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# Older Adults' Perspectives on Screening for Cognitive Impairment Following Critical Illness: Pre-Implementation Qualitative Study

**OBJECTIVES:** Screening for cognitive impairment following ICU discharge is recommended but not part of routine care. We sought to understand older adults' perspectives on screening for cognitive impairment following an ICU admission to inform the design and delivery of a cognitive screening intervention.

DESIGN: Qualitative study using semi-structured interviews.

**SUBJECTS:** Adults 60 years and older within 3 months of discharge from an ICU in an academic health system.

**INTERVENTIONS:** Interviews were conducted via telephone, audio recorded and transcribed verbatim. All transcripts were coded in duplicate. Discrepancies were resolved by consensus. Codes were organized into themes and subthemes inductively.

**MEASUREMENTS AND MAIN RESULTS:** We completed 22 interviews. The mean age of participants was  $71\pm6$  years, 14 (63.6%) were men, 16 (72.7%) were White, and 6 (27.3%) were Black. Thematic analysis was organized around four themes: 1) receptivity to screening, 2) communication preferences, 3) information needs, and 4) provider involvement. Most participants were receptive to cognitive screening; this was influenced by trust in their providers and prior experience with cognitive screening and impairment. Participants preferred simple, direct, compassionate communication. They wanted to understand the screening procedure, the rationale for screening, and expectations for recovery. Participants desired input from their primary care provider to have their cognitive screening results placed in the context of their overall health, because they had a trusted relationship, and for convenience.

**CONCLUSIONS:** Participants demonstrated limited understanding of and exposure to cognitive screening but see it as potentially beneficial following an ICU stay. Providers should use simple, straightforward language and place emphasis on expectations. Resources may be needed to assist primary care providers with capacity to provide cognitive screening and interpret results for ICU survivors. Implementation strategies can include educational materials for clinicians and patients on rationale for screening and recovery expectations.

**KEY WORDS:** cognitive impairment; implementation; post-intensive care unit; qualitative

In older adults, an episode of critical illness is often a life-altering experience. Survivors of critical illness are at risk for long-term deficits that persist after resolution of their acute illness. These deficits often include new or worsening cognitive impairment that manifests functionally as an acquired dementia (1-10). One out of four adults have a degree of cognitive impairment 12 months after an ICU stay similar in severity to that of patients with mild Alzheimer's disease, and one out of three have impairment typically associated with moderate traumatic brain injury (11). In older patients,

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# KEY POINTS

**Question:** An understanding of older adults' perspectives on routine cognitive screening following critical illness is needed to design an intervention for post-ICU cognitive impairment.

**Findings:** Thematic analysis was organized around four themes: 1) receptivity to screening, 2) communication preferences, 3) information needs, and 4) provider involvement. Older adults are generally receptive to cognitive screening following critical illness and prefer direct communication with screening results placed into the overall context of their health.

**Meaning:** Implementation strategies can include educational materials for clinicians on rationale of screening and information for patients about post-ICU cognitive impairment, screening procedures, and expectations for recovery.

cognitive declines of the magnitude seen following critical illness result in an increased likelihood of nursing home admission, caregiver burden, and subsequent mortality (12, 13).

Given the burden of cognitive impairment in this population, experts recommend screening individuals with risk factors for developing post-ICU cognitive impairment (14-16). Post-ICU cognitive screening is also supported by general population dementia screening guidelines that recommend assessing cognitive function whenever impairment is suspected or the patient is at increased risk (17, 18). Risk factors for dementia in the general population include increasing age and genetic predisposition as well as several modifiable risk factors (e.g., smoking, diabetes, and hypertension) (19). Risk factors for new dementia in older ICU survivors include a diagnosis of sepsis, acute neurologic dysfunction including delirium, and the need for renal replacement therapy during the ICU stay (20). Diagnosing new cognitive impairment or dementia when present after an ICU stay is necessary to connect patients and their caregivers with support, provide evidence-based care that has been shown to reduce the progression of cognitive impairment to dementia, and improve our understanding of the modifiable factors related to intensive care that contribute to

this morbidity. Cognitive screening tools effectively detect cognitive impairment and use of these tools results in early intervention, however, it is not yet known how best to implement cognitive screening in the post-ICU population (17, 21). Knowledge gaps include knowing how to integrate screening into ICU follow-up care and how best to connect patients and families with needed resources following a positive screen.

The overall objective of this pre-implementation qualitative study was to understand older adults' perspectives and preferences in routine screening for cognitive impairment following an ICU admission. The results of this work will directly inform the design and implementation of a post-ICU cognitive screening intervention in our health system.

### **METHODS**

### **Design and Setting**

We conducted a qualitative interview study of older adults discharged from any ICU (cardiac, surgery, neurologic, or medical) in the Atrium Health Wake Forest Baptist Health System (North Carolina). We recruited from all ICUs in the health system to increase the generalizability of our results and in anticipation of designing an intervention accessible to all critically ill patients. Eligible ICUs included an urban academic teaching hospital as well as two community hospitals in the surrounding area.

### Participants and Recruitment

We recruited participants who were admitted to any ICU in the health system between February and May 2022. Participants were eligible if they were 60 years old or older at ICU discharge and had an ICU length of stay of at least 72 hours in the 3 months prior. Participants were excluded if they were discharged to hospice or did not speak English or Spanish. We used the electronic health record to screen for eligible participants. We reviewed our sample on two separate occasions to confirm a diverse sample. Participants provided verbal consent over the phone prior to the interview with a waiver of signed informed consent. This study was approved by the Institutional Review Board (IRB) at Wake Forest University School of Medicine (IRB00069792, "Understanding Brain Recovery Following Critical Illness") on November

20, 2020. Procedures were followed in accordance with the ethical standards of the IRB and with the Helsinki Declaration of 1975.

### **Data Collection**

Patient demographic information was collected by review of the electronic health record and via survey questions within the interview. Our multidisciplinary study team with expertise in implementation science, geriatrics, and critical care created the interview guide. All questions were open-ended and designed to stimulate conversation on cognitive screening following critical illness (Appendix A for our interview guide, http://links.lww.com/CCX/ B195). When available, we invited caregivers or additional family members to provide input as well. The interviews were conducted via telephone by author (A.K.), a medical student with training in qualitative research methods who was naive to the research participants. Interviews were audio recorded and transcribed verbatim with identifying data removed. Transcripts were compared with the audio recordings and edited for accuracy, and then imported to ATLAS.ti Version 9 (ATLAS.ti Scientific Software Development GmbH, Cologne, Germany) for coding and analysis.

### **Qualitative Analysis**

Thematic analysis was performed by members of the study team with expertise in critical care and qualitative research methods using a mixed inductive and deductive approach (22). Initially, authors (A.K., T.W., and J.A.P.) performed open coding on 20% of the transcripts. Based on these initial inductive codes and with input from our multidisciplinary investigative team, a primary codebook was developed. The authors (A.S., T.W.) independently reviewed an additional 20% of transcripts to test and refine the codebook. All transcripts were subsequently coded independently by two study team members (A.K., A.S., T.W., J.A.P.). The team met weekly to discuss modification of the codebook and any coding discrepancies, which were resolved by consensus. Following coding, the study team iteratively reviewed and discussed coded text by individual code and groups of codes. Themes and subthemes were identified according to their prevalence and salience in the data.

## RESULTS

We attempted to contact 81 patients discharged from the ICU. We were able to successfully connect with 47 patients and 22 consented to a telephone interview. The mean age of participants was  $70.9 \pm 6.2$  years, 14 (63.6%) were men, 16 (72.7%) were White, and 6 (27.3%) were Black/African American. Four caregivers completed the interview in place of the patient at the patient or caregiver's request. 12 participants (54.5%) were discharged from a medical ICU, 5 (22.7%) from a cardiac ICU, and 3 (13.6%) from a surgical ICU. Additional characteristics of the enrolled participants are shown in **Table 1**.

Four themes were identified to understand older adults' perspectives on screening for cognitive impairment following an ICU stay. These themes are summarized below and additional supportive quotations are provided in **Supplemental Table 1** (http://links.lww. com/CCX/B195).

1) Receptivity to screening: Participants' receptivity to screening was influenced by multiple factors including their relationship with their providers and their prior knowledge or experience about cognitive screening and cognitive impairment.

# **TABLE 1.**Characteristics of Participants

Patients, <i>n</i>	22
Age, yr, mean ± sp	71±6
Sex, female, n (%)	8 (36.4)
Race, <i>n</i> (%)	
White	16 (72.7)
Black	6 (27.3)
Mechanical ventilated, $n$ (%)	7 (31.8)
Vasopressors used, n (%)	10 (45.5)
Prior mental health diagnosis, n (%)	7 (31.8)
ICU location, n (%)	
Medical ICU	12 (54.5)
Cardiovascular ICU	5 (22.7)
Neuro ICU	2 (9.1)
Surgical ICU	3 (13.6)
ICU length of stay, d, median (IQR)	4 (4–5)
Hospital length of stay, d, median (IQR)	8 (6–10)

IQR = interguartile range.

- 2) Communication preferences: Participants preferred simple, direct, and compassionate communication from clinicians about cognitive screening and the possibility of cognitive impairment.
- 3) Information needs: Participants wished to better understand the screening procedure, the rationale for cognitive screening, and the expectations for recovery from cognitive impairment.
- 4) Provider involvement: Participants desired input from their primary care provider to have their cognitive screening results placed in the context of their overall health, because they had a trusted relationship, and for convenience.

### **Receptivity to Screening**

Most participants were receptive to screening for cognitive impairment following an ICU stay and saw it as potentially beneficial. Participants' receptivity to cognitive screening was influenced by multiple factors. Some stated that they had trust or confidence in their care provider and therefore would defer to the provider's knowledge and recommendation for screening. Participants felt their providers had their best interest in mind, and they trust their provider or care team to make recommendations regarding screening.

I'd take it that she's watchin' after me. She's wanting to take care of me. (74 year old, female)

Other participants described their experiences with cognitive impairment in their family, such as a family member with Alzheimer's disease or dementia, which made them more open to cognitive screening.

I would take it as something I need to actually be concerned about, and check into it 'cause my mother had Alzheimer's, and I'd be concerned. I'd be concerned about if Alzheimer's is setting in on me for loss of memory... (76 year old, male)

Several participants described a link between cognitive impairment and aging, and felt that screening was important in older adults for this reason.

We all have issues remembering things, I guess as we get older. I know I do, so yeah. It wouldn't hurt to have a screening done periodically, I think. (65 year old, male)

Other participants had a general desire for knowledge about their health, which made them open to any recommended screening or diagnostic procedure, not necessarily limited to cognitive screening. I mean, everybody wanna know somethin' about their own health, I think. I know I do. I wanna know about as much as I can. (72 year old, male)

Additional reasons for receptivity to screening included the belief that screening would help set expectations and a course of action (e.g., resources and treatment), and it would encourage involvement of family in their care.

Well, I think it's best if they feel like they have a memory issue, they need to have a family member with them that understands things maybe a little bit better than what they may understand, and that way if the doctor can't really explain it, they'll get it through to the patient, then they can get it through to the family, and then the family can proceed to make sure that the person understands in their own way and help them that way because it's very important for people. (70 year old, female)

A few participants were more skeptical about cognitive screening. One participant questioned the purpose of screening and whether it would be done just to bill insurance. Another said it is difficult to trust anyone and does not want someone "experimenting" on them, which contrasts with the trust in providers and care teams that the majority of participants shared.

Again, is it necessary? Is it necessary? If they just want to do it for their information, is it necessary? Is it really going to help? We have look at all that. (76 year old, male)

### **Communication Preferences**

Most participants felt that providers should use simple, direct, and straightforward language ("layman's terms") when discussing cognitive impairment, and wanted providers to be honest with them about potential memory issues and the need for screening.

I prefer a doctor that if you tell me regardless how bad or good it is, I want it straight up 'cause a lot of times when you sugar coat things and you change the situation and everything, then it makes it worse, and people don't understand, and they get scared and panicked, and a lot of times there's just no reason for it. (70 year old, female)

Several participants mentioned the importance of providers demonstrating compassion and using

reassuring, comforting language in their approach to discussing cognitive issues. A few shared that providers should avoid using disrespectful language, noting that a diagnosis with a cognitive condition can be difficult for the patient and family to hear, or that living with cognitive impairment can already feel "degrading," and others felt that providers should reassure patients that there is hope for their recovery from cognitive impairment.

...sometimes just a little compassion from someone other than family and someone else sometimes, it speaks a volume as well. I would just say just not bein' disrespectful or degrading...because just the disease within itself can be very degrading as well. (82 year old, female)

Some participants felt it was important to include a family member or caregiver in the cognitive impairment conversation.

I usually like to have somebody at the second hand that listen, too, because a lot of the things I just can't remember. (62 year old, female)

When asked about in person, telephone, or online screening options, most participants preferred an inperson cognitive screening, because if felt more personal to them.

Because I'd want it one-on-one. I wouldn't wanna do it on the computer, and I wouldn't wanna do it on the phone. I like eyeball. I'm old school. I like eyeball to eyeball. (74 year old, female)

### Information Needs

Participants understanding of cognitive screening varied considerably, and most said that cognitive screening is rarely asked about in their healthcare visits, as the focus is on their physical ailment and treatment. Most participants were not familiar with common cognitive assessments (e.g., memorizing a short list of words, counting backwards, drawing a clock). Those that were familiar with cognitive screening described participating in screening during their annual Medicare Wellness visits.

I really think that they're more concerned about the ailment that you had, and concerned more towards taking care of that physical problem than any other problem you might be having. (73 year old, male).

Participants identified multiple information needs that they wished to be communicated to them with a cognitive screening intervention. Some desired a description of the screening to gain a better understanding of the process, including how long the screening would take and what the patient would be asked to do.

Again, what are you lookin' for? How do you do this test...? (60 year old, female)

Others wanted to understand the rationale for cognitive screening, including the link between an ICU stay and cognitive impairment, their personal risk for cognitive impairment, and/or any specific behaviors that prompted their clinician to recommend screening for them.

It's just like working on your car. I want to know why—the reason why you fix this, same way with your body (63 year old, male)

Participants also expressed interest in understanding expectations for their cognitive recovery and next steps at the time of cognitive screening. An emphasis on recovery was desired by numerous patients, as they felt providers should also tell the patient what could be done to treat cognitive issues, and provide resources or make a referral for further testing or treatment.

In other words, okay, you have this issue, what are you going to do about it? It's kind of like, what are some next steps? That to me would be important. (72 year old, female)

### Provider Involvement in Cognitive Screening

Participants were asked about their preferences for provider involvement in both screening assessment and discussion of screening results, including involvement of the inpatient care team, a cognitive specialist, or their primary care provider. Most participants expressed a desire to both be screened by and discuss screening results with their primary care physician (PCP) for various reasons. Several described that discussing results with their PCP would allow the results to put into the context of their overall health, whereas others stated they felt more comfortable with their PCP because they had a strong relationship with the provider. Some said it was more convenient to see their PCP as opposed to returning to the hospital or meeting with a new provider.

It's easier to understand and trust somebody that you've been going to for quite awhile verses somebody that you just go in and see one time like that. They really don't know your background. They really don't know you as a person and stuff like that, so the primary doctor would be able to distinguish whether they believe that it could be something that she truly doesn't remember or if it's just maybe a bad day or something of sort. (70 year old, female)

A few participants were open to beginning the cognitive screening process with the inpatient care team (ICU or hospital team) either prior to or after discharge.

### DISCUSSION

We found older adults with a recent ICU admission are receptive to cognitive screening following hospital discharge and see it as potentially beneficial in their ICU recovery, often drawing on trust in their care providers and prior family experience with dementia or memory concerns. Participants felt detecting cognitive impairment, if present, may help them to set expectations and involve family in their care as needed. Our qualitative study also elicited several information needs and communication preferences that will be important to address in the implementation of a cognitive screening intervention in the post-ICU population. For example, participants described a desire to understand the rationale for post-ICU cognitive screening as well as information about next steps at the time of initial screening.

Barriers to screening for cognitive impairment have been evaluated in the general population but not specifically in older adults recovering from critical illness (23–25). Existing research has shown the diagnosis of dementia or cognitive impairment is often delayed in routine care. Barriers to screening include lack of support, time and financial constraints, stigma, and diagnostic uncertainty surrounding dementia (26). Although these barriers likely exist for ICU survivors, there may also be unique barriers in this population. Care following ICU discharge is often fragmented; for example, 6-month rehospitalization rates for this patient population exceed 35% (27, 28). Patients may spend time in the hospital or at a rehabilitation or skilled nursing facility and routine care appointments may be delayed. Unmet needs are also high in ICU survivors; patients may need durable medical equipment, coordination with government assistance and community health programs, rehabilitation therapy, and medication reconciliation after discharge (29). The priority in follow-up care is often on physical and organ failure recovery, not cognition. Participants in our study did describe that physical care and recovery were often the focus at their follow-up appointments and cognitive concerns or symptoms were not discussed.

Despite these barriers, our results support that older adults are generally receptive to screening for cognitive impairment following an episode of critical illness. This finding is similar to what has been reported in prior qualitative work evaluating undiagnosed cognitive impairment and dementia in the general population and those with medical comorbidities. Palazzo et al (30) found that older adults generally support an early diagnosis of cognitive impairment, describing benefits including time to adjust and plan for the future, involve caregivers or family in their care, and identify resources. In their qualitative work, participants emphasized the importance of thoughtful communication by a trusted provider and that a conversation about undiagnosed cognitive impairment should include advice about prognosis, treatment, and resources if cognitive impairment or dementia was diagnosed. Participants in our study also voiced a preference that communication around cognitive screening in the post-ICU setting involve an established healthcare professional when possible. For most participants, this was their primary care provider though other participants were open to the inpatient care team beginning these discussions.

The communication preferences and information needs identified by interview participants have implications for implementing post-ICU cognitive screening in practice (**Fig. 1**). Participants demonstrated limited understanding of and exposure to cognitive screening prior to their ICU stay and a desire to know the specifics of the screening procedure. Given this finding, an implementation strategy may be educational materials specifically for older

adults describing the risks of cognitive impairment after critical illness and the screening process. Participants identified a need to understand the rationale for screening and its relationship to their ICU stay as well as a desire to understand the results of their screening test within the context of their overall health. These findings should inform the content of education provided to patients and caregivers and highlight the communication challenges associated with the prognostic uncertainty of post-ICU cognitive impairment. For example, some patients will experience temporary post-ICU cognitive impairment with resolution over months, whereas others suffer persistent cognitive deficits, and a permanent diagnosis of mild cognitive impairment or dementia may be appropriate. An effective post-ICU cognitive screening program will need to equip patients, their care partners, and primary care providers with information about post-ICU cognitive impairment and its possible trajectories. Our results demonstrate that this information should be provided in simple, direct and straightforward language. Participants in our study felt it was important this information is delivered with compassion and, when appropriate, hope about the possibility of recovery.

Our qualitative study found that participants wanted to discuss screening results with their primary care provider (rather than a cognitive specialist or inpatient care team). Unfortunately, detection of post-ICU cognitive impairment at routine PCP visits is rare (31). Health systems will need to support PCPs in providing post-ICU cognitive impairment screening and discussing results if routine screening is implemented in the primary care setting. Importantly, PCPs often lack information about complications of critical illness in their patients and the follow-up implications (32). To enhance the effectiveness of a post-ICU cognitive screening program, information about post-ICU cognitive impairment, referral options, and available resources to support patients and families should be made available to PCPs by the ICU care team promptly after discharge as well as directly to patients and their families.

Finally, participation in screening for cognitive impairment in community-dwelling older adults has been shown to be strongly influenced by perceived benefits of screening (23). Emphasizing the potential benefits to older adults recovering from critical illness may also help with uptake in clinical practice. The older adults in our study identified setting expectations, involving

Needs Identified by Participants	Potential Implementation Strategies	
Patients may have limited understanding of cognitive screening procedures	Develop patient-facing materials describing screening, recovery, and available resources to disseminate at discharge and follow-up	
Patients want information on recovery trajectories and next steps delivered at time of screening	Develop materials for patient describing recovery trajectories and resources available in health system and community	
Patients prefer results are communicated by trusted provider and placed in context of their overall health	Prepare PCPs to discuss post-ICU cognitive impairment, expectations for recovery, and resources available	

Figure 1. Needs identified and potential implementation strategies. PCP = primary care physician.

family in their care if needed, and understanding recovery trajectories as possible benefits of routine screening.

Our study used rigorous qualitative methodology and involved a multidisciplinary team with diverse perspectives in all phases of our study from conceptualization, design of interview guide, analysis, and interpretation of results. We enrolled older adults with a recent ICU stay who would be the target of a cognitive screening intervention and included participants discharged from both academic and community ICUs in this study. Participants were enrolled from a single health system and were all English speakers which may limit the generalizability of our findings. We also contacted participants via telephone and did not capture the experience of those residing in a skilled nursing facility post-discharge. We relied only on the patient reported experience and did not have information on additional factors that may influence receptivity to screening including factors related to the acute care hospitalization (i.e., physician or nurse interactions) or information regarding family or caregiver experience. Finally, our findings are drawn from those participants willing to take part in this interview study. Those that declined participation may not be as receptive to a post-ICU cognitive screening intervention.

### CONCLUSIONS

Participants demonstrated limited understanding of and exposure to cognitive screening, indicating a need for providers to address the rationale for screening, relate it to the patient's ICU stay, and explain specific details of the screening procedure to ensure patient understanding of the screening process.

Providers should use simple, straightforward language when discussing screening, and place emphasis on recovery and expectations moving forward. Resources should be provided to primary care providers to support interpretation of cognitive screening following critical illness and next steps. Implementation strategies can include educational materials for clinicians on rationale of screening and ICU risk and information for patients about post-ICU cognitive impairment, screening procedures, and expectations for recovery.

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