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ORIGINAL RESEARCH

A Mixed Methods Assessment of Strain and Related Support Needs of Family Caregivers of Hospitalized Older Adults with Delirium

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Background: High distress is common among delirium caregivers, yet little is known about their caregiver strain and support needs across a comprehensive spectrum including physical, financial, and spiritual domains.

Purpose: The purpose of this sequential mixed methods study was to assess strain and related support needs of family caregivers of older adults with delirium.

Patients and Methods: Family caregivers of older adults hospitalized with delirium were recruited from an Acute Care for Elders (ACE) Unit at an academic medical center. Semi-structured interviews were used to expand on caregiver perceptions of strain and related support needs that were initially reported in quantitative assessments. A side-by-side tabular joint display was used to display quantitative and qualitative results, then weaving was used to explain and integrate the results from both phases in narrative form.

Results: An attempt to screen 380 caregiver/patient dyads resulted in 16 dyads enrolled in the study with 2 caregiver interviews. Caregivers were predominantly female (75%), in good health or better (81%), had some college or higher (82%), and half of the caregivers were White (56%). Many caregivers (69%) reported high levels of strain. Descriptively, strain scores were higher among caregivers who were female, White, and older, with no previous delirium experience, and with no delirium education. Good communication with staff, facilitation of family communication, and peer social support were emphasized as being important for their ability to cope.

Conclusion: With an understanding of delirium caregiver strain and support needs, healthcare professionals are better positioned to buffer the impact of strain on family caregiver health and well-being. The findings of this study can inform future interventions to decrease delirium caregiving strain.

Keywords: acute care for elders unit, caregiver burden, caregivers, delirium, hospitalization, social support

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Introduction

Delirium, an acute confusional state, is a common syndrome affecting between 1.75 and 7 million hospitalized adults 65 years old and older,[1] leading to an estimated healthcare cost of $164 billion.[2] Delirium is associated with an increased risk of mortality[3] as well as persisting physical[4] and cognitive functional declines.[5] Among patients with high cognitive functioning at baseline, delirium was associated with significantly lower cognitive functioning 36 months post hospital discharge.[6] One model of delirium superimposed on dementia pathophysiology asserts that neurological processes of dementia make the brain vulnerable to the insults of delirium, namely neuroinflammation, which accelerates neuronal injury and dysfunction, exacerbating cognitive decline in persons living with dementia (PLWD).[7] Findings from a study

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that used medications to prophylactically reduce inflammation reduced post-operative global cognitive decline (such as memory, attention, and psychomotor skills), reinforcing the neuroinflammation pathophysiology pathway.[8]

As people are living longer with more complex conditions, more people will face the task of caregiving for older adults with delirium. Clinical guidelines encourage the inclusion of families in delirium care.[9,10] Studies have shown trained family caregivers can play an important role in delirium care,[11] but they often feel unprepared to do so.[12] Additionally, family caregivers tend to experience high levels of distress during delirium episodes, which could impede involvement.[13–15] Studies have found that family caregiver distress during delirium episodes is common with up to 70% experiencing distress.[15] This distress is also often rated as severe by caregivers.[14] Studies have been conducted on distress among caregivers of adults with delirium, yet few studies have assessed strain in caregivers of adults with delirium. For this study, distress is defined as an immediate response to the caregiving situation. Strain is defined as the stressors impact on the caregivers physical, emotional, social, and financial well-being.[16] The limited studies that have assessed caregiver strain in delirium have included participants with dementia or delirium. 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 the delirium 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.[17,18] The lack of robust evidence,[19] particularly on medical and Hospitalist units, on the needs and effective strategies to reduce delirium caregiver strain leaves professionals with no guidelines for intervention. Additionally, no known studies have factored in an Acute Care for Elders Unit, which includes geriatric specialty care, in the assessment of delirium family caregiver needs. To address this gap in the literature, the aim of this sequential mixed methods study was to assess strain and related support needs of family caregivers of older adults with delirium on an Acute Care for Elders Unit. 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 care approaches in older adult patients with delirium. Based on the literature, it is hypothesized that 70% of caregivers will report high strain.

Methods

A cross-sectional "QUAN->qual" sequential mixed methods design was used to reach the study aim. The "QUAN->qual" notation indicates that the quantitative methods drive the study methodology with qualitative methods as a secondary methodology.[20] The arrow implies a sequential design in which quantitative data is collected before the qualitative data. The quantitative phase is then used to inform the qualitative phase. In congruence with this study design, the quantitative caregiver strain results were used to inform the qualitative semi-structured interviews on caregiver perceptions of strain and support needs. All results were merged to develop clinical and research implications. The study procedures are depicted in Figure 1. The Mixed Methods Procedural Diagram. The Caregiver Strain Index,[21] in the quantitative strand, was used to develop the interview guide in the qualitative strand. 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

From January 2019 to February 2020, patients were screened on a Hospitalist Unit, which was also 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.

Participants for this study were identified through reviewing medical records and the Acute Care for Elders (ACE) Tracker, a report that summarizes key geriatric information in patients on inpatient medical units. The report includes Nursing Delirium Screening Scale (NuDESC)[22] scores. This delirium screen is performed by the ACE Unit bedside nurses as part of routine care, with a score of 2 or higher considered a positive delirium screen. For this study, we used a NuDESC cut-off score of 1 or higher as the first screen to identify as many patients with delirium as possible. Delirium was confirmed by a researcher using the Confusion Assessment Method[23] to determine eligibility. Participants were

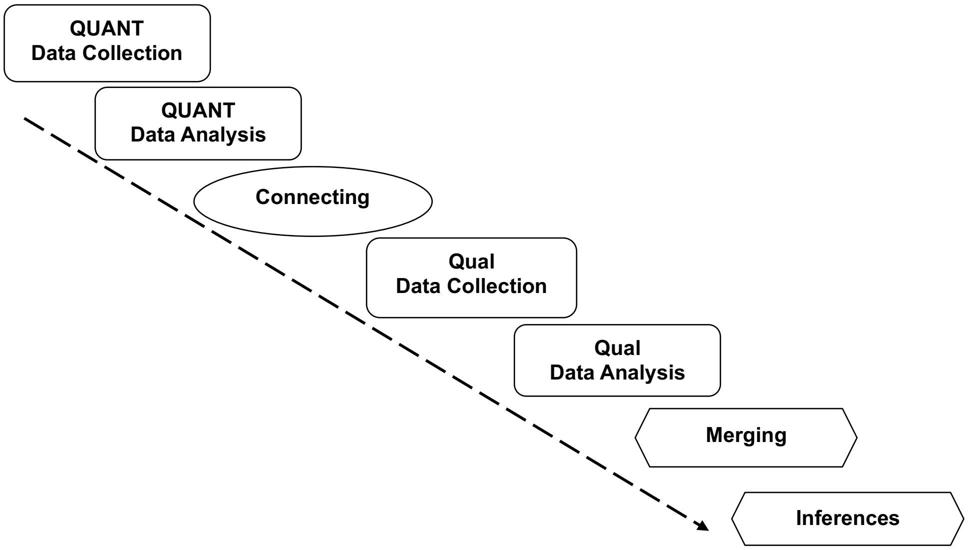

Figure 1 Mixed Methods Procedural Diagram.

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,[23] 4) the family caregiver was the primary caregiver or provided more than 10 h 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 that interfered with the ability to perform the necessary data collection procedures. Research staff contacted patients and caregivers for enrollment and quantitative data collection at a time that was convenient for them, which could occur any day during the hospitalization.

This study was approved by the University of Alabama at Birmingham's Institutional Review Board for adhering to an ethical conduct of research. Older adult patients provided verbal assent, and their legally authorized representatives provided permission and written consent to enroll in themselves and the older adult patients into the study. The participants informed consent included publication of anonymized responses and direct quotes.

Quantitative Measures

Data were collected on patient demographics, patient function (ie, delirium assessment, cognitive screens, and functional screen), caregiver demographics, patient hospital factors (ie, service, discharge diagnosis, restraint use, and anti-psychotic use), caregiving factors (ie, strain, duration, hours of care, activities, relationship to patient, distance between patient and caregiver before hospitalization), and the caregiver delirium experience (previous delirium experience, receipt of delirium education from staff, delirium education content, satisfaction with education). Receipt of delirium education from staff only includes education that preceded the research staff's contact with the caregiver, which occurred at only one time during the hospitalization.

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. The NuDESC has good psychometric properties with a sensitivity and specificity of 85.7% and 86.8%, respectively, compared to the Confusion Assessment Method (CAM).[22] 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 (ie, sleep disturbances and lifting), emotional strain (ie, feeling overwhelmed and upsetting changes), social strain (ie, family adjustments), personal strain (ie, work adjustment and inconvenience), and financial strain.[21] The CSI has 13 items with yes and no response options. One point is given for each item that has a yes response. A no confers

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zero points. The score was then dichotomized into a high (a score of 7 or higher) or low (a score of 6 or lower) strain variable. The CSI has demonstrated a 0.86 Cronbach's alpha for internal consistency of the 13 items with good construct validity.[21]

Confusion Assessment Method (CAM) was used to confirm delirium status and is administered by assessing onset, attention, thinking, and level of consciousness in patients as well as using informant responses.[23] 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.[24] 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.

AD8 was used to detect pre-existing dementia, thus identifying delirium superimposed on dementia 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%.[25]

The Katz Index was used to determine baseline (pre-illness) level of patient physical functioning and is documented in the medical record. The Katz Index includes six activities of daily living (ie, bathing, dressing, toileting, and feeding), which are scored based on independent (0 = completely dependent, 1 = partially dependent, or 2 = completely independent). Scores range from 0 to 12 with 12 being completely independent and 0 being completely dependent.[26] Responses were taken by the research assistant from the patient and/or person who is familiar with the patient's baseline.

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.[27] The Cronbach's alpha for each subscale was 0.814, 0.665, 0.827, 0.812 and demonstrated good predictive validity.[27]

Quantitative Analysis

Descriptive statistics were used to summarize demographic, caregiving, and clinical data. Survey scores were also reported using descriptive statistics. Caregiver characteristics were compared descriptively among caregivers with high strain. In order to ensure data quality, supervising faculty member (REK) provided intensive training for CAM data collection and consult for each CAM interview. We reviewed and reached a consensus for each completed CAM. Quantitative surveys were checked with the participant present to answer questions and ensure no missing information. Data were checked for outliers and abnormal responses to ensure accuracy.

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.[20] Family caregiver participants were recruited for interviews 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. A purposive sampling strategy was used to target caregivers with high caregiving strain and those from varied backgrounds, for example, caregivers of different races, genders, and relationships to the care-recipient. 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 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.[28] 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 2. Screening for study eligibility yielded 380 patient/caregiver dyads to be contacted. Of the 380 dyads, 64% were unable to be fully screened. Screens were completed for 136 patient/caregiver dyads, of which, 108 were ineligible. Twenty-eight patient/caregiver dyads were screened and eligible for the study, and 12 choose not to participate (43%). All participant dyads that enrolled 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.

Older adult patient participants had a mean age of 82.6yrs ± 8.3. They were mostly female (75%) and a little over half were 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%) at the time of researcher contact or given at least one dose of an anti-psychotic medication within the past 48 hours (19%). Most patients' baseline functioning before hospitalization was low and tended to decline during hospitalization. Most patients (94%) screened positive for dementia according the AD8. Patient characteristics are displayed in Table 1.

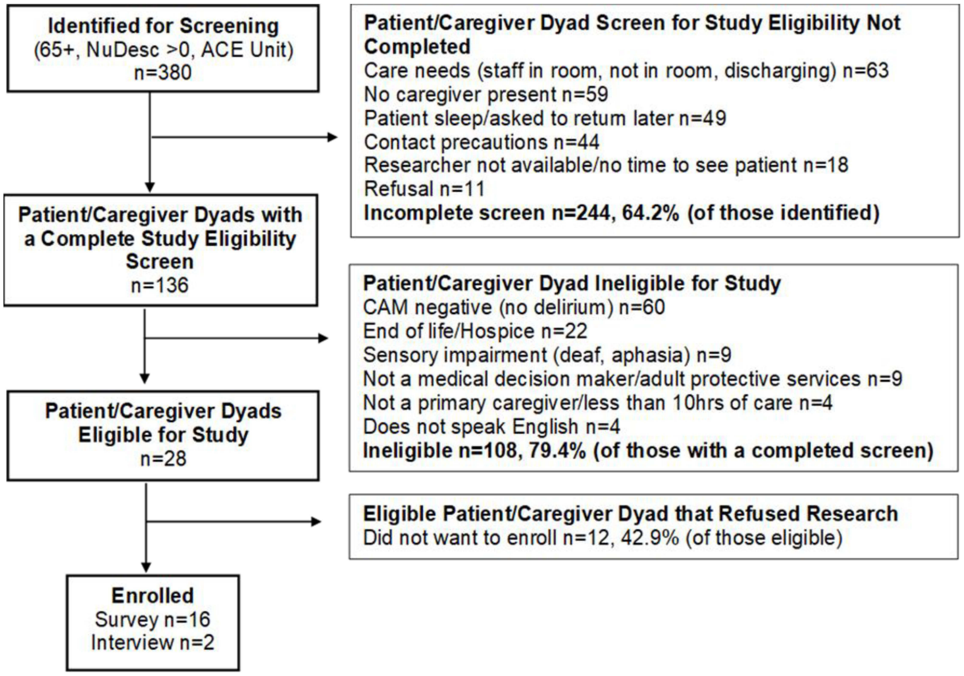

Figure 2 Participant Flow Diagram.

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Table 1 Patient and Caregiver Characteristics

Caregiver Characteristics n=16			**Patient Characteristics** n=16		
Age	55.6yrs±11.7 (39–80)		Age	82.6yrs±8.3 (68–100)	
Gender	Male	4(25%)	Gender	Male	4(25%)
	Female	12(75%)		Female	12(75%)
Race	White	9(56%)	Race	White	9(56%)
	Black/African American	7(44%)		Black/African American	7(44%)
Education	HS Diploma/GED	3(19%)	Service	Medical Hospitalist	16(100%)
	Some College/ Associates	4(25%)	Antipsychotic Med in Last 48hrs	Yes	3(19%)
	Bachelors	3(19%)	Restraints	Yes	3(19%)
	Graduate/Professional	6(38%)	Discharge Diagnosis	Cardiovascular	3(19%)
Self-Rated Health	Excellent	5(31%)		Endocrine	3(19%)
	Good	8(50%)		Nervous/Psychiatric	3(19%)
	Fair	2(13%)		Urinary	3(19%)
Family Relationship	Spouse/Significant other	2(13%)		Musculoskeletal	2(13%)
	Son/Daughter	11(69%)		Immune	1(6%)
	Brother/Sister	1(6%)		Integumentary	1(6%)
	Other	2(13%)	Baseline ADL*	5.3±4.8 (0–12)	
Living Distance Between Patient and Caregiver	Lives with patient	8(50%)	Hospital ADL**	2.1±3.0 (0–9)	
	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 Activities (before hospitalization)	ADLs	8(50%)			
	IADLs	16(100%)			
	Emotional or Religious support	14(88%)			
Social Support	Received support 25.4±7.6 (13–41) Support satisfaction 8.6±2.7 (3–12) Negative interactions 6.9±2.3 (4–14)				

Notes: *ADL= Katz Activities of Daily Living. **Most recent Katz Index performed to assess current ADL performance during acute illness at time of data collection.

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 also displayed in Table 1.

Most caregivers (75%) had reported witnessing delirium in someone else in the past. During the hospitalization, 44% received information related to delirium by the time they were contacted by the researcher. 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 did not receive information, most (94%) wanted to receive more information about delirium. Results related to the hospital experience are displayed in Table 2.

Caregivers had high caregiving strain (69%). 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%). 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 strain among caregivers who did receive information. These proportions were not tested with inferential statistics due to low sample size.

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,

Table 2 Hospital Delirium Experience

Previous delirium experience	Yes No	12(75%) 4(25%)
Received information related to delirium in the hospital at the time of researcher contact	Yes No	7(44%) 9(56%)
Information content (n=6)	Causes, overview, importance of cognitive stimulation, brain changes, connection to alcohol misuse	
Caregiver report of who provided the information to the caregiver (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%)

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> 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 could not leave the hospital. Caregivers suggested better communication from physicians so they did not 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 doctor's 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 3. Caregivers reported high levels of strain in all the domains on the Caregiver Strain Index and 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 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 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 reported difficulties communicating with family and feelings of imposing on friends, which was not asked on the survey.

Discussion

Caregivers reported high levels of strain, with caregivers who were female, White, no previous delirium experience, no information on delirium, having higher strain than their counterparts. Support for caregivers who have never witnessed delirium before should be especially prioritized due to high levels of strain in this group. 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. In addition to communication, caregivers highlighted the importance of receiving delirium education, approaches to responding to their family member with delirium, respite, and consideration of caregiver physical and mental health for care and discharge plans. Caregivers also reported difficulties with nutrition, sleep, physical activity, their own chronic illness, guilt, and difficulty concentrating.

The findings of this study highlight the areas of strain and support that may be useful in addressing delirium caregiver needs to improve their coping and well-being. The prevailing literature on delirium caregiver interventions have not addressed many of these wholistic areas (such as physical health, finances, emotional health) of strain and have mostly focused on staff and family understanding of delirium following education.[19] Delirium education was connected to notable differences in caregiver strain in this study. Boltz et al assessed the effects of a function promotion intervention among hospitalized people with dementia and their family caregivers.[31] Around 42% of participants had delirium on admission. The intervention included teaching family caregivers' delirium prevention strategies. They also used the Caregiver Strain Index to assess caregiver strain but saw no differences in strain. These discordant findings of strain across studies demonstrate a need for further investigation, especially in delirium superimposed on dementia populations.

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Table 3 Integrated Results Joint Display (n=16)

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 do not 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 lose track of simple things like that". [wallet was stolen] CG2 "I had given up work. So I did not have work to worry about". 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%		
Personal	Changes in personal plans	81%	"…we had plans to go to a friend's house for Christmas and because of his issues he said I cannot go you know I cannot 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 "Convenience and personal space no forget that. You kind of have to be prepared to give that up". CG2	"Taking him to the hospital was better and allowed me to at least get some distance from it every day". CG1 "It's, 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 does not feel they have to be at the hospital 15hrs a day because of the doctor's schedule. Ones early and ones late whatever". CG1
	Confining	56%		
	Inconvenient	56%		
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 "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	"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%		

Religion/ Spirituality	Not a part 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 bishop's 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 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

Notes: Verbatim family caregiver quotes are used. Brackets are used to de-identify names and places and provide essential context.

One study that provided psychological care for patients with delirium and families during hospitalization reported better psychological recovery.[32] More wholistic approaches to delirium family caregiver support that include interpersonal, emotional, spiritual, physical health, and environmental components may be more advantageous in improving family caregiver health outcomes than previous interventions.

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 sample, while still gaining the richness and depth of family caregiver perspectives. The perspective of delirium family care needs on a medical/Hospitalist Unit also provides additional insight to family caregiver needs outside of the ICU.

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 health system in which this study occurred had an institutionalized protocol for bedside nurses to complete delirium screeners on all admitted patients. This allowed for easy identification of patients with positive delirium screens. However, several barriers to recruitment of this population remained. Recruitment of actively hospitalized patients and/or their caregivers is notoriously difficult but is necessary to address hospital-related experiences with less recall bias. The primary recruitment barrier was the inability to conduct study assessments with the wide range of hospital care activities, as well as difficulty in contacting legally authorized representative caregivers in-person. This barrier was addressed by the research staff by working evening and weekends. However, this did not enhance contact of caregivers. Asking beside nurses and other unit staff if the patients' family visited and their normal visitation times was more fruitful. Communication with staff was facilitated by the study's primary investigator getting approval and acceptance from the unit nurse manager before initiating study activities. Communication was enhanced by research staff attending care rounds to gain information regarding patient eligibility and care needs that might prohibit access. Study buy-in from unit leaders and maintenance of relations with unit staff throughout the study was essential.

For the interviews, many caregivers did not respond to multiple follow-up calls. Among those who responded, several reported not wanting to participate in the interview because they were overwhelmed with their caregiving activities or grief from the death of their family member. Although sample size is a prominent limitation, the findings of this study hold significant potential for informing future interventions and address a significant gap in the literature. Another limitation was possible recall bias during qualitative interviews. 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. This study was conducted on an ACE Hospitalist Unit; therefore, these findings may not be generalizable to intensive care settings or general Hospitalist Units. The most distressed caregivers may have refused participation, and the study results may be bias towards caregivers with lower strain. Caregivers experiencing unsatisfactory care may have been more likely to enroll and may bias results for delirium education findings. Data were not collected regarding the timing of delirium onset (ie, present on admission versus hospital acquired) and on what delirium day the researcher collected the survey data. We also do not know if caregivers who had not received delirium information at the time of data collection received education at a later time during the hospital stay.

Data Accessibility

Upon request to the corresponding author, data may be made available depending upon privacy or ethical restrictions.

Ethical Considerations

This study involved human participants and was evaluated by a qualified research ethics committee prior to undertaking the research in line with the Declaration of Helsinki. This study was approved by the University of Alabama at Birmingham's Institutional Review Board, which is the Research Ethics Committee for the University (approval no. IRB-300002501) on November 27, 2019.

Consent to Participate

Older adult participants, who had delirium, provided verbal assent, and their legally authorized representatives provided permission and written informed consent to enroll themselves and the older adult patient into the study.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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J.K. Vickers has no conflicts of interest to disclose.

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