

Research Article

Perspectives on the Delirium Experience and Its Burden: Common Themes Among Older Patients, Their Family Caregivers, and Nurses

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Abstract

Background and Objectives: While there are qualitative studies examining the delirium-related experiences of patients, family caregivers, and nurses separately, little is known about common aspects of delirium burden among all three groups. We describe common delirium burdens from the perspectives of patients, family caregivers, and nurses.

Research Design and Methods: We conducted semistructured qualitative interviews about delirium burden with 18 patients who had recently experienced a delirium episode, with 16 family caregivers, and with 15 nurses who routinely cared for patients with delirium. We recruited participants from a large, urban teaching hospital in Boston, Massachusetts. Interviews were recorded and transcribed. We used interpretive description as the approach to data analysis.

Results: We identified three common burden themes of the delirium experience: *Symptom Burden* (Disorientation, Hallucinations/Delusions, Impaired Communication, Memory Problems, Personality Changes, Sleep Disturbances); *Emotional Burden* (Anger/Frustration, Emotional Distress, Fear, Guilt, Helplessness); and *Situational Burden* (Loss of Control, Lack of Attention, Lack of Knowledge, Lack of Resources, Safety Concerns, Unpredictability, Unpreparedness). These burdens arise from different sources among patients, family caregivers, and nurses, with markedly differing perspectives on the burden experience.

Discussion and Implications: Our findings advance the understanding of common burdens of the delirium experience for all groups and offer structure for instrument development and distinct interventions to address the burden of delirium as

an individual or group experience. Our work reinforces that no one group experiences delirium in isolation. Delirium is a shared experience that will respond best to systemwide approaches to reduce associated burden.

Keywords: Burden, Confusion, Delirium, Hospitalization, Severity

Delirium, an acute disorder of attention and cognition, is a common, life-threatening, and costly clinical syndrome in older persons (Inouye, Westendorp, & Saczynski, 2014). Delirium is distressing to patients and their caregivers (Partridge, Martin, Harari, & Dhesi, 2013), prolongs hospital stays (Pisani et al., 2009), and is associated with increased risk of cognitive decline (Girard et al., 2010), loss of functional independence (Rudolph et al., 2010), and death (Pisani et al., 2009; Witlox et al., 2010). In the United States, delirium affects up to 50% of hospitalized seniors and costs over \$164 billion per year (Inouye et al., 2014).

Delirium can impact patients, family members, and health care professionals in complex and distressing ways, producing feelings of physical and psychological burden among patients, family members, and health care professionals (Buss et al., 2007). Common characteristics of delirium include abrupt onset and disturbance in attention, cognition, level of consciousness, and perceptual impairments that tend to fluctuate (Inouye et al., 2014). While previous qualitative studies describe the individual burdens experienced by patients, family caregivers, and nurses, little is known about aspects of delirium burden that are common amongst all three groups, limiting the ability to develop effective evidence-based interventions to help manage common burden experiences. This qualitative study describes common burden experiences that may inform the development of instruments to measure burden and interventions to improve delirium management and reduce burden broadly.

The Delirium Experience

To frame our work, we considered multiple dimensions of burden that could potentially contribute to patient, family caregiver, and nurse perspectives on delirium-related burden. We first reviewed the literature on patient, family caregiver, and nurse burden generally and as it pertains to delirium specifically.

Patient Burden

Patient burden has been defined as concern about the impact of illness on family caregivers, resulting in the patients' feelings of distress, guilt, and diminished sense of self, which can be found in patients with various medical conditions (Simmons, 2007). Key areas associated with patient-reported burden include impaired physical functioning, as well as negative impact on quality of life, social and leisure activities, social relationships, and psychological well-being (Zarit, Todd, & Zarit, 1986). Dementia patients with superimposed delirium experience substantial burden, with

emotional responses including anger, fatigue, depression, and stress (Morandi et al., 2015a). Fear and visual hallucinations are the most commonly reported symptoms of the experience (Grover, Ghosh, & Ghormode, 2015), as well as bewilderment and discomfort. Many patients have vivid recollections of the delirium experience, with major aspects being the sudden change of reality, inability to distinguish between the real and unreal, and imagined immersion in dramatic emotional scenes (Dupplis & Wikblad, 2007).

Patients have described feeling powerless and abandoned, as well as distant from and dismissed by family caregivers and hospital staff (Pollard, Fitzgerald, & Ford, 2015). Feeling threatened by hospital staff, patients experiencing delirium reported becoming aggressive, refusing care, and seeking to flee the frightening situation (Bélanger & Ducharme, 2011). After resolution of the delirium episode, patients have reported strong feelings of guilt, shame, and regret (Pollard et al., 2015; Van Rompaey, Van Hoof, van Bogaert, Timmermans, & Dilles, 2016).

Family Caregiver Burden

Family caregiver burden has been defined as a multidimensional response resulting from the negative appraisal and perceived stress of caring for an ill individual (Zarit et al., 1986). Most studies on family caregiver burden have been set within the context of Alzheimer's disease or other chronic progressive illnesses (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Chiao, Wu, & Hsiao, 2015; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). While the rapid onset and variability of delirium symptoms present different challenges than those stemming from dementia, many aspects of burden such as uncertainty and the potential need for long-term support are similar. For example, Zarit and colleagues defined multiple aspects of family caregiver burden that also apply to delirium, including the impact of caring on family caregivers' health status, financial strain, limitation of social activity, and disturbed feelings (Zarit et al., 1986).

Family caregiver burden has also been conceptualized as needs-based (Braithwaite, 1992), with emphasis on failure to meet another's basic needs that result in family caregiver stress. This needs-based model proposes that the stress process is driven by the primary stressors of the patient's illness, creating care demands which lead to additional sources of stress, defined as secondary strains (Judge, Menne, & Whitlatch, 2010). Secondary strains result from interruptions in the family caregiver's family, work-related, and social/recreational roles (Pearlin, Mullan, Semple, & Skaff, 1990). To family caregivers, the

unexpected, rapid, and unpredictable nature of delirium can be upsetting (Day & Higgins, 2015). Family caregivers have reported lack of awareness about delirium, resulting in feelings of loss and difficulty understanding the sudden changes in a loved one's behavior and emotions. These sudden changes in the patient contribute to feelings of distress and shock for caregivers (Grover et al., 2015; Morandi et al., 2015b). Family caregivers have reported feeling anxious, frightened, frustrated, and unprepared (Bull, 2011) and experiencing significant burden and stress when caring for delirious patients (Breitbart, Gibson, & Tremblay, 2002; Partridge et al., 2013). Family caregivers also report depression, poor health, financial burden, and overall stress (Breitbart et al., 2002).

Nurse Burden

There is limited research on nurse burden in relation to patient's delirium. In previous studies, nurses reported high work-related stress, overwork, and burden in relation to fatigue, distress, time pressure, and lower decision authority (Adriaenssens, De Gucht, Van Der Doef, & Maes, 2011). In one qualitative study, nurses reported high subjective burden when caring for patients with delirium, resulting in emotional stress and strain (Judge et al., 2010). Elevated feelings of burden have been attributed to the unpredictable nature of delirium, safety issues, uncertainty about how to best meet patients' needs, increased workload, conflict between providing adequate care for delirious and nondelirious patients, and frustration due to lack of knowledge about best practice approaches. Nurses reported higher burden when caring for patients with hyperactive delirium (Mc Donnell & Timmins, 2012).

One study found that delirium severity and the presence of perceptual disturbances were significant predictors of nurse and patient distress (Breitbart et al., 2002). Fear for their own safety, diminished self-esteem, and inner conflicts also contribute to nurse burden (Bélanger & Ducharme, 2011).

Nurses have reported a lack of understanding of the causes of delirium and failing to distinguish delirium from other clinical conditions, such as dementia, depression, and other psychiatric disorders (Rice et al., 2011; Steis & Fick, 2008). Nurses also report difficulty understanding delirious patients' realities and perceive them as being in a different world and out of reach (Stenwall, Sandberg, Jönhagen, & Fagerberg, 2007). The complexity of delirium contributes to difficulty in interpreting patients' needs, potentially leading to increases in both nurses' and patients' discomfort (Stenwall et al., 2007).

Common Burdens

Few studies have been conducted on common delirium-related burden among patients, family caregivers, and nurses. Breitbart and colleagues examined the delirium

experience in patients with cancer, their family caregivers, and their nurses (Breitbart et al., 2002). All three groups experienced distress related to the delirium episode (Breitbart et al., 2002). A majority of patients with delirium recall their experience as highly distressing with equal distress reported for hypo- and hyperactive delirium episodes (Breitbart et al., 2002). Family caregivers reported significantly more distress regarding the patient's delirium than the nurses or patients themselves (Breitbart et al., 2002). Nurses who provide direct, prolonged and intimate care for patients with delirium reported delirium severity and presence of perceptual disturbances were the most significant predictors of distress (Breitbart et al., 2002).

In two complementary papers, researchers examined the delirium experience in patients with delirium superimposed on dementia (Morandi et al., 2015a) and among family caregivers and health care staff (Morandi et al., 2015b). Both groups experienced emotional burden, including depression, fear, and suffering in reaction to caring for a patient with delirium. Both groups reported concerns about the adequacy of care or issues with care load, as well as distress associated with patients' behavior (Morandi et al., 2015a; Morandi et al., 2015b). A synthesis of qualitative and quantitative literature suggests that the recollection of delirium is generally distressing in patients but that distress may be greater in relatives and professional caregivers witnessing delirium episodes, and that in all three groups this distress may foster long-term psychological sequelae (Partridge et al., 2013). These studies have identified common experiences related to delirium burden, including unpredictability, sudden awareness of change, difficulty communicating, fatigue, and lack of support, with shared emotions including stress, frustration, and feeling alone (Morandi et al., 2015a; Morandi et al., 2015b; Partridge et al., 2013). Therefore, in this study, we describe common burden experiences among patients, family caregivers, and nurses in order to provide knowledge that can be used to develop delirium burden measurements and evidence-based interventions to help manage common burden experiences.

Design and Methods

This qualitative interview study was approved by the Institutional Review Boards of all participating institutions. We enrolled convenience samples and obtained written informed consent from patients and verbal consent from family caregivers and nurses. The patient consent included a specific paragraph giving the interviewer permission to contact their caregivers. Before obtaining informed consent, we screened patients for their capacity to consent using a standard instrument assessing ability to evince choice, to understand relevant information, and to appreciate the research situation and its likely consequences. We audio-taped all interviews and all participants agreed that deidentified data could be used for publication.

Sample and Procedures

Patients

Inclusion criteria for patients included age 70 years or older, admission to the general medicine service of a large, urban, acute-care academic medical center, ability to communicate effectively in English (including adequate hearing), residence within a 40-mile radius of the hospital, and a positive screen for delirium. We screened patients for delirium during an in-person assessment with the Confusion Assessment Method (CAM) (Inouye et al., 1990), by chart review using a validated approach (Saczynski et al., 2014), or based on patient self-report after the acute episode with an experienced and clinically trained assessor confirming fulfillment of CAM criteria and verified by clinical expert adjudication. In addition, patients had to be able to remember the delirium episode in the hospital. We excluded patients with dementia to assure ability for robust qualitative interviews using three levels of dementia screening: medical chart review, bedside screening, and caregiver assessment. We also excluded active alcohol abuse, diagnosis of schizophrenia or active psychosis, developmental delay, and terminal condition.

After initial eligibility screening via medical record review, and obtaining the attending's approval to approach the patient, the research assistant (RA) administered the CAM to assess patients' delirium status (Inouye et al., 1990). The RA asked patients who met delirium criteria for verbal consent to be contacted 1 month after discharge (intended to allow for sufficient recovery time for a qualitative interview). For patients lacking capacity to consent, the RA obtained patients' verbal assent to approach their health care proxy or next of kin to obtain verbal consent for contacting the patient after discharge. About one month after discharge, the RA conducted a phone-based CAM assessment (Marcantonio, Michaels, & Resnick, 1998) with patients to ensure that the delirium had cleared. Trained interviewers traveled to patients' homes, skilled nursing facilities, and rehabilitation centers, obtained written consent, and conducted an audio-recorded 30–45-min semistructured qualitative interview. The RA also consented and interviewed patients who scored negative for CAM delirium during screening but reported a delirium episode (confirmed by medical record or delirium expert adjudication). The average time span between delirium episode and interviews was 29 days for patients (range 5–86) and 11 days for family caregivers (range 0–43). Four patients met delirium criteria at 1 month after discharge and their interviews were conducted later than one month after discharge.

Family Caregivers

We only included family caregivers if they had observed a family member with delirium during hospitalization and were able to communicate in English. We considered a family member to be any person who knew the patient well,

as defined by a brief screening process that included living with the patient or with face-to-face contact at least once a week.

For CAM-positive patients, the RA asked the patient to identify a family caregiver who has or may visit them in the hospital. If the patient was unable to provide this information, the RA obtained the patient's family or proxy contact information from the medical chart. The RA contacted the family caregiver by phone and, if the family caregiver agreed to participate, completed the AD-8 dementia screening questionnaire (Galvin et al., 2005), an 8-item, informant-based screening tool for detection of dementia. If the family caregivers' responses indicated patient's dementia, we excluded *the patient* from the study. However, the family caregiver was invited to participate in an interview to describe his or her experiences related to the patient's delirium episode. An experienced interviewer conducted and audio-taped the family caregiver interviews by phone or in person as close to the patient's delirium episode as possible.

Nurses

All nurses had at least a bachelor's degree and experience with caring for hospitalized delirious patients aged 70 years and older. We recruited nurses on general medicine floors of the hospital during an in-service session and followed-up with an e-mail to explain the full details and purpose of the study. We asked interested nurses to participate in a 15–20-min semistructured qualitative interview in-person or by phone.

Interview Guides

To construct separate, but complementary interview guides for each group, the research team discussed patient-centered, family-caregiver-centered, and nurse-centered perspectives of the delirium experience and developed questions based on the relevant literature (Bélanger & Ducharme, 2011; Buss et al., 2007; Duppils & Wikblad, 2007). We also used the NEECHAM (Neelon, Champagne, Carlson, & Funk, 1996) and the Strain of Care for Delirium Index (Milisen et al., 2004) to inform interview questions to assess the impact of delirium on the burden of care, disruption in nursing routines, patient and family caregiver experience of care, and other areas.

For patients, we designed twelve questions to elicit information on common symptoms (e.g., "Did you see or hear things that others did not? Can you please describe?"), feelings associated with the experience (e.g., "What sort of feelings did you experience during this episode?"), and duration and impact of the confusion episode (e.g., "How long did you feel the impact of the episode after the worst was over?"). For family caregivers, our goal was to assess the family member's perspective of the severity of the delirium episode, as well as the impact of the episode on caregiving burden and the family caregiver's own quality of life. We included 10 questions such as, "What caused you

the most distress about the confusion episode that [patient name] experienced?” and “What aspects of the episode had the biggest impact on you?” Nurse interviews focused on domains of importance from the nursing perspective in caring for delirious older persons. The 13 questions tapped areas of personal burden, for example, “How do the delirium symptoms affect you and your work?” as well as management and resource concerns, for example, “What training and resources have been/would be helpful in caring for delirious patients?”

We also posed open-ended questions to each group to potentially discover domains not included in the interview guides, for example, “Is there anything else you would like to share with us about your experience with the confusion episode?” While we used the medical term “delirium” for nurses after confirming that they understood the meaning, we first asked patients if they remembered having an acute confusion episode during hospitalization and we asked family caregivers if they observed one. If they confirmed, we continued the interviews using the term, “confusion episode” because the term delirium is not well recognized. All questions to patients and family caregivers were made in reference to the delirium episode during the patients’ hospitalization.

Data Analysis

We digitally recorded and professionally transcribed all interviews. We used Atlas.ti (Atlas.ti GmbH, Berlin, Germany), a state-of-the-art software designed to manage qualitative data. To analyze data and to identify themes describing the delirium experience from patient, family caregiver, and nurse perspectives, we used interpretive description (Thorne, 2008), a qualitative approach to developing knowledge within clinical fields.

We assigned two coders to each of our three groups: patients (J. Gallagher, E. M. Schmitt); family caregivers (H. J. Lee, E. M. Schmitt); and nurses (L. Gleason, E. M. Schmitt). We trained all coders in qualitative methods. The teams began by reading transcripts and performing independent open coding using descriptive phrases to capture important concepts in the data. After reading the first few transcripts, two members of each team discussed their initial codes and began creating a coding scheme. Teams recorded important ideas and related thoughts. The clarified the meaning of codes through an iterative process. Teams proceeded with coding, repeating the process of individual and then group coding. As new codes emerged, coders consolidated codes into conceptual categories to produce a more developed code key. We used consensus methodology, including a third coder, to resolve any disagreements in coding. Coders recoded all transcripts using the final code key.

Teams analyzed reports of all codes to identify themes related to their group’s experience of delirium burden. We continued recruitment, coding, and analysis until we reached thematic saturation. Teams collaborated to

triangulate data by discussing data from each group’s perspective. Data were shared with all authors, including delirium experts from multiple disciplines. We created a matrix to describe common aspects of delirium burden from each group’s perspective.

Results

Sample

Sample descriptions for all groups are shown in Table 1. Patients ($n = 18$) had a mean age of 79 years (range 70–92), about half were female (56%), and most were white (83%). Patients’ admitting diagnoses included sepsis (17%), respiratory disease (17%), gastrointestinal disorder (17%), renal disease (17%), cardiovascular disorder (11%), and other (22%). Eight (45%) had a positive CAM in the hospital, 8 (45%) reported a previous delirium episode that was confirmed in the medical record, and 2 (11%) self-reported their previous episode. One patient did not remember his delirium episode and was excluded. Family caregivers ($n = 16$) had a mean age of 57 years (range 29–80) and were mostly female (63%) and white (94%). The caregiver relationship to the patient included spouse (25%), child (63%), and other (12%). Over half of family caregivers lived with the patient (56%), and all reported that they saw the patient at least once a week. Nurses ($n = 15$) had a mean age of 32 years (range 23–60), were all female and predominantly white (93%). Most nurses (80%) had a Bachelor’s degree and 20% had a Master’s degree. The nurse sample had a mean 7 (range = 0.5–30) years of nursing experience and worked a range of shifts. We did not conduct patient–caregiver–nurse triadic interviews nor patient–nurse or family caregiver–nurse dyadic interviews.

Common Themes Across Groups

We identified three major themes of delirium-related burden common among patients, family caregivers and nurses: Symptom Burden, Emotional Burden, and Situational Burden. The Symptom Burden theme encompassed subthemes of common burden that were related to experiencing (patients), observing (family caregiver), and managing (nurse) symptoms of the patient’s delirium. The theme of Emotional Burden encompassed a range of emotions associated with experiencing or managing delirium. The theme of Situational Burden encompassed burden experiences triggered by having to manage delirium, including loss of control and lack of support. Themes and subthemes are summarized in Table 2 and below. Supplementary Table 1 provides extensive exemplary quotes.

Symptom Burden

The major symptoms described within Symptom Burden were disorientation, hallucinations/delusions, impaired communication, memory problems, personality changes, and

Table 1. Characteristics of Study Populations

Characteristic	Patients (N = 18)	Caregivers (N = 16)	Nurses (N = 15)
Age, mean years (SD)	79 (70–92)	57 (29–80)	32 (23–60)
Female sex, <i>n</i> (%)	10 (56)	10 (63)	15 (100)
White ^a race, <i>n</i> (%)	15 (83)	15 (94)	14 (93)
Admitting Diagnosis ^b , <i>n</i> (%)			
Sepsis	3 (17)		
Respiratory Disease	3 (17)		
Gastrointestinal Disorder	3 (17)		
Renal Disease	3 (17)		
Cardiovascular Disorder	2 (11)		
Other	4 (22)		
Delirium Assessment, <i>n</i> (%)			
Positive CAM ^c Screen	8 (45)		
Medical Chart Review	8 (45)		
Self-Reported and Verified ^d	2 (11)		
Caregiver Relationship, <i>n</i> (%)			
Husband/Wife		4 (25)	
Son/Daughter		10 (63)	
Other		2 (12)	
Nursing Education, <i>n</i> (%)			
Bachelor			12 (80)
Masters			3 (20)
Nurses Years of Experience, mean (range)			7.3 (0.5–3.0)

Note: ^aOther races had *n* = 1 in cells and therefore cannot be shown; ^b% >100% due to rounding; ^cCAM = Confusion Assessment Method [38]; ^dAssessor confirmed fulfillment of CAM criteria.

sleep disturbances. All three groups perceived these symptoms of delirium as burdensome, but for different reasons. For example, patient's disorientation and hallucinations/delusions caused significant burden to all groups, but differed based on each perspective. Patients described that not knowing where they were and/or seeing things that were not really there caused feelings of burden for them. Family caregivers explained that observing patients' disorientation and hallucinations and not knowing if the symptoms would go away was the hardest for them. Nurses reported that a major source of burden was feeling that they were unable to properly care for the patients because of difficulty managing the patients' hallucinations.

Impaired communication, memory problems, and sleep disturbances also caused burden to each group. Patients described as burdensome their problems with communication (e.g., their inability to say what they wanted), their memory deficits (e.g., being unable to recall what happened during the delirium episode), and vivid nightmares. Family caregivers were burdened by the inability to communicate with patients due to patients' symptoms, by patients' inability to remember who visited them, and difficulty arousing patients from sleep. Nurses were burdened by the inability to discuss care plans with patients, as well as by an increased workload due to patients' memory loss with inability to follow instructions, and difficulty helping patients experiencing sleep disturbances to rest.

All three groups reported that patients' personality changes caused burden for them. Patients described being startled by the change in their personality. For example, a patient reported: "I was more short-tempered, more annoyed, and I'm just not that way."

Family caregivers expressed that the hardest part of the delirium experience was observing a change in personality of their loved one. A family caregiver explained: "It's scary because she would never raise her voice to me in a normal day. She is so laid back. She would never snap at me. So it scares me because I know she's sick."

Nurses described how these sudden changes in the patient affected their work. A nurse shared how she had to change her work plan based on the discrepancy between the report of a patient she received during shift change and the patient she actually saw: "...you'll get report, 'She's 90 years old, really sweet woman and with pneumonia. She's doing great,' and you go in there and she's really not that sweet little 90-year-old that was just described to you."

Emotional Burden

Patients, family caregivers, and nurses all reported feeling anger and frustration, emotional distress, fear, guilt, and helplessness. All common emotions were negative, but differed in scope. For example, patients reported frustration at the way they were treated in the hospital. In contrast, family caregivers and nurses were frustrated with patients who refused care and were yelling at them.

Table 2. Common Burden Themes Among Patients, Family Caregivers, and Nurses

Theme	Subtheme	Patients	Family Caregivers	Nurses
Symptom burden	Disorientation	Not knowing where they are or not recognizing loved ones	Patient unable to recognize family	Patients' disorientation impacts care
	Hallucinations/Delusions	Seeing/hearing things that are not really there	Patient's hallucinations	Hallucinations make care challenging
	Impaired Communication	Trouble getting words out	Patient's inability to express needs	Patient's inability to communicate needs
	Memory Problems	Gaps/blanks in memory	Patients have no recollection of visits	Need to repeat instructions
	Personality Changes	More short-tempered/not feeling like themselves	Patient acting out of character	Patient different than what was described during shift change
	Sleep Disturbances	Intense nightmares/vivid dreams	Patient difficult to arouse	Increased demands getting patients to sleep
Emotional burden	Anger/Frustration	About the way they are treated	Not wanting to be around the patient	Inability to manage patient behavior
	Emotional Distress	Avoiding hospitals since delirium	Worry about patients when not with them	Thinking about patient after work
	Fear	Of losing their mind	Changes in the patient will be permanent	Dangerous/violent patients
	Guilt	Delirium disturbed family	Not spending needed time with patient	Competing interests among patients
	Helplessness	Not permitted to get out of bed	Not being able to help patient	No interventions seem to help
Situational burden	Loss of Control	Inability to make decisions	Questioning if care is appropriate	Patients unwilling to receive care
	Lack of Attention	Ignored by health care staff	Lack of communication from staff	Unable to give needed attention
	Lack of Knowledge	Lack of information about delirium	Lack of information about delirium	Lack of experience in caring for patients with delirium
	Lack of Resources	No social worker or psychiatrist	Patient is not receiving adequate care	Lack of staffing, especially at night
	Safety Concerns	Distressed by being restrained/ Loss of confidence in physical and mental abilities	Patient engaging in dangerous behavior	Inability to execute treatment plan because of patients' restiveness
	Unpredictability	Delirium can happen again	Patient behavior/Symptoms fluctuate	Unpredictability of patients' status
	Unpreparedness	Unprepared for becoming confused	Unprepared for patient not recognizing them	Unprepared for treating delirium

All three groups experienced lingering emotional distress. For example, patients reported feeling afraid of the hospital or expressed fear that the delirium could recur:

And I still to this day, and this is more the result of the hospital stay, I think, I'm avoiding hospitals. ...I had two hospital appointments that I've canceled because of the noise and the lights and the people moving very fast.

Family caregivers and nurses kept thinking about patients' wellbeing even when they were not with the patients. A family caregiver shared:

It is very difficult. When I am home, I am worried about her.

All three groups described fear. Patients and family caregivers feared that changes to the brain and in behavior could be permanent, and nurses feared violent patients. Other emotional burdens identified were guilt and helplessness. Patients felt guilty for disturbing their family, and caregivers and nurses felt guilty for not spending enough time with patients. The feeling of helplessness occurred in patients who were ordered to stay in bed, and in family caregivers and nurses because they felt they could not help the patients. A nurse reported: "...when we actually have a delirious patient and nothing seems to be working, I don't know what would be better, I guess, and that's what makes it very frustrating because you feel very helpless."

Situational Burden

The theme of Situational Burden was comprised of external or situational factors related to the delirium, including the loss of control, consequences of loss of control, lack of support (such as lack of attention, knowledge, or resources to care for a delirious patient), safety concerns, unpredictability of the delirium course, and feelings of being unprepared for the delirium symptoms. All groups experienced burden around the loss of control of the situation. Patients described their loss of autonomy:

I'm not a control person, but I like to be in control of me at least, and I was not allowed to be, really. I had to stay in the hospital clothes. I had to stay in the bed because I had an IV. I had to stay in bed (...). They told me to and such.

Family caregivers questioned if patients were receiving the care they needed. Nurses felt loss of control because of the pressure to follow physicians' treatment plans and because of the delirium interfering with the patients' ability to follow the treatment plan (e.g., refusing treatment, unsafe behaviors). Patients and family caregivers perceived a lack of attention from hospital staff, and nurses were aware that they could not give patients all of the care that they needed. A nurse reported:

Patients that are confused, setting off the bed alarm, not making sense in what they are saying, and it is hard especially when you are caring for [a] full assignment of patients. I feel like you do not give them the attention that they need.

Patients, family caregivers, and patients all reported a lack of knowledge about delirium and how to manage its symptoms, as well as inadequate resources, such as an inadequacy or lack of trained hospital staff, information, and support. As a family caregiver stated:

But it would have been better had we been warned ahead of time of this potential, rather than to have to just suddenly see it, and it also would have been better perhaps if we had been given any kind of guidelines on how to manage it...

All groups expressed safety concerns around restraints and burden related to the unpredictable and fluctuating course of delirium. Patients described how they were surprised by the delirium, family caregivers described how hard it was that the patient did not recognize them, and nurses felt that they should know more about the patient, for example, their true baseline and home situation before the delirium occurred.

Patients, family caregivers, and nurses experienced each common burden from either parallel or different perspectives. For Symptom Burden, all three groups had parallel experiences and feelings of burden related to the similar expression of the delirium symptoms. By contrast, for

Emotional Burden, all three groups experienced similar emotional responses, but from different perspectives. For example, patients described their emotional reaction to the behavior of others towards them, while family caregivers and nurses explained their reactions to the behavior of the patient. Both Symptom and Emotional Burden appear to primarily be comprised of internal burdens, or burdens arising from within the patient, family caregiver, or nurse (e.g., thoughts and feelings about the delirium and its consequences). Situational Burden appears to be comprised of external burdens arising from outside the three groups related to lack of receiving or inability to provide support pertinent to the delirium experience.

Discussion

This study is the first to compare the delirium experience among patients, family caregivers, and nurses and to identify commonalities in their delirium experiences. Our findings suggest that following a delirium episode, patients, family caregivers, and nurses experience significant distress and share many of the same feelings of burden. Our findings align with previous studies that have reported separately on burden among patients, family caregivers, and nurses following a delirium episode. For example, our findings support symptoms of disorientation, difficulties in communication, and hallucinations/delusions, as well as adverse emotional symptoms including fear and loss in patients and caregivers identified by Morandi and colleagues (Morandi et al., 2015a; Morandi et al., 2015b). The emotional distress in patients, family caregivers, and nurses in our data also supports previous findings that delirium distress extends beyond the patient's experience and is shared by family caregivers and nurses (Breitbart et al., 2002). Our findings differ from and extend previous work by showing that the same symptoms create burden in different ways among patients, family caregivers, and nurses, with markedly differing perspectives on the experience. For example, hallucinations can precipitate fear in patients, worry in caregivers, and heightened care demands for nurses. The intensity of burden triggered by different symptoms also varied across groups. While our study has revealed that the types of symptoms creating burden are unified across patients, family caregivers, and nurses, the diverse distress reactions and perceptions of the three groups will necessitate distinct approaches for intervention.

Our results suggest that due to delirium's unpredictability, rapid onset, and ominous effect on recovery and rehabilitation, as well as increasing demand on acute nursing workload, a new concept and measurement of delirium severity and consequent burden may be useful to distinguish it from the burden model related to progressive, irreversible illnesses such as dementia, Amyotrophic Lateral Sclerosis (ALS), and Parkinson's Disease (Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Our findings contribute to a new understanding of individual and common aspects of

delirium burden that will support future research, development, and implementation of evidence-based interventions, including bedside care, education, and training to alleviate burden and to provide support to patients, family caregivers, and health care professionals.

Limitations

We conducted our study in one large acute-care facility, and generalizability will need to be verified. Our study and analysis did not include patient–family caregiver–nurse triads, but relied on separate recall of delirium experiences by members of each group. While we verified presence of delirium in patients, for all three groups we neither specifically investigated how delirium burden differed from burden related to other comorbid conditions, nor did we include this information in the analysis. Therefore, it is possible that some of the burden described was not related to delirium itself but to other acute illnesses, chronic comorbid conditions, or other concurrent events. While we excluded older adults with dementia who also experience delirium, this substantial group of older adults merits study (Fick, Kolanowski, Waller, & Inouye, 2005). Our study contributes meaningful data to better understand the experience of delirium across groups. Further study is required to validate our findings.

Implications

These findings offer important implications for patients, family caregivers, and clinicians who care for patients with delirium. First, this study documents the substantial distress associated with delirium across all groups, and serves to emphasize the importance of prevention to diminish the tremendous emotional stress and burden associated with delirium. Given that 40% of delirium is preventable with proven nonpharmacologic approaches, relief of suffering and burden is another impetus to consider these approaches. One proven approach is the widely disseminated Hospital Elder Life Program (HELP) (Inouye et al., 1999). This cost-effective program provides support to patients through interventions such as therapeutic activities, relaxation therapy, sleep enhancement, social work and chaplaincy consultation, support to families through bedside training, and support to nursing staff through comprehensive educational and training programs about delirium and its management. While a variety of delirium prevention programs exist (Marcantonio, Flacker, Wright, & Resnick, 2001; Olveczky, Mattison, & Mukamal, 2013), HELP is unique in being effective for both prevention and treatment of delirium symptoms, for targeting support to all of the groups examined in this study, and for providing resources to address situational burden. Such programs may offer an effective means to diminish the immense symptom burden, emotional burden, and situational burden related to a delirium episode.

Our findings carry important implications for hospital leadership teams. High perceived burden will negatively impact nursing attitudes, work satisfaction, and retention. Devoting increased resources to nurse education, staffing, and support may promote awareness and mitigate some of the burden of delirium which is common in the older population. Increasingly, hospitals have recognized the importance of delirium screening and institution of evidence-based interventions as part of quality improvement or risk reduction programs. Our study provides a powerful additional incentive to further these efforts to enhance person-centered, humanistic care designed to relieve suffering and burden for patients, families, and nurses.

Conclusion

We identified common burden themes related to symptoms, emotions, and situational delirium among patients, family caregivers and nurses experiencing delirium. While instruments and interventions may be targeted to any of these groups, our work reinforces that no one group experiences delirium in isolation. Delirium is a shared experience and will respond best to systemwide approaches to reduce associated burden.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None reported.

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