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An Investigation of Strain and Support Needs of Caregivers of Older Adults with Delirium and Allied Health Promotion Interventions

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AN INVESTIGATION OF STRAIN AND SUPPORT NEEDS OF CAREGIVERS OF OLDER ADULTS WITH DELIRIUM AND ALLIED HEALTH PROMOTION INTERVENTIONS

by

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A DISSERTATION

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AN INVESTIGATION OF STRAIN AND SUPPORT NEEDS OF CAREGIVERS OF OLDER ADULTS WITH DELIRIUM AND ALLIED HEALTH PROMOTION INTERVENTIONS

JASMINE K. VICKERS

HEALTH EDUCATION AND HEALTH PROMOTION

ABSTRACT

Delirium, or the sudden onset of confusion, is common, highly distressing, debilitating, and deadly among hospitalized older adults and is associated with adverse outcomes for their family caregivers. As people are living longer with more complex conditions, more people will face the task of caregiving for older adults with delirium. Family caregivers can make meaningful contributions to delirium care, but high distress, insufficient knowledge, and lack of skills often seen in caregivers can lead to maladaptation and negative health outcomes. A few studies have focused on distress in caregivers from witnessing delirium episodes; however more research is needed to understand the strain of caregiving on physical, emotional, social, and financial well-being as well as perceived support needs. This assessment will inform the identification of strategies that may improve coping in caregivers and inform family-centered care. Therefore, the aim of this dissertation research is 1) to determine the levels of strain and to gain an in-depth understanding of experiences and support needs of caregivers of older adults with delirium (paper one), 2) to review the literature on hospital-based delirium education interventions for patients and families (paper two), and 3) to assess the outcomes of a clinical model of care that aims to reduce hospital-associated disability thus reducing caregiver strain (paper three). Overall, the findings of this dissertation reveal high levels of strain in delirium caregivers and point to the potential utility of hospital-based delirium education activities and care approaches to address the strain and support needs of delirium caregivers. Future studies should assess the utility of comprehensive interventions to support delirium caregivers via unit-level redesign and delirium educational approaches with a randomized controlled trial design.

Keywords: Delirium, caregiver strain, caregiver support, health education, cognitive impairment, Acute Care for Elders.

DEDICATION

I dedicate this dissertation to my God who in the days of disaster, supported me, and brought me to a beautiful place (II Samuel 22:19-20). A place I hope to be for others. Darkness may surround our days, but there is great joy in being filled with a light that cannot be overcome by darkness.

I also dedicate this dissertation to Dr. Kellie Flood. Her passion and success in improving care for older adults is unmatched. It was her passion that led me to focus on this field of work. May her legacy of healing endure for many generations.

Finally, I dedicate this dissertation to the patients and caregivers who are facing some of the most difficult challenges of their life in navigating sickness and confusion. Your passion, wisdom, resilience, and transparency are inspiring. To all the participants: you so graciously welcomed me while in the throes of your troubles. Your strength and sincerity inspired and well-equipped me to face my own ailments; and it is my earnest desire that your time and responses will help us better care for you and many others in the future.

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work. I am blessed to work with so many heroes who accomplish miracles of mercy and kindness every day. I also want to thank my co-workers: Emily Simmons, Shari Harrell, David James, Christy McDougal, Katrina Booth, and others who have taught me so much. I can't imagine working with a better team. Thank you for your feedback and support of my work.

I want to thank all of the participants. Without them this work would not have been possible. They sacrificed much, during very difficult times, in hopes of improving care for future patients and caregivers. I appreciate and honor this sacrifice.

I also want to thank my family who have supported me and encouraged me throughout all my academic efforts. My family's faith and joy in me has carried me through many days and has been my strength.

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Finally, I want to thank God whose love and character continues to inspire and sustain me each day. I couldn't have even imagined I would be where I am today, but God saw fit to do exceeding, abundantly, above all I could ask or think. I know that the good work He started He will see it to completion.

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LIST OF ABBREVIATIONS

ACE	Acute Care for Elders
ADL	Activities of Daily Living
CI	Cognitive Impairment
HAD	Hospital Associated Disability
IADL	Instrumental Activities of Daily Living
RCT	Randomized Controlled Trial

INTRODUCTION

Delirium is period of confusion that develops over a short period of time where people may exhibit behaviors such as disturbances of awareness or attention and changes in cognition such as memory deficits, disorientation, and language disturbance[1]. The exact cause of delirium is not completely understood. However, it is thought that delirium is caused by multiple, varying, and interacting factors[2]. Several important risk factors for delirium in older adults have been identified, including cognitive impairment, functional impairment, visual impairment, alcohol misuse, older age, and comorbidities in individuals at baseline as well as polypharmacy, psychoactive drugs, restraints, and abnormal labs (such as abnormal albumin, sodium, and glucose levels) during hospital admissions[2]. In some situations, one factor can cause delirium by itself (a sufficient cause), but it is more common for multiple factors to interact and cause delirium[2]. These factors are thought to contribute to delirium development through interferences with neurotransmission, cellular metabolism, neuronal injury, inflammation, and blood flow[2].

In a review of published studies with predominantly older adult samples, delirium was common both at admission (18%-35%) and when newly developed in the hospital (29%-64%)[2]. Delirium occurrence varied by hospital service, ranging from 11%-14% in general medical hospital services, 19%-82% in intensive care, and 47% in palliative or cancer care[2]. Delirium is estimated to affect between 1.75 to 7 million hospitalized adults 65 years old and older[3], with annual healthcare costs estimated to be $164 billion[2].

Specifically, patients that experienced delirium had healthcare cost that were 2.5 times higher than patients without delirium[4].

Delirium is also deadly and disabling. Delirium was associated increased risk of mortality, with patients who experience delirium being at a two to four times greater risk compared to patients who do not experience delirium[2]. Case fatality rates have been reported between 25% and 33%[5]. Persisting physical[6] and cognitive functional declines[7] were also associated with delirium. Surgical patients that had delirium had a statistically significant higher risk of decline in ability to perform tasks essential for independent living, such as shopping and housekeeping (instrumental activities of daily living), a month after surgery [6]. Among patients that had high cognitive functioning at baseline, delirium was associated with statistically significantly lower cognitive functioning 36 months post hospital discharge[8].

Delirium is even more dangerous in older adults with preexisting dementia (delirium superimposed on dementia or DSD). Older adults who had DSD had cognitive functioning declines that occurred twice as fast as those with dementia only[9]. Additionally, delirium occurs more frequently in older adults with dementia with prevalence rates that range from 22% to 89%[10]. Although the prevalence and adverse outcomes for older adults with DSD is higher, the literature on the experiences, caregiver strain, and educational interventions in older adults with DSD and their caregivers is scarce[11-12].

Current clinical guidelines encourage the inclusion of families in delirium care[13-14], and studies have found that, when supported, families can assist effectively with delirium prevention, detection, and management[15-17]. However, inclusion in delirium care can be challenging for caregivers because caregivers often have insufficient knowledge of what delirium is and how to respond when it occurs[18-20] and often experience high levels of distress during delirium episodes themeselves[17,18,21,22]. Indeed, studies show that family caregiver distress during delirium episodes is common with up to 70% experiencing distress[18]. This distress is also often rated as severe by caregivers[17]. However, few studies have assessed caregiver strain which is the strain on the caregiver's physical, emotional, social, and financial well-being[23] in caregivers of adults with delirium. Understanding delirium caregiver strain and support needs would provide a more comprehensive picture and could inform the development of more effective strategies to reduce family caregiver strain as well as inform family-centered delirium care.

The guiding theoretical framework for this dissertation is the Transactional Model of Stress and Coping[24] and its application to caregiving[25]. The model posits that stressor demand, appraisal of stressor, and resources to cope with the stressors, all shape coping efforts and ultimately the outcomes of well-being, functioning, and health behaviors[24,25]. The overall aim of this study is to explore how delirium contributes to caregiver strain as well as enhancing positive coping through identifying caregiver support needs and health promotion interventions. With a better understanding of caregiver strain and support needs in delirium, healthcare professionals will be better equipped to buffer the impact of strain on family caregiver health and well-being. Hospital interprofessional team approaches to care may be advantageous in meeting the informational, instrumental, and emotional support needs for coping efforts such as emotional and spiritual support from hospital chaplains and instrumental support from nurses.

This dissertation consists of three papers, three pre-print manuscripts, which all collectively address the overarching aim mentioned above. The aim of paper one is to address the gap in the literature by summarizing the reported strain and support needs of caregivers of older adults with delirium. A mixed methods approach was used to elicit information. Descriptive statistics were used to describe patient and caregiver demographics, patient medical factors, caregiving factors, caregiver delirium experience, delirium severity, delirium burden, psychiatric behaviors, and caregivers' social support. Themes regarding caregivers' support needs were developed from interviews of caregivers. The subsequent papers reviewed two types of interventions that could be effective in addressing the caregivers' reported strain and support needs.

The aim of paper two is to review the literature on patient and caregiver delirium educational interventions in hospital settings to identify effective interventions and intervention components.

The aim of paper three is to calculate and assess the associations between mobility of hospitalized older adults with cognitive impairment and a Virtual ACE clinical model. The Acute Care for Elders (ACE) Unit is a clinical model of care that involves a redesign of care on the unit level. ACE Units include geriatric expertise, training and institutionalization of screening and care pathways, and interdisciplinary teams. ACE Units have been associated with reduced hospital readmissions, hospital cost, length of stay, geriatric syndromes, and functional decline in older adult patients. Reported outcomes of ACE Units could well address some of the most commonly reported stressors and support needs of delirium caregivers via prevention of delirium (and related psychiatric behaviors), prevention of functional decline, and the enhancement patient and family support through interdisciplinary teams. A summary of the findings and the implications of the three papers are presented in the conclusion section.

A MIXED METHODS ASSESSMENT OF STRAIN AND RELATED SUPPORT NEEDS OF FAMILY CAREGIVERS OF HOSPITALIZED OLDER ADULTS WITH DELIRIUM

by

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ABSTRACT

Background: Delirium, or the sudden onset of confusion, is common, highly distressing, debilitating, and deadly among hospitalized older adults and is associated with adverse outcomes for their family caregivers. Family caregivers can make meaningful contributions to delirium care, but high distress, insufficient knowledge, and lack of skills often seen in caregivers can lead to maladaptation and negative health outcomes.

Methods: The purpose of this sequential mixed methods study was to assess strain and related support needs of family caregivers of older adults with delirium. During the initial quantitative phase strain was assessed and descriptive statistics were used to describe patient and caregiver demographics, patient medical factors, caregiving factors, caregiver delirium experience, delirium severity, delirium burden, psychiatric behaviors, caregivers' social support, and characteristics of caregivers with high strain. During the follow-up qualitative phase, detailed information on caregiver perceptions of strain and related support needs were gathered through semi-structured interviews among family caregivers.

Results: Many caregivers (69%) reported high levels of strain, delirium burden, and distress related to patient behaviors. On average caregivers who were female, White, and older, with no previous delirium experience, and no information had higher strain than their counterparts. Caregivers consistently reported that good communication with staff was essential to their ability to cope and their well-being as well as facilitating family communication and opportunities for social support among individuals facing similar challenges.

Conclusion: We have a limited understanding of how demographic and caregiving factors interact and impact strain. Caregiver delirium education could be a potential target for interventions to decrease caregiving strain.

INTRODUCTION

Delirium, or acute confusional state, is a common syndrome affecting between 1.75 to 7 million hospitalized adults 65 years old and older[1]; leading to an estimated healthcare cost of $164 billion[2]. Delirium is also associated with an increased risk of mortality[3] as well as persisting physical[4] and cognitive functional declines[5]. Among patients that had high cognitive functioning at baseline, delirium was associated with significantly lower cognitive functioning 36 months post hospital discharge[6].

As people are living longer with more complex conditions, more people will face the task of caregiving for older adults with delirium. Current clinical guidelines encourage the inclusion of families in delirium care[7-8], however family caregivers tend to experience high levels of distress during delirium episodes[9-12]. Studies have found that family caregiver distress during delirium episodes is common with up to 70% experiencing distress[11]. This distress is also often rated as severe by caregivers[10]. Studies have been conducted on distress among caregivers of adults with delirium and there are a plethora of studies on caregiver strain among caregivers of adults with dementia; yet few studies have assessed strain in caregivers of adults with delirium. For this study, distress will be viewed as an immediate response to the caregiving situation, but strain will be viewed more holistically- in the sense of how these experiences and stressors impact the caregivers physical, emotional, social, and financial well-being[13].

The studies that have assessed caregiver strain in delirium have included participants with dementia and/or delirium. In these studies, delirium and neuropsychiatric symptoms such as agitation and delusions, were identified as the strongest predictors of caregiver strain[14-15]. Yet research is needed to assess caregiver strain in a sample that only includes family caregivers of adults with delirium, as predictors of strain may be different in this population.

Although distress is known to be high in delirium caregivers, previous caregiver delirium education interventions have been ineffective in addressing distress or strain in caregivers[16-18]. Interventions that include print or verbal explanations of delirium were associated with no changes in caregiver distress or caregiver mood[16-17]. One multicomponent intervention was associated with statistically significant declines in anxiety but not caregiver strain[18]. Thus, although clinical guidelines and studies have shown trained family caregivers can play an important role in delirium care, they often feel unprepared to do so; and there is a lack of robust evidence on the needs and effective strategies to reduce family caregiver strain.

The aim of this sequential mixed methods study was to assess strain and related support needs of family caregivers of older adults with delirium. This comprehensive assessment of strain could lead to the development of strategies that buffer the impact of delirium stressors on adaptation and health outcomes in caregivers and inform family-centered care approaches in older adult patients with delirium.

METHODS

A cross-sectional sequential mixed methods design was used to reach the study aim. In QUAN->qual sequential mixed methods design, the quantitative phase is used to inform the qualitative phase[19]. In congruence with this study design, the quantitative results of this study were used to inform the qualitative data collection and all results were merged to develop clinical and research implications. The study procedures are depicted in the Procedural Diagram listed in Appendix A. The purpose of the quantitative phase was to assess the levels of strain and other factors, using demographic, caregiving, and clinical data from surveys, assessments, and medical record reports. Surveys of reported strain were used to guide interviews for more insight into challenges and perceived support needs for these challenges. The purpose of the follow-up qualitative phase was to explorer caregiver perceptions of strain and related support needs, using semi-structured interviews among family caregivers. The data were then merged by displaying and interpreting the results jointly. Implications for clinical and research interventions, were then drawn from the integrated data. Methods by quantitative and qualitative phase are described in detail below.

Quantitative Sample

Patients were screened on an Acute Care for Elders (ACE) Unit in a southeastern academic medical center. The Acute Care for Elders (ACE) Unit is a clinical model of care that involves a redesign of care on the unit level. ACE Units include geriatric expertise, training and institutionalization of screening and care pathways, and interdisciplinary teams. This unit also had Hospital Elder Life (HELP) volunteers actively serving during data collection. HELP volunteers engage patients in various activities to prevent delirium and on this unit volunteers were also visiting patients with delirium if appropriate.

Participants for this study were identified through reviewing medical record, Acute Care for Elders (ACE) Tracker, reports of patients on inpatient medical units. The report includes Nursing Delirium Screening Scale (NuDESC)[20] scores, which were used to identify patients that screen positive for delirium (NuDESC score of 2 or higher).

Participants were eligible for the study if 1) the patient was 65 years old or older and 2) the family caregiver was 19 years old or older, 3) the older adult had delirium as defined by the Confusion Assessment Method[22], 4) the family caregiver was the primary caregiver or provides more than 10 hours of care a week, 5) the family caregiver was available during the hospital admission to complete study surveys. Older adult and family caregiver dyad was excluded if 1) the older adult was actively dying or not expected to be discharged alive; 2) older adult or family caregiver did not speak or write English, was very hard of hearing, or blind; or 3) the older adult had hospital care needs interfere with the ability to perform the necessary data collection procedures.

Quantitative Measures

Data were collected on caregiver and patient demographics (age, gender, race, level of education for caregiver only); patient hospital factors (unit, service, discharge diagnosis, functioning, restraint use, anti-psychotic use, dementia screen); caregiving factors (caregiving duration, hours, activities, relationship to patient, distance between patient and caregiver before hospitalization); caregiver delirium experience (does caregiver know anyone who has experienced delirium before, caregiver receipt of delirium education from staff, delirium education content, satisfaction with education);

Caregiver Strain Index; Family Caregiver Delirium Burden Instrument; Neuropsychiatric Inventory Questionnaire; AD8; and Social Support Scale.

The Katz Index was used to determine level of patient physical functioning, and is documented in the medical record. The Katz Index includes six activities of daily living (i.e. bathing, dressing, toileting, feeding), which are scored based on independent (0=completely dependent, 1=partially dependent, or 2=completely dependent). Scores range from 0 to 12 with 12 being completely dependent and 0 being completely independent. Responses were taken by the research assistant from the patient and/or person who is familiar with the patient's baseline.

Nursing Delirium Screening Scale (NuDESC) was used as a screener for delirium to identify patients to contact. The screen is a brief five-item scale that is scored based on patient observations[20]. The NuDESC has good psychometric properties with a sensitivity and specificity of 85.7% and 86.8% respectively compared to the CAM[20]. This was completed by beside nurses and abstracted from the medical record reports.

Caregiver Strain Index (CSI) was used to assess caregiver strain and measures whether the caregiver reports difficulty with physically straining situations (i.e. sleep disturbances, lifting), emotional strain (i.e. feeling overwhelmed, upsetting changes), social strain (i.e. family adjustments), personal strain (i.e. work adjustment, inconvenience), and financial strain[21]. The CSI has demonstrated a 0.86 Cronbach's alpha for internal consistency of the 13 items and demonstrated good construct validity[21].

Confusion Assessment Method (CAM) was used to determine delirium status and is administered by assessing onset, attention, thinking, and level of consciousness in patients as well as using informant responses[22]. The CAM has been shown to be a valid and reliable tool, with high sensitivities (94%), specificities (89%), and interrater reliabilities (0.70-1.00) across studies compared to physician diagnoses[23]. The CAM requires an acute onset and fluctuation course of delirium symptoms with inattention as well as disorganized thinking or an altered level of consciousness.

Neuropsychiatric Inventory Questionnaire (NPI-Q) is an informant-based assessment of neuropsychiatric symptoms and associated caregiver distress[25]. In the NPI-Q presence and severity of 12 neuropsychiatric symptoms (i.e. delusions, agitation, anxiety, apathy, nighttime disturbance) are rated by caregivers, then for each positive symptom, caregiver distress is rated from not at all distressing to extremely distressing on a five-point scale[25]. The NPI-Q demonstrated high correlation with the previously validated NPI for the total symptom (0.91) and distress subscales (0.92) and also has adequate test-retest reliability for total symptoms (0.80) and distress subscales (0.94) [25].

Family Caregiver Delirium Burden (DEL-B-C) Instrument was used to assess the subjective experience of delirium burden in family caregivers[26]. DEL-B-C has eight questions that cover situational, emotional, and symptom burden domains[26]. The instrument has demonstrated good internal consistency with a Cronbach's alpha of 0.82 and test-retest reliability correlation of 0.7340.

AD8 was used to detect dementia thus identifying DSD patients. The AD8 assess changes in memory, thinking, judgement, interest, and learning with 8 items. Using a cut-off point of two the AD8 demonstrated a sensitivity of 74% and a specificity of 86%[27].

Social Support Scale by Krause and Markides measures social support received (within the four domains of informational, tangible, emotional and integration support), satisfaction with social support, and negative interactions[28]. The Cronbach alphas for each subscale was 0.814,0.665, 0.827, 0.812 and demonstrated good predictive validity[28].

Quantitative Analysis

Descriptive statistics were used to summarize demographic, caregiving, and clinical data. Survey scores were also reported using descriptive statistics. Caregiver characteristics were also compared descriptively among caregivers with high strain.

Qualitative Sample

A nested sample was used for this study, which involves using a subsample of participants in the quantitative strand for the qualitative strand[19]. Family caregiver participants for interviews in the qualitative phase of the study were recruited based on expressed interest during data collection in the quantitative phase. A question on the survey allowed caregiver participants to select whether they were open to an interview in the future. If they checked yes, they were asked to enter contact information. Caregivers who reported high strain, based on a Caregiver Strain Index score of 7 or higher, were contacted for an interview after the patient participant had been discharged from the hospital.

Qualitative Data Collection

For the qualitative phase, data were collected using semi-structured phone interviews. Caregivers provide their name, phone number, and preferred time of contact on the survey, and JV contacted the participants according to their preferences. Multiple phone calls and voice messages were left if the caregiver did not answer the first time. Interviews were conducted between 1 and 4 months after the discharge of the patient participant. All data were collected and analyzed by JV. Interviews were audio recorded with written notes by the JV. Interviews lasted between 45 minutes to an hour.

Results from the CSI were used to guide interview questions to probe the challenges that were reported on the survey. Participants were asked if they could think of any challenges that they had in the hospital or ways they could have been supported better for each domain of the CSI (physical, emotional, social, personal strain, and financial). A religious domain was added and is not a part of the CSI domains. Religion and spirituality strain and support needs were added to interview questions to inform the chaplains work, who are integral to care teams at the study location.

Qualitative Data Analysis

Audio recordings of interviews were transcribed verbatim and entered into NVivo 11Pro© software to assist with analysis. Constant comparison method was used to develop codes and themes[31]. The transcript of the first interview was reviewed, and themes from caregiver responses were developed inductively. These themes were used and refined when reviewing the subsequent interview transcript. Themes and exemplar quotes were reported.

Mixed Methods Integration

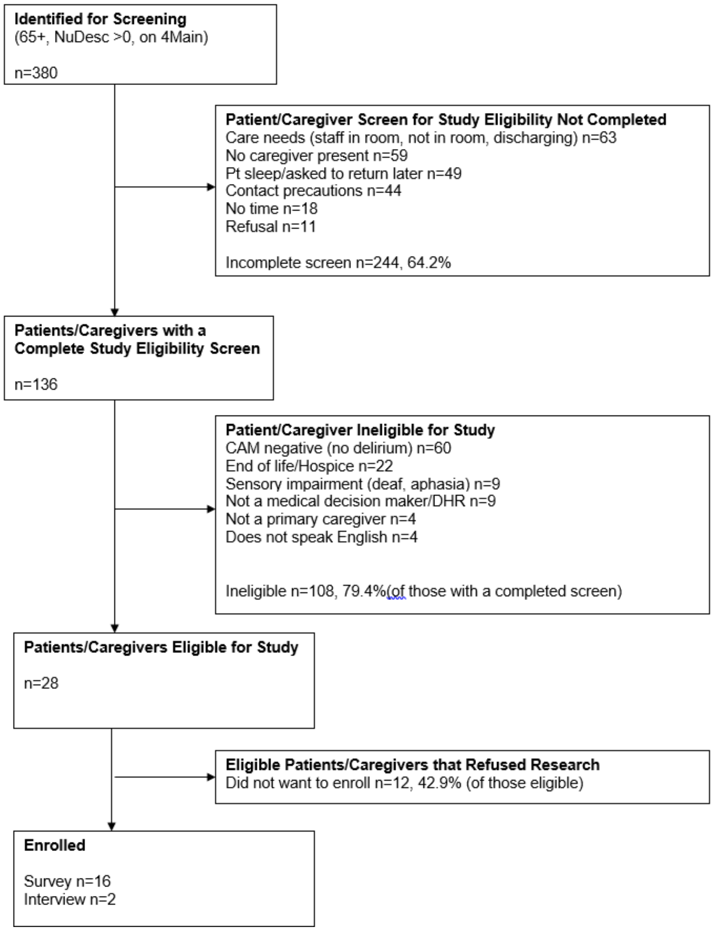
Results from the quantitative and qualitative phases were mixed to provide a more comprehensive perspective on strain and support needs in family caregivers. A side-by-side tabular joint display was used to display strain levels and related themes with family caregiver quotes[29]. Then weaving was used to explain and integrate the results from both phases in narrative form[30].

RESULTS

Quantitative Results

Recruitment yielded 16 patient caregiver dyad participants. Participant flow is depicted in Figure 1. Screening for study eligibility yielded 380 patient/caregiver dyads to be contacted. Of the 380 dyads, 64% were unable to fully screen due to hospital care needs (26%), no available caregiver (24%), patient was sleep (20%), hospital contact precautions (18%), no time or availability of the researcher (7%), or refusal before assessments (refusal of patient, caregiver, or unit staff) (5%). Screens were completed for 136 patient/caregiver dyads, of which, 108 were ineligible. Most patients were ineligible because they were not delirious (56%) based on the Confusion Assessment Method conducted by the research assistant. Patients and caregivers were also ineligible because patient was at the end-of-life (20%), patient or primary caregiver had a sensory impairment (8%), caregiver was not the medical decision maker (8%), caregiver was not a primary caregiver (4%), or patient or caregiver does not speak English (4%). 28 patient/caregiver dyads were screened and eligible for the study, and 12 choose not to participate (43%). All participant dyads that enrolled, 16, completed the survey. Of the 16 dyads that completed the survey, 2 participants agreed and were able to be contacted for the semi-structured interview.

Figure 1: Participant Flow Diagram



Older adult patient participants had a mean age of 82.6yrs±8.3. They were mostly female (75%) and White (56%). All were on a medical hospitalist service, with most having a discharge diagnosis pertaining to cardiovascular, endocrine, nervous/psychiatric, or urinary systems. Around a fifth of patients were restrained (19%) or given anti-psychotic medications (19%). Most patients' baseline functioning before hospitalization was low and tended to decline during hospitalization. Patient characteristics are displayed in Table 1.

Table 1: Patient Characteristics

Patient Characteristics		
Age	82.6yrs±8.3 (68-100)	
Gender	Male	4(25%)
	Female	12(75%)
Race	White	9(56%)
	Black/African American	7(44%)
Service	Medical Hospitalist	16(100%)
Restraints	Yes	3(19%)
Anti-psychotic meds	Yes	3(19%)
Discharge Diagnosis	Cardiovascular	3(19%)
	Endocrine	3(19%)
	Nervous/Psychiatric	3(19%)
	Urinary	3(19%)
	Musculoskeletal	2(13%)
	Immune	1(6%)
	Integumentary	1(6%)
Baseline ADL Functioning	5.3±4.8 (0-12)	
Hospital ADL Functioning	2.1±3.0 (0-9)	

Caregiver participants had a mean age of 55.6yrs±11.7. They were mostly female (75%), White (56%), in good health (81% good or excellent health), and highly educated with most (82%) reporting some college education or higher. Most caregivers were daughters/sons (69%). Half of the caregivers were living with the patient participant (50%) and had been caregiving for 0-5 years (50%). Caregivers before hospitalization were mostly providing either 11-20hrs (40%) or more than 101hrs (40%) of care weekly, and half (50%) were helping patient participants with activities of daily living (dressing, feeding, bathing, etc.). In the hospital, most caregivers provided either 0-5hrs (31%) or 16hrs or more (38%) of care daily. Caregiver characteristics are displayed in Table 2.

Table 2: Caregiver Characteristics

Caregiver Characteristics		
Age	55.6yrs±11.7 (39-80)	
Gender	Male	4(25%)
	Female	12(75%)
Race	White	9(56%)
	Black/African American	7(44%)
Education	HS Diploma/GED	3(19%)
	Some College/Associates	4(25%)
	Bachelors	3(19%)
	Graduate/Professional	6(38%)
Self-Rated Health	Excellent	5(31%)
	Good	8(50%)
	Fair	2(13%)
Family Relationship	Spouse/Significant other	2(13%)
	Son/Daughter	11(69%)
Other=granddaughter and longtime friend	Brother/Sister	1(6%)
	Other	2(13%)
Living Distance Between Patient and Caregiver	Lives with patient	8(50%)
	1-10 Miles	6(38%)
	11+ Miles	2(13%)
Caregiving Duration	0-5 years	8(50%)
	6-10 years	4(25%)
	11+ years	4(25%)
Caregiving Hours (weekly before hospitalization)	11-20hrs weekly	6(40%)
	21-100hrs weekly	3(20%)
	101+hrs weekly	6(40%)
Caregiving Hours in the Hospital (daily)	0-5hrs daily	5(31%)
	6-10hrs daily	3(19%)
	10-15hrs daily	2(13%)
	16+hrs daily	6(38%)
Caregiving Activities (before hospitalization)	ADLs	8(50%)
	IADLs	16(100%)
	Emotional/Companionship or Religious support	14(88%)

Most caregivers (75%) had reported witnessing delirium in someone else in the past. During the hospitalization, 44% received information related to delirium and the physician or nurse practitioner alone or with other staff usually provided the information. Caregivers reported that the content of this information was usually an overview of delirium, an explanation of potential causes, or the importance of cognitive stimulation. Most caregivers (85%) that had received information on delirium reported being satisfied or very satisfied. Among caregivers who did and didn’t receive information, most (94%) wanted to receive more information about delirium. Results related to the hospital experience are displayed in Table 3.

Table 3: Hospital Delirium Experience

Hospital Delirium Experience		
Previous delirium experience	Yes No	12(75%) 4(25%)
Received information related to delirium in the hospital?	Yes No	7(44%) 9(56%)
Information content (n=6)	Causes, overview, importance of cognitive stimulation, brain changes, connection to alcohol misuse	
Who provided the information to you (n=7)	Physician/NP (n=3), multiple providers (n=3), other (n=1)	
Satisfaction with information provided (n=7)	Very Satisfied Satisfied Unsatisfied	1(14%) 5(71%) 1(14%)
Would you like to receive more information about delirium?	Yes	15(94%)

Caregivers in this study had high caregiving strain (69%), high delirium burden, high distress related neuropsychiatric behaviors, and moderate social support. Most patients (94%) screened positive for dementia according the AD8. Study measure results are listed in Table 4.

Table 4: Study Measures Results

Study Measures		
Caregiver Strain Index Robinson, 1983 n=14	7.9±2.6 (4-12) 69% high strain	• Measures overall caregiver physical, emotional, social personal and financial strain. • Higher scores indicate higher strain. • Index Range 0-12

Family Caregiver Delirium Burden Instrument Racine, D'Aquila, Schmitt, et al, 2018 n=16	18.4±10.7 (0-40)	• Measures situational, emotional, and symptom burden related to delirium in family caregivers. • Higher scores indicate higher burden. • Burden Score Range 0-40
Neuropsychiatric Inventory Questionnaire Kaufer, Cummings, Ketchel et al, 2000 n=16	6.7±2.4 (3-9) Behavior Score	• An assessment of neuropsychiatric symptoms and associated caregiver distress. • Measures behaviors and severity of patient and the distress of the caregiver. • Higher Scores indicate higher severity and distress. • Behavior Score Range 0-12 • Behavior Severity Score Range 0-36 • Distress Score Range 0-60
	14.4±7.2 (4-24) Behavior Severity Score	
	19.2±12.0 (4-39) Distress Score	
AD8 Galvin, Roe, Powlishta, et al., 2005 n=16	5.0±2.3 (1-8) 94% screened positive	• Dementia screen for patients. • Score Range 0-8 • Score of two or higher is a positive dementia screen.
Social Support Scale Krause & Markides, 1990 n=14	25.4±7.6 (13-41) Received Score	• Measures social support received, satisfaction with social support, and negative interaction. Social support of caregivers. • Higher scores indicate higher received support, higher satisfaction with support, and higher negative interactions. • Received Score Range 11-44 • Satisfaction Score Range 3-12 • Negative Interaction Score Range 4-16
	8.6±2.7 (3-12) Satisfaction Score	
	6.9±2.3 (4-14) Negative Interaction Score	

Female caregivers more frequently had high strain (75%) compared to males (50%). Whites more frequently had high strain (78%) compared to African-Americans/Blacks (57%). No caregivers with fair health had high strain; compared to 60% of caregivers with excellent health and 88% of caregivers with good health. Among caregivers who had not witnessed delirium in someone else, 100% reported high strain, as compared to 58% of caregivers with delirium experience. Among caregivers who did not receive information related to delirium in the hospital 89% had high strain, as compared to 43% with high among caregivers who did receive information. Caregivers with higher strain had worse average scores of delirium burden, severity of psychiatric behaviors and related distress, functional impairment, and lower social support. Means of caregiver age, patient age, and caregiving hours were also higher among caregivers with high strain. These proportions and averages were not tested with inferential statistics due to low sample size. The high strain and caregiver characteristics descriptive comparisons are listed in Table 5.

Table 5: High Strain and Caregiver Characteristics Descriptive Comparisons

High Strain and Caregiver Characteristics Descriptive Comparisons		
Male 50% with high strain	Female 75% with high strain	
Whites 78% with high strain	African-American/Black 57% with high strain	
Fair Health 0% with high strain	Good Health 88% with high strain	Excellent Health 60% with high strain
No Previous Delirium Experience 100% with high strain	Previous Delirium Experience 58% with high strain	
Did Not Receive Delirium Information 89% with high strain	Received Delirium Information 43% with high strain	

Qualitative Results

Caregivers interview responses (n=2) are reported according to Caregiver Strain Index domains to elicit more in-depth information from the questions asked in the quantitative phase. CG1 was a middle-aged White female who was a caregiver to her husband. CG2 was a middle-aged White male who was a caregiver for his mom. Both reported having few financial concerns and were not working.

Emotional Strain and Support Needs. When asked about emotional challenges, caregivers discussed difficultly coping with many emotions. Feelings tended to be the response to upsetting behaviors of the patient and clinical procedures (such as using restraints). Caregivers reported struggling with feeling turmoil and having guilt. One caregiver shared that "*...your mind is in turmoil all the time*" (CG1) and she mentioned *"you feel guilty for what he is saying, you are guilty when you see him, you are upset from what they say, and understanding at the same time for the safety of everyone around him that is what had to be done" (CG1).*

To cope the with the emotional strain, caregivers suggested an information sheet to prepare caregivers with at risk patients for what could happen. They requested more frequent communication and information for care transitions and to help with feelings of being overwhelmed and lost. One caregiver reported that her communication and the information she received from a nurse practitioner helped to ease her anxiety, *"The communication she gave helped me because she knew it would relieve me of anxiety of having to deal with what I had to do" (CG1).*

Financial Strain and Support Needs. Both caregivers that were interviewed were retired and relatively financially secure, however, one caregiver had his wallet taken in the hospital which caused strain for him during the hospital stay. For support, he acknowledged that finances could be a concern for other caregiver and suggested that staff have resources to help those with low income. *"If I was dealing with the situation and didn't have readily available funds, I would probably want to know where I could get things covered" (CG2).*

Personal Strain and Support Needs. When discussing personal strain, caregivers reported feelings of confinement because they felt that they couldn't leave the hospital. Caregivers suggested better communication from physicians so they didn't have to wait around all day and could go home and get away for a little bit. *"It's.. I know their* *schedules are extremely difficult for dealing with this but if there just was one communication method, a voicemail is so quick and easy… at least the caregiver doesn't feel they have to be at the hospital 15hrs a day because of the doctors schedule. One's early and one's late whatever" (CG1).*

Physical Strain and Support Needs. Caregivers reported the physical strain of having pre-existing conditions that made caregiving difficult as well as the lack of sleep. Caregivers reported that it was helpful to have a healthcare provider that was aware of caregivers' health conditions and took it into consideration when developing a care plan for after discharge. One caregiver discussed the relief of staff knowing and taking her condition into consideration. She shared that "*…the rest of the staff was informed about my condition. So the staff was very… they knew they were aware and they tried to make things as easy for me as they could."* (CG1). Caregivers also reported that the patient being in the hospital allowed the caregiver to go home and get sleep. "*I'd go home at the end of the day and try to get some sleep. Although sleep is a relative term when you with something like this*" (CG1).

Religious/Spiritual Strain and Support Needs. One caregiver reported some trouble getting local clergy to visit, but was pleased with the hospital chaplains visit. He also desired to have a chapel or quiet space he could go. *"It would have been nice to have a chapel to have gone to a quiet place like that" (CG2).*

Social Strain and Support Needs. Caregivers reported frequent social strain of having to or not knowing how to communicate about the illness, and imposing on friends for help. It was noted that preexisting family strain exacerbates difficulty of communication/visitation management. One caregiver discussed his challenges with communicating with his sister. "*Yeah they have never gotten involved with this and my sister was the hardest person to communicate with*." (CG2). The other caregiver mentioned some family communication challenges with her daughter-in-law. *"...both of us were previously married and have children by previous marriages and so we have emotional issues with [patient]'s daughter who had been estranged from him up 18, 19 months and had no idea of his condition*" (CG1).

The caregiver who had a hard time communicating with his sister, suggested having an ombudsman or someone who could help them communicate with other family members and staff. "*I wish someone would have talked to my sister for me an impartial person. Maybe this is where an ombudsman could come in*" (CG2). The other caregiver mentioned the benefit of having family and friends to talk with, "*so that's the biggest thing getting his two siblings involved and you know just letting go of some of the, not keeping it all plugged up and handling it all by myself for so long*" (CG1).

Integrated Results

Integrated results are displayed in Table 6. Caregivers reported high levels of strain in all of the domains on the Caregiver Strain Index, and also frequently reported high levels of strain for those domains in the interviews. Additionally, in the interviews, participants typically expanded on the various experiences and types of strain. For emotional strain, caregivers confirmed feelings of being overwhelmed, having to make emotional adjustments in the interviews, and also reported experiencing guilt which was not asked in the Caregiver Strain Index. For financial strain, many caregivers reported difficulties with financial strain and work on the survey, but the two caregivers participating in the interviews did not report major financial strain and did not work. For personal strain, caregivers confirmed strain related to changing plans, feeling confined, and feeling inconvenienced in the interviews. Additionally, caregivers reported issues communicating with staff, need for more information, and having unmet personal needs in the interview which was not asked on the survey.

For physical strain, caregivers confirmed strain related to physical conditions and sleep difficulties in the interviews, and also reported issues with low access to quality food and physical activity opportunities which was not asked on the survey. Religious and spiritual strain was not assessed quantitatively and therefore there is not an integration of the quantitative and qualitative data. The caregivers interviewed did not report major strain with religion or spirituality, but reported important support needs as mentioned above. For social strain, caregivers confirmed strain related to family adjustments in the interviews, and also reported difficulties communicating with family and feelings of imposing on friends which was not asked on the survey.

Table 6: Integrated Results Joint Display

Caregiver Strain Index			Interview Responses	
CSI Domains	CSI Survey Questions	Survey Results	Strain Quotes	Support Need Quotes
Emotional	Completely overwhelmed	81%	"…your mind is in turmoil all the time" CG1 "As far as the care though, I didn't feel overwhelmed but was overwhelmed by the reality of the news."CG2 "you feel guilty for what he is saying, you are guilty when you see him, you are upset from what they say, and understanding at the same time for the safety of everyone around him that is what had to be done."CG1	"The communication she gave helped me because she knew it would relieve me of anxiety of having to deal with what I had to do." CG1 "I did not feel as overwhelmed as I did at home because at the hospital any help, any help, is good help."CG2 "…think if someone presents with some kind of hallucination or delusion at the get go there is nothing wrong with giving a fact sheet to somebody saying we don't know what's wrong with your loved one but if delusions become physical and compromise anyone's safety restraints maybe required." CG1
	Make emotional adjustments	69%		
	Upsetting behavior	50%		
	Upsetting changes	63%		

Financial	Financial strain	69%	“They took the money and left…because you are in a different environment and you are going to do things differently than habit and it’s very easy to loose track of simple things like that.” CG2	“If I was dealing with the situation and didn’t have readily available funds, I would probably want to know where I could get things covered.” CG2
	Work adjustments	75%	“I had given up work. So I did not have work to worry about.” CG2	
Personal	Changes in personal plans	81%	“…we had plans to go to a friends house for Christmas and because of his issues he said I can’t go you know I can’t go and do that. It seemed like everything in December and January. All these plans we had made to do things with other people or go somewhere everything was canceled.”CG1	“Taking him to the hospital was better and allowed me to at least get some distance from it everyday.” CG1 “Its, I know their schedules are extremely difficult for dealing with this but if there just was some communication method, a voicemail is so quick and easy… at least the caregiver doesn’t feel they have to be at the hospital 15hrs a day because of the doctors schedule. Ones early and ones late whatever.” CG1
	Confining	56%		
	Inconvenient	56%	“Convenience and personal space no forget that. You kind of have to be prepared to give that up.”CG2	
Physical	Physical strain	38%	“I could not figure out a way to do my kind of workouts and my kind of eating and do what I was doing for my mom. I couldn’t figure that out. I never could figure that out so.” CG2 “I didn’t even have time to think about how I was going to manage my nutrition, my basic functions, nutrition and movement.” CG2	“That was part of the reason I brought him to the hospital because my physical condition. I could not keep up with what was going on in our home so. Taking him to the hospital on the advice of a friend was the best thing for me as well as needing him to be in a safer environment because we just neither one were safe in our home.” CG1 “And the rest of the staff was informed about my condition. So the staff was very, they knew they were aware and they tried to make things as easy for me as they could.” CG1
	Sleep disturbed	75%	“I’d go home at the end of the day and try to get some sleep. Although sleep is a relative term when you with something like this.” CG1	
Religion/ Spirituality	Not apart of CSI		“So there was a little bit of a challenge getting someone to come out and fulfill our spiritual needs. It was a fluke. It was not something that’s going to be normal and it was easy to work around by calling the Bishops office and dealing with it through the diocese.”CG2	“The people at the hospital were great and the chaplain was he’s fantastic so that was not an issue really.”CG2 “It’s really just prayer or meditation or whatever you do to sort of just deal with those things emotionally and mentally.”CG2 “It would have been nice to have a chapel to have gone to a quiet place like that.”CG2

Social	Make family adjustments	75%	“You have to ask somebody else to help you and yeah it takes a toll. Everybody pays a toll for this kind of thing.” CG1 “Yeah they have never gotten involved with this and my sister was the hardest person to communicate with.” CG2 “…both of us were previously married and have children by previous marriages and so we have emotional issues with [patient]’s daughter who had been estranged from him up 18, 19 months and had no idea of his condition.”CG1	“I wish someone would have talked to my sister for me an impartial person. Maybe this is where an ombudsman could come in” CG2 “That was immensely beneficial not not just for the information but because you had people who exactly where you were and just you had a common thread you knew what each of us were experiencing.”CG1 “So that’s the biggest thing getting his two siblings involved and you know just letting go of some of the, not keeping it all plugged up and handling it all by myself for so long.” CG1

DISSCUSION

Caregivers reported high levels of strain, delirium burden, and distress related to neuropsychiatric behaviors. On average, caregivers who were females, Whites, and older, with more caregiving hours, no previous delirium experience, no information on delirium, with higher delirium burden, and those with lower social support had higher strain than their counterparts. Additionally, on average caregivers of individuals with lower functioning, higher age, more severe psychiatric behaviors had higher strain. Caregivers consistently reported that good communication with staff was essential to their ability to cope and their well-being as well as facilitating family communication and opportunities for social support among individuals facing similar challenges.

The findings of this study highlight the areas of strain and areas of support that maybe useful in addressing caregiver needs to improve their health and well-being. Interventions to support caregivers of older adults with delirium may benefit from addressing the strain and including the support needs mentioned. Interventions should include pathways for enhanced communication with providers and with other family and friends. Environmental modifications such as walking signage for physical activity, more comfortable room furniture, and close healthier food options may help to address some of the physical support needs. Additionally, caregivers may benefit from an online or in-person peer support or support group opportunities. Chaplains and dedicated spaces for a chapel may also be helpful in enhancing spiritual well-being.

There were several limitations of this study. The primary limitation of this study was the small sample size in the quantitative and qualitative phases. Inferential statistics were not used due to inadequate power to detect differences. Saturation was not reached for interviews. The primary barrier for recruitment for the study was the inability to conduct study assessments with the wide range of hospital care activities, as well as difficulty in contacting caregivers in-person. For the interviews, many caregivers did not respond to multiple follow-up calls, and several who responded reported not wanting to participate in the interview because they were overwhelmed with their caregiving situation. Another limitation was recall bias. All the caregiver responses were self-reported and subject to recall bias. Recall bias may be enhanced due to the highly distressing nature of the situation.

A strength of this study was the use of mixed methods. Mixed methods research is advantageous for this study because multiple perspectives can aid in understanding the complexities of caregiving. Quantitative studies dominate the methodology of the family caregiver strain studies, while qualitative studies dominate the support needs literature. There is a need for more mixed methods research that can identify strain and related support needs across a larger more generalizable sample, while still gaining the richness and depth of family caregiver perspectives. Breaking down the prevailing silos of quantitative and qualitative approaches by mixing approaches will allow for new knowledge and insights to be generated that could inform more effective care and intervention strategies for caregivers.

CONCLUSION

On average as delirium burden, psychiatric behaviors, and related distress in caregivers increased so did strain, but there is a need for an assessment of how these factors interact to predict strain. With a better understanding of caregiver strain and support needs in delirium, from the findings of this study and others, healthcare professionals can buffer the impact of strain on family caregiver health and well-being. Hospital interprofessional team approaches to care may be advantageous in meeting the informational, instrumental, and emotional support needs for coping efforts such as emotional and spiritual support from hospital chaplains and instrumental support from nurses. Delirium experience and education had notable differences, which may mean strain is amenable to change through education and interventions.

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HOSPITAL-BASED DELIRIUM PATIENT AND FAMILY EDUCATION INTERVENTIONS: A LITERATURE REVIEW

by

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Format adapted for dissertation

ABSTRACT

Background: Delirium is common in hospitalized older adults and is highly distressing. Caregivers of older adults have reported high levels of distress and unmet needs therefore interventions are needed to address the distress and needs of patients and families facing delirium. The aim of this study is to review published delirium education interventions.

Methods: The PubMed database was used to search for patient and/or caregiver delirium educational interventions in the hospital.

Results: Most interventions targeted family members for intervention and included activities other than delirium education. Most interventions that included education at one point in time were not associated with statistically significant delirium improvement. All interventions in this review that educated both the patient and family member had a statistically significant change in at least one delirium outcome. All interventions that included an environmental modification also reported a statistically significant change in at least one delirium outcome. No studies reported statistically significant reductions in delirium duration.

Conclusion: For this review, several potentially beneficial characteristics and activities of delirium education interventions have been identified, such as including education at multiple time points and environmental modifications. These educational interventions will require further testing in clinical trial design.

INTRODUCTION

Delirium, or the sudden onset of confusion, is common[1], debilitating[2-4] and deadly[5] among hospitalized older adults and is associated with adverse outcomes for their family caregivers[6-8]. As people are living longer with more complex conditions, more people will face the task of caregiving for older adults with delirium. Current clinical guidelines encourage the inclusion of families in delirium care[9-10], and studies have found that, when supported, families can assist with delirium prevention, detection, and management[7,11-12]. Family members can make important contributions to preventing delirium and enhancing comfort during delirium episodes through providing vital information for clinical assessments (such as functional and cognitive assessments), advocacy, care coordination, assisting with decision making, providing emotional support, motivating and supporting patients in engagement in delirium prevention activities[13]. However, family members are infrequently included in plans for care in acute settings or taught appropriate care interactions for delirium prevention[13].

In a randomized control trial, delirium has been shown to be preventable in hospitalized adults through a multicomponent intervention aimed to address precipitating (i.e. bladder catheter, psychoactive medications, infections, restraints) and predisposing factors (i.e. cognitive impairment, sensory impairment, electrolyte imbalance) related to delirium[14]. Another randomized control trial found that this intervention was highly effective when family members helped provide the intervention activities alongside hospital staff[15].

However, inclusion in delirium care can be challenging for caregivers because caregivers often have insufficient knowledge of what delirium is and how to respond when it occurs[16-18]. One study found that up to 78% of family caregivers wanted more information on delirium, and only 55.6% reported knowing what delirium was[19]. Family caregivers have reported wanting more information on causes of delirium, progression, treatment, commonality, and advice on how to respond when delirium occurs[20].

Education and engagement of patients and family members in healthcare decision making is essential. Few studies have assessed methods of family delirium education or impact of education on patient outcomes[19,21-22]. Several scholars have emphasized the need for more research in this area, as there is potential for improvement of family distress and patient health outcomes through family education[19]. Therefore, the aim of this study is to provide a scoping review of the literature on patient and caregiver delirium educational interventions in hospital settings, and identify components and characteristics that were effective.

METHODS

The PubMed database was used to search for patient and/or caregiver delirium educational interventions in the hospital. Several search terms were used to find relevant articles. Listed in Table 1 are all the search terms that were used. Articles were included if they contained all four of the following criteria: 1) a delirium educational intervention was being tested, 2) included an assessment of delirium-related outcomes (i.e. delirium incidence, caregiver delirium knowledge, patient functioning), 3) included delirium education provided to patient, family member, and/or an informal caregiver, 4) education intervention occurred in a hospital setting. Interventions that did not specify delirium education content or used verbiage such as education on neuropsychologic sequalae were not excluded.

Articles that included literature or systematic reviews or were not in English were excluded. Articles were excluded if the primary target was hired staff at the institution where the educational intervention was being delivered and not patients and families. Educational interventions that occurred on hospital units and in other settings were not excluded. Titles, abstracts, and full text, if necessary, were reviewed to determine if it met the inclusion criteria. Summaries and synthesis are provided of the intervention components, and intervention outcomes are compared descriptively based on intervention characteristics.

Table 1: Literature Review Search Terms

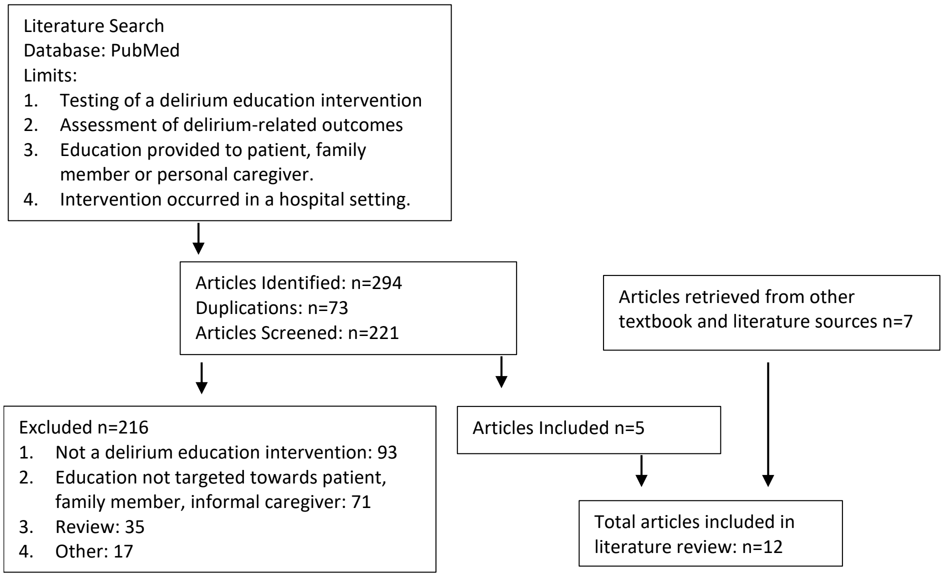
Search Terms	**Items**
delirium and ("patient education" or "health education" or "caregiver education" or "family education")	83

"delirium education" and (patient or family or caregiver)	18
delirium and (intervention or program) and (prevention or treatment) and education and (patient or family or caregiver) Items: 145	145
((("Patient Education as Topic"[Mesh]) OR "Health Education"[Mesh])) AND delirium	48

RESULTS

From the four searches, 294 articles, including duplications, were retrieved. Of the 294 articles retrieved, 5 met the inclusion criteria and were included in this review. The most common reasons for exclusion were that the study did not include a delirium education intervention and the delirium education intervention was not targeted towards the patient or a family/caregiver (i.e. staff education). The search limitations and reasons for article exclusion are listed in Figure 1. Two articles included the implementation of the same intervention. The more recent study, Boltz et al. 2015, included a sample of patients that all had dementia at baseline and was more racially diverse compared to the Boltz et al. 2014 study[13,23].

Figure 1: Flow Diagram



Research Questions. Most studies included an assessment of the interventions' impact on delirium[13,23-29,31] and psychosocial factors in caregivers[27,30,32]. Delirium incidence[24,26,28-29,31] was the most frequently assessed. Delirium duration[26,28-29], severity[13,23,28], and time to first episode[26] were also assessed. Delirium knowledge[30,32] was the most frequently assessed psychosocial factor in family/caregivers. Family/caregiver distress[30], anxiety[13,23], depression[13,23], and satisfaction with care[30] were also assessed. Several studies assessed other patient-related factors such as functioning and functional recovery (physical and psychological)[13,23-24,33], comfort and affective responses[31,33], as well as hospital and ICU length of stay[13,23,28-29]. A few studies also included the assessment of the feasibility of the intervention[13,23,32].

Sample Characteristics. Most studies had a sample size of 50 participants or more[13,23-24,26-32] and several had 100 participants or more[24,26-30]. Eight articles did not report patient race, but among those that did, most samples were predominately white[23,25,32]. Most of the articles that reported patient age had a mean age of 65 years old or higher or had 50 percent of participants that were 65 years old or older[13,23-24,26,29,32]. Only three articles reported having a sample that included 50 percent or more participants with dementia or 25 percent or more participants with delirium upon admission to the hospital[13,23,30]. Several studies excluded participants with delirium or dementia at hospital admission[26,28-29,32-33].

Study Location and Type of Unit. Studies were conducted in the United States[13,23,25,31-33], South America[29], Canada[26-27], and Asia[28,30]. Interventions occurred on medical untis[13,23,29], surgical or ICU units[24-25,28,31,33], palliative care units[26-27,30], or a mixture of units[32].

Theory. Four of the studies included a theory or model of care that framed the intervention[13,23-24,32] or learning strategies (i.e. Social Cognitive Theory)[13]. Literature review results of study characteristics are listed in Table 2.

Table 2: Literature Review Study Characteristics

Study Characteristics Results		
Research Questions	• Most studies assessed the interventions' impact on delirium in patients and psychosocial factors in caregivers	
Outcomes measured	• Delirium incidence and delirium knowledge were the most common outcomes measured. • Delirium duration, severity, and time to first episode, family/caregiver distress, anxiety, depression, and satisfaction with care were also assessed.	
Sample Characteristics	• Most studies had a sample size of 50 participants or more. • Most samples were predominately white. • Most samples had a mean age of 65 years old or higher. • Few samples included patients with delirium and/or dementia. • Several studies excluded participants with delirium or dementia at hospital admission.	• The interventions that included a high proportion of patients with dementia or delirium at admission had statistically significant improvements in delirium severity and function.
Study Location & Unit Types	• Studies were conducted in the United States, South America, Canada, and Asia. • Interventions occurred on medical units, surgical or ICU units, palliative care units, or a mixture of units.	• Interventions in palliative care settings all had non-statistically significant changes in delirium outcomes. • Interventions on surgical or ICU units had a higher number of non-statistically significant impacts on delirium incidence and duration as compared to interventions on medical units.
Theory	• Four of the studies included a theory or model of care that framed the intervention.	• Among interventions that were guided by theory, three out of the four interventions had statistically significant improvements in delirium outcomes, and the fourth study had statistically significant improvements in functioning.

Intervention Components. All studies included patient and/or family/caregiver education based on inclusion criteria. Most interventions were targeted at family/caregivers[24-27,29-30], several targeted patients and family/caregivers[13,23,28], and a few targeted patients only[31,33]. Education to patients and family/caregivers generally included information on what delirium is and its symptoms[26-32], prevention and treatment of delirium[13,23,26-27,32], as well as risk factors and causes[27,30-32].

Most studies also included other components beyond educating patients and family/caregivers. Several interventions included staff education, staff coaching, or staff support in addition to patient or family/caregiver education[25-29]. The communication of delirium risk among staff or the use of interdisciplinary teams were also a part of several interventions[13,23,26,33]. Several interventions included patient-centered care or communication between staff and patients or family/caregivers[13,23,28,31-32]. Families/caregivers were also taught specific strategies for communicating with the patient if he/she became delirious in a few studies[24-25,27]. Environmental modifications, such as the provision of sensory aids, cognitive stimulation activities, mobility devices, and clocks, were conducted in three studies[13,23,29].

Educational Implementers. Most individuals providing delirium education were nurses[13,23-24,26-27,31-32]. Other healthcare professionals[28,30,33] and researchers[24-25,29], with no mention of any healthcare professional role, made up the other implementers of delirium education.

Intervention Dose and Delivery. Most interventions involved multiple educational sessions or follow-up support from healthcare professionals[13,23-25,28,32-33], while several provided education only once[26-27,29,31]. All delirium education included verbal explanations. Some interventions also included print materials for education[13,23,24,29-30], such as handouts or booklets, while one intervention included a video option[13,23].

Intervention Fidelity. Several articles mentioned staff trainings[13,23,26-27,30,32], and staff assessments or adherence checks[13,23,26,32], but only one mentioned continuous intervention fidelity reinforcement throughout the intervention[32]. No articles mentioned using a manual of operations, but one article did mention the use of a structured training protocol[32].

Study Design. Most interventions had a usual or standard care control[24,26,29,30], while one intervention compared two intervention arms[13,23]. Most studies included a chi-square analysis or Fishers exact test[13,23,26-31,33]. A paired t-test[32], ANOVA[13,23,25,31], or independent samples t-test[24,26,28-30] were also frequently used. A few used non-parametric test[26,29,33] and one used multiple regression[24].

Delirium Measures. Half of the studies used a validated delirium measure[13,23-24,29] or clinical diagnosis[28,31]. Delirium measures used in the study include the Intensive Care Delirium Screening Checklist[24], Confusion Assessment Method[13,23,29], Confusion Rating Scale[26], DSM IV[28], 11 item checklist[25], and a clinical interview[31].

Strengths and Limitations. The most commonly reported limitation was generalizability (due to unit, race, or cognitive status composition)[13,23-24,29], small sample size[13,23,25,28,32], or using a chart review or recall bias[13,23,30,33]. The most commonly reported strength was having no baseline differences in patient or family/caregiver characteristics[13,23-24,31,33]. Several authors mentioned using a validated instrument and/or testing for reliability in their sample[13,23-25,29].

Study Outcomes. See Table 3 below for a listing of intervention associations with delirium outcomes. All studies used a $p<0.05$ to determine statistical significance, with the exception of a few studies that included a Bonferroni correction[13,23-24,30]. There were statistically significant decreases and non-statistically significant changes in delirium severity[13,23,28] and incidence[24,26,28-29,31]. Delirium duration and days was the only delirium measure for which no study was associated with statistically significant improvements[26,28,29]. In regards to knowledge, one study found significant improvements in delirium knowledge[32], while two other studies found significant and non-significant changes in certain domains of knowledge (i.e. causes and frequency)[27,30].

Table 3: Intervention Associations with Delirium Outcomes

Delirium	**Statistical Significance**	**# of articles**[(citations)]
Severity	Significant Decrease	2[2,3]
	Non-Significant	1[7]
Incidence	Significant Decrease	2[7,8]
	Non-Significant	3[1,5,10]
Days/Duration	Significant Decrease	0
	Non-Significant	3[5,7,8]
Knowledge	Significant Increase	1[11]
	Non-Significant	0
	Mixed	2[6,9]

Literature review results for the intervention characteristics are listed in Table 4. Most interventions that included education at one point in time was not associated with statistically significant improvement in delirium outcomes[26,27,29,31] (exception is statistically significant improvement in delirium incidence in Martinez et al. 2012). The intervention that had fidelity checks had a statistically significant improvement in delirium knowledge[32], and the intervention that had multiple education delivery format options had statistically significant reduction in delirium severity and improvement in functioning[13,23]. Among interventions that were guided by theory, three out of the four interventions had statistically significant improvements in delirium outcomes which include delirium severity and knowledge; while the fourth study had statistically significant improvements in functioning but not incidence[13,23-24,32].

The interventions that included a high proportion of patients with dementia or delirium at admission still had statistically significant improvements in delirium severity and function[13,23], and one had mixed knowledge outcomes[30]. Interventions in palliative care settings all had non-statistically significant changes in delirium outcomes[26-27,30]. Interventions on surgical or ICU units had a higher number of non-statistically significant impacts on delirium incidence and duration[26,27] as compared to interventions on medical units[13,23,29]. All interventions that included environmental modifications had a statistically significant improvement in at least one delirium outcome[13,23,29].

All interventions that educated both the patient and family/caregiver had a statistically significant change in at least one delirium outcome[13,23,28], however interventions that educated patients only had no statistically significant change in delirium outcomes[31,33]. Interventions that included staff education with coaching or support had statistically significant improvements in their outcomes which include delirium severity and knowledge[13,23,32].

Future research. Several researchers identified a need for future research on replicating the interventions in larger samples[13,23-24,28,32], discovering different educational strategies and delivery methods[24-25,29,32], understanding intervention dosing needs and the essential components of the interventions[13,23,32], as well as adapting interventions to palliative care settings[26,30]. Additionally, authors mention the need for future research to understand different ways family/caregivers can be involved with care, their perceptions on giving care, and how healthcare providers can facilitate care[24-25].

Table 4: Literature Review Intervention Characteristics

Literature Review Intervention Characteristics		
Intervention Components	• Most interventions were targeted at family/caregivers several targeted patients and family/caregivers, and a few targeted patients only. • Several interventions also included staff education, staff coaching, staff support, interdisciplinary teams, or patient-centered care. • Family/caregiver's were also taught communication strategies for interacting with the patient with delirium. • Environmental modifications, such as the provision of sensory aids, cognitive stimulation activities, mobility devices, and clocks, were conducted in three studies.	• All interventions that educated both the patient and family/caregiver had a statistically significant change in at least one delirium outcome • Interventions that educated patients only had no statistically significant change in delirium outcomes. • Interventions that included staff education with coaching or support had statistically significant improvements in delirium and/or knowledge outcomes. • All interventions that included environmental modifications had a statistically significant improvement in at least one delirium outcome.
Education Implementers	• Most individuals providing delirium education were nurses. • Other healthcare professionals and researchers also provided education.	
Intervention Dose & Delivery	• Most interventions involved multiple educational sessions or follow-up support from healthcare professionals while several provided education only once. • All delirium education included verbal explanations. Some interventions also included print materials for education such as handouts or booklets, while one intervention included a video option.	• Most interventions that included education at one point in time was not associated with statistically significant improvement in delirium outcomes. • The intervention that had multiple education delivery format options had statistically significant reduction in delirium severity and improvement in functioning.
Intervention Fidelity	• Several studies had staff trainings and adherence checks.	• The intervention that had fidelity checks had a statistically significant improvement in delirium knowledge
Intervention Outcomes	• Delirium duration and days was the only delirium measure for which no study was associated with statistically significant improvements. • One study found significant improvements in delirium knowledge while two studies found mixed changes.	

DISCUSSION

Overall, there was a lack of intervention fidelity, theory use, and use of diverse delivery methods. Few authors assessed their intervention’s association with satisfaction with care or patient comfort. There is also a need for better strategies in palliative care settings. There was a lack of robust intervention fidelity measures and theories or models to frame interventions. Since most of the studies that took these measures saw some statistically significant improvement in delirium, it will be important for future studies to consider using theories or models to guide study hypothesis and educational activities, as well as assuring adherence to study protocols throughout the intervention.

Most education delivery methods were oral, and the one study that provided options for education delivery had statistically significant improvements in delirium. Studies often cited the need for exploring education through different mediums, but giving participants the opportunity to choose the delivery medium may be useful approach for future interventions.

No studies reported statistically significant reductions in delirium duration. Measures of satisfaction with care and comfort may be meaningful outcomes in patients and family/caregivers where delirium cannot be or wasn’t prevented. No studies performed in palliative care units had statistically significant improvements in delirium incidence, severity, duration, or time to first episode. The authors of one study mention that delirium risk factors tend to be different in palliative care populations and prevention in end-of-life care tends to be more difficult than in standard geriatric populations[26]. Additionally, providers were wary of the burden of educating family/caregivers while their loved one is going through terminal illness[27]. These authors suggest that delirium education should happen much earlier than end-of-life care[27], but more research may help understand how delirium education can be better adapted to palliative care[26,30].

CONCLUSION

This review identified hospital-based delirium education interventions. Some intervention components that were associated with improved outcomes may be promising approaches for better healthcare of older adult patients coping with or at high risk for delirium and their families. Characteristics such as multicomponent interventions, environmental modifications, and education targeted at patients and their families would benefit from further investigation. This review also highlighted populations that are less amenable to change, including patients receiving palliative and critical care. Further research is needed to determine effective approaches in these populations.

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AGE-FRIENDLY CARE AND MOBILITY IN HOSPITALIZED OLDER ADULTS WITH COGNITIVE IMPAIRMENT

by

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ABSTRACT

Background: Hospitalization of older adults with cognitive impairment (CI) has been associated with higher risk for adverse outcomes. Acute Care for Elders (ACE) Units were developed to meet the unique hospital care needs of older adults and have been associated with reductions in functional decline and readmissions. Virtual ACE, which was developed to disseminate ACE principles across hospital units, included training interprofessional providers to utilize screens and care protocols to optimize care for older adults on eight units at a large academic medical center. The aim of the study is to examine associations between the Virtual ACE model of care, patient mobility, and related outcomes among older adults with cognitive impairment on hospital admission.

Methods: We conducted a pre/post analysis of the impact of Virtual ACE training on targeted mobility and related geriatric outcomes in 192 older adults with CI admitted to eight medical-surgical units in 2015 through 2018. Chi-Square tests were used to examine the associations between Virtual ACE and patient outcomes.

Results: Sample characteristics (n=57) pre and (n=135) post Virtual ACE were not statistically significantly different. There were statistically significant improvements in the proportion of patients mobilized from bed to chair (30% vs. 51%, p=0.011) and ambulating into the unit hallway (12% vs. 27%, p=0.046) pre vs. post Virtual ACE. Although not statistically significant, there were also improvements in the proportion of patients ambulating in their hospital room (39% vs. 50%, p=0.214) and documentation of activities of daily living (ADL) screens (70% vs. 80%, p=0.196). There were non-

significant reductions in mobility-related outcomes including high pressure injury risk (26% vs. 22%, p=0.618) and restraint use (5% vs. 0%, p=0.046) during the hospital stay. Pain scores were similar before and after Virtual ACE.

Conclusion: Virtual ACE was associated with increased mobility and slight reductions in mobility-related adverse outcomes. As increased hospital mobility improves patient functioning post-discharge, Virtual ACE has the potential to impact hospital-associated disability both during and following hospitalization for vulnerable adults with CI.

INTRODUCTION

A large proportion of hospitalized older adults experience functional decline, hospitalization-associated disability, and related adverse outcomes. Hospitalization-associated disability, defined as the loss in ability to perform at least one activity essential for living without needing assistance, occurred in around 30% of hospitalized older adults for medical illness[1]. The risk for these adverse outcomes are more pronounced for older adults who are hospitalized and have cognitive impairment (dementia or an all-cause cognitive impairment)[2]. Hospitalization of older adults with cognitive impairment is associated with increased hospital mortality, delirium, length of stay, institutionalization, new infections, functional decline, and poor nutrition status[2] .

Acute Care for Elders (ACE) Unit is a model of care that was developed in the early 1990's to meet the unique hospital care needs of older adults and prevent iatrogenic conditions and hospital-acquired disability. The main features of the ACE model of care include: proactive geriatric assessment by hospital staff from various professions, nurse-driven care plans and protocols, early discharge and care transitions planning, and daily interprofessional team meetings to review medical care and prevent iatrogenesis[3]. Geriatricians or geriatric advanced practice providers are usually involved in team meetings and/or serve as attendings. Additionally, within the ACE model of care, special attention is given to the physical environment to ensure it is conducive to safe mobility and cognitive stimulation (i.e. uncluttered hallways, large clocks, handrails, calendars) [4,5].

Addressing risk and maintaining health in mobility, mentation, medications, and what matters are critical to quality care of older adults and has been promoted by the Institute for Healthcare Improvement and The John A. Hartford Foundation.

ACE Units have been associated with reductions in cognitive[6] and functional decline[5-7], mortality[8], and institutionalization after hospital admission[5-6]. Additionally, ACE units have been associated with reductions in readmissions[9], length of stay[6,10], and hospital costs[9-10]. Studies have also found increased quality of life[11], completion of geriatric assessments by staff[12-13], and increased satisfaction of the patient, caregiver, and provider[12].

ACE units have been associated with better patient functioning and reduced hospital costs; yet they are geographically restricted, and tend to reach a small proportion of all older adults that are hospitalized. Therefore, the Virtual ACE intervention was developed to disseminate ACE unit principles across hospital units. Virtual ACE involves training interprofessional teams in geriatric principles, to enhance care provided to older adults on non-ACE units. This training increased patient screens such as function (62.5% vs. 88.5%, $p<0.001$) and delirium (4.2% vs.96.5%, $p<0.001$), increased mobility (36.4% vs. 63.5%, $p=0.04$), and was associated with reductions in abnormal delirium screens (13.6% vs. 4.8%, $p=0.16$) [13].

Another critical hospital-related adverse outcome is the decrease in mobility during hospitalization. Hospitalization has been associated with significant declines in mobility that were sustained up to two years post-discharge[14]. Additionally, low levels of mobility in the hospital are associated with poorer functional outcomes[15-18]. Studies have found low mobility is common in the hospital, even among patients that were able to walk[19-20].

Hospital-based mobility interventions have successfully increased mobility in the hospital or prevented functional decline[21-23]. Mobility in patients with cognitive impairment has been rarely studied in ACE model research, but one study found less ambulation decline in patients with mild to moderate cognitive impairment that were cared for by an interdisciplinary team[24]. As a result of the scarcity of research on hospital mobility interventions in the cognitive impairment population, we sought to study the levels of mobility among older adults with cognitive impairment present on hospital admission. The aim of the study is to examine associations between the Virtual ACE model of care, patient mobility, and related outcomes (pain, pressure injuries, restraints, and staff documentation of functional screens) among older adults with cognitive impairment on hospital admission.

METHODS

Study Design

A pre/post study design with a convenience sample was utilized to compare patient outcomes before and after the implementation of the Virtual ACE model of care. For this study, we analyzed a subset of the Virtual ACE data of patients age 65 and over with CI as determined by admission cognition screen. Participants were prospectively contacted for data collection between March 2015 through September 2018 by a research assistant. Additionally, data were abstracted from the medical record at the time of patient contact for data collection. Data were collected by research assistants during weekdays for at least four weeks before and after the Virtual ACE implementation.

Sample

This study took place in a large southeastern academic medical institution. Participants were eligible to be included in this study if they were 65 years old or older, screened positive for cognitive impairment on hospital admission, and were admitted to one of the study hospital units. There were eight hospital units on which patients were contacted which include two gastroenterology units, one gynecology unit, one hospitalist unit, two orthopedic units, and two trauma units.

Intervention

Virtual ACE is a unit-based care delivery redesign approach to implementing evidence-based geriatric care by equipping interprofessional staff to utilize: standardized geriatric screens, care protocols and pathways, and other resources such as the ACE

Tracker[25] (a medical record report for care coordination and interprofessional team review). This care is typically provided without the direct oversight of a geriatrician or geriatric advanced practice provider. Care is tailored to address the Institute for Healthcare Improvement's 4M's: mobility, mentation, medications, and what matters. The Virtual ACE model of care involved assessment, screenings, and care pathways for each of the 4M's. Virtual ACE's alignment with the 4M's through assessments and care pathways is depicted in Table 1.

Table 1 Virtual ACE and 4M Alignment

4 M's	**Assessments & Screenings**	**Care Pathways**
Mobility	Johns Hopkins Highest Level of Mobility Scale (JHMS)[26]; Activities of Daily Living (Katz)[27]	Mobility Pathway
Mentation	Six Item Screener (SIS)[28]; Nursing Delirium Screening Checklist (NuDesc)[29].	Delirium Prevention Pathway
Medications	Pain Score 0-10 or Nonverbal Scale; BEERs Meds; Number of Scheduled Meds; Antipsychotic Use.	Pain Pathway, Order sets, Transitions of Care Rounds review
What Matters	Does the patient have an Advance Directive?	Transitions of Care Rounds

Virtual ACE content was delivered via in-person staff trainings (three to four 1-hour training sessions), train the trainer approach, online modules, e-mail/in-person huddles, and/or bulletin boards/handouts. Training was sustained via booster sessions, on-unit nurse coaching, and/or orientation modules for on-boarding new staff. The Virtual ACE model of care is described in detail in Booth et al, 2018[13].

Measures

Age, race, and gender were collected from the medical record. Medical service, documented order for physical therapy, and history of falls were also collected from the medical record. The Katz Index[27] was used to determine level of patient physical functioning, and is documented in the medical record. The Katz Index includes six activities of daily living (i.e. bathing, dressing, toileting, feeding), which are scored based on independence (0=completely dependent, 1=partially dependent, or 2=completely dependent). Scores range from 0 to 12 with 12 being completely dependent and 0 being completely independent. Responses are taken from the patient and/or person who is familiar with the patient's baseline.

The Six-Item Screener (SIS)[28] was used to determine cognitive impairment. The SIS is given on admission by nursing staff for patients that are able to complete it, and documented in the medical record. Patients without SIS scores documented were excluded. SIS scores were abstracted from the medical record for the purposes of this study. The SIS measures recall and temporal orientation. Points are given for errors, and a higher score indicates greater likelihood of cognitive impairment. A score of two or higher was considered a positive screen for cognitive impairment. Therefore, those with a score of two or higher were included in this study. The six-item screener has a good sensitivity (89.6) and specificity (79.4) for cognitive impairment at cut-off of two or more errors[28]. The gold standard for cognitive impairment was based on physician clinical assessment and diagnosis.

The Acute Care Mobility Assessment (ACMA) tool was used by the research assistant to assess mobility of the participants in the hospital. This brief questionnaire assessed four levels of patient mobility in the prior 24 hours by asking patients, in the past 24 hours did you: move from bed to chair, walk in the room, walk in the hallway, and walk off the unit. For this study, frequencies where dichotomized to yes or no responses, as frequency of walking was low and skewed. Use of assistive devices and/or hospital staff for assistance with mobility was noted. In this study of mobilization of cognitively impaired patients we did not analyze the outcome “walking off the unit” due to low occurrence for patient safety reasons. The ACMA was assessed in person by the research assistant with patient, family, and/or staff informants who were most familiar with recent ambulation.

Mobility-related geriatric outcomes were also assessed for this study and included: pain, pressure injury risk, restraint use, and documentation of patient level of functioning by staff. Pain was measured using pain scores documented by bedside nurses as a part of routine care. Pain scores range from zero to ten, with zero meaning no pain and ten being the worst imaginable pain. The pain score was dichotomized as lower than seven or seven or higher, a cutoff score used by our hospital for severe pain. Pain scores were abstracted from the medical record. Pressure injury risk was determined using the most recently documented Braden Pressure Ulcer Risk[30] score. A score of 17 or lower was considered a high risk for skin breakdown and a high risk for pressure injury. Braden score was assessed by bedside staff, and abstracted from the medical record. Restraints were determined based on a documented form of active use of restraints in the medical record at the time of data collection. The research assistant reviewed the medical record for documentation of Katz scores. Score was abstracted if present.

Analysis

Descriptive statistics were used to report patient characteristics and outcomes. Chi-square tests with continuity corrections were used to examine the associations between the Virtual ACE model of care and study outcomes. Patient characteristics were assessed to describe patient population and assess any differences between pre vs. post intervention samples. Chi-square tests (categorical variables) and T-tests (continuous variables) were used to examine differences in patient characteristics before and after the Virtual ACE implementation. An alpha of 0.05 was used. Statistical Package for the Social Sciences (SPSS) version 24.0 was used to perform statistical analysis.

RESULTS

A convenience sample of 192 older adults (65 years old and older) who screened positive for cognitive impairment (Six Item Screener score of 2 or higher), were included in this study. There were no statistically significant differences in pre vs. post cohort (Table 2). Participants had a mean age of 78.0 years. More than half were female 115(60%) and White 125(65%). More than a third were Black/African-American 67(35%). Around two-thirds had physical therapy ordered 115(62%) and were on a medical service at the time of data collection 130(68%). Almost half had a history of falls in the prior 3 months 85(44%). Participants had an average baseline Katz score of 7.74, indicating impairment in basic activities of daily living.

Table 2: Patient Baseline Characteristics

Patient Characteristics		Pre Virtual ACE n=57	Post Virtual ACE n=135	Total n=192	p-value
Age		77.4yrs±8.5	78.3±8.3	78.0±8.4	0.508
History of Falls	Yes	25(44%)	60(44%)	85(44%)	1.00
Gender	Male	22(39%)	55(41%)	77(40%)	0.908
Katz at Baseline		7.36±4.8 n=44	7.88±4.5 n=117	7.74±4.5 n=161	0.521
Physical Therapy Ordered	Yes	36(63%) n=57	79(61%) n=129	115(62%) n=186	0.933
Race	White	34(60%)	91(67%)	125(65%)	0.387
	Black	23(40%)	44(33%)	67(35%)	
Service	Medical	38(67%)	92(68%)	130(68%)	0.842
	Surgical	16(28%)	39(29%)	55(29%)	
	Emergency Department	1(2%)	2(2%)	3(2%)	
	Gynecology	2(4%)	2(2%)	4(2%)	

The proportion of patients mobilized from bed to chair (30% vs. 51%, p=0.011), and ambulating into the hallway (12% vs. 27%, p=0.046) significantly increased post-Virtual ACE (Figure 1). There was a non-significant increase in patients walking in their room (39% vs. 50%, p=0.214). Pain scores of seven or higher were similar in the pre vs. post intervention cohorts (5% vs. 6%, p=1.00) (Figure 2). There were reductions in high-pressure injury risk (26% vs. 22%, p=0.618) and restraints (5% vs. 0%, p=0.046). The decrease in restraint use was a statistically significant. Staff documenting patient activities of daily life function screen in the medical record increased (70% vs. 80%, p=0.196).

Figure 1: Mobility in the Past 24 Hours in Hospitalized Older Adults with Cognitive Impairment

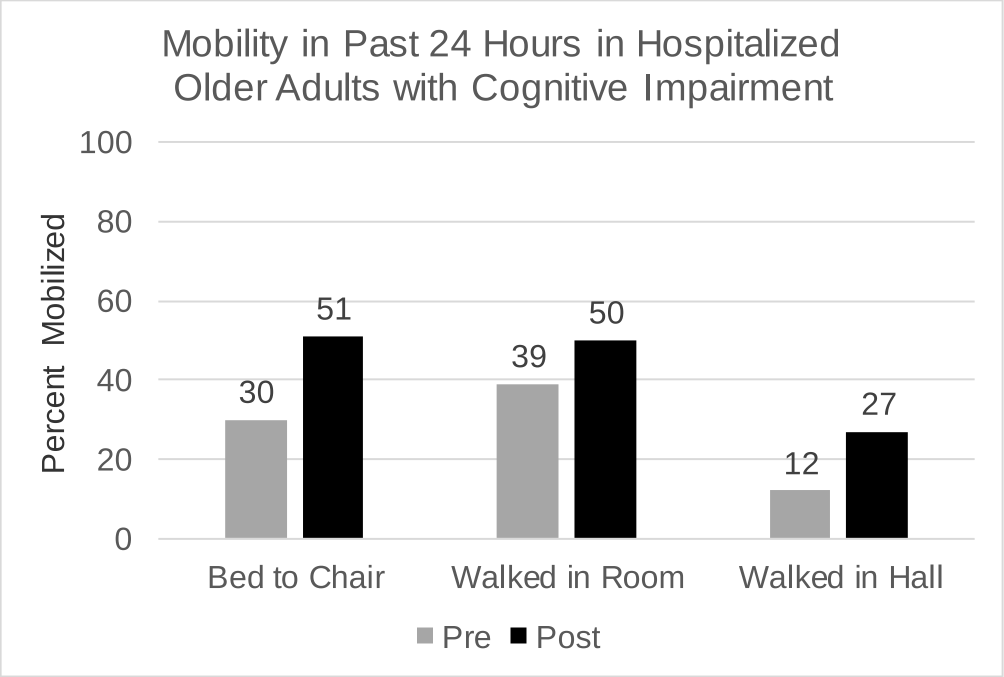
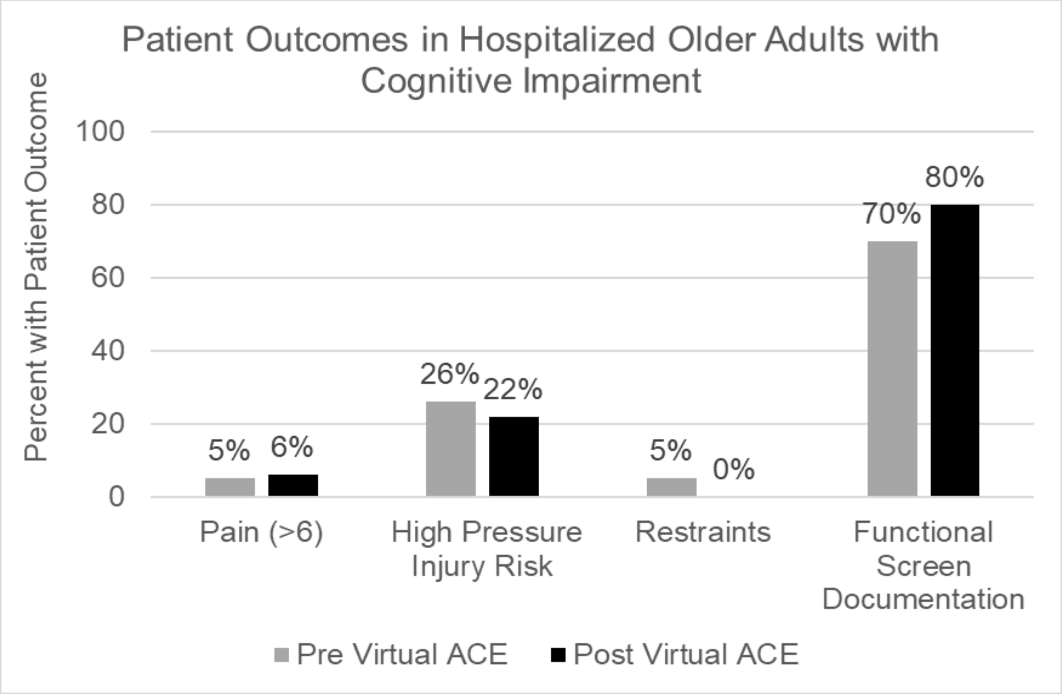


Figure 2: Patient Outcomes in Hospitalized Older Adults with Cognitive Impairment



DISCUSSION

Increased mobility, with improved mobility-related geriatric outcomes was found to be associated with the Virtual ACE model of care. We demonstrated that an ACE care model that did not require the resources of a geriatrician or geriatric advance practice providers on a dedicated unit to improve mobility outcomes in older adults. When equipped, providers working together from multiple professions in various specialties can provide quality geriatric-informed care, without the traditional ACE unit and geriatric provider resources. Quality geriatric care can be diffused more broadly, meeting the needs of the ever-growing population of older adults. Additionally, we demonstrated that units can adopt new workflows with inter-professionals from a wide variety of units that can improve care.

Strengths of the study include an exclusive focus on a high-risk population, that urgently requires hospital-based interventions to protect and maintain cognitive and physical functioning for aging well. Additionally, participants were selected from a variety of medical and surgical units which speaks to the feasibility and generalizability of this model of care in various populations of older adults. There are several limitations to this study. The SIS does not distinguish between different types of cognitive impairment such as delirium or dementia subtypes, therefore, the type of cognitive impairment among this sample is unknown. Use of the SIS as an inclusion criterion could have inadvertently excluded sicker patients, for whom the intervention may not have been as successful. The SIS requires verbal participation of the patients, and patients who are unresponsive on admission are likely to not have had a documented SIS. The research assistant collecting the data was not blind to intervention status thus potentially introducing bias in data collection. Additionally, the Virtual ACE model of care requires extensive coaching, which requires dedicated staffing.

For future research, randomized controlled trial (RCT) designs are needed to assess ACE models of care. The findings of one review of the literature of ACE models, documented a lack of RCT research designs with most RCT studies occurring in the 90's with the first generation of ACE research[31]. Additionally, more RCT research is needed to assess ACE unit mobility outcomes. For all hospital-based research, mobility outcomes in individuals with cognitive impairment is needed to determine the long-term benefits on participant's cognition and physical functioning. Finally, more research is needed to understand the impact of the Virtual ACE model of care in critical care settings.

CONCLUSION

Reduction of hospital-associated disability is paramount. As Naglie and colleagues[24] stated, older adults with cognitive impairment may benefit the most from ACE unit models with regard to mortality, ambulation, and residential status. As a result of the high risk that comes with hospitalization, this population should continue to be studied in ACE model of care research. This study found increased hospital mobility which has been found to improve patient functioning post-discharge[21]. Therefore, Virtual ACE and age-friendly care initiatives have the potential to maintain function and enhance outcomes in hospitalized older adults with cognitive impairment.

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OVERALL CONCLUSION

As a large proportion of the population continues to age with chronic conditions, delirium prevention, identification, and treatment will grow in importance; and because delirium has been found to be highly disabling and distressing for individuals and their family caregivers, identifying care protocols and health promotion interventions to address these issues are of the utmost importance. The findings of this dissertation highlighted family caregiver strain and support needs while identifying individual, interpersonal, and organizational health promotion interventions to address patient and family caregiver distress from delirium episodes.

In paper one it was found that most caregivers reported high strain and adverse impacts on their personal, emotional, social, and financial well-being in addition to high distress, and high situational delirium burden. Caregivers reported several measures that were or would have been helpful and the most frequently reported support need was good communication with healthcare providers and the caregiver’s friends and family. In paper two several health promotion intervention characteristics that were found to be effective were highlighted and included: educating patients and family caregivers, providing staff education and hands-on support, implementing environmental modifications, providing education at multiple time points and with multiple delivery formats, and conducting intervention fidelity checks. In paper three a hospital unit level redesign approach to promote geriatric-friendly care was associated with increased mobility in older adults that screened positive on admission for cognitive impairment.

The most frequently reported support need of communication could be addressed in implementing a Virtual ACE model of care as described in paper three. This redesign involves an inter-professional team approach where the healthcare staff communicate with each other to better coordinate care for the hospital stay and post-discharge. This approach is often associated with better patient and family centered care which could decrease distress for patients and family members. Additionally, need for information, education, and skills for the family caregiver to better care for their family member with delirium was another frequently reported support need. Many of the health promotion interventions involved educating patients and families, and with the identified characteristics (educating multiple people, at multiple times, with multiple delivery formats, and with environmental and hands-on staff support) comprehensive interventions could help to decrease distress. However, more research is needed to evaluate the effects of these interventions. Another frequently reported support need was social support among peers (other delirium family caregivers) as well as family members and friends of the caregivers. Both educational and unit redesign approaches did not adequately address this need. Additional information on the most frequently reported findings of strain and support needs are listed with intervention components of allied interventions to address support need in Table 1.

Table 1: Caregiver Strain, Support Needs, and Allied Health Promotion Intervention by Paper

Paper 1 Strain	Paper 1 Support Needs	Paper 2 Intervention Component	Paper 2 Intervention Component
Communication • Family discord or not knowing how to inform other family members • Lack of information from healthcare providers on patient status • Fragmented care transition support and communication • Not knowing how to communicate/reassure patient when they are experiencing delirium	• Leaving messages with updates • Provider should ask if they are understanding the situation correctly • Need for more information on facilities/services patient will be discharged to • Need for patient/family advocate to enhance mutual understanding and advocate to providers when patient/family has unmet needs or concerns • Education and hands-on support from peers or healthcare providers on how to communicate with patient and how to respond to delirium behaviors	• Staff training on how to communicate with patients and family • Information and skills training on communicating with individuals with delirium	• Inter-professional teams improve communication between healthcare provider, care coordination, and care transitions.
Education/Information • Not knowing what to expect • Disturbed by patient behaviors • Not knowing how to respond to behaviors	• Education and hands-on support from peers or healthcare providers on how to communicate with patient • Education on how to respond to delirium behaviors • Fact sheets that are given to family caregivers at risk for delirium	• Staff educated to give information and skills training for caregivers to cope and respond to delirium behaviors • Fact sheets, brochures, and videos created to communicate education to patients/families	N/A
Social support • Pre-existing discord with superimposed health crisis makes connection and communication difficult • Guilt for having to ask for help or impose on friends	• Positive emotional, informational, and tangible support of family and friends. • Peer support: being able to talk with others who are going through the same thing • Need for a physical space on hospital unit for healthcare professional and peer support activities • Online support groups	N/A	N/A

Caregiver Physical and Mental Health • Caregiver chronic and serious illness that limits caregiving ability • Not being able to sleep, difficult to sleep in hospital room • Poor nutrition/eating habits, no time for physical activity • Mental distress, guilt, and difficulty concentrating	• Healthcare providers that take into consideration family caregiver physical and mental health in hospital and care transition decisions. As well as communicate options in light of caregiver health condition. • Hospital as respite care	• Environmental modifications could also help the caregiver with sleep and a more relaxing environment	• ACE unit models have been shown to improve function and increased mobility which could decrease physical strain on caregiver.

Future research is needed to expand our understanding of health promotion interventions impact on strain or distress of delirium caregivers. In the literature review of delirium education interventions only, 25% of studies assessed a psychosocial outcome of family caregivers (ie. distress, anxiety, depression). Out of the three interventions that assessed a psychosocial outcome, none were associated with changes in distress or strain. One was associated with no changes in mood, while one multicomponent intervention was associated with statistically significant declines in anxiety. Specifically, randomized controlled trial designs, of intervention with characteristics mentioned above, would provide robust evidence of the interventions' impact on patient and family caregiver outcomes.

Of the education and unit level interventions reviewed in this dissertation, most activities did not address peer and family social support activities which were frequently reported by caregivers as important. More creative approaches that are cost-effective and sustainable (such as online support communities. caregiver mentors, patient family advocates) should be integrated in patient and family delirium interventions and quality improvement projects to ensure this need is met. This could also be an important factor in reducing distress and improving mood, since previous interventions were not robustly effective in reducing them. Additionally, public policy and community level were not well addressed by the interventions proposed. More research and evidence-based collections of effective public policies that could met the needs specified by delirium caregivers is needed.

Future research is also needed to gain a better understanding of not only the level of distress, but the impact of the delirium caregiving experience on the personal, emotional, social, physical, and financial well-being of caregivers. Although this study uniquely aimed to address this gap in the literature, more research is needed to confirm and expand findings, especially considering the study's small sample size. A nuanced and holistic understanding of caregiver strain and support needs is critical to developing effective interventions. Additionally, future research is needed within populations with cognitive impairment to develop and test ways to maintain function. Mobility interventions, especially when coupled with good geriatric care, have been shown to improve functioning. However, evidence is scarce in populations with cognitive impairment. This study documents preliminary findings of increased mobility; however, more robust evidence is needed on sustainable hospital-based mobility interventions and their impact on physical and cognitive functioning post-discharge.

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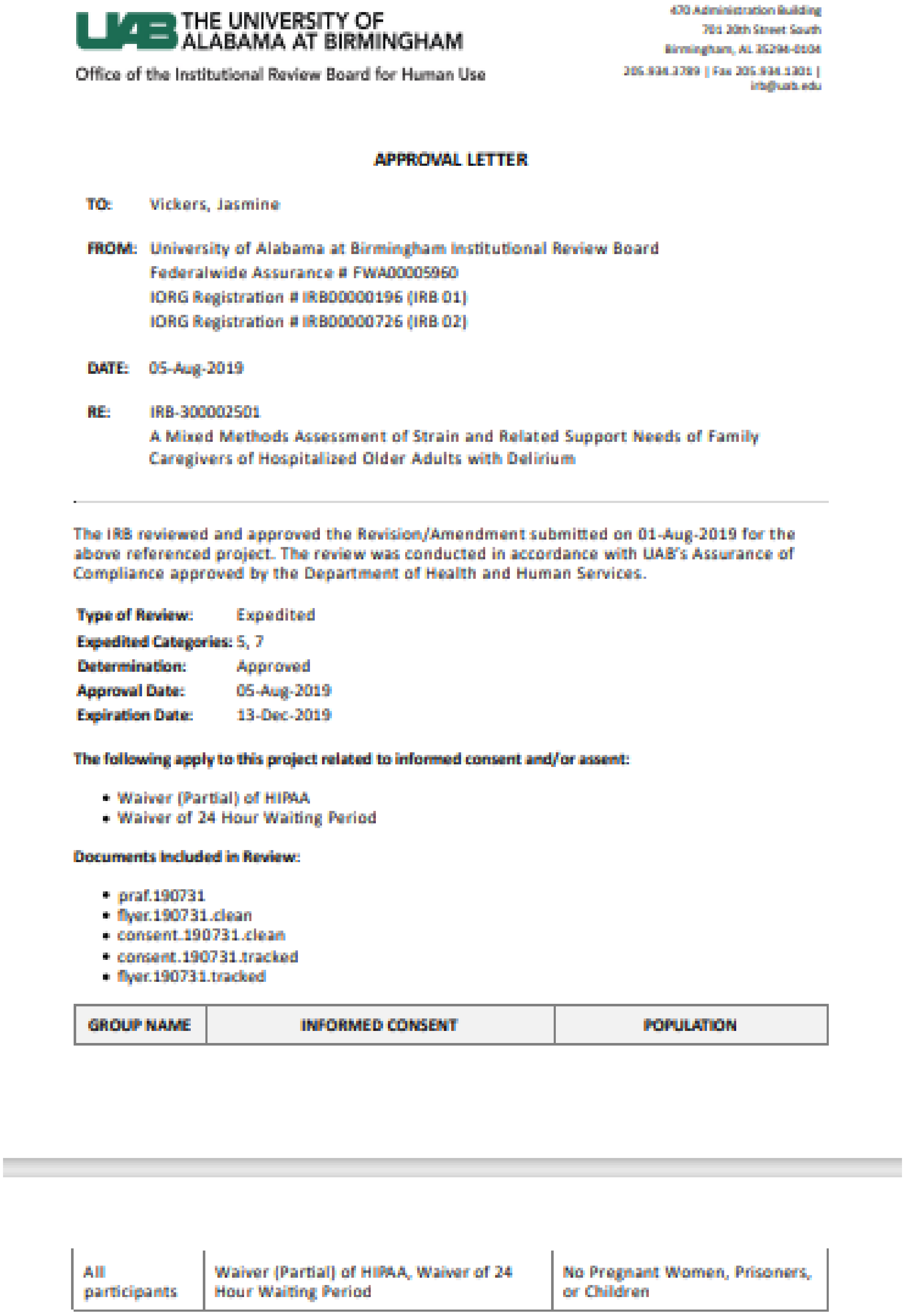
APPENDIX A

IRB APPROVALS



THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 | irb@uab.edu

APPROVAL LETTER

TO: Vickers, Jasmine

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 05-Aug-2019

RE: IRB-300002501
A Mixed Methods Assessment of Strain and Related Support Needs of Family Caregivers of Hospitalized Older Adults with Delirium

The IRB reviewed and approved the Revision/Amendment submitted on 01-Aug-2019 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited
Expedited Categories: 5, 7
Determination: Approved
Approval Date: 05-Aug-2019
Expiration Date: 13-Dec-2019

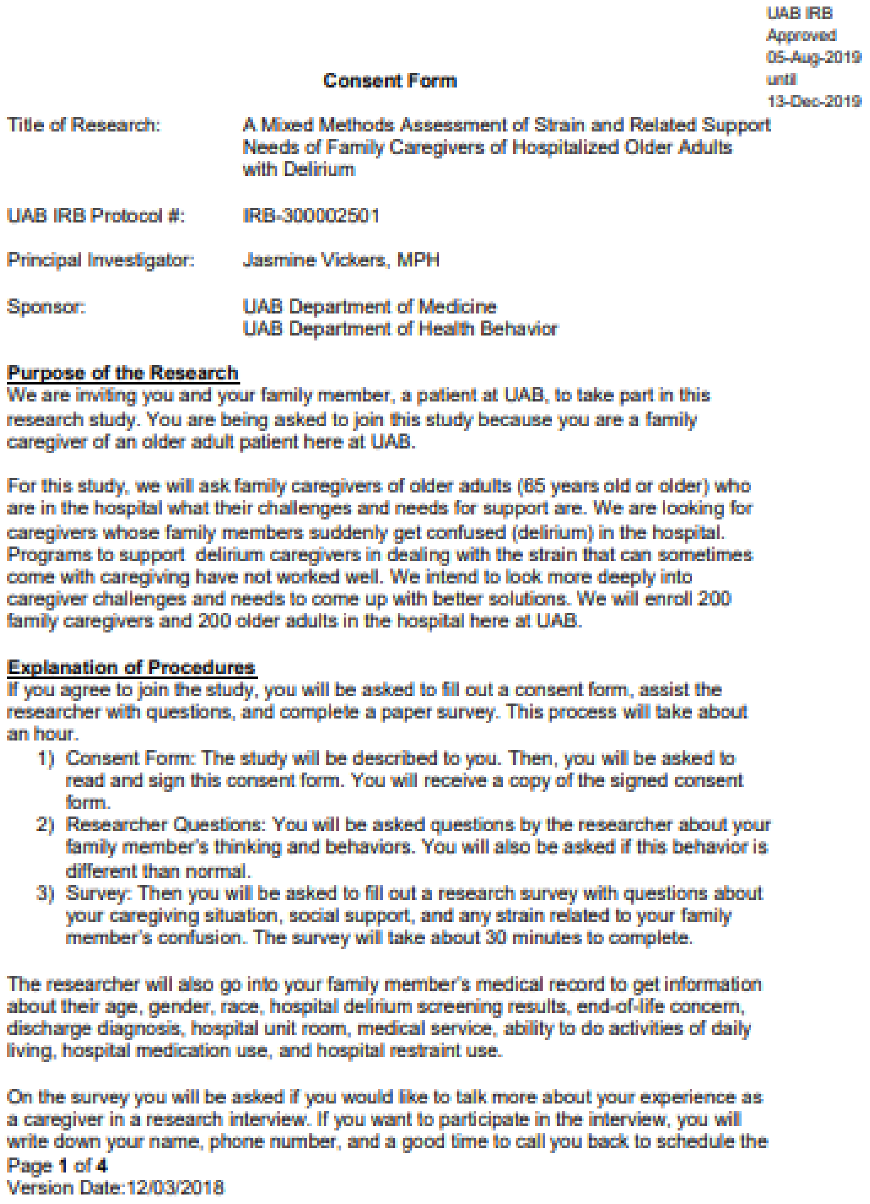
The following apply to this project related to informed consent and/or assent:

- Waiver (Partial) of HIPAA
- Waiver of 24 Hour Waiting Period

Documents Included in Review:

- praf.190731
- flyer.190731.clean
- consent.190731.clean
- consent.190731.tracked
- flyer.190731.tracked

GROUP NAME	INFORMED CONSENT	POPULATION
All participants	Waiver (Partial) of HIPAA, Waiver of 24 Hour Waiting Period	No Pregnant Women, Prisoners, or Children



UAB IRB
Approved
05-Aug-2019
until
13-Dec-2019

Consent Form

Title of Research:	A Mixed Methods Assessment of Strain and Related Support Needs of Family Caregivers of Hospitalized Older Adults with Delirium
UAB IRB Protocol #:	IRB-300002501
Principal Investigator:	Jasmine Vickers, MPH
Sponsor:	UAB Department of Medicine UAB Department of Health Behavior

Purpose of the Research

We are inviting you and your family member, a patient at UAB, to take part in this research study. You are being asked to join this study because you are a family caregiver of an older adult patient here at UAB.

For this study, we will ask family caregivers of older adults (65 years old or older) who are in the hospital what their challenges and needs for support are. We are looking for caregivers whose family members suddenly get confused (delirium) in the hospital. Programs to support delirium caregivers in dealing with the strain that can sometimes come with caregiving have not worked well. We intend to look more deeply into caregiver challenges and needs to come up with better solutions. We will enroll 200 family caregivers and 200 older adults in the hospital here at UAB.

Explanation of Procedures

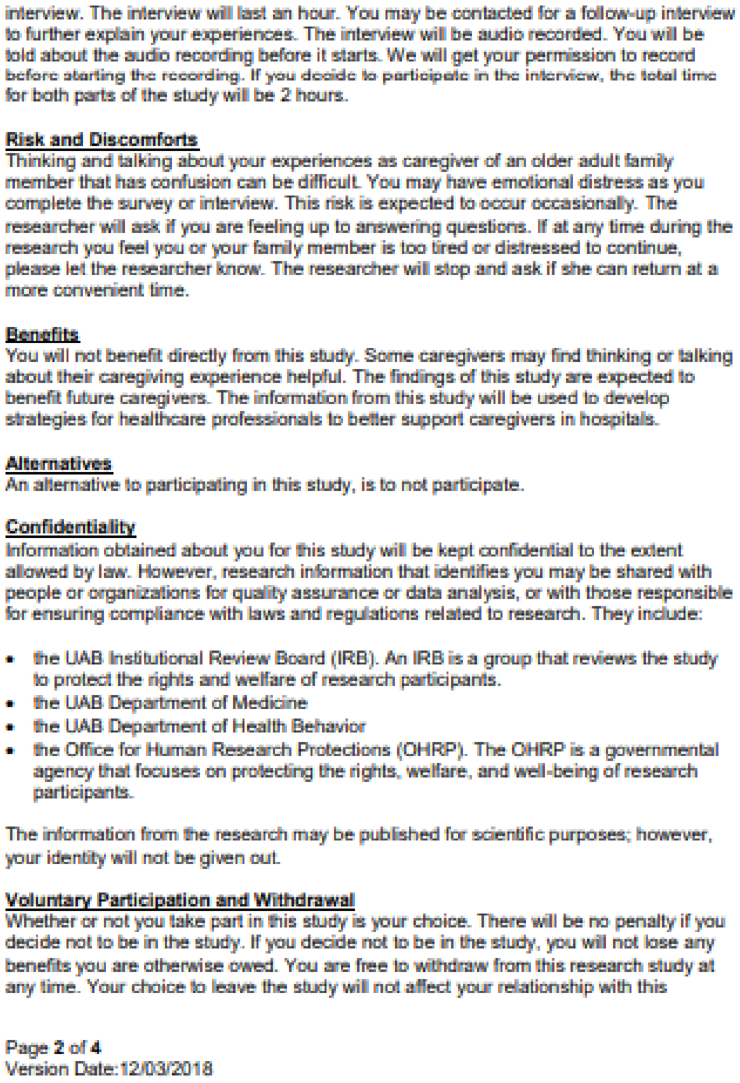
If you agree to join the study, you will be asked to fill out a consent form, assist the researcher with questions, and complete a paper survey. This process will take about an hour.

1) Consent Form: The study will be described to you. Then, you will be asked to read and sign this consent form. You will receive a copy of the signed consent form.
2) Researcher Questions: You will be asked questions by the researcher about your family member's thinking and behaviors. You will also be asked if this behavior is different than normal.
3) Survey: Then you will be asked to fill out a research survey with questions about your caregiving situation, social support, and any strain related to your family member's confusion. The survey will take about 30 minutes to complete.

The researcher will also go into your family member's medical record to get information about their age, gender, race, hospital delirium screening results, end-of-life concern, discharge diagnosis, hospital unit room, medical service, ability to do activities of daily living, hospital medication use, and hospital restraint use.

On the survey you will be asked if you would like to talk more about your experience as a caregiver in a research interview. If you want to participate in the interview, you will write down your name, phone number, and a good time to call you back to schedule the

Page **1** of **4**
Version Date:12/03/2018



interview. The interview will last an hour. You may be contacted for a follow-up interview to further explain your experiences. The interview will be audio recorded. You will be told about the audio recording before it starts. We will get your permission to record before starting the recording. If you decide to participate in the interview, the total time for both parts of the study will be 2 hours.

Risk and Discomforts

Thinking and talking about your experiences as caregiver of an older adult family member that has confusion can be difficult. You may have emotional distress as you complete the survey or interview. This risk is expected to occur occasionally. The researcher will ask if you are feeling up to answering questions. If at any time during the research you feel you or your family member is too tired or distressed to continue, please let the researcher know. The researcher will stop and ask if she can return at a more convenient time.

Benefits

You will not benefit directly from this study. Some caregivers may find thinking or talking about their caregiving experience helpful. The findings of this study are expected to benefit future caregivers. The information from this study will be used to develop strategies for healthcare professionals to better support caregivers in hospitals.

Alternatives

An alternative to participating in this study, is to not participate.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with people or organizations for quality assurance or data analysis, or with those responsible for ensuring compliance with laws and regulations related to research. They include:

- the UAB Institutional Review Board (IRB). An IRB is a group that reviews the study to protect the rights and welfare of research participants.
- the UAB Department of Medicine
- the UAB Department of Health Behavior
- the Office for Human Research Protections (OHRP). The OHRP is a governmental agency that focuses on protecting the rights, welfare, and well-being of research participants.

The information from the research may be published for scientific purposes; however, your identity will not be given out.

Voluntary Participation and Withdrawal

Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you are otherwise owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this

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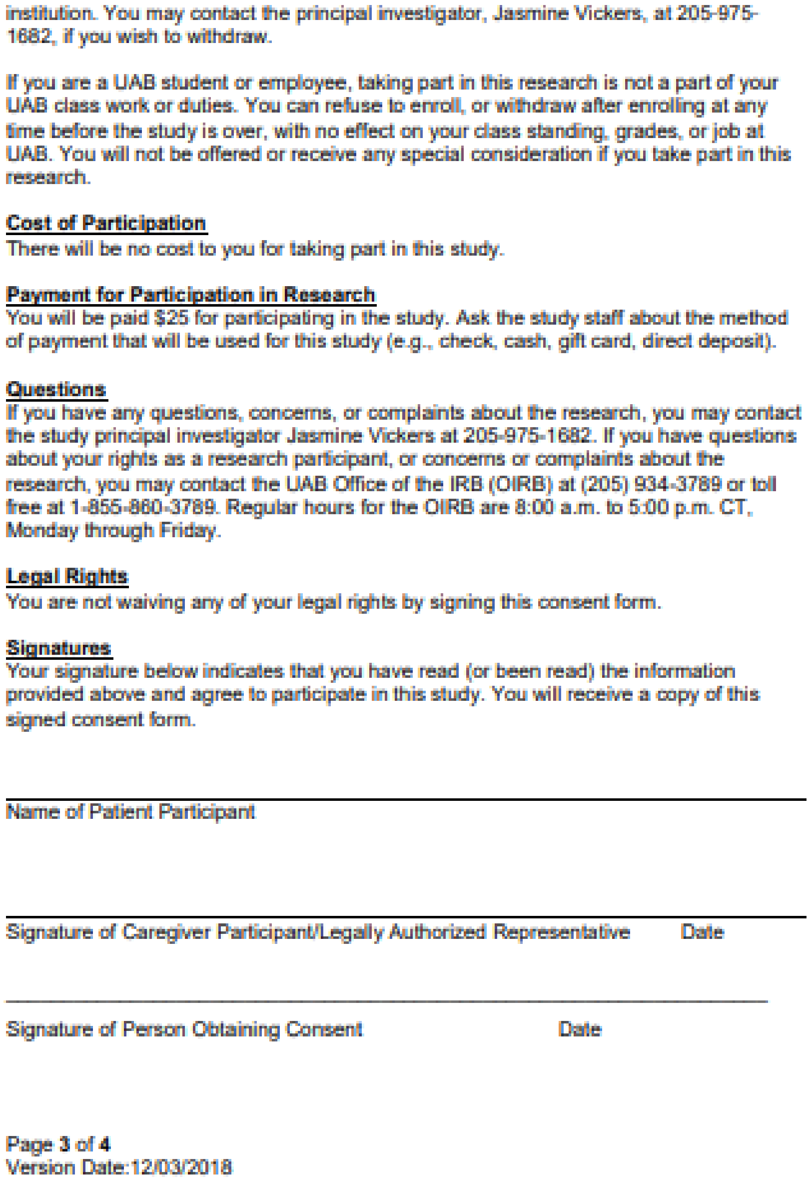

institution. You may contact the principal investigator, Jasmine Vickers, at 205-975-1682, if you wish to withdraw.

If you are a UAB student or employee, taking part in this research is not a part of your UAB class work or duties. You can refuse to enroll, or withdraw after enrolling at any time before the study is over, with no effect on your class standing, grades, or job at UAB. You will not be offered or receive any special consideration if you take part in this research.

Cost of Participation

There will be no cost to you for taking part in this study.

Payment for Participation in Research

You will be paid $25 for participating in the study. Ask the study staff about the method of payment that will be used for this study (e.g., check, cash, gift card, direct deposit).

Questions

If you have any questions, concerns, or complaints about the research, you may contact the study principal investigator Jasmine Vickers at 205-975-1682. If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB (OIRB) at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday.

Legal Rights

You are not waiving any of your legal rights by signing this consent form.

Signatures

Your signature below indicates that you have read (or been read) the information provided above and agree to participate in this study. You will receive a copy of this signed consent form.

Name of Patient Participant

Signature of Caregiver Participant/Legally Authorized Representative Date

Signature of Person Obtaining Consent Date

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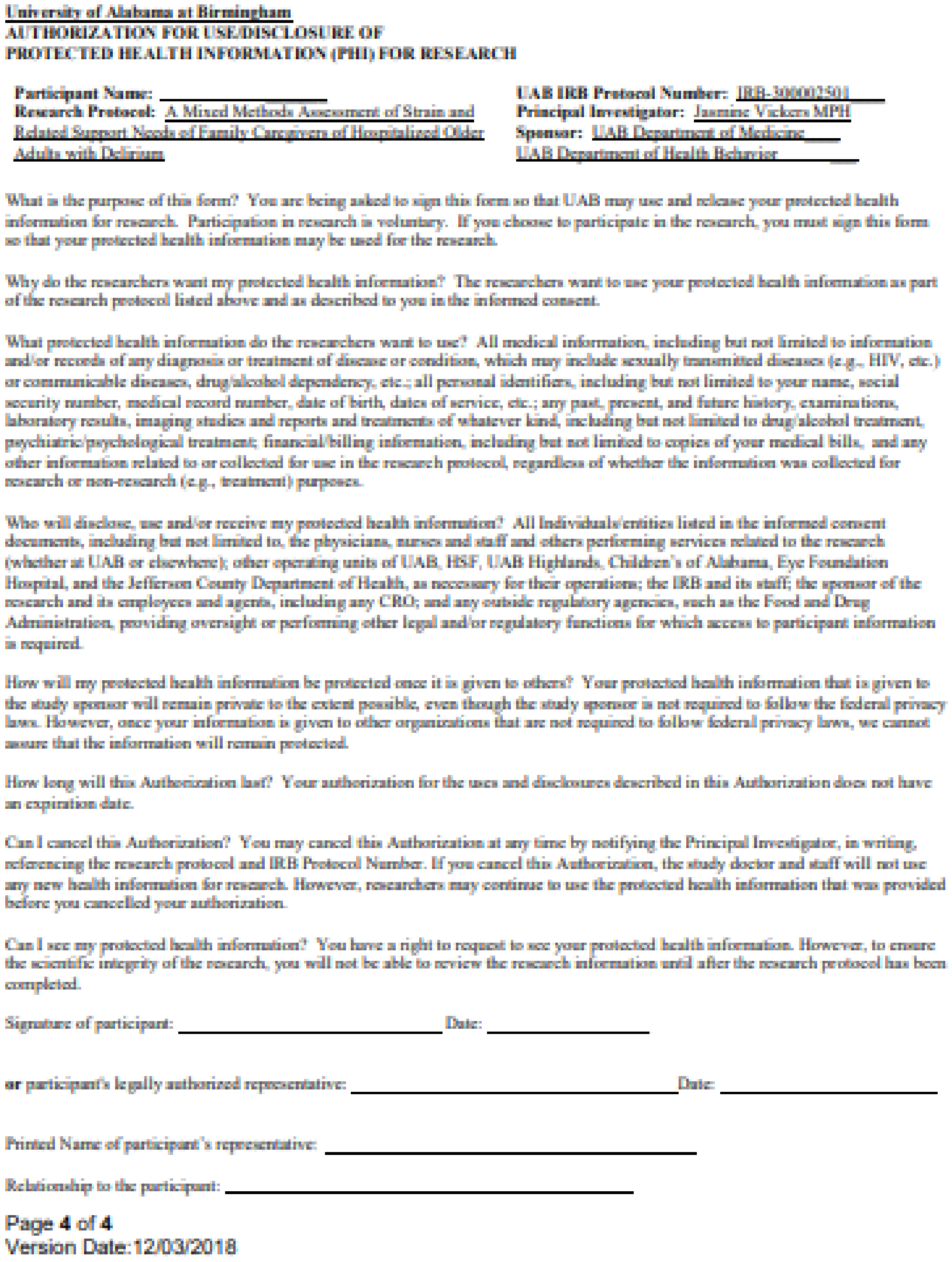
Version Date:12/03/2018



University of Alabama at Birmingham
AUTHORIZATION FOR USE/DISCLOSURE OF
PROTECTED HEALTH INFORMATION (PHI) FOR RESEARCH

Participant Name: ____________________
Research Protocol: A Mixed Methods Assessment of Strain and Related Support Needs of Family Caregivers of Hospitalized Older Adults with Delirium

UAB IRB Protocol Number: IRB-300002501
Principal Investigator: Jasmine Vickers MPH
Sponsor: UAB Department of Medicine
UAB Department of Health Behavior

What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your protected health information for research. Participation in research is voluntary. If you choose to participate in the research, you must sign this form so that your protected health information may be used for the research.

Why do the researchers want my protected health information? The researchers want to use your protected health information as part of the research protocol listed above and as described to you in the informed consent.

What protected health information do the researchers want to use? All medical information, including but not limited to information and/or records of any diagnosis or treatment of disease or condition, which may include sexually transmitted diseases (e.g., HIV, etc.) or communicable diseases, drug/alcohol dependency, etc.; all personal identifiers, including but not limited to your name, social security number, medical record number, date of birth, dates of service, etc.; any past, present, and future history, examinations, laboratory results, imaging studies and reports and treatments of whatever kind, including but not limited to drug/alcohol treatment, psychiatric/psychological treatment; financial/billing information, including but not limited to copies of your medical bills, and any other information related to or collected for use in the research protocol, regardless of whether the information was collected for research or non-research (e.g., treatment) purposes.

Who will disclose, use and/or receive my protected health information? All Individuals/entities listed in the informed consent documents, including but not limited to, the physicians, nurses and staff and others performing services related to the research (whether at UAB or elsewhere); other operating units of UAB, HSF, UAB Highlands, Children's of Alabama, Eye Foundation Hospital, and the Jefferson County Department of Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees and agents, including any CRO; and any outside regulatory agencies, such as the Food and Drug Administration, providing oversight or performing other legal and/or regulatory functions for which access to participant information is required.

How will my protected health information be protected once it is given to others? Your protected health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.

Can I cancel this Authorization? You may cancel this Authorization at any time by notifying the Principal Investigator, in writing, referencing the research protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However, researchers may continue to use the protected health information that was provided before you cancelled your authorization.

Can I see my protected health information? You have a right to request to see your protected health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

Signature of participant: ____________________ Date: ____________

or participant's legally authorized representative: ____________________ Date: ____________

Printed Name of participant's representative: ____________________

Relationship to the participant: ____________________

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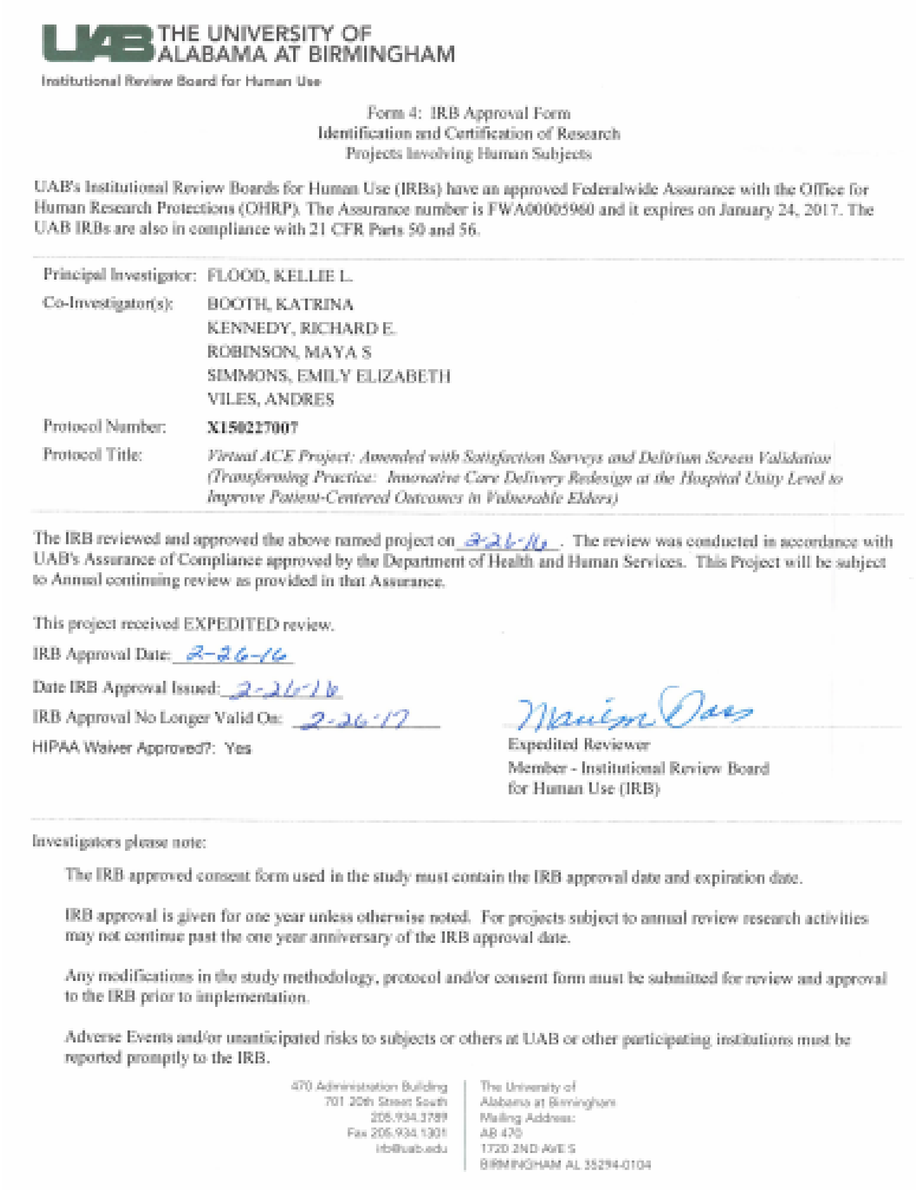
Version Date:12/03/2018



THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on January 24, 2017. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: FLOOD, KELLIE L.

Co-Investigator(s):
BOOTH, KATRINA
KENNEDY, RICHARD E.
ROBINSON, MAYA S
SIMMONS, EMILY ELIZABETH
VILES, ANDRES

Protocol Number: **X150227007**

Protocol Title: *Virtual ACE Project: Amended with Satisfaction Surveys and Delirium Screen Validation (Transforming Practice: Innovative Care Delivery Redesign at the Hospital Unity Level to Improve Patient-Centered Outcomes in Vulnerable Elders)*

The IRB reviewed and approved the above named project on 2-26-16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 2-26-16

Date IRB Approval Issued: 2-26-16

IRB Approval No Longer Valid On: 2-26-17

HIPAA Waiver Approved?: Yes

Expedited Reviewer
Member - Institutional Review Board
for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

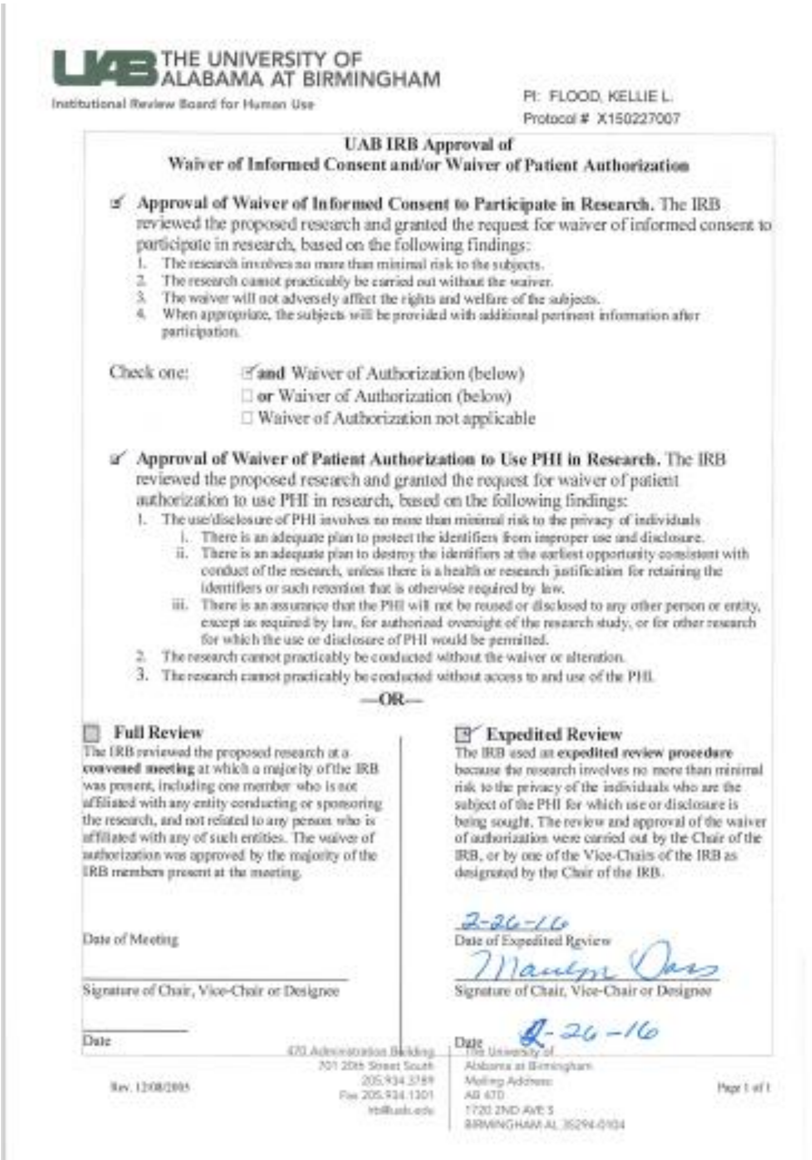
IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

470 Administration Building
701 20th Street South
205.934.3789
Fax 205.934.1301
irb@uab.edu

The University of
Alabama at Birmingham
Mailing Address:
AB 470
1720 2ND AVE S
BIRMINGHAM AL 35294-0104



THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

PI: FLOOD, KELLIE L.
Protocol # X150227007

UAB IRB Approval of Waiver of Informed Consent and/or Waiver of Patient Authorization

☑ **Approval of Waiver of Informed Consent to Participate in Research.** The IRB reviewed the proposed research and granted the request for waiver of informed consent to participate in research, based on the following findings:

1. The research involves no more than minimal risk to the subjects.
2. The research cannot practicably be carried out without the waiver.
3. The waiver will not adversely affect the rights and welfare of the subjects.
4. When appropriate, the subjects will be provided with additional pertinent information after participation.

Check one:
☑ **and** Waiver of Authorization (below)
☐ **or** Waiver of Authorization (below)
☐ Waiver of Authorization not applicable

☑ **Approval of Waiver of Patient Authorization to Use PHI in Research.** The IRB reviewed the proposed research and granted the request for waiver of patient authorization to use PHI in research, based on the following findings:

1. The use/disclosure of PHI involves no more than minimal risk to the privacy of individuals
    i. There is an adequate plan to protect the identifiers from improper use and disclosure.
    ii. There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention that is otherwise required by law.
    iii. There is an assurance that the PHI will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted.
2. The research cannot practicably be conducted without the waiver or alteration.
3. The research cannot practicably be conducted without access to and use of the PHI.

—OR—

☐ **Full Review**
The IRB reviewed the proposed research at a **convened meeting** at which a majority of the IRB was present, including one member who is not affiliated with any entity conducting or sponsoring the research, and not related to any person who is affiliated with any of such entities. The waiver of authorization was approved by the majority of the IRB members present at the meeting.

Date of Meeting

Signature of Chair, Vice-Chair or Designee

Date

☑ **Expedited Review**
The IRB used an **expedited review procedure** because the research involves no more than minimal risk to the privacy of the individuals who are the subject of the PHI for which use or disclosure is being sought. The review and approval of the waiver of authorization were carried out by the Chair of the IRB, or by one of the Vice-Chairs of the IRB as designated by the Chair of the IRB.

2-26-16
Date of Expedited Review

Marilyn Doss
Signature of Chair, Vice-Chair or Designee

Date 2-26-16

Rev. 12/08/2005

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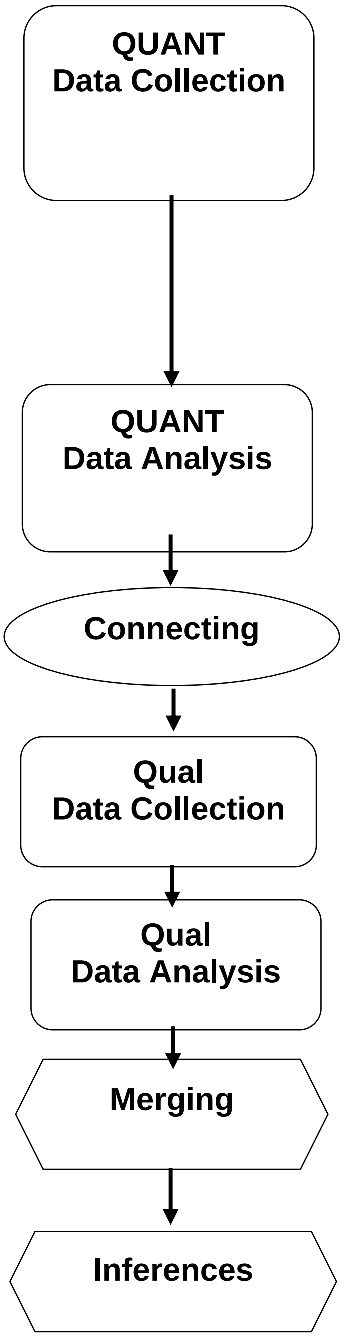
APPENDIX B

PROCEDURAL DIAGRAM



Procedures	Products
Demographic: patient and caregiver age, gender, and race Caregiving: burden, distress, duration, caregiver relationship, distance from care recipient, delirium experience, receipt of delirium education Caregiving Burden: CSI Clinical: hospital service, discharge diagnosis, current ADL functioning, restraint use, anti-psychotic use, delirium and dementia assessment. Delirium Assessment: CAM, NPI Dementia Assessment:AD8	Counts CSI score CAM positive or negative AD8 positive or negative NPI symptom score NPI severity score NPI distress score
Descriptive statistics (n=16)	Frequencies & percentages Means & standard deviations
Identify caregivers with high caregiving burden (CSI 7 or greater) for interview contact Refine interview protocol as needed	
Semi-structured interviews (n=2)	List of sample for interviews Revised interview protocols
Coding & thematic analysis	Text & interview transcript
Explain QUANT and Qual results	Codes and themes
Implications for educational/clinical interventions and research	Written report Joint display of CSI results, burden themes, and support themes Written report

CSI=Caregiver Strain Index; CAM=Confusion Assessment Method; NPI= Neuropsychiatric Inventory Questionnaire ADL=Activities of Daily Living