team pre-assessment was conducted in January 2021 to help formulate the specific interventions for this project and care team post-assessment was conducted at the conclusion of the pilot project.

Additionally, secondary outcome measures were collected to monitor processes throughout this project. For example, patient MyChart registration rates were tracked by EMR data extraction, and patient satisfaction for communication measured by HCAHPS Patient Satisfaction were monitored. Additionally, compliance of nurses' documentation of daily patient education was compared to PCS scores to evaluate if daily patient education influences PCS score outcomes and caregiving readiness.

Data Analysis

Descriptive statistics was used to evaluate the characteristics of the population in this project (stroke survivor's diagnosis, caregiver age, and caregivers' education level). A one-tailed paired t-test analysis was used to examine the change in PCS scores before and after introducing the stroke support bundle and individualized interventions. Microsoft Excel was used to calculate statistical values.

Ethical Considerations

The UC Irvine Institutional Review Board (IRB) form, Request for Determination Non-Human Subjects, was completed and approved before project implementation (Appendix L). This project was also reviewed at UC San Diego Health's Aligning and Coordinating Quality Improvement, Research, and Evaluation (ACQUIRE) Committee for IRB Review and was determined that it does not require IRB review or approval (Appendix L). All participants were protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), protecting the privacy of patients' health information (Department of Health and Human Services, 2013). This project did not include any potential patient identifiers in the data collection, and the DNP student disclosed all risks to all participants. Participant confidentiality was maintained by coding the participants using unique identification numbers. All data gathered was accessible only to the DNP student and stored in a secured location, preventing unauthorized access (both electronically and physically) to other individuals.

Stakeholders/Barriers

The entire interdisciplinary stroke care team, nursing staff, providers, rehabilitation team members, and care management were integral to this pilot's success. Of utmost importance, were the bedside neuro nurses who facilitated the intervention and the interdisciplinary stroke team who was responsible for being aware of the knowledge gaps and caregiving needs identified on the tool and ensuring that additional support services are provided in the specified domains. Support from leadership

amongst the various health teams ensured a cohesive delivery of support services for stroke survivors and their families.

Moreover, the current COVID-19 pandemic was an ongoing potential barrier to this initiative. As COVID-19 cases impact hospital patient volume and visitation policies, access to family caregivers and stroke patients were affected. The recruitment process was affected by the COVID-19 surge and the omicron variant. Hospital visitation policies were tightened up and patient census shifted to accommodate the increase in COVID-19 cases in the health system. Despite this, ongoing care for stroke patients occurred and promotion of family visitation for caregiver teaching was allowed as much as possible.

Formative Process Evaluation

The interdisciplinary care team needs assessment assisted in formative evaluation and identifying the most significant perceived needs of family caregivers upon hospital discharge. Furthermore, monthly evaluations were conducted at each project site's staff meeting. Anecdotal feedback at both January and February staff meetings has provided positive feedback. Constructive feedback includes modifications of workflow and how to integrate the assessment tool into conversations with family caregivers operationally. Practices among nursing staff vary, with some nurses reading the questions to the family caregivers, handing the questionnaire to the family caregiver to fill out themselves, or using it as a conversational piece to dictate bedside education. This response rate may be due to the existing workflow, with assessments conducted via pen and paper. There were also challenges gathering paper surveys, requiring close follow-up and monitoring, contributing to the participation rate. Therefore, adding this assessment to the EMR for ease of navigation and data recording was suggested. This proposal has been approved by Patient Education Committee, Clinical Practice Informatics Council, and Stroke Leadership Council for pilot integration into the EMR.

CHAPTER V: RESULTS AND CONCLUSIONS

Results

Among the 24 qualifying family caregiver participants, we received a 79% response rate (n=19) between January and March 2022. One patient passed away, three participants were not assessed or offered participation in this project, and one qualifying participant had their stroke survivor transferred out of the stroke unit before discharge. 31.58% of family caregivers were older than 60 years old, 21.05% were 51 to 60 years old, 15.79% were 41 to 50 years old, and 5.26% were 31 to 40 years old. A majority of them had a bachelor's or graduate degree as their education level (68.42%, n=13). All participants had a familial relationship with the stroke survivor, either as a spouse (47.37%), sibling (31.58%), or son/daughter (21.05%). Principle stroke diagnoses included acute ischemic stroke (42.11%, n=8), subarachnoid hemorrhage (31.58%, n=6), intracerebral hemorrhage (15.79%, n=3), and transient ischemic attack (10.53%, n=2). Table 1 below outlines the characteristics of the population of interest in detail.

Table 1 Participant Characteristics

Patient Characteristics (n=19)	(N (%))
Principle Diagnosis	
Acute Ischemic Stroke (AIS)	8 (42.11)
Subarachnoid Hemorrhage (SAH)	6 (31.58)
Intracerebral Hemorrhage (ICH)	3 (15.79)
Transient Ischemic Attack (TIA)	2 (10.53)
Family Caregiver Characteristics (n=19)	
	(N (%))

Relationship to Stroke Survivor

No answer	0 (0)
Spouse	9 (47.37)
Son or daughter	4 (21.05)
Sibling	6 (31.58)
Friend	0 (0)

Family Caregiver Age

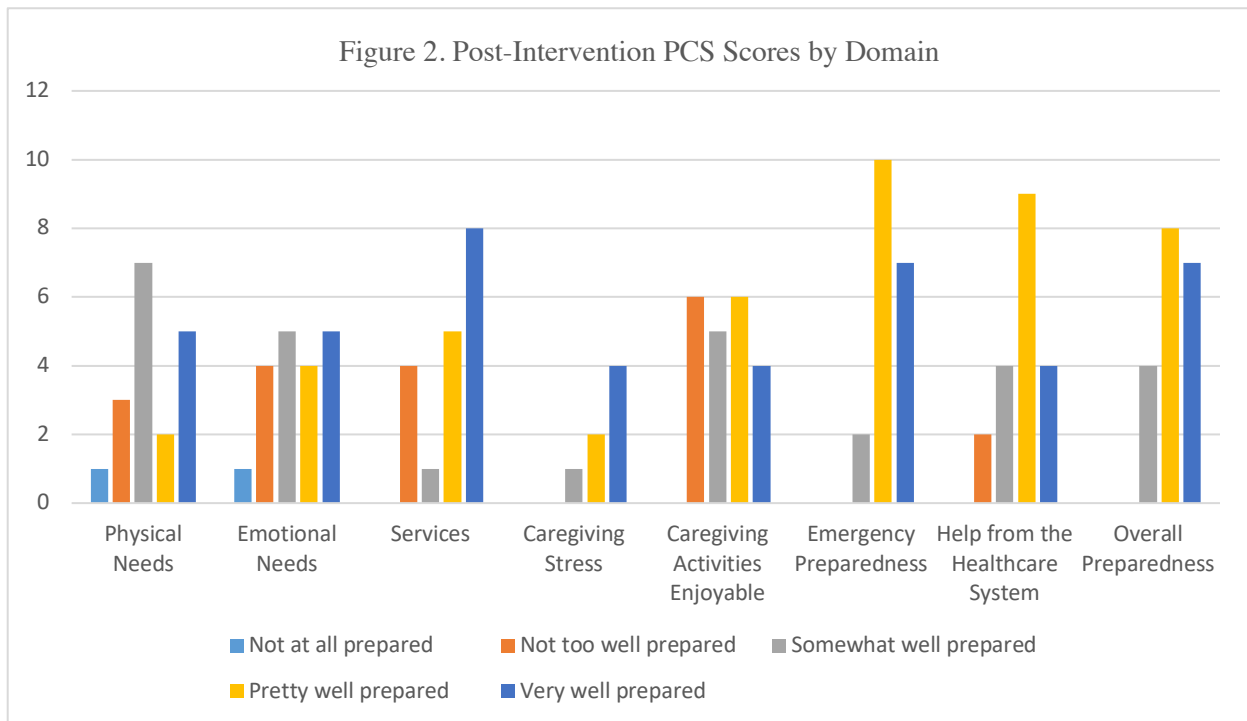
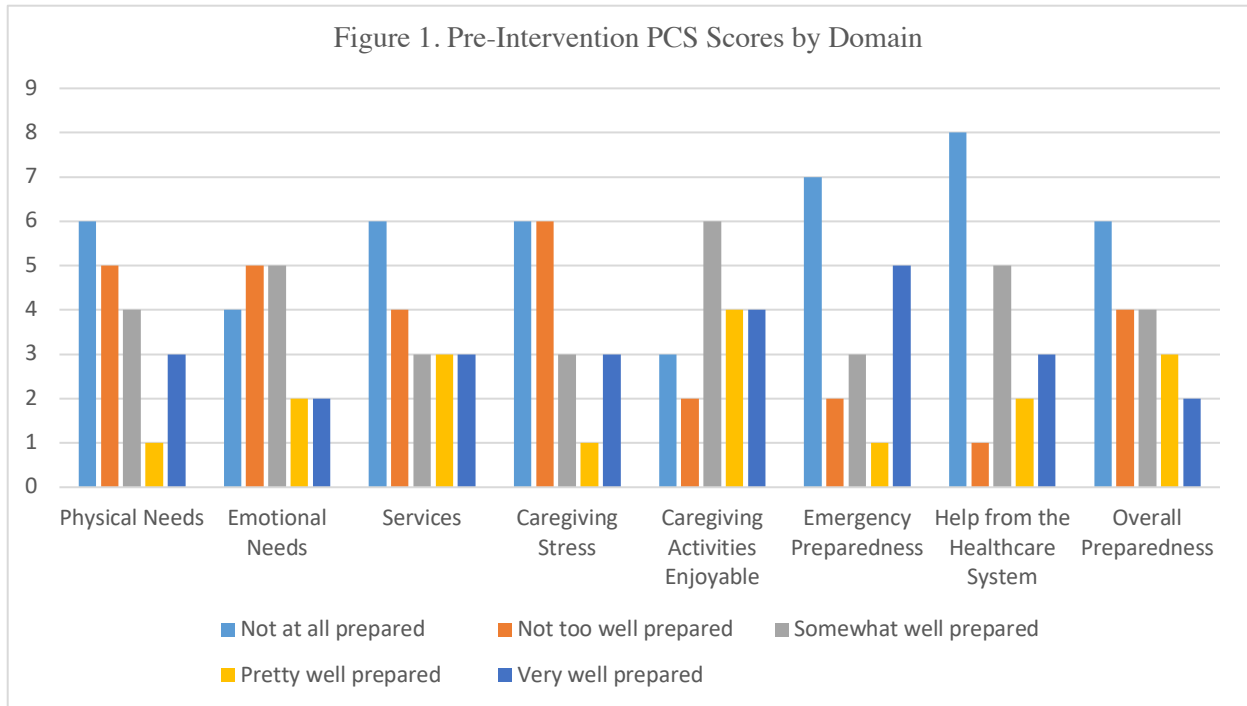
No answer	5 (26.32)
20-30 years old	0 (0)
31-40 years old	1 (5.26)
41-50 years old	3 (15.79)
51-60 years old	4 (21.05)
60+ years old	6 (31.58)

Education Level

No answer	6 (31.58)
High School/GED	0 (0)
Associates Degree	0 (0)
Bachelor's Degree	9 (47.37)
Graduate Degree	4 (21.05)

Family Caregiver Readiness

Family caregiver readiness was quantified using the PCS tool of the Family Care Inventory, of the Family Collaboration Scale. With a 79% participation rate (n=19), statistical analysis reveals an improvement in family caregiver readiness after exposure to the family caregiver support bundle (p=0.00258). Results from pre- and post-intervention PCS assessment by outlined by domain are demonstrated in Figure 1 and Figure 2.



Furthermore, anecdotal feedback from family caregivers provided a qualitative look into their experiences. A family caregiver recounted his experience in the ICU as a “rollercoaster, with everything happening so fast” and having “never experienced anything like this”. Within his discharge assessment he

shared that they were provided “excellent care and had good support, everyone knew exactly how to make a difficult situation a little bit easier”. Family caregivers also requested information regarding CPR refresher courses, setting up home healthcare, and ordering/receiving items needed for at-home health care.

Stroke Interdisciplinary Care Team Needs Assessment

Before the project implementation, an interdisciplinary care team needs assessment tool was disseminated. The needs assessment assisted in identifying the most significant perceived needs of family caregivers upon hospital discharge of their loved one. Results of this interdisciplinary team needs assessment (n=28) demonstrated stroke patients' most essential needs upon hospital discharge include education about mobility (85.18%), communication (62.97%), activities of daily living (66.67%), and information about depression, anxiety, and coping skills (74.08%). The care team also identified a lack of knowledge regarding community resources and support to assist long-term care provision.

After care team education and implementation of this project, a post-survey (n=15) illustrated the following domains to be the continued areas of greatest needs: mobility (53.33%), information about depression, anxiety, and coping skills (53.33%), and understanding risk factors and lifestyle changes (57.15%). A domain that was not identified in the pre-intervention assessment survey that was identified post-pilot was education regarding prescribed medications (53.33%). Furthermore, when asked about the care teams' areas of strength in providing stroke family caregiver support, responses illustrated that education regarding mobility (19.64%), education regarding participation in activities of daily living (14.29%), and education regarding nutrition (12.5%) and medications (12.5%) were the top strengths of the care team. Table 2 outlines care team assessment survey results in detail.

The care team was also queried regarding the project's intervention tools used and its ease of use. Respondents stated that the patient tool posters with individualized interventions were either useful (78.57%) or very useful (21.43%), the caregiver assessment tool as useful (64.29%) or very useful

(28.57%), and the caregiver support pamphlet as useful (64.29%) or very useful (21.43%). The care team also reinforced the importance of ensuring family caregiver “comfort with what help the patient needs if they are being discharged home”.

Table 2 Interdisciplinary Care Team Survey Respondents

Interdisciplinary Care Team Role	(N (%)) Pre-Pilot	(N (%)) Post-Pilot
Physician	0 (0)	0 (0)
Nurse Practitioner	1 (3.57)	0 (0)
Registered Nurse	11 (39.29)	12 (80)
Rehab Therapist (SLP, PT, OT)	5 (17.86)	0 (0)
Social Work/Case Management	10 (35.71)	3 (20)

Secondary Outcomes

HCAHPS Survey Results

With the implementation of this project, Hospital Consumer Assessment of Health Providers and Systems (HCAHPS) scores in the domains of “communication with nurses”, “discharge information”, and “care transitions” were reviewed. HCAHPS is the survey tool utilized for all adult inpatient visits and are included in the Centers for Medicare and Medicaid (CMS) calculations for Value Based Purchasing (VBP) initiatives (CMS, 2021). In review of the responses, patient survey scores are analyzed by Top Box percentage and Percentile Rank. Top Box percentage is the percentage of patients who select the highest possible answer, while Percentile Rank indicates where the clinical area stands in comparison to other clinical areas in the organization (CMS, 2021). The three-months prior to the project were reviewed in comparison to the three-month pilot period, January to March.

The figures below outline the HCAHPS scores from both the Neuro ICU and PCU combined. Figure 3 and 4 illustrate the domains of “communication with nurses” and “discharge information”. “Communication with Nurses” had a Top Box percent score that was consistently within the 50th and 75th

percentile over the pilot period, while there is an improvement in Top Box percentage in the domain of “Discharge Information”. Despite this, the clinical areas’ percentile rank fluctuated with a general downward trend throughout the time frame of this project. It is important to note that the response rate for March (n=10) was significantly lower than the previous months, reflecting the possible decline in responses, the decrease in patient discharges during the month of March, or the effect of hospital visitation policies. Despite this, it is noteworthy to highlight the upward trend in both Top Box percentage and Percentile Rank in the domain of “care transitions (Figure 5).

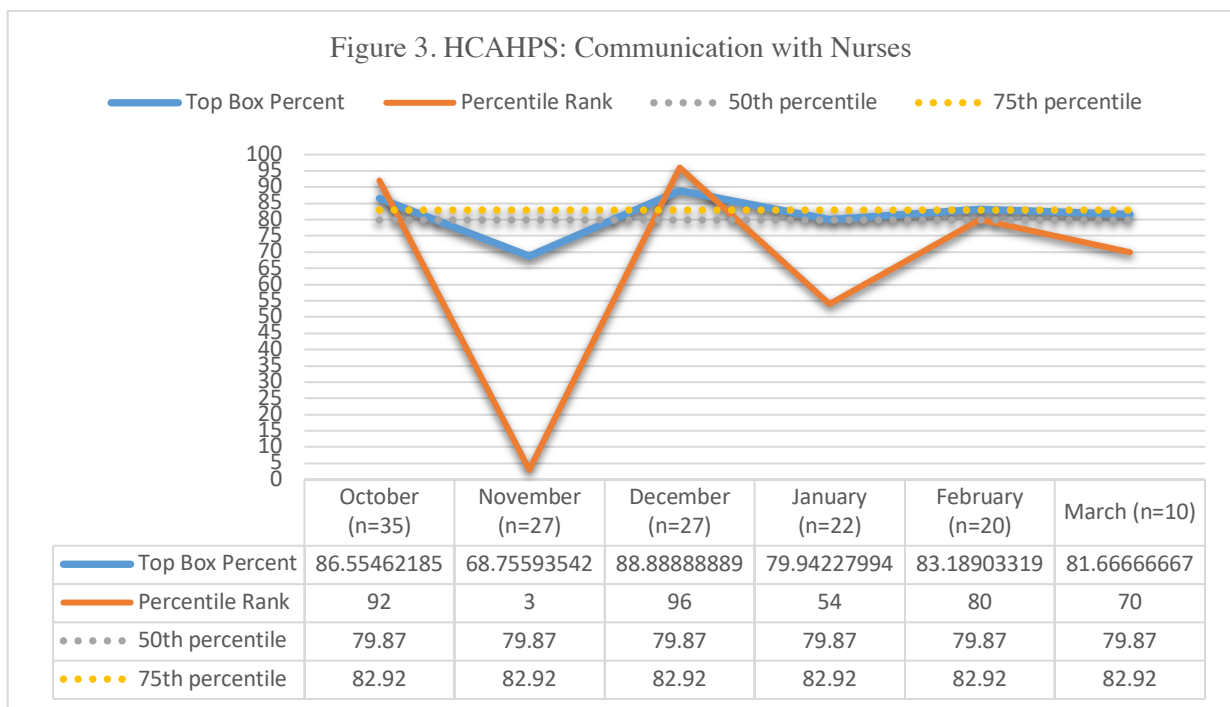


Figure 4. HCAHPS: Discharge Information

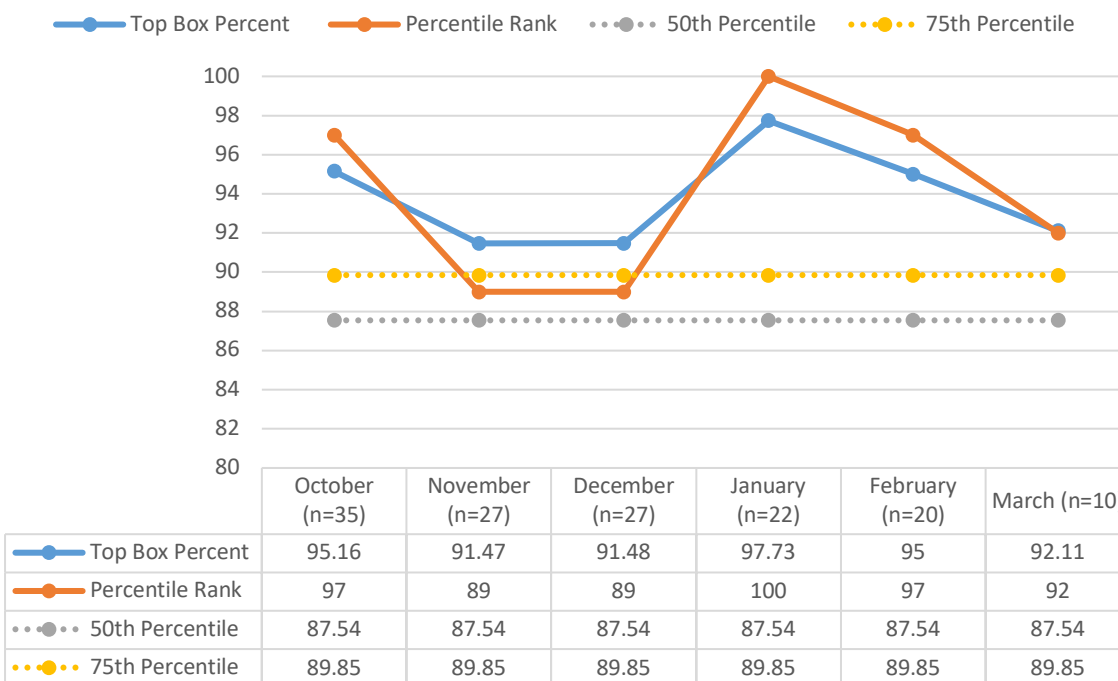
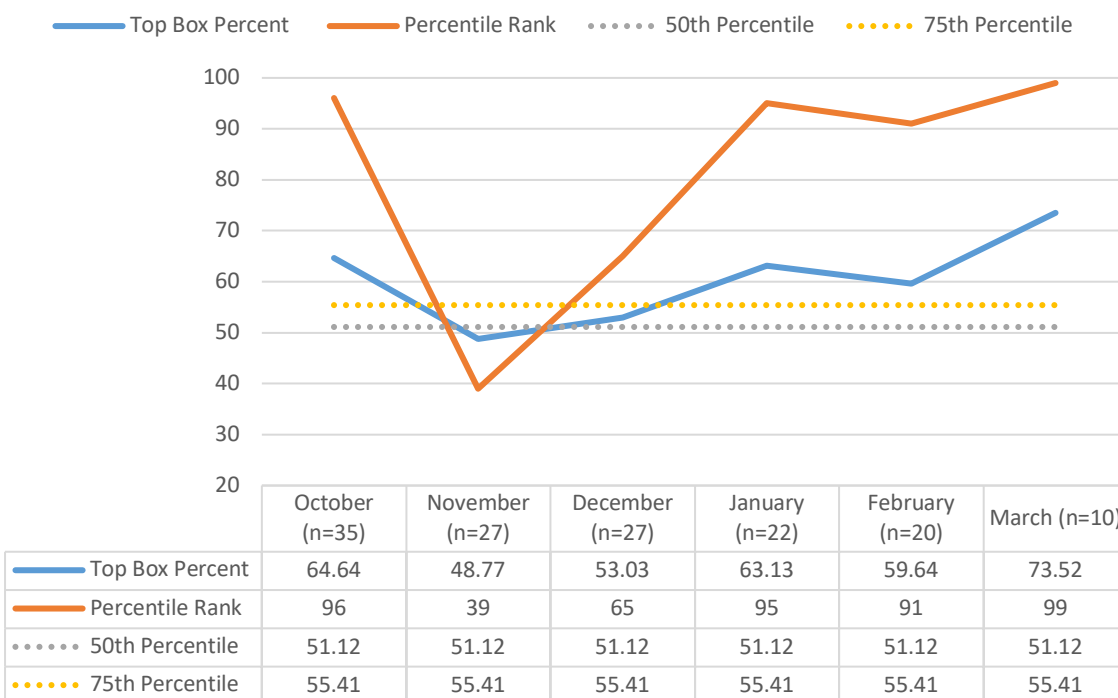


Figure 5. HCAHPS: Care Transitions



Daily Stroke Education Documentation

The Joint Commission Quality Measures for Disease-Specific Care Certification, specifically its standardized performance measures for comprehensive stroke centers, include providing ongoing stroke education during hospitalization. This measure, STK-8, outlines the standard that stroke patients or their caregivers were provided education materials regarding: activation of emergency medical services, follow-up after discharge, discharge medications, stroke risk factors, and warning signs and symptoms of stroke (The Joint Commission, 2021). As a secondary measure of this project, daily stroke education audits were conducted as outlined in Table 3. In comparison to the three-month time frame (October 2021 to December 2021) prior to project implementation (January 2022 to March 2022), there is an upward trend in daily stroke education conducted in the La Jolla site, where this DNP project was implemented.

Table 3. Daily Stroke Education Audit

	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22
Hillcrest	69%	66%	54%	59%	85%	72%
La Jolla	28%	49%	50%	45%	73%	96%
Combined	47%	56%	52%	49%	81%	79%
Hillcrest numerator	189	103	89	165	189	146
Hillcrest denominator	273	155	166	280	222	204
La Jolla numerator	92	111	102	270	98	79
Combined numerator	281	214	191	435	287	225
Combined denominator	601	380	369	884	356	286

MyChart Patient Portal Activation Rates

Lastly, we reviewed the engagement of family caregivers with the patient portal as a result of this DNP project. Included in this support bundle was instructions on how to activate proxy access to

MyChart, a personalized and secure on-line access to the patients' medical records (UC San Diego Health, 2022). In the three-month time period prior to this project, there was a total of 642 patient on the neurology, neuro stroke, neurocritical care, and neurosurgery service. Among them, 57.3% had activated MyChart accounts (n= 368), 32% pending activation (n=206), and 8.26% inactivated MyChart accounts (n=53). In comparison, there were 278 eligible patients on the combined neuro services during the pilot project time period. With implementation of this project, there was a 57.56% activation rate (n=160), 31.3% pending activation (n=87), and 8.9% inactivated MyChart accounts (n=25).

Discussion

This project evaluates the utilization of a caregiver assessment tool before hospital discharge as an effective method for clinicians to develop a tailored family caregiver support program at a comprehensive stroke center. As a result, this project further reinforces the need for family caregiver engagement during stroke survivor hospitalization, highlights consistent themes of education and support, and emphasizes the integral role of the family caregiver in the stroke survivors' recovery.

Anecdotal feedback from the interdisciplinary stroke team throughout the study included themes of the necessity of family engagement and family caregiver support. This became apparent when hospital visitation policies were restricted due to the COVID-19 surge, prohibiting visitation hours and limiting visitation in the hospital setting. Moreover, domains of greatest needs identified by both the care team and family caregivers aligned with one another, before and after the initiation of this project. For example, both times the care team was assessed, they identified mobility, communication, depression, anxiety, and coping skills as essential in addressing with family caregivers before hospital discharge. Similarly, participants revealed the same domains in physical needs, emergency preparedness, help from the healthcare system, caregiving stress, and navigating healthcare services as areas that they were "not at all prepared" or not too well prepared" upon their baseline assessment. After participants were given the caregiver support bundle and individualized interventions, post-intervention PCS responses reflected an

improvement in responses to “somewhat well prepared” to “pretty well prepared” in these corresponding domains. Other experiences shared by family caregivers revealed themes of unclear or overwhelming information on their discharge paperwork, finding it difficult to locate pertinent phone numbers to schedule follow-up appointments. The improvement in PCS scores overall ($p=0.00258$), coupled with positive responses in each domain, illustrate the impact of an assessment-driven caregiver support bundle during hospitalization.

In reflection of the secondary outcomes of this project, HCAHPS survey responses are in alignment with the improvement of PCS scores upon discharge. HCAHPS scores in the domain of “communication with nurses” remained steady throughout the project, and the domains of “care transitions” and “discharge information” improved. There was a decline in scores in March for “discharge information”; however, March also included the lowest number of participants in this project ($n=5$). Daily stroke education audits reflect an improved documentation of stroke education provided to patients and families throughout this project. Implementing a caregiver assessment tool and the additional educational tools offers more resources for nurses to provide stroke survivors and their families during hospital stay. Lastly, MyChart activation rates were examined as a secondary measure of this project. The caregiver support bundle was utilized as a vehicle to remind family caregivers to activate proxy access to MyChart to help in engagement with the care team; however, the review of activation rates demonstrates minimal changes in the pre-project and post-project outcomes.

An assessment tool, such as the PCS, may serve as a guiding intervention to facilitate conversations regarding family caregiver readiness. While it is not the only caregiver assessment tool in the literature, the PCS tool provides a basis to identify knowledge gaps, and strengths, in a quantifiable manner for healthcare providers to measure and assess. Findings from this project support the evidence in the literature identifying stroke caregiver needs during the recovery phase needs (Lou et al., 2015; Lutz et al., 2015; Lutz et al., 2016; Pesantes et al., 2017). It is essential that the entire stroke interdisciplinary care team actively involve family caregivers in the plan of care and conduct ongoing assessments to determine

caregiver readiness as the stroke survivor progresses through the stroke continuum (Lou et al., 2015). The American Heart Association guidelines for adult stroke rehabilitation and recovery recommend Class 1A evidence for caregiver support through education, training, and counseling through a support structure that includes caregivers in treatment planning and decision making (Winstein et al., 2016). As utilized in this DNP project, a caregiver assessment tool provides an avenue for providers to anticipate and recognize the concerns of family caregivers, while addressing these recommendations.

Limitations

This project was limited to a small patient population cohorted in highly specialized neuro stroke units. Because of this, and the specificity of the participants and sample size, the findings may not be transferable to other family caregivers and stroke survivors in other hospital areas. Additionally, the recruitment process was affected by the COVID-19 surge and the omicron variant. Hospital visitation policies were tightened up, and patient census shifted to accommodate the increase in COVID-19 cases in the health system. As a result, some patients who met the criteria for the project did not have any family caregivers at the bedside to engage with, while others were present on an inconsistent basis. The 7-day follow-up assessment, as initially planned in the project proposal, posed to be a challenging feat as those family members at the bedside did not have any contact information on record or were unavailable to provide feedback. Therefore, outcomes were shifted to admission and discharge assessment scores. Additional limitations include challenges with follow-up due to paper surveys and collection between nursing units, education for float staff, and availability of time and resources to dedicate towards providing caregiver support while maintaining daily operations.

Future Implications

In order to ensure sustainability of this project, active engagement of the entire stroke interdisciplinary team is essential. It requires a multidisciplinary approach to leverage each specialty's expertise to provide adequate education and resources to family caregivers as they navigate the new normal in the care of their loved one. Furthermore, standardization of the implementation of the caregiver

assessment tool will assist in mitigating workflow processes. The integration of the caregiver assessment tool in the EMR aims to assist in this workflow, automatically generating educational materials and alerting specific team members (such as rehab therapy, social work, and case management) to provide individualized interventions as necessary. Additionally, examining the stroke survivor's pre- and post-stroke modified Rankin Score (mRS) and NIH stroke scale score (National Institutes of Health Stroke Scale) in relation to caregiver readiness may also reveal the impact of stroke severity and functional outcomes on caregiver burden and their subsequent needs. Finally, as this caregiver assessment and caregiver support program continues to build its foundation, this DNP project may be disseminated to other stroke units, and other care areas that heavily rely on family caregivers in the patients' recovery.

Conclusion

Family caregivers are fundamental in the stroke survivor's ability to transition back to the community after hospitalization from a stroke. Often, and understandably so, the focus of the care is on the patient in the hyperacute and acute setting during hospitalization. However, it is evident that the family caregiver plays a crucial role within the care team in their recovery and must be involved from the very beginning of the stroke trajectory. The administration of a family caregiver assessment tool provokes the identification of specific needs that would not otherwise be discussed and may help facilitate the plan of care when transitioning from hospital to home. In addition, a caregiver assessment tool and providing targeted resources invite family caregivers into the care planning process and help them understand the stroke survivor's health management. This can assist with mitigating further complications of stroke in the future, coping with anticipated and unanticipated stressors, and optimize recovery and quality of life.

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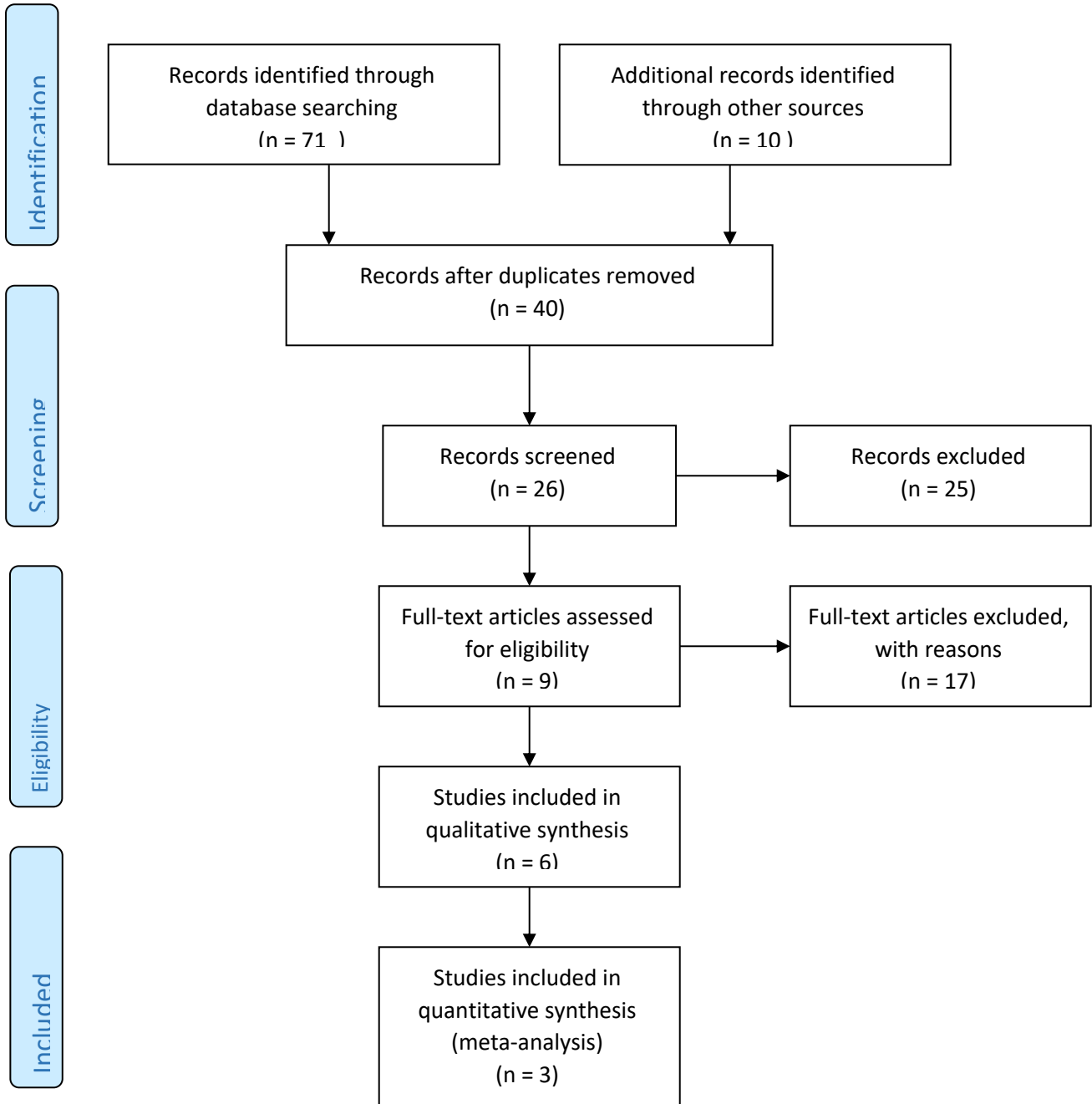
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Appendix A

PRISMA 2009 Flow Diagram



Appendix B

Table of Evidence

First author (YEAR) Title of Article	Conceptual Framework	Theme	Design/Method	Sample/Setting	Major valuables (outcomes) studied (their definitions)	Measurement (instruments or tools to measure outcomes)	Data analysis method	Findings	Appraisal Worth to use?
Lutz (2017) Improving Stroke Caregiver Readiness for Transition from Inpatient Rehab to Home	Grounded theory	phases of stroke recovery; evolving needs; caregiver assessment; support programs	Qualitative; interviews with stroke family caregivers	Inpt rehab; family caregivers of stroke pts	Readiness	Semi-structured interviews and sociodemographic questionnaire	Dimensional analysis and constant comparative techniques	Identified critical areas where caregivers felt unprepared to assume caregiving role after discharge. Recommendations: (a) conduct risk assessment of patient/caregiver, (b) identify/prioritize gaps between pt needs and caregiver commitment/capacity, © develop plan for improving caregiver readiness	Level VI; yes
Cheng (2018) Effectiveness of a Strength-Oriented Psychoeducation on Caregiving Competence, Problem-solving abilities, Psychosocial Outcomes and Physical Health Among Family Caregiver of Stroke Survivors: A randomized controlled trial	Relational/problem-solving model	caregiver assessment; caregiver education; support programs	Prospective multi-center, single-blinded RCT	Adult stroke pts and family caregivers	IV: strength oriented psychoeducation program DVs: caregiving competence, problem solving coping, depressive sx, burden, resources, and physical health	Questionnaire	Generalized estimating equation and multiple regression models and chi-square tests	Greater improvements of caregiver competence, problem-solving coping abilities, and social support satisfaction; greater improvements in family functioning at one-month post-intervention, increased number of social support, and lower level of burden at 3-month follow-up	Level II; Yes

<p>Lutz (2015) The Crisis of Stroke: Experiences of Patients and Their Family Caregivers</p>	<p>Grounded theory</p>	<p>phases of stroke recovery; evolving needs</p>	<p>Interviews with stroke family caregivers</p>	<p>N = 19 stroke survivors and 15 family caregivers</p>	<p>Stroke experience and how pts/caregivers managing postdischarge</p>	<p>Semi-structured interviews and sociodemographic questionnaire</p>	<p>Dimensional and comparative analysis</p>	<p>Conceptual framework illustrating trajectory of the crisis of stroke: 3 phases - the stroke crisis, expectations for recovery, and the crisis of discharge</p> <p>Caregivers do not have a good understanding of the role to which they are committing, often underprepared</p>	<p>Level V; yes</p>
<p>Rath (2020) The Experience of a NCC Admission and Discharge for Patients and Their Families: A Qualitative Analysis</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Qualitative QI</p>	<p>N = 232 patients Setting: Academic hospital; all pts admitted to Neuro ICU during 18-mo period</p>	<p>Adequate resources upon discharge and any unanswered questions</p>	<p>Semi-structured interviews and sociodemographic questionnaire</p>	<p>Thematic content analysis; inductive and deductive coding</p>	<p>Access to resources at discharge: major themes - satisfied, okay but could be improved, dissatisfied with ICU and discharge, post-ICU care was bad, or ongoing health concerns.</p> <p>Most commonly described theme was "it was okay".</p> <p>Most common unmet need was "premature discharge" (n=12), "unclear discharge" (n=11), "poorly prepared" (n=9), "ghosted" (n=9)</p> <p>Unanswered questions: major themes: neutral, positive, negative, medical questions, ongoing medical concerns/questions, remembrance.</p> <p>Commonly coded responses within theme of areas of improvement: "bad post-ICU care" (n=15); "lacking follow-up" (n=14); "recovery needs" (n=15); "disease complication" (n=14); "got info" (n=14)</p>	<p>Level V; yes</p>

<p>Tsai (2015) Needs of Family Caregivers of Stroke Patients: A Longitudinal Study of Caregivers' Perspectives</p>	<p>None</p>	<p>phases of stroke recovery; evolving needs; caregiver assessment; support programs</p>	<p>Longitudinal study</p>	<p>N = 60 family caregivers Neuro ICU; primary caregivers</p>	<p>Patient/family caregiver characteristics DV: family needs</p>	<p>Sociodemographics, length of stay, # diagnosed chronic diseases, NIHSS, Barthel Index; Needs Questionnaire for Family Caregivers by Kreutzer and Marwitz (collected at discharge, 2 weeks post-hospitalization, 3 months post-hospitalization)</p>	<p>Descriptive statistics and inferential statistics</p>	<p>Total needs decreased as illness duration increased. Needs differed significantly between the four time points. Leading need domains remained consistent: health information, professional support, community networks.</p> <p>Major factors affecting care needs:: admission NIHSS, length of hospital stay, physical dependence of pts</p>	<p>Level VI; yes</p>
<p>Pascual (2018) Evaluating the Impact of Personalized Stroke Management Tool Kits on Patient Experience and Stroke Recovery</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Human-centered design</p>	<p>N = 10 stroke survivors</p>	<p>IV: Tool kit (handout w/ local resources and stroke educational materials, educational flashcards, wellness items) DV: toolkit preference</p>	<p>3-item survey</p>	<p>Unknown</p>	<p>Tool kit less optimal during inpatient/early outpatient periods. TIA may be optimal candidates to receive tool kits to prevent future event.</p>	<p>No control group, no</p>

<p>2019-2021, Canadian Stroke Best Practice Guidelines</p>	<p>Practice Guideline Evaluation and Adaptation Cycle</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Systematic review</p>	<p>NA</p>	<p>NA</p>	<p>NA</p>	<p>NA</p>	<p>Recommendations for family/caregiver: Patients, families and caregivers should be screened for their level of coping, risk for depression, and other physical and psychological issues [Evidence Level B]. Ideally screening should take place at each transition. Patients, families and caregivers should be assessed at each transition (starting with first contact with the healthcare system) to determine their needs, readiness for information and ability to integrate knowledge related to education, training, psychosocial support, and health and social services [Evidence Level B]. Support for patients, families and caregivers should begin at admission and continue through discharge to the next stage or setting of care [Evidence Level B].</p>	<p>Level VII; yes</p>
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<p>Pescantes (2017) An Exploration into Caring for a Stroke-Survivor in Lima, Peru: Emotional Impact, Stress Factors, Coping Mechanisms and Unmet Needs of Informal Caregivers</p>	<p>None</p>	<p>phases of stroke recovery; evolving needs</p>	<p>Qualitative study</p>	<p>N = 16 primary caregivers Public rehab facility, private rehab facility, primary healthcare center serving low-income individuals</p>	<p>DV: Caregivers' experience about initial circumstances, initial medical treatment and information received, caregiver's emotional reaction, and perception regarding life after stroke</p>	<p>Semi-structured interviews and sociodemographic questionnaire</p>	<p>Thematic content analysis</p>	<p>Emotional Impact: suffered emotional; highest immediately after stroke and first few months; one-third expressed depressive symptoms Stress Factors: lack of independence and time to engage in social activities, financial impact, own health issues Caregivers' coping mechanisms/support: Financial support, help from family members, social support, strength/hope in religion Caregivers' perceived needs: Almost all expressed need to see a psychologist or another specialist to improvement health but non recieved any professional help - some stated they would like to look for help but could not leave the patient by themself.</p>	<p>Level VI; yes</p>
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<p>Abu (2020) The readiness of family in treating post-stroke patients at home: a literature review</p>	None	caregiver assessment; caregiver education; support programs	Systematic review	<p>Keywords: stroke, caregiver, family, preparedness, readiness; PubMed, ScienceDirect, Wiley Online Library; articles in the last 5 years</p>	Readiness of family in treating post-stroke patients at home	NA - systematic review	None identified	<p>Instrument used for measuring family readiness: Preparedness Caregiver Scale (PCS); PATH-s (Preparedness Assessment for the Transition Home After Stroke) Factors that affect readiness: pre-stroke caregiving experience, strength of caregiver relationships with patients; caregiver understanding and involvement in care; family roles/responsibilities</p>	Level V; yes
<p>Camicia (2021) Using the preparedness assessment for the transition home after stroke instrument to identify stroke caregiver concerns pre-discharge: uncertainty, anticipation, and cues to action</p>	None	caregiver assessment; caregiver education; support programs	Cognitive interviewing techniques; qualitative	N = 20 stroke caregivers of patients admitted to an IRF	IV: PATH-s assessment tool DV: caregivers ability to recognize potential concerns about stroke and caregiving role	PATH-s instrument	thematic analysis	<p>Core concepts: uncertainty and anticipation and completing the PATH-s cued the caregivers to take actions. An assessment tool may serve as an intervention to facilitate caregiver preparation.</p>	Level V; yes
<p>Hagedoorn (2019) The association of collaboration between family careivers and nurses in the hospital and their preparedness for caregiving at home</p>	None	caregiver assessment; caregiver education; support programs	Cross sectional design	N = 281 questionnaires from family caregivers Convenience sample of family caregivers who visited pts during hospitalization and had contact with nurses and involved in discharge planning	IV: family caregiver characteristics, caregiver frequency and duration of support at home, caregiver level of collaboration DV: preparedness for caregiving,	Preparedness for Caregiving Scale (PCS) of the Family Care Inventory; Family Collaboration Scale (FCS)	SPSS statistics; descriptive statistics	<p>Family caregivers who perceive a higher level of collaboration with nurses show a higher degree of preparedness for caregiving at home after discharge; limited body of evidence exploring relationship between family caregivers' collab w/ nurses in the hospital and caregiver's readiness</p>	Level V; yes

<p>Hughes (2017) Improving stroke transitions: development and implementation of a social work case management intervention</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>RCT</p>	<p>N = 35 stroke survivors and 20 caregivers</p>	<p>IV: case management intervention (Michigan Stroke Transitions Trial) DV: transitional care experience</p>	<p>Does not specify</p>	<p>Does not specify</p>	<p>initial findings - implementation requires intensive team approach; there is a need for programs aimed at identifying and addressing unmet psychosocial needs</p>	<p>Level II; Yes</p>
<p>Tseung (2019) Implementing caregiver support programs in a regional stroke system</p>	<p>CFIR (Consolidated Framework for Implementation Research)</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Qualitative descriptive study</p>	<p>N = 43 Regional rehab specialists, education coordinators, community and long-term care specialist, regional/district program directors, health professionals from 11 Ontario Stroke System regions</p>	<p>DV: perception of the availability, importance, effectiveness of caregiver programs; current practices r/t caregiver support; factors influencing implementation of caregiver programs</p>	<p>Interview and focus group questions</p>	<p>Inductive thematic analysis</p>	<p>4 themes related to caregiver program implementation: (1) establishing the need for caregiver education and support - caregivers are a distinct group requiring support and programs can improve outcomes/prevent burden (2) incorporating caregiver programs into the system of care across the care continuum - support should start as part of routine care in acute care (3) uncertainty regarding ownership and responsibility for implementation (4) addressing regional variations related to access, availability, and culture.</p>	<p>Level VI; yes</p>

<p>Gaio (2019) Effect of a passive intervention on carers of stroke survivors during the early poststroke period</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>QI report</p>	<p>Caregivers of stroke survivors (n = 100, 56 received intervention and 44 part of standard care group)</p>	<p>IV: inpatient seminar and Q/A session DV: caregiver burden and depression</p>	<p>Family Strain Questionnaire-Short Form (FSQ-SF); Beck Depression Inventory II</p>	<p>Retrospective analysis; G* power using statistical software</p>	<p>No significance difference between FSQ-SF score and prevalence of depression at admission and at discharge. However FSQ-SF at discharge significantly reduced with intervention</p>	<p>Level IV; yes</p>
<p>Hartford (2019) Stroke survivors' experiences of team support along their recovery continuum</p>	<p>Empowerment theory</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Qualitative descriptive study</p>	<p>N = 24 stroke survivors, spousal caregivers, stroke support group coordinators, and speech pathologist</p>	<p>DV: healthcare and social structures from the perspective of patients/caregivers</p>	<p>Semi-structured interviews and sociodemographic questionnaire</p>	<p>three-stage qualitative analysis</p>	<p>Two dominant themes: Experiences of managing stroke - unmet needs and fulfilling unmet needs by circumventing barriers Resources of support - financial support and social support These is a lack of teamwork between stroke survivors, family caregivers, and health professionals. Fragmented care due to inequities in rehabilitation programs and health services. Although stroke recovery groups were a significant source of support for stroke survivors and their caregivers, participants perceived they were overlooked by stroke recovery HCPs. Recommends an empowerment approach to stroke rehabilitation with collaboration between the entire care team. "</p>	<p>Level VI; yes</p>

<p>Forster (2015) The development and implementation of the structured training programme for caregivers of inpatients after stroke (TRACS) intervention: The London stroke carers training course</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Cluster randomized design</p>	<p>N = 54 interdisciplinary stroke team members</p>	<p>IV: 14 training components for caregivers (London Stroke Carers Training Course) training program DV: attendance and training session feedback</p>	<p>Royal College Nursing delegate feedback</p>	<p>None identified</p>	<p>Training days were well attended with positive feedback, however cascade method of implementation was not as effective. Argued that training in the acute inpatient phase may not be the most appropriate setting due to other stressors during this time period.</p>	<p>Level IV; yes</p>
<p>Gesell (2019) Implementation of a billable transitional care model for stroke patients: the COMPASS study</p>	<p>RE-AIM framework</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Cluster randomized pragmatic trial</p>	<p>N = 2751 events among N = 2689 patients diagnosed with ischemic stroke, hemorrhagic stroke, or TIA, and directly discharged home</p>	<p>IV: COMPASS-TC (PAC/APP/RN coordination with phone call 2-days post-discharge, in-patient clinic visit within 14 days discharge, and prior to discharge electronic based TC planning tool) DV: hospital characteristics, patient demographics</p>	<p>RE-AIM framework; hospital characteristics,</p>	<p>Descriptive statistics and inferential statistics</p>	<p>COMPASS-TC implementation varies widely - biggest challenge reaching patients d/t system difficulties maintaining consistent delivery of follow-up visits and pt preferences for alternate post acute care. COMPASS-TC was associated with better functional status.</p>	<p>Level VI; yes</p>

<p>Lutz (2020) Implementation of a Transitional Care Model for Stroke: Perspectives From Frontline Clinicians, Administrators, and COMPASS-TC Implementation Staff</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Qualitative</p>	<p>N = 43 conference call transcripts with hospital clinicians from 19 intervention hospitals utilizing COMPASS-TC</p>	<p>IV: COMPASS-TC implementation DV: clinician identification of successes and challenges with integration into clinical workflow</p>	<p>RE-AIM framework</p>	<p>iterative thematic analysis</p>	<p>Organizational readiness was an additional key factor to successful implementation, in that hospitals that were not "organizationally ready" had more difficulty addressing implementation challenges.</p>	<p>Level VI; yes</p>
<p>Weinstein (2016) Guidelines for Adult Stroke Rehabilitation and Recovery: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association</p>	<p>None</p>	<p>caregiver assessment; caregiver education; support programs</p>	<p>Systematic review</p>	<p>relevant articles on adults in medical literature through 2014</p>	<p>Best clinical practices in the rehabilitative care of adults recovering from stroke</p>	<p>NA - systematic review</p>	<p>None identified</p>	<p>Stroke rehabilitation is a sustained and coordinated effort from interdisc team requiring communication and coordination among team members. Systems of care need to evolve to respond to healthcare reform efforts.</p>	<p>Level VII; yes</p>

Appendix C

Sue and Bill SCHOOL OF NURSING
University of California, Irvine
LITERATURE SEARCH, SELECTION AND RETRIEVAL LOG

Date	Name of Database	Key Words	No. of Abstracts	Literature			
				Abstracts excluded	Duplicates removed	Abstracts included	Full article retrieved
4/26/2021	CINAHL	Stroke patients, post-stroke, family, patient-family relations, family relations, family, families, caregivers, caregiver burden, caregiver support, family caregiver status, caregiver role strain, discharge planning, discharge, transitional care, transition	13	3	8	1	0
4/26/2021	CINAHL	Stroke patients, post-stroke, family, patient-family relations, family relations, family, families, caregivers, caregiver burden, caregiver support, family caregiver status, caregiver role strain, coping support, support groups, support, assistance program, transitional care, transition	8	2	4	1	0
4/29/2021	CINAHL	Stroke patients, post-stroke, family, patient-family relations, family relations, family, families, caregivers, caregiver burden, caregiver support, family caregiver status, caregiver role strain, family caregiver, care-giver, carer, caregiver home care readiness, readiness	4	0	3	1	0

4/26/2021	PubMed	Stroke, post-stroke, patients, survivors, caregivers, caregiver, carer, family, families, patient discharge, discharge, transitional care, transition	35	12	7	14	9
4/26/2021	PubMed	Stroke, post-stroke, patients, survivors, caregivers, caregiver, carer, family, families, assistance program, support group, transitional care, transition	8	2	6	0	0
4/26/2021	PubMed	Stroke, post-stroke, patients, survivors, caregivers, caregiver, carer, family, families, readiness	3	0	3	0	0

PI(C)OT:

Among stroke survivors and family caregivers discharging from a comprehensive stroke center, how can caregiver preparedness assessment in conjunction with a stroke survivor and caregiver support program, compared to usual care, influence discharge readiness and address gaps in caregiver readiness?

Date	Names of Database	Key Words	No. of Abstracts	Literature			
				Total No of Abstracts excluded	Total No of Duplicates removed	Total No of Abstracts included	Total No of Full article retrieved
4/29/2021	CINAHL PubMed	See above	71	19	31	17	9

Appendix D

Clinical Practice Guideline

See below for critique using the AGREE II tool and clinical practice guideline, *Guidelines for Adult Stroke Rehabilitation and Recovery* (American Heart Association, 2016).

DOMAIN 1. SCOPE AND PURPOSE

1. The overall objective(s) of the guideline is (are) specifically described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Provide synopsis of best clinical practices in the rehabilitative care of adults recovering from stroke

2. The health question(s) covered by the guideline is (are) specifically described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Organized in 5 major sections: rehabilitation program (organizational and levels of care), prevention and medical management of comorbidities, assessment, sensorimotor impairments + intervention, transitions in care

3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Adults recovering from stroke

DOMAIN 2. STAKEHOLDER INVOLVEMENT

4. The guideline development group includes individuals from all relevant professional groups.

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/> Strongly Agree
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Comments

Group members (PTs, MDs, RNs, OTs, RPs) nominated by committee chair based on previous work on relevant topic areas and were approved by AHA Stroke Council's Scientific Statement Oversight Committee and Manuscript Oversight

5. The views and preferences of the target population (patients, public, etc.) have been sought.

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/> Strongly Agree
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Comments

6. The target users of the guideline are clearly defined.

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/> Strongly Agree
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Comments

Yes, in subtitle it states "a guideline for healthcare professionals from the American Heart Association/American Stroke Association"

DOMAIN 3. RIGOUR OF DEVELOPMENT

7. Systematic methods were used to search for evidence.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments



8. The criteria for selecting the evidence are clearly described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input checked="" type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments



9. The strength and limitations of the body of evidence are clearly described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input checked="" type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments



10. The methods for formulating the recommendations are clearly described.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Guideline uses framework established by the AHA concerning classes and levels of evidence for use in guidelines (displayed in tables within the guideline)

11. The health benefits, side effects, and risks have been considered in formulating the recommendations.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input checked="" type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Yes, each subsection includes discussion regarding benefits/risks

12. There is an explicit link between the recommendations and the supporting evidence.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

13. The guideline has been externally reviewed by experts prior to its publication.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

See above

14. A procedure for updating the guideline is provided.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input checked="" type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Doesn't specify how this guideline will be updated, but it explains how this guideline has updated prior AHA stroke-related guidelines

DOMAIN 4. CLARITY OF PRESENTATION

15. The recommendations are specific and unambiguous.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Each section outlines specific recommendation based on each category and subcategory

16. The different options for management of the condition or health issue are clearly presented.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input checked="" type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

17. Key recommendations are easily identifiable.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Organized methodically by system, level of care, and specialty. Recommendations are summarized in charts with associated class and level of evidence.

DOMAIN 5. APPLICABILITY

18. The guideline describes facilitators and barriers to its application.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input checked="" type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

Not a lot of discussion about application; if any, general points are made.

19. The guideline provides advice and/or tools on how the recommendations can be put into practice.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input checked="" type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

General recommendations

20. The potential resource implications of applying the recommendations have been considered.

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input checked="" type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
Strongly Disagree						Strongly Agree

Comments

General recommendations

21. The guideline presents monitoring and/or auditing criteria.

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input checked="" type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/> Strongly Agree
---	----------------------------	----------------------------	---------------------------------------	----------------------------	----------------------------	--

Comments

In regards to topic of interest (caregiver support), recommends a "checklist" however does not recommend any specific tools

DOMAIN 6. EDITORIAL INDEPENDENCE

22. The views of the funding body have not influenced the content of the guideline.

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/> Strongly Agree
---	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	---

Comments

None that I can identify

23. Competing interests of guideline development group members have been recorded and addressed.

1 <input checked="" type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/> Strongly Agree
--	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	--

Comments

None that I can identify

OVERALL GUIDELINE ASSESSMENT

For each question, please choose the response which best characterizes the guideline assessed:

1. Rate the overall quality of this guideline.

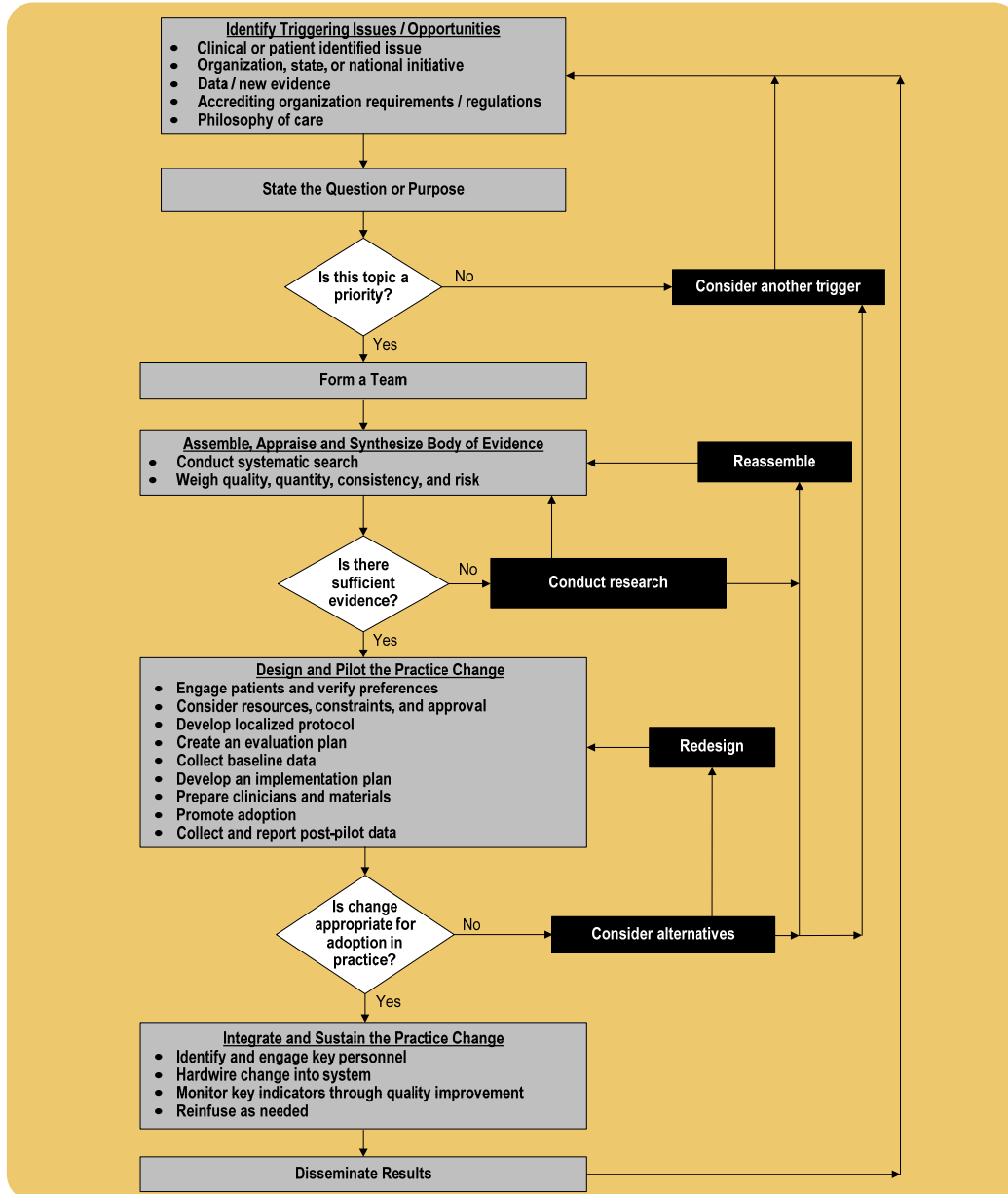
1 <input type="checkbox"/> Lowest possible quality	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input checked="" type="checkbox"/> Highest possible quality
--	----------------------------	----------------------------	----------------------------	----------------------------	----------------------------	--

2. I would recommend this guideline for use.

YES	<input checked="" type="checkbox"/>
YES, With modifications	<input type="checkbox"/>
NO	<input type="checkbox"/>

Appendix E

The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



◆ = a decision point

REQUESTS TO:
 Department of Nursing / University of Iowa Hospitals and Clinics
 Iowa City, IA 52242-1009 / Email: UIHCnursingresearchandebp@uiowa.edu
 Revised June 2015 © University of Iowa Hospitals and Clinics

DO NOT REPRODUCE WITHOUT PERMISSION



Abby Edilloran <aedillor@uci.edu>

Permission to Use The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care

Kimberly Jordan - University of Iowa Hospitals and Clinics <survey-bounce@survey.uiowa.edu>
Reply-To: Kimberly Jordan - University of Iowa Hospitals and Clinics <kimberly-jordan@uiowa.edu>
To: aedillor@uci.edu

Thu, May 13, 2021 at 8:32 AM

You have permission, as requested today, to review and/or reproduce *The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care*. Click the link below to open.

[The Iowa Model Revised \(2015\)](#)

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Citation: Iowa Model Collaborative. (2017). Iowa model of evidence-based practice: Revisions and validation. *Worldviews on Evidence-Based Nursing*, 14(3), 175-182. doi:10.1111/wvn.12223

In written material, please add the following statement:

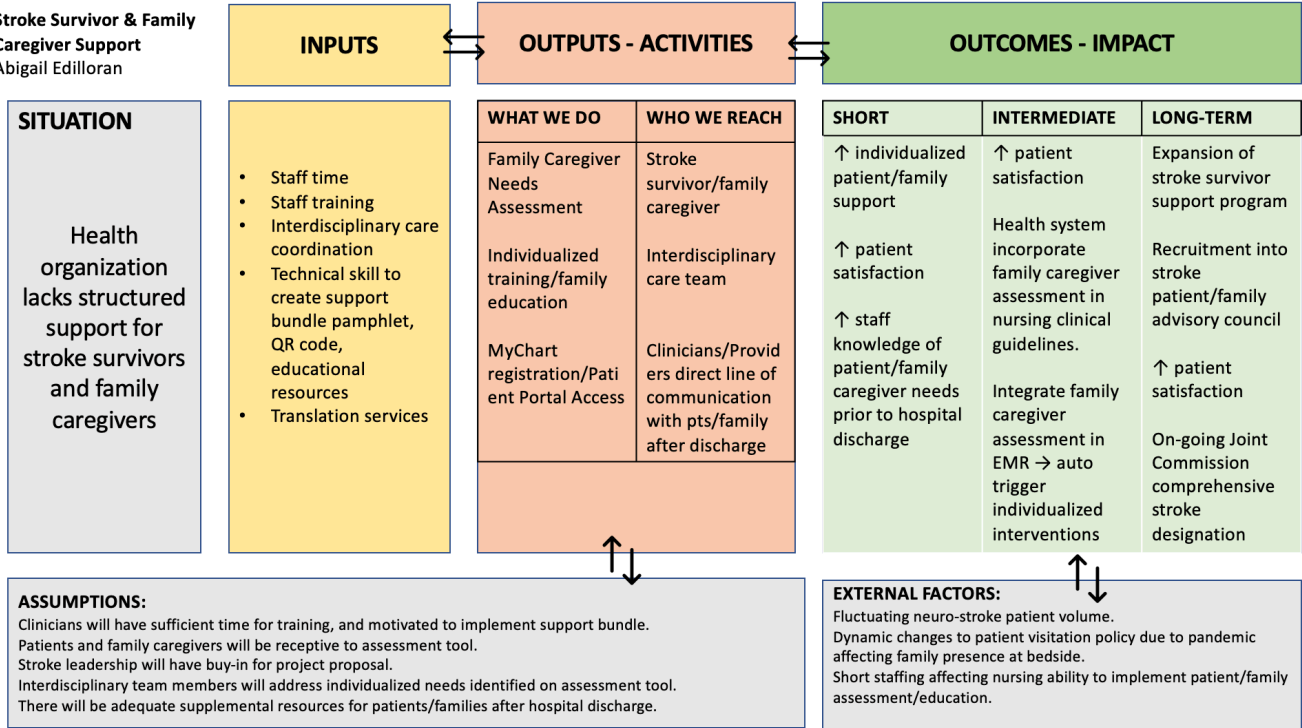
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Please contact UIHCNursingResearchandEBP@uiowa.edu or 319-384-9098 with questions.

Appendix F

Logic Model

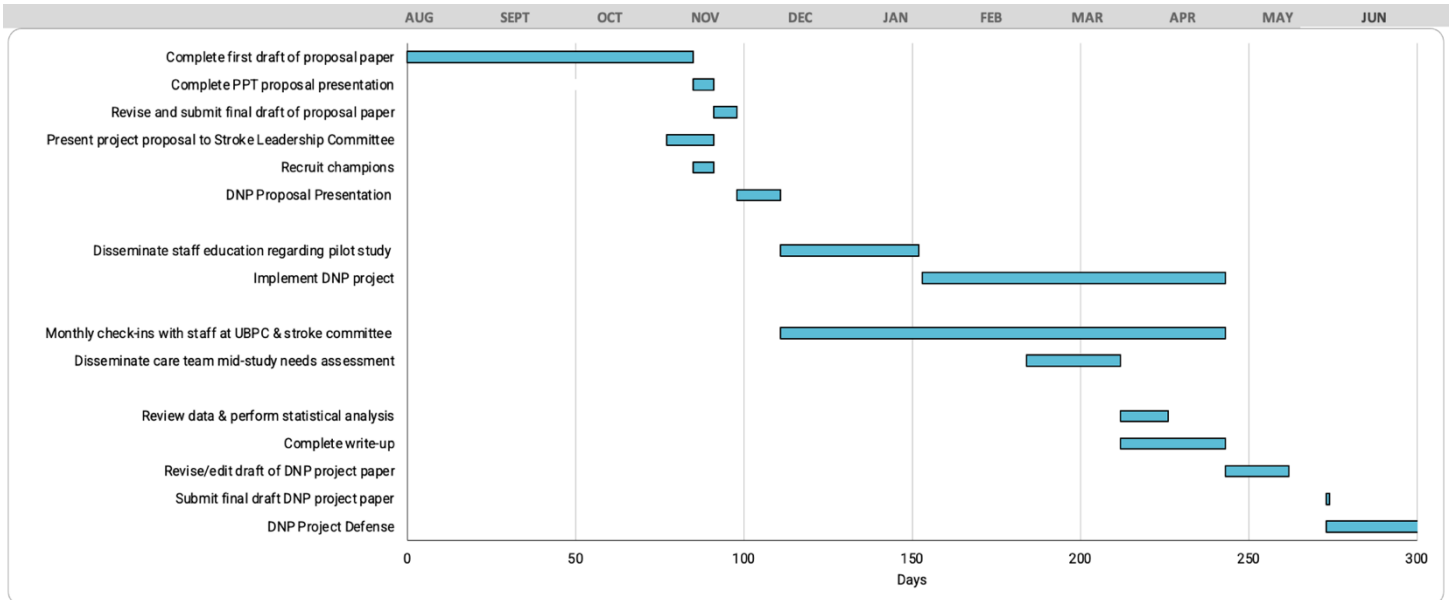
Stroke Survivor & Family
Caregiver Support
Abigail Edilloran



Appendix G

Project Timeline: Gantt Chart

TASK NAME	START DATE	END DATE	START ON DAY*	DURATION* (WORK DAYS)	
PLANNING					
Complete first draft of proposal paper	8/1	10/25	0	85	100%
Complete PPT proposal presentation	10/25	10/31	85	6	100%
Revise and submit final draft of proposal paper	10/31	11/7	91	7	100%
Present project proposal to Stroke Leadership Committee	10/17	10/31	77	14	100%
Recruit champions	10/25	10/31	85	6	100%
DNP Proposal Presentation	11/7	11/20	98	13	100%
IMPLEMENTATION					
Disseminate staff education regarding pilot study	11/20	12/31	111	41	100%
Implement DNP project	1/1	4/1	153	90	100%
MONITORING					
Monthly check-ins with staff at UBPC & stroke committee	11/20	4/1	111	132	100%
Disseminate care team mid-study needs assessment	2/1	3/1	184	28	100%
ANALYSIS & WRAP-UP					
Review data & perform statistical analysis	3/1	3/15	212	14	100%
Complete write-up	3/1	4/1	212	31	100%
Revise/edit draft of DNP project paper	4/1	4/20	243	19	100%
Submit final draft DNP project paper	5/1	5/2	273	1	100%
DNP Project Defense	5/1	6/1	273	31	100%



Appendix H: Site Approval Letter of Support

Letter of Cooperation with Outside Organization for UCI DNP Project

Date: 10/20/21

Dear: (name of DNP Student): Abigail Edilloran

This letter confirms that I, as an authorized representative of UC San Diego Health allow the above-named Doctor of Nursing Practice student access to conduct a leadership, policy, quality improvement, or evidence-based practice project activities at the listed site(s) as discussed with the DNP student and outlined below. These activities may commence after the DNP student has consulted with UCI IRB about the proposed project.

- **Project site(s):** (list specific site name and address for all sites within which the organization is providing student access to conduct the project)

UC San Diego Health - Jacobs Medical Center
9300 Campus Point Drive
La Jolla, CA 92037

- **Project purpose:** (briefly summarize the project purpose, plan and expected outcomes)

The purpose of this project is to determine if the utilization of a caregiver assessment tool before hospital discharge is an effective method for clinicians to develop a tailored stroke survivor and family caregiver support bundle at a comprehensive stroke center.

- **Project activities:** (briefly summarize the activities that will commence at the site, including any baseline data collected, educational interventions, PDSA cycle proposed...)

Family caregivers of stroke survivors on the Neuro ICU and PCU will be requested to complete the PCS tool upon admission and discharge from hospital stay. They will be given a family caregiver stroke support bundle and based on their PCS assessment results will receive individualized targeted stroke caregiver support and education.

- **Target population:** (identify the population upon whom the project will focus)

Participants in this pilot study will include stroke survivors with a primary diagnosis of ischemic stroke, hemorrhagic stroke (intracranial hemorrhage, subarachnoid), or transient ischemic attack (TIA) and their family caregivers who are admitted to the Neuro ICU or PCU. Patients who are cohorted within the designated stroke units will be included in this study, and if a patient is transferred out of the designated stroke units during their hospital stay, they will no longer be included. Further inclusion criteria include English or Spanish speaking, stroke survivors with a designated family caregiver identified during hospitalization, patients discharged to home or nursing facility with an identified family caregiver involved in the patient's care.

- **Site(s) support:** (briefly describe the support the project site(s) agree to provide to support the project, such as space to conduct project activities, data retrieval from electronic records, facilitation of educational activities....)

The site agrees to allow this project to be conducted on the Neuro ICU and Neuro PCU, access to relevant data from the electronic medical records, appropriate staff education and training, and allows the implementation of the project's proposed intervention.

- **Data management plan:** (briefly describe the plan for management of data such as what data will be collected, whether it will be identified/de-identified, what protections will be in place for data protection...)

Data will be de-identified and all participants will be protected by HIPAA, protecting the privacy of patients' health information. Any potential patient identifiers will not be included in the data collection and all risk will be disclosed to all participants in this project. Participant confidentiality will be maintained by coding participants using individualized identification numbers. All data gathered will be accessible only to the DNP student and stored in a secured location, preventing unauthorized access (both electronically and physically) to other individuals.

- **Other agreements:** (briefly describe any additional agreements that have been made to support the project, if applicable)

NA

- **Anticipated end date:** (indicate the anticipated date that the project will be concluded at the site)

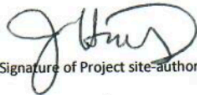
This pilot study is projected to be completed from January 2022 to March 2022.

It is understood that all DNP Scholarly Project related activities must cease if directed by UCI IRB. It is also understood that any activities that involve Personal Private Information or Protected Health Information must comply with HIPAA Laws and institutional policy.

Our organization agrees to the terms and conditions stated above. If there are any concerns related to this project, we will contact the DNP student named above and their DNP Scholarly Project Chair. For concerns regarding IRB policy or human subject welfare, we may also contact our own institutional IRB.

UCI IRB: <https://www.research.uci.edu/compliance/human-research-protections/researchers/irb-faqs.html>

With regards,



(Signature of Project site authorized representative)

Neurocritical care CNS

(Job title of authorized representative)

10/20/21

(Date signed)


Appendix I: Intervention Materials

Educational Video for Care Team:

<https://drive.google.com/file/d/1Jf11eqilxc1S1K1QMIN0byDvddSrZF8I/view>

Preparedness for Family Caregiving


How can I support my stroke patient?



mini PCS Tool here

Amazing Neuro Nurses!


Within 24 hours of hospital admission or identification of family caregiver, please request the primary family caregiver to complete the PCS tool. **For a score of 2 or less** in a single domain, please initiate the additional interventions within each domain indicated below. Please document in your plan of care for your shift when completed! Thank you!



My patient needs reinforcement with...


Physical Needs

- Reinforce individualized PT/OT/ST recommendations, utilize teachback method daily
- Refer to Communication Support Group



Stress & Coping

- Refer to community support groups
- Provide and review information AHA Stroke Family Warmline
- AHA: Being a Stroke Family Caregiver
- AHA: Emotional Changes after Stroke
- Provide information for AHA Stroke Caregiver Support Network



Help from Healthcare System

- Ensure UCSD MyChart Activation, navigate MyChart with patient/caregiver
- Set-up follow-up appointment upon discharge
- Provide contact # for Neuro Stroke Service

Services

- Tailored social work/case management referral
- Provide expanded list for community resources
- Refer to community support groups

Emergencies

- Reinforce individualized stroke risk factors utilizing teach back method
- Family caregiver to identify what to do in an emergency
- Educate regarding BEFAST warning signs/symptoms of stroke and red flags

UC SAN DIEGO HEALTH
Neuro Progressive Care Unit

Community Resources

for continuing care

San Diego Brain Injury Foundation: Providing information, support, education for brain injury survivors, caregivers and families in San Diego County. Phone: 619-294-6541 Website: www.sbdif.org

Meals on Wheels:
South Bay: 619-420-2782, San Diego: 619-295-9501,
East County: 619-447-8782, North County 760-736-9900
Website: www.meals-on-wheels.org

FACT San Diego: resource for San Diego County residents who are looking for transportation options, Phone: 1-888-924-3228 Website: www.factsd.org

Stroke Treatment & Recovery (STAR) Scripps Hospital: Stroke Exercise and Speech Programs, Support Groups, San Diego: 619-260-7161, South Bay: 800-727-4777
Website:
www.scripps.org/services/neurology/stroke/treatment-recovery

Scan this code for more support groups, classes, and services across San Diego!



A Message from Your Stroke Team

Dear Friends,

UC San Diego Health is committed to providing the finest care to our stroke patients. We are dedicated in the prevention and treatment of stroke and are here to help you and your family recover from your stroke.

The goal of this booklet is to help you during your stay in the hospital as well as provide resources for after you leave. Members of our team will review this information with you.

Sincerely,

The UCSD Health Stroke Team

My To-Do List

- COMPLETE THE PREPAREDNESS FOR CAREGIVING ASSESSMENT**
Your nurse will ask a few short questions twice during your hospital stay to help us understand how we can best support you and your family.
- PARTICIPATE IN DAILY ROUNDS & BEDSIDE TRAINING**
Know when the stroke team will be available to speak to you about any updates, questions, or concerns you may have. Participate in therapy sessions and bedside education so you feel prepared to care for your loved one at home.
- WRITE DOWN MY CONCERNS/QUESTIONS**
Leaving the hospital after a stroke can be overwhelming. To help prepare for what's next in recovery, hospital staff will speak to you about what you can expect.
- ACTIVATE MYCHART**
MyUCSDChart is an online and accessible tool that securely houses your family member's electronic medical record online.



What can I do about depression?

Depression is a serious condition and can keep you from being a good caregiver. Learn the signs of depression and get help if you experience several of these symptoms for two weeks or more.

- Feelings of hopelessness, sadness or anxiety.
- Loss of interest or pleasure in activities.
- Feeling worthless or guilty.
- Change in appetite or weight.
- Loss of energy or fatigue.
- Sleeping too much or too little.
- Lack of interest in personal hygiene.
- Lack of interest in sex.
- Inability to concentrate or make decisions.
- Depression can often be treated with medication. If you need help dealing with your emotions, find a support group or counselor. If you have thoughts of death or suicide, seek help immediately.

Stroke Family Warmline:

The Stroke Family Warmline connects stroke survivors and their families with an American Stroke Association team member who can provide support, helpful information or just a listening ear.

Trained specialists in the ASA's National Engagement Center can answer your questions about stroke. Call us 8 a.m.-5 p.m. CT Monday-Friday at 1-888-4-STROKE (1-888-478-7653).

Caregiver Support

How can I avoid burnout?

Take it one day at a time. You can take steps to avoid caregiver burnout by:

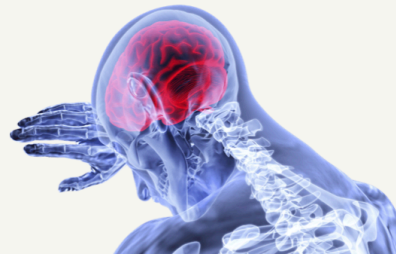
- Learning more about your loved one's condition and how to manage it.
- Discussing your feelings with a friend or joining a support group for caregivers.
- Finding caregiving resources that are available in your community.
- Asking for and accepting help from others.
- Using day care or respite care so you can take time for yourself.
- Using relaxation techniques such as meditation, yoga or breathing exercises.
- Taking care of yourself by eating well, exercising and getting plenty of rest.
- Talking to a counselor or therapist, if needed.

What is a Stroke?



When a stroke happens, every minute matters.

A stroke is a "**brain attack**". It can happen to anyone at anytime. It occurs when blood flow to an area of brain is cut off. When this happens, brain cells are deprived of oxygen and begin to die, which causes damage to the brain. When this damage occurs, that part of the brain may not work as well as it did before. This can cause problems with walking, speaking, seeing, or feeling. A survivor may experience physical effects, emotional effects or both.



UCSD Resources

Resources available to you during your hospital stay

Spiritual Services

Spiritual care is an integral part of the healing process. Our staff includes chaplains and volunteer spiritual care leaders from many different faiths. Together, they provide compassionate and caring spiritual support to patients and their families. Different beliefs, cultures and values are respected.

Chaplain services are free and include:

- Crisis intervention
- Comfort and emotional support
- Spiritual consultations and guidance
- Support in decision making and ethical dilemmas
- Prayers, blessings, rituals and sacraments
- Making arrangements with patients' clergy or spiritual leaders
- End-of-life support

If you are interested in chaplain services, please tell your nurse or call Volunteer Services at **619-543-6370**.

Meditation Rooms

Open to people of all faiths, our meditation rooms provide a place for prayer, meditation and reflection.

- **Jacobs Medical Center Serenity Room:** Located on the first floor.
- **UC San Diego Medical Center Meditation Room:** Located on the first floor of the Inpatient Tower, off the west entrance of the Hillcrest hospital.

What is caregiver burnout?

Caregiver burnout is caused by long-term stress that can affect your physical, emotional and mental well-being. It can be overwhelming trying to meet the constant demands of your caregiving role and it may have a negative effect on how you care for yourself and your loved one. Many caregivers don't take time to care for themselves and they begin to show signs of caregiver burnout. **Your health and well-being benefit your loved one just as they benefit you.** Learn the signs of caregiver burnout and seek help if you're having them.

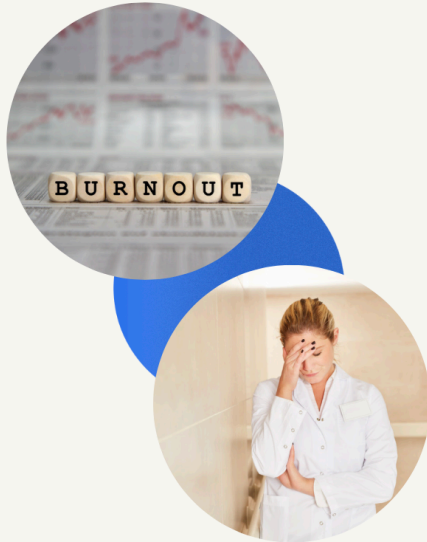
What are the signs of caregiver burnout?

As a caregiver, you're under a lot of stress. Long-term stress can lead to health problems. So, watch out for signs of burnout, including:

- Denial about your loved one's condition.
- Anger toward the person you're caring for.
- Social withdrawal from friends and activities you enjoy.
- Anxiety about caregiving responsibilities.
- Depression and anxiety.
- Exhaustion and lack of energy to do things.
- Losing control physically or emotionally.
- Trouble falling or staying asleep.
- Difficulty concentrating.
- Unhealthy behaviors such as drinking or smoking too much.

If you're experiencing any of these warning signs, take steps to get your life back into balance.

Caregiver Burnout



Do you have questions for your doctor or nurse?

Take a few minutes to write down your questions for the next time you see your health care professional.

UCSD Resources

Family Houses

At the Family Houses at UC San Diego Health, our mission is to provide a home away from home for families of patients undergoing critical or long-term care at UC San Diego Health. We are here to make a tough situation a little bit easier.

Please talk to your social worker, care coordinator, or member of the healthcare team for a referral.

If you are a family or patient needing assistance, please call **619-543-7977** (Bannister Family House) or **858-249-4800** (La Jolla Family House)

La Jolla Family House: 3787 Miramar St. La Jolla, CA 92092

From Hospital to Home

What to expect

Emotional Changes

Right after a stroke, a survivor may respond one way, yet weeks later respond differently. Some survivors may react with sadness; others may be cheerful. These emotional reactions may occur because of biological or physiological causes due to stroke. Others are a normal reaction to the challenges, fears, and frustrations that one may feel trying to deal with the effects of stroke. These changes may vary with time and can interfere with rehabilitation. Often, talking about the effects of the stroke and acknowledging these feelings helps stroke survivors deal with these emotions.

Common emotional changes after stroke include:

- Emotional lability, reflex crying, or labile mood
- Post-stroke depression
- Lack of motivation
- Frustration
- Anxiety
- Anger
- Apathy



Physical Changes

The physical impact a stroke may have on a survivor can vary greater and may change over time. The effects of a stroke is largely dependent on the part of the brain that was impacted. Some possible effects of stroke include:

- Fatigue
- Pain
- Loss of vision
- Dysphagia (difficulty swallowing)
- Difficulties sleeping
- Seizures
- Difficulties controlling the bladder or bowels
- Difficulties moving parts of the body
- Diminished sensation in parts of the body

To learn more about how these conditions may impact you, possible treatment options, and tips for managing these post-stroke conditions, speak to your provider, nurse, or therapist.

Stroke Warning Signs

The five warning signs of stroke are:

1. Sudden onset of weakness or numbness on one side of the body
2. Sudden speech difficulty or confusion
3. Sudden difficulty seeing in one or both eyes
4. Sudden onset of dizziness, trouble walking or loss of balance
5. Sudden, severe headache with no known cause

If you or your loved one experience any of these symptoms, **call 911** immediately and the ambulance will take you to the nearest emergency room.

[American Stroke Association: Caregiver Guide to Stroke](#)

Appendix J: Data Collection Instrument

The Preparedness for Caregiving Scale

YOUR PREPARATION FOR CAREGIVING					
<p>We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.</p>					
	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4
9. Is there anything specific you would like to be better prepared for? _____					

MEAN SCORE of the number of items answered: _____					

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Stewart & Archbold (1986, 1994)

Appendix K: Care Team Needs Assessment

STROKE CARE TEAM NEEDS ASSESSMENT TOOL

The UCSD Stroke Center is in development of a Virtual Stroke Survivor Support Group with special focus on the needs of people who suffered from stroke and/or are affected from a loved one with stroke. To help us best meet our patients' needs as we prepare for this program, **please complete the following survey!**

What is your role on the care team: (circle one)

MD RN SLP PT RT SW CM Other: _____

Would you participate in facilitating in Virtual Stroke Support sessions? YES NO

If no, why not? _____

Would you prefer each support session to last:

- a. 1-1.5 hours every month
- b. 2 hours quarterly (every 3 months)
- c. Other _____

In your experience with stroke survivors and their caregivers, what are their greatest needs upon discharge? Please rate on a scale from 0 to 5 (0: no needs, 1: minimal needs, 2: some needs, 3: moderate needs, 4: many needs, 5: most needs)

Education regarding nutrition	
Education regarding mobility	
Education regarding communication	
Education regarding participation in activities of daily living	
Education regarding prescribed medications	
Information about depression, anxiety, and coping skills	
Understanding risk factors and lifestyle changes	
Opportunities to share stories and experiences with others in a similar situation	

Is there anything else you can identify that a stroke support group can help with a stroke survivor's transition home from the hospital?

What are some anticipate barriers/solutions?

Would you like more information on how to help develop the stroke support program at UCSD? Please provide your name and contact information below:

Name: _____

E-mail: _____

Questions? Interested in helping to plan this program? Contact Abby Edilloran 858-240-6493 or aedilloran@health.ucsd.edu

Appendix L: UCSD IRB Exempt and UCI Non-Human Subjects Determination Form

Date: 10/27/2021
To: Abigail Edilloran
Re: Project # 246
Stroke Survivor and Family Caregiver Support

Dear Abigail,

Your project has been reviewed by the UCSD ACQUIRE (Aligning and Coordinating Quality Improvement, Research, and Evaluation) Committee. The ACQUIRE Committee approval of this project included a determination that the project is not regulated as research involving human subjects as defined in 45 CFR 46 or 21 CFR 56 and does not require Institutional Review Board review or approval. Consistent with UCSD policy and federal regulations, the UCSD Human Research Protections Program (HRPP) has delegated authority to the ACQUIRE Committee to make such determinations. The Director and/or Medical Director of the HRPP are members of the ACQUIRE Committee.

Though certified as not human subjects research, the project leader should ensure that the activities associated with the project are conducted in compliance with applicable UCSD and Rady Children's Hospital-San Diego policies and ethical standards as well as local, state, and federal regulations.

In addition, this approval is based on the intended work and scope of activities outlined in the proposal that was submitted. If the nature or scope of this activity changes substantially, then a re-evaluation by the ACQUIRE Committee would be necessary.

Please note the suggestions from the reviewers to improve the project/increase the impact: "Report out on results of caregiver needs assessment and resources provided or changes made as a result of the needs assessment."

Should you have any questions, please contact the Robert El-Kareh at relkareh@health.ucsd.edu.

Sincerely,



Robert El-Kareh, MD, MS, MPH
Chair, ACQUIRE Committee
relkareh@health.ucsd.edu



SECTION 1: DETERMINING WHETHER AN ACTIVITY IS HUMAN SUBJECTS RESEARCH PER DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) REGULATIONS

PART A: DETERMINATION OF “RESEARCH”

45 CFR 46.102(d): *Research* - a *systematic investigation*, including research development, testing and evaluation, *designed to develop or contribute to generalizable knowledge*.

1. Does the proposed activity involve a *systematic approach*?

A *systematic* approach involves a predetermined system, method or a plan for studying a specific topic, answering a specific question, testing a specific hypothesis, or developing theory. A systematic approach includes the collection of information and/or biospecimens, and analysis either quantitative or qualitative.

Consider the following questions:

- Are you conducting an investigation, an inquiry to gather facts, or an examination of a phenomenon?
- Is it systematic, involving a system, method, or plan that will be employed consistently throughout data collection?
- Is this a retrospective review of more than three (3) patients' medical records with intent to document a specific situation or the experience of the individuals individual (i.e. case studies)?

NO: The activity does not constitute research and IRB review is not required.
Click: [Skip to Part C](#)

YES

2. Is the intent of the proposed activity to *develop or contribute to generalizable knowledge*?

Activities *designed to develop or contribute to generalizable knowledge* are those activities designed to draw general conclusions, inform policy, or generalize outcomes beyond the specific group, entity, or institution (i.e., to elaborate, to be an important factor in identifying or expanding truths, facts, information that are universally applicable).

Consider the following questions:

- Will the results of your activity be presented as representing the larger population from which your sample was recruited? (Answer, 'No', if the data applies only to the specific study population)
- Will your findings be presented beyond the class or department setting, such as presented at the Undergraduate Research Symposium, a conference, or published in a peer-reviewed journal or used in a graduate level thesis or dissertation?
- Is the *quality improvement (QI)/quality assurance project* initiated with a goal of improving the performance of institutional practices in relationship to an established standard, with the intent to contribute to generalizable knowledge (“widely applicable”) (i.e. is it [QI research](#))?

NO: The activity does not constitute research and IRB review is not required.
Click: [Skip to Part C](#)

YES

PART B: DETERMINATION OF "HUMAN SUBJECT"

45 CFR 46.102(f): *Human subject* - a *living individual* about whom an investigator (whether faculty, student, or staff) conducting research obtains: (1) Obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or (2) Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens.

1. Does the research involve obtaining information or biospecimens about *living individuals* through *intervention* or *interaction* with the individuals?

Intervention includes both physical procedures by which information is gathered (for example, venipuncture) and manipulations of the subject or the subject's environment that are performed for research purposes.

Interaction includes communication or interpersonal contact between investigator and subject.

Consider the following question:

- Will you be interacting with the respondents or intervening in their daily routine, including over the phone, by email or via the internet?

NO

YES: The research involves *human subjects* and *IRB review may be required*. Consider whether the research may qualify for self-determination. Please review the [Exempt Self-Determination Tool](#).

2. Does the research involve obtaining **identifiable private information** or **identifiable biospecimen** about living individuals?

Private information includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and that the individual can reasonably expect will not be made public (for example, a medical record information). Private information must be individually identifiable.

Identifiable is where the identity of the subject is or may be ascertained by the researcher, or will be associated with the information. The research could involve the use of *coded* data.

Identifiable biospecimen is a biospecimen for which the identity of the subject is or may readily be ascertained by the investigator or associated with the biospecimen. The research could involve the use of *coded* specimens.

Coded means a living individual's identifiable information such as name or social security number has been replaced by a code, such as a number, letter, or combination thereof *and* there is a key to link the code to the identifiable information of that individual. *Coded data are considered identifiable.*

Consider the following questions:

- Will your research gather identifiable information or identifiable biospecimens about **living individuals**?
- Will you collect information that would allow you or another researcher to identify the subjects (examples: Name, Social Security Number, phone number, mailing address, email address, medical record number or any other number or code that pertains specifically **to an individual**)?

NO

YES: The research involves human subjects and IRB review is required. Submit a new IRB application for exempt or expedited research.

3. If **NO to #2**, does the research involve the use or disclosure of **protected health information (PHI)** about deceased individuals?

NO

YES: The research does not involve human subjects and IRB review is not required.

Check here to confirm that all of the following are true:

- 1) The use or disclosure is solely for research on the PHI of decedents; and
- 2) The PHI is necessary for research purposes.
- 3) If requested by the covered entity (UCI), the Lead Researcher will be required to provide documentation of the death of the individual(s).

4. Does the research involve use or disclosure of any of the 18 PHI identifiers below?

Use is any sharing, employment, application, utilization, examination, or analysis within the entity.

Disclosure is any release, transfer, provision of access to, or divulging outside of entity.

- Names
- Dates*
- Postal address
- Phone or fax Number
- Email Address
- Facial Photos/Images
- Social Security Numbers
- Medical Record Numbers
- Health Plan Numbers
- Account Numbers
- License/Certificate Numbers
- Vehicle ID Number
- Device identifiers/Serial numbers
- Web URLs
- IP Address Numbers
- Biometric Identifiers
- Other unique identifier

** All elements (except years) of dates related to an individual (including birth date, admission date, discharge date, date of death and exact age if over 89)*

NO

YES: The research involves human subjects and IRB review is required. Submit a new IRB application for exempt or expedited research.

5. Does the research involve the use of coded private information/specimens?

NO

YES: The investigator(s) cannot readily ascertain the identity of the individual(s) to whom the coded private information/specimens pertain. Confirm one of the following:

IMPORTANT! If none of the options below apply, the activity involves human subjects research and IRB review is required. Submit a new IRB application for exempt or expedited research with the Protocol Narrative – No Subject Contact: Use of Identifiable Private Information and/or Identifiable Specimens

The holder of the key and investigator have entered into an agreement prohibiting the release of the key to the investigator under any circumstances, until the individuals are deceased.

Check here to confirm that an agreement (email is sufficient) with the holder of the key code is available and kept on file.

The investigator has documentation of written policies and operating procedures from a repository or data management center that prohibits the release of the key to the investigators under any circumstances, until the individuals are deceased. Provide documentation of the written policies and operating procedures.

Check here to confirm that copy of the written policies and operating procedures is available and kept on file.

There are other legal requirements prohibiting the release of the key to the investigators, until the individuals are deceased.

Check here to confirm that copy of the legal requirement is available and kept on file.

PART C: HHS CONDUCTED OR SUPPORTED RESEARCH

6. Has UCI received an award through a grant, contract, or cooperative agreement directly from HHS (e.g. NIH, NSF, DoD) for non-**exempt** human subjects research and all activities involving human subjects are carried out by employees or agents of another institution (i.e. Subaward involved)?

NO

YES: The activity involves **human subjects research** and **UCI IRB review is required**.
Submit a new IRB application for expedited or full committee research.

SECTION 2: DETERMINING WHETHER RESEARCH IS CLINICAL INVESTIGATION PER FDA REGULATIONS

PART D: DETERMINATION OF "HUMAN SUBJECT"

21 CFR 50.3(g): *Human subject* - an individual who is or becomes a participant in research, either as a recipient of the test article or as a control. A subject may be either a healthy human or a patient.

7. Does the research involve a **test article** as defined by FDA?

Test article means any food additive, color additive, drug, biological product, electronic product, medical device for human use, or any other article subject to regulation under the act or under sections 351 and 354-360F of the Public Health Service Act.

NO

YES

8. Does the research involve a **human subjects** as defined by FDA above?

An individual becomes a **human subject** for FDA purposes if their data or specimens are used as the recipient of the test article or control. For example, when retrospective data are used as the control, the individuals become human subjects. Likewise, when an individual's blood sample is used to test an assay, the individual becomes a human subject.

Specimen includes the use of leftover specimens that are not individually identifiable (e.g., a remnant of a human specimen collected for routine clinical care or analysis that would otherwise have been discarded).

NO: The research does **not** involve **human subjects** and IRB review is not required.

YES

9. Is the research a *clinical investigation*?

A *clinical investigation* is any experiment that involves a test article and one or more human subjects, and that meets any one of the following:

- Any administration of approved drugs for research purposes that is not according to their approved indications, route of administration, population, or dose
- Any activity that evaluates the safety or effectiveness of a medical device
- Any activity the results of which are intended to be later submitted to, or held for inspection by, the FDA as part of an application for a research or marketing permit

A *medical device* is any instrument, apparatus, implement, machine, contrivance, implant, in vitro reagent, or other similar or related article, including any component, part, or accessory, including software applications that are either:

- intended for use in the diagnosis of disease or other conditions, or in the cure, mitigation, treatment, or prevention of disease, in man or other animals, or
- intended to affect the structure or any function of the body, and which does not achieve its primary intended purposes through chemical action within or on the body and which is not dependent upon being metabolized for the achievement of its primary intended purposes

NO

YES: The research involves human subjects and IRB review is required. Submit a new IRB application for expedited or full committee research.

SECTION 3: ACTIVITY INFORMATION

1. List the Lead Researcher/Investigator, Faculty Sponsor (as applicable), and/or Administrative Contact below.

UCI Lead Researcher/Investigator:

Name: Abigail Edilloran

UCI Email: aedillor@uci.edu

Department: Sue and Bill Gross School of Nursing

UCI Faculty Sponsor:

Name: Dr Jung In Park

UCI Email: junginp@hs.uci.edu

Department: Sue and Bill Gross School of Nursing

UCI Administrative Contact:

Name:

UCI Email:

Department:

2. Specify Activity Title (if applicable).

Stroke Survivor and Family Caregiver Support

3. Identify the funding source. Check all that apply:

Student project that will incur no costs.

<input type="checkbox"/> Department or campus funds (includes department support, unrestricted funds, start-up funds, personal funds, campus program awards, etc.)
<input type="checkbox"/> Subject/subject's insurance/third party payer
<input type="checkbox"/> Non-cash support from manufacturer/sponsor (e.g., free drug, device, research materials)
<input type="checkbox"/> Grant/Subaward OR <input type="checkbox"/> Contract/Subcontract <i>(provide details below)</i> Prime Awardee(s): Type Here Sponsor Name(s): Type Here SPA Proposal or Award #(s): Type Here <input type="checkbox"/> <i>[If not submitting to the IRB] Check here to confirm a copy of the human subjects portion of the grant is available and kept on file.</i> <input type="checkbox"/> <i>[If submitting to the IRB] Check here to confirm a copy of the human subjects portion of the grant will be submitted to the IRB.</i>
4. Describe the purpose of the proposed activity.
The purpose of this project is to determine if the utilization of a caregiver assessment tool before hospital discharge is an effective method for clinicians to develop a tailored stroke survivor and family caregiver support bundle at a comprehensive stroke center.
5. COVID-19: Does this research include a focus on SARS-CoV-2/COVID-19 (Coronavirus)?
<input checked="" type="checkbox"/> NO <input type="checkbox"/> YES: Please consider whether Ancillary Committees for COVID-19 Research apply.
6. Describe the subject population (category/group and age range) or the type of information/specimens to be studied.
Participants in this pilot study will include stroke survivors with a primary diagnosis of ischemic stroke, hemorrhagic stroke (intracranial hemorrhage, subarachnoid), or transient ischemic attack (TIA) and their family caregivers who are admitted to the Neuro ICU or PCU. Patients who are cohorted within the designated stroke units will be included in this study, and if a patient is transferred out of the designated stroke units during their hospital stay, they will no longer be included. Further inclusion criteria include English or Spanish speaking, stroke survivors with a designated family caregiver identified during hospitalization, patients discharged to home or nursing facility with an identified family caregiver involved in the patient's care.
7. Provide a brief description of the procedures.
Family caregivers of stroke survivors on the Neuro ICU and PCU will be requested to complete the Preparedness for Caregiving (PCS) tool upon admission and discharge from hospital stay. They will be given a family caregiver stroke support bundle and based on their PCS assessment results will receive individualized targeted stroke caregiver support and education.

8. Does the activity involve the use of survey or interview questions?

IMPORTANT! The proposed activity cannot meet the definition of **research**; otherwise the activity may require IRB approval.


No: This activity does not involve the use of survey or interview questions.

Yes: Survey or questions: **Preparedness for Caregiving Scale (PCS) of the Family Care Inventory Tool** **OR**

[If not submitting to the IRB] Check here to confirm the survey or questions are maintained as a separate document and kept on file.

[If submitting to the IRB] Check here to confirm a copy of the survey or questions will be submitted to the IRB.

9. Does the activity involve the use of information and/or biospecimens?

No: This study does not involve the use of information or biospecimens. 
This form is now complete; please review the responses for accuracy and completeness.

Yes: Complete the remaining questions below.

10. Specify the time-frame of the information/specimens to be accessed (e.g. January 2002 to 2024).

11. Provide a complete list of the data points, variables, and/or information that will be collected and/or analyzed (i.e. data abstraction form).

IMPORTANT! Access is limited to the items included in the list. Please be sure to update this list to include additional (de-identified) items as applicable.

Variables or information: **Type Here** **OR**

[If not submitting to the IRB] Check here to confirm the list is maintained as a separate document [i.e. case report form (CRF; eCRF)] and kept on file.

[If not submitting to the IRB] Check here to confirm the list is maintained as a separate document [i.e. case report form (CRF; eCRF)] and kept on file.

12. Were the information/specimens originally collected for research purposes?

<input type="checkbox"/> No: Explain how the information/biospecimens were originally collected (e.g., clinical care): Type Here
<input type="checkbox"/> Yes: The information/biospecimens were originally collected for research purposes under a UCI IRB approved protocol; provide protocol number (HS#): Type Here
<input type="checkbox"/> Yes: The information/biospecimens were originally collected for research purposes under a non-UCI IRB approved protocol. The IRB Approved Consent Form does not preclude the proposed activity. <input type="checkbox"/> <i>[If <u>not</u> submitting to the IRB] Check here to confirm that a copy of the IRB Approval Notice and Consent Form for the original research is maintained and kept on file.</i> <input type="checkbox"/> <i>[If submitting to the IRB] Check here to confirm that a copy of the IRB Approval Notice and Consent Form for the original research collection will be submitted to the IRB.</i>
<input type="checkbox"/> Yes: The information/biospecimens were originally collected for research purposes by a Commercial Vendor. The Vendor's Policy does not preclude the proposed activity.
13. Were the information/specimens collected specifically for the currently proposed project?
<input type="checkbox"/> No <input type="checkbox"/> Yes
14. Indicate the source and how the study team will access the de-identified information and/or de-identified biospecimens. <i>Check <u>all</u> that apply:</i> IMPORTANT! <ul style="list-style-type: none"> • When accessing/transferring data from a non-profit, please contact Grace J. Park at parkgj@uci.edu. • When accessing/transferring data from a for-profit, please contact the Industry Contract Officer at UCI Beall Applied Innovation assigned to your department. • When transferring tangible research material between organizations, please contact UCI Beall Applied Innovation at MaterialTransfer@uci.edu.
<input type="checkbox"/> Internet sources; specify: Type Here <input type="checkbox"/> <i>Check here to confirm that internet site's privacy statement does not prohibit use of their information.</i>
<input type="checkbox"/> Commercial Entity/Vendor; specify: Type Here
<input type="checkbox"/> The study team will request de-identified patient information/data from UCI Health Information Management Services. "Unstructured" information are obtained from the electronic medical records system (Epic) (e.g., physician notes, clinical notes, etc).

<input type="checkbox"/> The study team will request access through UCI IRB Approved Research. Check all that apply: <ul style="list-style-type: none"> <input type="checkbox"/> UCI Health Trauma Research Registry (HS# 2011-8640) <input type="checkbox"/> UCI Experimental Tissue Resource (ETR) / Pathology Research Biorepository (HS# 2012-8716) <input type="checkbox"/> UCI Health Honest Broker/Data Steward (HS# 2012-8757) <ul style="list-style-type: none"> "Structured" data elements are obtained from the enterprise data warehouse (e.g., diagnosis, procedures, lab results, etc). Describe the following: Cohort selection criteria/clinical terms from the Cohort Discovery Tool (e.g., Demographics: Gender, Diagnoses: Asthma, Procedures: Operations on digestive system): Type Here Expected cohort size/patient count: Type Here Cohort attributes or data elements (e.g., lab test values, medication, etc.): Type Here <input type="checkbox"/> UCI Center for Artificial Intelligence in Diagnostic Medicine (CAIDM) Honest Broker Biomedical Imaging Research Support Service (HS# 2018-4417) <input type="checkbox"/> UCI COVID-19 Biobank (HS# 2020-5783) <input type="checkbox"/> Other; specify and provide protocol number (HS#): Type Here
<input type="checkbox"/> The study team will request non-UCI Health records; specify: Type Here Explain how the study team has access to this clinical data: Type Here
<input type="checkbox"/> The study team will obtain biospecimens directly from the UCI Health unit/department (this is not the ETR); specify: Type Here <ul style="list-style-type: none"> <input type="checkbox"/> [If not submitting to the IRB] Check here to confirm that Pathology Clearance is available and kept on file. <input type="checkbox"/> [If submitting to the IRB] Check here to confirm that Pathology Clearance will be submitted to the IRB. <p>Per HRP Policy 15 and the UCIMC Anatomical Pathology/Surgical Pathology - Procedure Number: S-23, all specimens removed from clinic or the operating room must be sent to UCI Health Pathology for review and documentation by a pathologist. To obtain Pathology Clearance, contact Dr. Robert Edwards (redwards@uci.edu) or Delia Tifrea (dtifrea@hs.uci.edu).</p>

**SECTION 6: UCI DETERMINATION OF HUMAN SUBJECTS RESEARCH
FOR HRP STAFF AND IRB ONLY – RESEARCHERS DO NOT COMPLETE THIS SECTION.**

The proposed activity as described **DOES NOT** constitute human subjects research. **IRB review is NOT REQUIRED.** This determination only applies to the activities described in this request. If there are any changes that may alter this determination the investigator may request another written determination.

<input type="checkbox"/> The proposed activity as described constitutes exempt human subjects research eligible for self-exemption. IRB review is NOT REQUIRED. Complete the Exempt Self-Determination Tool and maintain a copy of the tool and any supporting documentation in the research record. This determination only applies to the activities described in this request. If there are any changes that may alter this determination the investigator may request another written determination.	
<input type="checkbox"/> The proposed activity as described constitutes human subjects research ineligible for self-exemption. Submission of an IRB Application IS REQUIRED. IRB Approval must be obtained before the research can begin. Please complete and submit an IRB Application with the appropriate protocol narrative. All forms are available on the Applications & Forms web page under IRB forms. If you have questions or needs additional guidance on the IRB submission process, please contact HRP staff for guidance at irb@research.uci.edu .	
<p>Type Here</p> <hr/> HRP Staff or IRB Chair	<p>Type Here</p> <hr/> Date