

Perceptions of Families of Intensive Care Unit Patients Regarding Involvement in Delirium-Prevention Activities: A Qualitative Study

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BACKGROUND Nonpharmacologic delirium-prevention strategies are commonly used in the intensive care unit by bedside nurses. With up to 80% of intensive care unit patients becoming delirious, and lacking treatment options, prevention is key. However, with increasing nurse workloads, innovative delirium-prevention strategies such as involving the patient's family are needed.

OBJECTIVE To gain insight into opinions of patients' families regarding active participation in delirium-prevention activities to inform specific recommendations for involving patients' families in such activities.

METHODS Purposeful sampling was used. Patients' families were contacted to be interviewed about their opinions and attitudes on participation in nonpharmacologic delirium prevention activities while visiting the intensive care unit. An interview guide was created and used to facilitate discussion. Interviews were conducted, transcribed verbatim, and coded by 2 independent coders. Themes were identified, defined, and compared between independent coders; disagreements were resolved by the study team.

RESULTS After 10 interviews were conducted, thematic saturation occurred. Three major themes emerged: (1) consistent family presence and participation in care, (2) improving ease of interactions between family and patient, and (3) delirium education for families.

CONCLUSION Family members want to be involved with care and delirium prevention; however, many times they do not know what to do without the direction of a health care provider. Family members would benefit from open dialogue with the bedside nurse to increase family comfort and involvement in care. (*Critical Care Nurse*. 2017;37[6]:e1-e9)

CE 1.0 hour, CERP B

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Describe how family members interact and support their loved one when they visit the intensive care unit.
2. Identify items from home that family members believe would assist with communication to aid in delirium prevention.
3. Identify the family preferences in regards to the method and timing of delirium prevention education.

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Patient-centered care has been an important part of medicine since the 1970s; however, inclusion of the patient's family and recognizing their role in care has only recently gained support.^{1,2} Family-centered care is the view that the family of critically ill patients are members of the care team and also have needs themselves.^{3,4} Family participation in the intensive care unit (ICU) setting is increasingly used in various ways.²

To date, most family-centered research has focused on the opinions of providers and family members about the family being present at the bedside and during patient-care rounds.^{2,5} When the family is involved in care, they report more satisfaction and reassurance.⁶ Evaluations involving the family in active patient-care tasks, such as bathing or passive range-of-motion activities, are limited.² To our knowledge, no studies have evaluated the role of the patient's family in active delirium-prevention activities in an ICU setting.²

Delirium occurs frequently in the ICU, affecting up to 80% of patients, and results in adverse patient outcomes as well as increased health care costs.⁷⁻¹⁰ Adverse outcomes include long-term cognitive impairment, a higher 6-month mortality rate, increased time receiving ventilatory support, and longer hospital stays.^{7,10-13}

Nonpharmacologic prevention activities emerged as the preferred management modality because there is limited evidence to support pharmacologic treatment or prevention.¹⁴ Nonpharmacologic prevention strategies

decrease the incidence of delirium by an average of 16%.¹⁵⁻³⁰ Delirium prevention is primarily conducted by the bedside nurse; however, with increasing demands on bedside nurses' time for other patient-care activities, nonpharmacologic delirium-prevention activities may not be a primary focus.³¹⁻³³ Solutions need to be investigated to increase delirium-prevention endeavors. Involving family members in delirium prevention may improve family satisfaction while decreasing delirium in ICU settings.

The Society of Critical Care Medicine's quality improvement initiative to manage pain, agitation, and delirium is referred to as the ABCDEF Bundle.³⁴ The most recent addition to that abbreviation is F, which represents Family, and further highlights the need to engage and empower the patient's family.³⁴ The identification of family involvement as a need by this international organization highlights the importance of developing novel, safe ways to include the family on a daily basis in patient care. Smithburger and colleagues³¹ evaluated the findings from 2 surveys on health care provider and family perceptions about involving the patient's family in nonpharmacologic delirium prevention. When health care providers were questioned, all nurses and most physicians (93%) thought families could assist with delirium prevention. Patients' family members were also surveyed about their willingness to be involved with nonpharmacologic delirium-prevention activities when they are visiting their loved one and they expressed extreme comfort in being involved.

The objective of this qualitative study was to gain insight, beyond that acquired through surveys, into family members' opinions and attitudes about participating in delirium prevention, and to learn if they expressed ideas about ways to be involved with care. The unique perspective of a qualitative analysis allows health care providers to better understand how to proceed with family engagement.

Methods

This qualitative study was approved by the University of Pittsburgh Institutional Review Board and took place from March to July 2015 in a 24-bed medical ICU at an academic medical center. Family members were included if they participated in the initial family delirium survey investigation and provided their consent and telephone number to be recontacted for a telephone interview.³¹ Before contacting eligible family members, an interview guide was created that focused on gaining further insight

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- 1) **Tell me a little bit about your relationship with the patient you visited in the ICU.** (Probes: Was it a surprise he or she was in the ICU? Has he or she been in the ICU previously? Have you visited him or her in the ICU before?)
- 2) **How did you interact with the patient when you visited?** (Probes: Describe the things that you did. What were things that made it difficult to interact; how did that make you feel? What things made it easier for you to interact; how did that make you feel?)
- 3) **What suggestions do you have to make things easier to interact with the patient?** (Items the unit could provide; discussions with the staff; things to bring in from home)
- 4) **How were you involved with care?** (Probes: How did a nurse or physician include you in care? What were the things that you were asked to do? *For each item asked to do ask:* How did this make you feel? How did the person approach you? How did that make you feel?)
- 5) **What things were you not involved with that you would have liked to have been involved with?**
- 6) **What could have made you more comfortable when you visited?**
- 7) **Some patients become confused when they are in an ICU. For example, they may not know where they are or why they are in a hospital. What are some ideas that you have that families could do to help decrease confusion?** (Other things that you have heard about but did not necessarily do; bring things in from home; helping them sleep such as using earplugs)
- 8) **There are several things that we try to do already in the ICU to decrease patient confusion. Please tell me your thoughts around if a family or visitor member can and would be willing to help**
 - a. Turn on lights during the day and off at night
 - b. Open window blinds during the day
 - c. Use earplugs at bedtime
 - d. Use an eyeshade at bedtime
 - e. Ask questions to keep the patient's mind active
 - f. Remind the patient where they are
 - g. Bring in eyeglasses (if applicable)
 - h. Bring in hearing aids (if applicable)
 - i. Play music in the room
- 9) **What do you think is the best way to teach other patient family members about ways to interact with the patient and decrease confusion? Some examples mentioned in the survey included one-on-one education or videos.**
 - a. Why do you think that this would be the best way to teach other family members?
 - b. What do you think is the best way for a family member to be approached about interacting with the patient and about education?
- 10) **What other thoughts do you have about interacting with the patient or being involved with care?**

Figure Interview guide.

into opinions and attitudes about family participation in nonpharmacologic delirium-prevention activities that were introduced on the family survey.³¹ The interview guide was used to help ensure the same basic lines of questioning were pursued with each interviewee. After

the interview guide was created, it was vetted by the study team and practitioners in the medical ICU and revised as needed. Revisions included the reduction of redundant questions and rephrasing to ensure clarity. The interview guide is shown in the Figure.

Purposeful sample was conducted, which included patients' family members with differing opinions on the original survey specifically concerning performing specific patient-care activities. Potential subjects were contacted; if they provided verbal consent for participation, they were included in the telephone interview investigation. The primary investigator (P.L.S.) conducted the in-depth, semistructured interviews and obtained verbal consent before the interview began. Each interview lasted approximately 10 to 15 minutes and was audio recorded and then transcribed. The grounded theory method of qualitative research was used owing to the exploratory quality of this study: We were eliciting opinions and perspectives from patients' family members. Conceptualization came from the data instead of being derived from an existing theory. The number of interviews to be conducted was based on reaching thematic saturation, when no additional data or new ideas were obtained by conducting more interviews.

Two investigators (P.L.S., A.S.K.) independently read and then coded the transcripts. A coding framework was used and basic themes emerged. Phrases and sentences captured from the interview were assigned codes; accompanying specific descriptions defined the codes. The

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investigators regularly met and discussed the coding definitions and assign-

ment of codes. Disagreement about code definitions and assignment of codes to phrases and sentences was resolved through discussion. Any definition or code assignment that could not be resolved between the 2 investigators was discussed with the senior investigator team (S.L.K., S.A.A.) for resolution. The coding was conducted using the qualitative research management software Nvivo (version 10; QSR International Pty Ltd). The coded phrases and sentences were then organized into categories that were used to identify major themes. The research team as a whole met to finalize the global themes based on the coded interviews. Demographic data were obtained from the initially conducted paper surveys and summarized using descriptive statistics.

Results

Of the 62 family members who completed the family opinion survey, 45 indicated they would be willing to be

Table 1 Theme and subtheme clusters

Theme	Subtheme
Consistent family presence and participation in care	Just be there Assist as needed Bring in home items
Improving ease of interactions between family and patient	Bedside nurse practice consistency Invitation to participate in care
Delirium education for families	Strategy for education Timing of education provision

contacted for a telephone interview.³¹ Of those 45 potential participants, 10 interviews, chosen by purposeful sampling, were conducted before thematic saturation occurred. Thematic saturation was determined independently by the 2 coders (P.L.S., A.S.K.). The median age of those completing the interviews was 54.5 years (interquartile range, 26-78 years) and 80% (8 of 10) were female. Most interviewees were either the patient's spouse (4 of 10) or child (4 of 10). The other 2 family members identified themselves as a sibling or parent.

Upon completion of the coding, 3 themes emerged about family involvement in delirium-prevention activities: (1) consistent family presence and participation in care, (2) improving ease of interactions between family and patient, and (3) delirium education for families. Themes and subthemes are listed in Table 1.

Consistent Family Presence and Participation in Care

Family members universally described ways in which they interacted with and supported their loved one while they visited. All family members wanted to be with their loved one and would be willing to help with anything that came up during the day. They wanted their loved one to know they were there and that needs were addressed throughout the day. Patient needs differed greatly but ranged from hygiene activities to improving patient comfort through touch or addressing needs, such as adjusting room temperature. Participants' comments included the following:

I wanted to see what was going on, and I wanted to see how he was. I just wanted to be . . . there.
(Participant 2)

I'd sit by the bedside and hold his hand, and he knew I was there. He expected me to be there.

And I'd wipe his mouth or whatever he needed. (Participant 3)

Basically [I] just stayed in the room with her and took care of her needs, you know, as they would come up. (Participant 4)

[I]f he needed anything . . . little, I would help him with that. [I]f he got cold, I'd turn the heat up. If he got hot, I'd turn the heat down. You know, mess with his blankets and everything. [A]nd I was able to work from his room, too. So if he needed anything, he knew I was there. (Participant 6)

So, with the patient's care, I still get pretty actively involved, trying to help the nurses [unintelligible] him, or help clean him up, because he gets pretty nervous whenever others are trying to bathe him, like really uncomfortable. (Participant 7)

Each family member interviewed described specific examples of when they felt their presence may have affected outcomes, especially when their loved one became confused or delirious. As shown by some of their remarks, they believed that by being in the room, they were able to assist:

Well, I would just, whatever he needed done, and nobody was there, I would do it. (Participant 3)

And she became paranoid. And so I would stay at nighttime, for a while, because that was her worst time, you know, because I would tell her, "You just go to sleep. I'll be here; I'll keep you safe." And it seemed to help a little bit. (Participant 4)

He was so agitated that he just kept screaming my name. And he wouldn't calm down until I got back there. So, you know, I would do anything they would ask me to help him do. (Participant 5)

Many family members also described how they brought in items from home for their loved one (8 of 10 participants; Table 2). They used these items to reorient their loved one, aid in communication, or keep their loved one engaged. Their observations while visiting their loved one determined the items they brought in, such as the following:

Table 2 Items brought or suggested by family members to help prevent delirium in intensive care unit patients

Items brought in by family members	Items suggested by family members
Books	Additional visitor chairs that are more comfortable
Clothes (eg, jogging pants)	Battery-operated alarm clock with lighted digital display
Deck of cards	Books
Dentures	Deck of cards
Earplugs	Crocheting supplies
Eyeshade	Dry shampoo
Eyeglasses	Earplugs
Fingernail clippers	Eyeglasses
Family pictures	Eyeshade
Newspaper	Handouts about patient diagnoses
Pen or pencil, paper	Hearing aids
Portable fan	Marker board wall calendar
Puzzle books	Pen, paper, clipboards
Razor for beard trimming	Pillow from home
Slippers	Puzzle books
Soft blanket	Visible clock in room
Small marker board for communication	
Tablet computer	
Whiteboard with calendar	
Wristwatch with large display	

But when he was on that ventilator, he . . . couldn't talk, so . . . we got paper and pencil and tried to write stuff down. That was one thing I guess I did. And I just tried to make him feel that I was there for him. (Participant 3)

We tried getting our own whiteboard and putting a calendar on it so that she knew what day of the week it was. Because, you know, the whiteboards don't always get updated by the nurses. (Participant 4)

Well, I would talk to him and tell him what was going on, and read the paper for him when he couldn't read it, . . . I'd just keep him up to date on things. (Participant 5)

And then I'll bring him, you know, like newspaper, his books. He hates . . . having a beard. So I bring

him in his like electric razors and that. And I bring him in—he hates hospital gowns, so when he can, he wears jogging pants. (Participant 7)

I mean, she's like a real news person, and so even though the TV was on the whole time, I brought the newspaper in and I just kind of read the headlines and stuff that she'd be interested in hearing about. (Participant 10)

Family members also suggested items that could be recommended to future visiting family members to bring from home that would help with communication or reorientation (8 of 10 participants; Table 2). Specific recommendations included the following:

I would just say have them bring books, or cards, or something and . . . like in a normal routine. You know what I mean? Well, like if it's an older person and like they enjoy doing puzzles, or . . . puzzle books and stuff like that. [B]ring the puzzles, or the cards, or whatever they're . . . they're used to doing. (Participant 1)

Yeah, definitely a calendar. Because I would be willing to bet she has no idea what day it is. And maybe have them X off the days, so, you know, if you just put a blank calendar, maybe have . . . the marker board calendar, the dry erase. (Participant 2)

Yeah, I think if people had like—even if they had their own pillow or something, you know. . . . It would be nice to have something familiar. (Participant 10)

Improving Ease of Interactions Between Family and Patient

Family members also described impediments to interacting with their loved one and hindrances to being comfortable visiting. The differences in bedside nursing practices, as well as not knowing exactly what to do or what they were allowed to do when visiting, were commonly described (5 of 10 participants). Although the bedside nurses the families encountered practiced on the same unit, the direction and preferences differed greatly. Family members also noted that having direction and, at times, an invitation to participate in care from the bedside nurse would aid in their level of comfort.

[T]hat one girl [nurse] said to me, “You can't keep walking up and down these halls all the time.” And yet he was in that very back; I had to walk the halls to get to him. That intimidated me, you know? (Participant 3)

Standardization across the board would be great. I mean, for example, over at [hospital A], I could come and go as I pleased. I never had to ask anybody. [I]f somebody was in the room, they might ask me to step out into the waiting room, or whatever, and come get me, but there was no locks on the door. I didn't have to call in. Nothing like that. Over at [hospital B], I did have to, you know, call in, and check with the nurse to make sure everything was OK to come back and everything. And that's fine. You know, I don't have a problem with that—standardization across the board. So if you do go from one hospital to the next, you're familiar with the processes and the procedures. (Participant 6)

Yeah, just the nurse suggesting that maybe you know, . . . “Can you please assist me?” Or “Are you comfortable in assisting me?” Sometimes . . . they're just a little hesitant to want to ask because they're so used to not having caregivers or loved ones help their loved ones. (Participant 7)

I think on the shift changes that maybe it would be good for the nurses to establish their own ground rules. [A]nd not in a scolding way, but in a just, you know, “Hey, do you plan to be here all day? If you are, there's going to be certain times where we really need to do some stuff, where we're kind of closed in the room and it might be best—you might be more comfortable if you're not in here.” (Participant 10)

One particular family member, who is also a nurse, stressed the importance of communicating with the bedside nurse and not be intimidated:

Well, don't let the health care workers intimidate you. I mean, I know that's difficult to say sometimes, . . . and some you need to tell that to because they are not intimidated. But some people are. And it's like, “Oh, I'm afraid to touch anything.”

And it's like, you know, "Ask us if you're unsure," but . . . don't let us intimidate you. Speak up and ask questions. (Participant 4)

Delirium Education for Families

The final major theme that emerged is that family members, although they interact with their loved one while they visit, would benefit from further education and reminders of ways to help with reorientation and decreasing confusion and delirium while they visit. Family members believed one-on-one discussions with a health care provider, coupled with reminders, would be the best approach (7 of 10 participants):

I think one on one. Talking to, you know, if they come to me and talk to me and explain what's going on and what they need done, I have no problem with it at all, you know. And if it's maybe . . . like a list as a reminder, things that I can do, you know, to help the patient or—and even help the nurse . . . I know they're strapped on their time, you know. (Participant 1)

Well, I . . . tend to ask a lot of questions until I understand what's going on. I think that for me, you know, under the circumstances if . . . a nurse doesn't have the time to do that, if a case manager or [someone] could communicate . . . those, you know, delirium symptoms or what to expect, or something like that. (Participant 6)

Video is OK. I think that would be a good follow-up after you have a one-on-one conversation, because one-on-one conversation is great because you're communicating, you're getting to know, but you can't retain everything because you're so—how do I want to say? Nervous, anxious, scared yourself for your loved one. (Participant 8)

I think one on one. I mean, I think we all get bombarded with the videos and the technology. (Participant 9)

Most family members also described that the delirium education would be best discussed at the beginning of the patient's stay (7 of 10 participants). Family suggested that not only could this assist with family feeling more welcomed and comfortable in the

unit but also know at the beginning of their loved one's time in the ICU how they can help.

Well, I would think . . . well, I wouldn't say immediately. After they're admitted there, give, you know, a couple hours, and then talk to them. . . . And I don't think it would hurt if they talked to them within a couple hours, maybe a little bit later, just trying to refresh their memory. (Participant 1)

I think when they first go in—that way, you would know you could do certain things and not be in trouble for [helping?] do it. (Participant 5)
I'd say within the . . . first day or so. Yeah, maybe somebody could . . . say, "Hey, you may run into a situation where your family member has delirium. Here's what to look for. Here's the signs. Here's some basic reasons on why it's happening." (Participant 6)

So in the beginning of ICU, the stay, whenever the caregivers are being introduced to the staff, just the staff to remind them that caregivers are welcome. (Participant 7)

Yeah, I think the first time, because you just want to, well, I, personally, wanted to get information, and, you know, as much information as I could from the health care provider, and to know the status. (Participant 9)

[Y]ou had this fine, perfectly healthy parent and all of a sudden you're in the ICU. So, I think as soon as you get there, or close, you know, somebody just might want to pull you aside and say, "Hey, here are some helpful hints while you're in here. You might want to review this, just because we've talked to people, you know, we see this all the time and this could help." (Participant 10)

Discussion

Family perceptions and opinions surrounding participation and interaction with loved ones, specifically regarding reorientation and delirium prevention, are complex. Family members have described the importance of being present in the ICU, whether that included active participation in care or through emotional,

supportive roles. Without any education or training from health care providers, family members have illustrated their desire to communicate with their loved one and their willingness to bring in items, such as pens, paper, and whiteboards, to assist with communications. Family members have also self-identified the need to keep their loved one orientated; attempts to do this included reading the newspaper, bringing in clocks and calendars, as well as conversing as much as possible.

The desire to be involved in care that we identified in this investigation does not differ from other reports of family involvement in the ICU.^{3,31,35-37} In the literature, different, active patient-care activities have been addressed. These activities include adjusting equipment, distracting the patient, tracheal suction, activities of daily living, positioning, moisturizing, eating, mouth care, eye care, bathing, and massage, with hygiene activities such as massaging, mouth and eye care, and bathing being the most agreeable activities by family members.² Our

Where feasible, units that aim to further involve patients' families should consider an open visitation policy.

investigation specifically explored willingness

to participate in activities that would help reorient the patient and decrease confusion, highlighting the family's willingness and desire to participate in care, through the provision of specific examples and stories.

The family members who participated in our interviews stressed the importance of open communication and discussion with the bedside nurse about ground rules as well as possible ways to be involved. An investigation conducted by Garrouste-Oregeas and colleagues³ found similar results. Whereas 97% of family members reported willingness to assist with patient-care activities, only a minority of family members (13.8%) started an activity without being encouraged by a health care provider.³ Family members wanting to participate in care many times do not want to get in the way of the health care provider.³¹

The family members may be unclear about what they can do to assist. Direct communication between the bedside nurse and the family member about expectations on day 1 of the ICU stay would be beneficial for family members' level of comfort and ability to engage in care. Health care providers have also identified the need for clear communication about rules and expectations. They believe this is important to maintain control over the situation and

patient.² As a result, we recommend that a conversation take place between the family members and the bedside nurse whenever a new bedside nurse takes over the patient assignment. It is also important that all nurses be consistent in enforcing any unit rules regarding family visitation and participation in care, to limit any mixed messages or confusion. This will not only open channels of communication but it can also serve as an opportunity to lay ground rules and expectations. Units should consider developing training materials for the bedside nurses to enhance their communication skills and comfort interacting with family members. Educational sessions, including role playing, would be one strategy to help disseminate the information.

The unit in which this investigation took place has an open visitation policy. The ability for patients' family members to visit at any hour of the day increased accessibility. Where feasible, units that aim to further involve patients' families should consider an open visitation policy. To effectively engage family members, expectations and support for bedside nurses must come from unit leadership.

Family members suggested various items they could bring or that could be provided by the unit to make communication and reorientation activities easier while they visit. Many of the suggested articles included personal belongings (ie, pillows, family pictures); however, other less-personal items, such as newspapers and whiteboards, should be considered for the nursing unit to provide. Family members suggested having the unit create checklists for the family about how to interact with their loved one while they visited, to help decrease confusion. Such a checklist could be provided in a pamphlet by the nursing unit during an initial education session with the family.

Although this study investigated and gained insight into family involvement in delirium prevention, there are a few limitations to this investigation. First, this study took place in a medial ICU at an academic medical center. This unit tends to care for patients with high illness-severity scores, indicating they have multiple comorbidities. The types of patients and family members may differ from those in a community hospital setting. Although thematic saturation occurred, the findings are from 10 interviews from 1 unit of 1 academic medical center; therefore, the experiences the family members had and the findings may not be generalizable to other populations and settings. Future investigations would benefit

from including family members from community hospitals and other types of ICUs.

Conclusion

Family members who visit loved ones in the ICU appear to want to be involved in care. However, frequently, the family does not know what they can do to help without the direction from health care providers. The next step in advancing delirium prevention is through family engagement, beginning with open communication and dialogue between the family and bedside nurses. Consulting the family about useful items that may comfort the patient and assist with cognitive stimulation also is important. The effect of these activities should be evaluated. Open communication and dialogue between family members and bedside nurses may lead to greater family involvement in delirium prevention, because of increased direction and increased level of comfort while in the unit. **CCN**

Financial Disclosures
None reported.

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See also

To learn more about delirium in the critical care setting, read "Feasibility and Effectiveness of a Delirium Prevention Bundle in Critically Ill Patients" by Smith and Grami in the *American Journal of Critical Care*, January 2017;26:19-27. Available at www.ajconline.org.

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