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Information and Counseling Gaps on Perioperative Neurocognitive Disorders Among Older Adults

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Abstract

Background: Perioperative neurocognitive disorders (PNDs) are among the most common complications in older adults after surgery. Awareness of PNDs is important as they often can be prevented, and early recognition can improve recovery. We sought to understand what older adults know about PNDs, the information provided, and the counseling provided to guide recovery when PND symptoms occur. We hypothesized that older adults rarely receive information regarding PND before surgery or counseling after experiencing symptoms.

Methods: We conducted a mixed methods study by (1) employing a survey to better understand the information patients received before surgery and (2) conducting semi-structured interviews in patients who subjectively experienced PNDs to better understand what counseling they received after experiencing symptoms. Surveys were distributed preoperatively to older adults undergoing elective surgery. Semi-structured interviews were conducted with older adults who had undergone

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Author Contributions

Cecilia Canales: study concept and design, acquisition of subjects and data, analysis and interpretation of data, and preparation of the manuscript. **Angela Chen:** acquisition of subjects and data, analysis and interpretation of data, and preparation of the manuscript. **Stephanie-Dee Sarovich:** acquisition of subjects and data, analysis of data, and preparation of the manuscript. **Ashley P. Oliver:** acquisition of subjects and data, analysis of data, and preparation of the manuscript. **Marcia Russell:** study concept and design, interpretation of data, and preparation of the manuscript. **Robert Whittington:** study concept and design, interpretation of data, and preparation of the manuscript. **Maxime Cannesson:** study concept and design, interpretation of data, and preparation of the manuscript. **Catherine Sarkisian:** study concept and design, interpretation of data, and preparation of the manuscript.

Conflicts of Interest

The authors declare no conflicts of interest.

surgery and experienced symptoms of PND. The quantitative data were summarized using descriptive statistics, and qualitative data were analyzed using a hybrid inductive and deductive approach.

Results: The response rate for survey participants was approximately 19%. Among survey participants ($n = 312$), 58% of participants were between 65 and 69 years of age, 24% were between 70 and 79 years of age, and 18% were ≥ 80 years of age. Before their scheduled elective surgery, 7% ($n = 22$) indicated a healthcare provider discussed the risk of PNDs during their preoperative visit. None of the patients received educational material regarding PNDs. Ten older adults participated in the semi-structured interviews, which revealed that 9 (90%) participants attempted to discuss symptoms after they occurred with a healthcare provider, but none received counseling or information on what to do next, and all were instructed to wait to see if symptoms persisted.

Conclusion: Our findings underscore that discussions about PND risk and symptom management do not occur as part of routine perioperative care, leaving patients without important information and guidance.

Keywords

anesthesia; cognitive outcomes; patient information; perioperative neurocognitive disorders; surgery

1 | Introduction

Perioperative neurocognitive disorders (PNDs) are the most common complications following surgery for individuals aged 65 years and older [1]. PNDs describe alterations in behavior or cognition that occur in the perioperative period [2, 3]. PNDs encompass a spectrum of conditions, including postoperative delirium (POD), delayed neurocognitive recovery, and mild or major postoperative neurocognitive disorders [2–4]. Over the past two decades, research has focused on understanding the mechanisms underlying PNDs, identifying predisposing risk factors, and developing standardized nomenclature to facilitate consistent comparisons across studies of PNDs [5–16]. Importantly, research has demonstrated that PNDs can often be prevented, and mitigation strategies can reduce the severity of symptoms or prevent their progression [17, 18]. Peden et al. [18], along with members of the Perioperative Brain Health Expert Panel, recommend discussions with patients and family regarding PND risks along with providing educational material as strategies to improve perioperative brain health.

Although professional organizations such as the American Geriatrics Society, the American College of Surgery, and the American Society of Anesthesiologists have recommended routine cognitive screening to help risk stratify, optimize, and counsel older adults for improved cognitive outcomes, a survey of anesthesiologists revealed these guidelines are rarely implemented in practice [19–21]. This lack of information and counseling can lead to misconceptions and mistrust in healthcare providers [22, 23]. A failure to adopt routine cognitive screening and counseling represents missed opportunities for early identification and patient optimization. Furthermore, a recent study found that many patients were often

unaware they had documented episodes of PND, highlighting gaps in communication between patients and providers [23]. More concerning, it means patients may not receive critical information about the potential for neurocognitive disorders after surgery or the steps necessary to manage symptoms effectively [18, 24].

The primary objective of this study was to examine the type and extent of information or counseling patients receive about PND from their multidisciplinary teams through surveys and semi-structured interviews. Additionally, we explored the resources patients use to seek information on managing PND symptoms and how this differs between patients with prior surgical experience and those who speak languages other than English. We hypothesized that patients receive limited and inconsistent information about PNDs throughout their perioperative journey, leaving a critical gap in understanding how to manage their symptoms if and when they occur.

2 | Methods

This mixed methods study followed the Good Reporting of a Mixed Methods Study (GRAMMS) reporting guidelines [25]. It was approved by the UCLA Institutional Review Board (IRB#23–000139), and written informed consent was waived by the IRB for the qualitative and quantitative portions of the study. Oral consent was obtained for the semi-structured interviews prior to recording the interview.

2.1 | Quantitative Data

The survey portion of the study was conducted from May 2023 to September 2023 at a large academic medical center in Los Angeles, California, which serves a broad patient population and acts as a referral center for patients from outside Los Angeles and other states. All patients aged 65 or older scheduled for elective noncardiac surgery under general anesthesia were offered the survey. To capture a range of perspectives on surgical history and potential experiences with PND, both individuals with prior surgical experience and those without were included. All participants had the capacity to consent for their elective surgery. Research staff distributed the surveys in the pre-treatment unit, offering the survey in either paper or tablet format based on participant preference. Surveys were provided in the eight most commonly spoken languages at our institution: English, Spanish, Chinese (Simplified Cantonese and Mandarin), Korean, Tagalog, Farsi, Armenian, and Vietnamese. Participants also received an information sheet in their preferred language detailing the study aims, the voluntary nature of participation, and the elements of informed consent.

The survey included a mix of yes/no and open-ended questions designed to understand what patients know about PND, the information patients receive about PND during preoperative visits (e.g., preoperative clearance with primary care physicians or surgeons), and what, if any, educational material they receive. To enhance content validity, three content experts, who are members of the American Society of Anesthesiology Brain Health Expert Panel and Brain Health Initiative, reviewed the survey prior to administration to ensure the relevance and clarity of the questions. To enhance face validity, the survey was first administered in English to five anesthesiology residents or faculty, and their feedback was used to refine the questions. This process was then repeated with native speakers of the other languages

in which the survey was available. We piloted the survey for 1 week before full deployment in the pre-treatment unit to identify any technical issues with the tablet or ambiguities. All survey responses were collected anonymously and securely stored using the Research Electronic Data Capture (REDCap) platform.

2.2 | Qualitative Data

Semi-structured interviews were conducted one-on-one with community-dwelling older adults who had undergone surgery at community, private, or academic hospitals. Participants were recruited through flyers posted in preoperative and surgical clinics or referred to the study by other participants. Two community partners, an older adult with mild cognitive impairment (MCI)/early dementia and experience with PND along with his caregiver spouse, also distributed flyers at dementia support groups. Potential participants underwent telephone screening by study staff to verify eligibility based on inclusion and exclusion criteria.

Inclusion criteria included older adults (aged 65 or older) who had undergone surgery within the past 2 years and reported experiencing memory problems they attributed to their surgery. Eligible participants who expressed willingness to participate were scheduled for a ZOOM interview. Participants initiated the interview by calling or logging into a unique ZOOM link. Oral consent was obtained before recording began, and participants using video were instructed to turn off their cameras prior to recording to maintain anonymity.

The interviews were conducted in English or Spanish using topic guides developed by the authors (Supporting Information: Supplement 1). Open-ended questions were structured around three key topics:

(1) Knowledge and beliefs about PND, (2) counseling from healthcare providers regarding management of PND after symptoms occur, and (3) other information seeking behavior. All interviews were conducted by Cecilia Canales, a trained clinical scientist (M.P.H. and M.S.) and physician (M.D.). Interviews were audio recorded, transcribed anonymously, and translated into English as needed using a certified translation service.

3 | Data Analysis

Descriptive statistics were used to summarize participants' demographics and categorical groupings. Descriptive statistics were used to characterize responses to individual survey items for quantitative data. We compared differences between respondents who had undergone previous surgery and those who had not, as well as between participants with an English language preference and those preferring a language other than English. Differences between groups were tested using Pearson's chi-squared test.

Statistical analyses were conducted using IBM SPSS Version 29 (Armonk, NY), with a p value < 0.05 considered statistically significant. Qualitative data analysis was conducted by two authors (C.C. and A.C.). The transcripts were analyzed by a hybrid inductive (whereby themes, codes, and categories emerge from the data) and deductive (whereby topics, themes, codes and categories are chosen a priori, based on the three topics previously described)

approach. After familiarization with the data, the authors identified additional recurrent themes related to patient experiences. Coding differences between authors were discussed until consensus was reached. NVivo Version 14 software (Lumivivo, Denver, CO) was used to assist in coding the data set.

4 | Results

4.1 | Quantitative Data

4.1.1 | Participant Characteristics: The survey response rate was approximately 19%, with a total of 312 participants (Table 1A). To maintain anonymity, particularly for those aged 90 and above, age was categorized by decades: 58% were 65–69 years old, 24% were 70–79 years old, and 18% were 80 years or older. Among the respondents, 168 (54%) were female, and 126 (40%) preferred a non-English language. Of the 312 patients surveyed, 194 (63%) had undergone previous surgery, and among these, 66 (34%) reported experiencing subjective memory changes or difficulty concentrating after their last surgery by answering “yes” or “no” to “Did you or loved ones feel you had memory changes or problems concentrating after surgery?” When analyzed by age group, 12 patients (18%) aged 65–69 years, 23 patients (35%) aged 70–79 years, and 31 patients (47%) aged 80 years or older reported these subjective memory changes.

4.1.2 | Knowledge and Information About PND: “Do you believe confusion or memory problems can occur after surgery?”

Of the total sample ($n = 312$), 198 patients (63.5%) responded “yes.” Among those with no prior surgeries, 67 of 118 patients (56.8%) answered “yes,” compared to 131 of 194 patients (67.5%) with previous surgical experience ($p = 0.056$, Figure 1). When comparing language preference, 115 of 186 patients (61.8%) with an English language preference answered “yes,” while 83 of 126 patients (65.9%) with a non-English language preference answered “yes” ($p = 0.47$).

“Prior to your scheduled surgery, did any healthcare provider talk to you about risks of confusion or memory problems after surgery or anesthesia?”

Twenty-two of the 312 patients (7%) answered “yes.” Among those with previous surgical experience, 15 of 194 patients (7.7%) responded “yes,” compared to 7 of 118 patients (5.9%) with no prior surgical experience ($p = 0.55$, Figure 2). All 22 patients who answered “yes” had an English language preference and were at least 70 years old ($n = 9$ for patients aged 70–79 and $n = 13$ for patients aged ≥ 80).

When asked “were you provided with any educational material or resources regarding cognitive changes after surgery or anesthesia?”

No one answered “yes.”

4.1.3 | Risks of PND: Patients were asked an open-ended question: “List factors you believe may increase the risk of developing confusion after surgery.” The top three responses were: (1) age, (2) amount of anesthesia, and (3) medications given during hospitalization.

Age was cited as a risk factor 107 times (34%), the amount of anesthesia 95 times (30%), and medications administered during hospitalization 41 times (13%).

4.1.4 | Protective Factors Against PND: An open-ended question asked patient to “list things you think may protect against developing confusion after surgery.” The top three responses were: (1) staying active, (2) leaving the hospital; and (3) talking to family. Staying active (i.e., exercising, walking, getting out of bed) was mentioned as a protective factor by 127 patients (41%). Leaving the hospital was mentioned by 82 patients (26%). Talking to family was mentioned by 58 patients (19%).

4.2 | Qualitative Data

4.2.1 | Participant Characteristics: Interview participants consisted of 10 older adults who previously had surgery (Table 1B). Of these, 6 (60%) of the older adults were female, and four (40%) of the interviews were conducted in Spanish. Five of the 10 participants (50%) underwent surgery at a community hospital, three (30%) underwent surgery at an academic hospital, and two (20%) underwent surgery at a private hospital. Seven of the 10 (70%) participants were at least high school graduates. None of the study participants in the semi-structured interviews participated in the survey data.

The three topics explored (1) knowledge and beliefs about PND, (2) counseling from healthcare providers regarding management of PND after symptoms occur, and (3) other information seeking behavior, yielded additional themes including lack of formal diagnosis, absence of discharge instructions or next steps, and an inability to have meaningful discussions with healthcare providers (Table 2).

4.2.2 | Topic 1: Knowledge and Beliefs About PND: Before surgery and experiencing symptoms, one participant had early dementia with a baseline diagnosis of MCI and was aware of the risk of PNDs. They are an active member of a dementia support group, and preserving cognition after surgery was a stated priority. Their first surgery after their MCI diagnoses was semi-emergent, while the second and third surgeries were elective. Before the elective procedures the patient proactively read scientific journals on topics of post-operative cognitive dysfunction (POCD) and searched the internet to find information. They had experienced a permanent decline in cognition after the first semi-urgent procedure and thought being better prepared would allow for better discourse with their providers and would help preserve their cognition. Two (20%) other participants (one English language preference and one non-English language preference) indicated they had heard of terms like “brain fog” or knew others who “were not the same” after surgery but never explored what that meant. One participant (English language preference) indicated their son is a physician and counseled them extensively before surgery regarding risks of memory changes after surgery.

4.2.3 | Topic 2: Counseling From Healthcare Providers Regarding Management of PND After Symptoms Occur: Nine (90%) participants discussed symptoms with a healthcare provider. One participant had a baseline diagnosis of MCI, and he scheduled a follow-up appointment with his neurologist. Five (50%) discussed symptoms

with their surgeon at the follow-up appointment, but none received additional consultations. Four (40%) participants were told that symptoms were normal and temporary and were instructed to wait for them to self-resolve; one (10%) participant was instructed to follow up with their primary care provider if symptoms persisted. Two (20%) scheduled appointments with their primary care provider to discuss symptoms and were both instructed to wait to see if symptoms persisted. One (10%) saw his geriatrician who gave them information about POCD and instructed the patients to wait. Only the patient who visited their neurologist received formal neurocognitive assessments, and one (10%) received educational material regarding PND from the geriatrician.

4.2.4 | Topic 3: Information Seeking Behavior: After surgery and experiencing symptoms, one participant indicated his geriatrician gave him information about POCD. Five (50%) participants reported searching the internet alone or with the help of friends or family to better understand the symptoms. Three of the five participants indicated they were searching for answers regarding how long they could expect to experience their symptoms, causes, and treatments (Figure 3). When asked what internet resources they used, all five patients indicated they searched primarily by entering terms into their search engine and used the resources based on the top results or what sounded “credible” or “legitimate” Participants described reading news stories or watching videos from doctors or patients that validated their symptoms and reflected their own experiences.

4.2.5 | Recurrent Themes: There were recurrent themes that emerged during the interviews:

4.2.5.1 | Theme 1: Lack of Formal Diagnosis. No participants remembered being told directly by a healthcare provider that they experienced POD while hospitalized, though 3 (30%) reported healthcare providers did discuss “delirium” with family or caregivers, and those family members shared that information with the participant.

4.2.5.2 | Theme 2: Lack of Discharge Instructions or Information. At hospital discharge, none of the participants (including those whose family indicated healthcare providers discussed delirium) were given discharge instructions on what to do or whom to contact should cognitive symptoms persist after discharge. Many participants (90%) also reported a lack of information or support regarding PND symptoms, causes, or treatments. As a result, they turned to the internet for guidance on understanding and managing their symptoms (Figure 3).

4.2.5.3 | Theme 3: Inability to Have Meaningful Discussions With Healthcare Providers. Participants (90%) expressed frustration at not being able to have meaningful discussions with their healthcare providers, often feeling dismissed, with comments such as “oh this happens sometimes, it should go away.” The most common instruction was to wait to see if symptoms persisted, without guidance on what to do in the meantime, how long they should wait, or who to talk to if symptoms persisted. Another source of frustration was the lack of ownership to deal with symptoms from healthcare providers regardless of specialty (surgery or primary care physician). Primary care providers and surgeons believed other physicians were responsible for providing further instructions if symptoms persisted.

This left the participants feeling alone in managing the symptoms of cognitive changes after surgery.

5 | Discussion

We found that in a large urban healthcare system, discussions about PND risk and symptom management are rarely occurring, leaving patients without important information and guidance. Our study also highlights significant gaps in patient education regarding the risk of PND before surgery and the lack of structured counseling on managing symptoms when they occur. While most survey respondents, regardless of surgical history or language preference, acknowledged that surgery can lead to cognitive complications, only 7% reported receiving any information about PND. Notably, discussions about PND occurred exclusively with English-speaking patients.

This finding aligns with prior research by Deiner et al. [20], who identified a disconnect between recommendations from major medical organizations and actual clinical practice regarding informing patients about the risk of POD and cognitive disorders. Our study further indicates that this gap extends beyond anesthesiologists to include surgical and primary care providers, suggesting that preoperative and postoperative cognitive health discussions are not routine components of patient care. Instead, patients primarily rely on personal experiences and informal networks for information, leading to incomplete or inaccurate knowledge. Li et al. [22] examined public discussions on PND and found a misalignment between professional recommendations and lay understanding, with widespread misconceptions about the role of perioperative care, including the role of anesthetic approach, despite multiple randomized controlled trials showing no difference between approach and PND risk [26, 27]. Despite increasing awareness of PNDs among healthcare providers and geriatric, anesthesia, and surgical professional societies [4, 13, 19, 20] having long recommended formal preoperative cognitive screening as part of risk assessment for PND, we are unaware of any data quantifying how often structured follow-up for cognitive symptoms are performed, with recent findings indicating that even when providers believe they are performed, they are rarely available in the medical record [21].

In a study by Cohen et al. [23], on POD after cardiac surgery, it revealed misalignment between documented episodes of POD and what was communicated to the patient. Participants in our study expressed confusion, frustration, and helplessness due to the absence of clear communication about PND. Addressing these emotional needs through comprehensive discharge instructions and follow-up support might help alleviate some of the burdens and improve overall well-being. Our study participants also reported significant frustration over the lack of ownership from healthcare providers in the follow-up and management of PND symptoms after hospital discharge. Many participants expressed uncertainty about which provider was responsible for addressing PND symptoms, leading to delays in recognition, diagnosis, and appropriate management. Given the temporal relationship between cognitive symptoms and surgery, many participants expected their surgical provider to take an active role in discussing PNDs. However, surgical teams often focus on immediate perioperative outcomes and may not routinely address long-term cognitive complications, leading to a perceived gap in care. On the other hand,

some participants expected their primary care provider to manage these symptoms, given their longstanding patient-physician relationship and broader role in chronic disease management. Studies have indicated that cognitive complications after surgery often go unrecognized in primary care settings, as there is no standardized approach to screening or intervention following hospital discharge [28, 29]. Standardized educational materials integrated into preoperative and post-operative care could potentially improve understanding and preparedness.

Most older adults undergo several preoperative appointments with surgeons for surgical planning and with geriatricians, primary care physicians, cardiologists, internists, or anesthesiologists for preoperative clearance and optimization. Yet key elements of communication and optimization are clearly lacking. Our study suggests more can be done to enrich a whole person-centered approach to surgery-related cognitive care. Geriatricians can play key roles within health institutions integrating clinical care that emphasizes the cognitive health of older adults before, during, and after surgery. This might be done with hospital-wide initiatives such as the Age-Friendly Health Systems [30] or by embedding key elements into the surgical workflow, such as comprehensive geriatrics assessments [31]. Such assessments would include cognitive screening and risk assessment, while also providing an opportunity for education alongside informed consent. Hogen et al. [32], noted that PNDs should be part of informed consent by surgeons, something that has clearly not made it into practice. Likewise, integrating subjective cognitive symptoms may be helpful in starting discussions with patients, given their inclusion in the definition of PNDs since 2018 [33].

6 | Limitations

The largest limitation of this study is its single-center design, which may not be representative of the broader population of older adults undergoing surgery. Further, participants self-identified for the semi-structured interviews, which may have resulted in a selection bias over expressing frustration or concern. The limited sample size for semi-structured interviews ($n = 10$) with half being from community hospitals precludes theme saturation and limits generalizability. Additionally, the study relied on self-reported data, which can be subject to recall bias and inaccuracies.

7 | Conclusion

Our findings underscore that discussions about PND risk and symptom management are not occurring as part of routine perioperative or primary care, leaving patients without essential information and guidance. This lack of communication may contribute to uncertainty and distress among patients, who struggle to navigate cognitive complications without clear direction from their healthcare team. Without information, patients and their families may be less equipped to advocate for care or recognize the need for further intervention.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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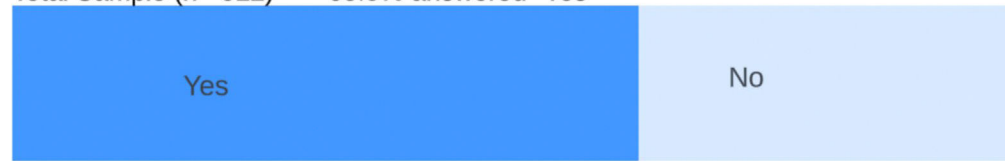
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Summary

- Key points
 - Few older adults receive information about neurocognitive disorders (PNDs) before surgery.
 - Patients experiencing symptoms of PNDs rarely receive post-surgical counseling.
 - Gaps in perioperative education leave patients uninformed about PND risks and recovery strategies.
- Why does this paper matter?
 - Perioperative neurocognitive disorders (PNDs) are common yet often overlooked complications in older adults, with only 7% recalling any preoperative discussion about cognitive risks and none receiving educational materials. This study reveals critical gaps in patient education and support, highlighting the urgent need for system-level interventions that integrate structured counseling into perioperative care pathways.

Do you believe confusion or memory problems can occur after surgery?

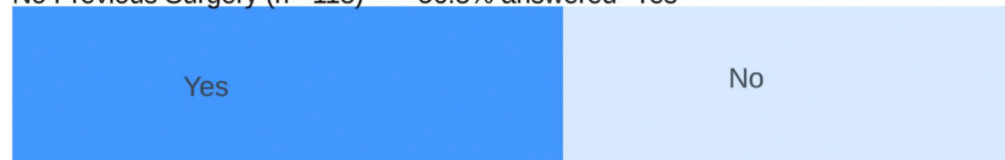
Total Sample (n= 312) 63.5% answered "Yes"



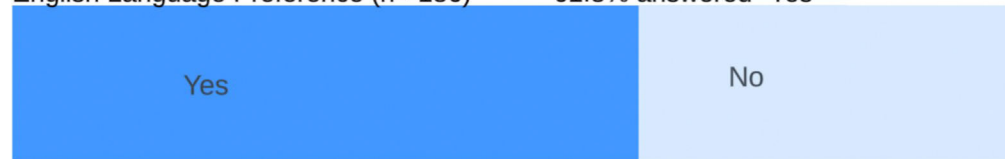
Previous Surgery (n= 194) 67.5% answered "Yes"



No Previous Surgery (n= 118) 56.8% answered "Yes"



English Language Preference (n= 186) 61.8% answered "Yes"



Non English Language Preference (n= 126) 65.9% answered "Yes"

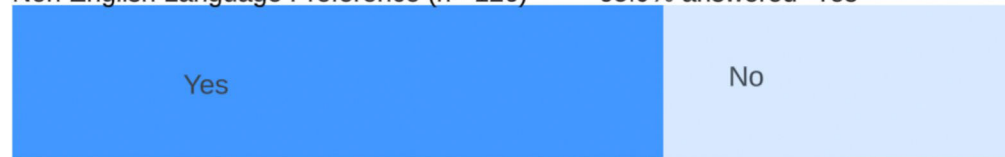


FIGURE 1 |.

Survey respondents who believe cognitive changes can occur after surgery. Presented by total sample and subgroups based on previous surgical experience and language preference.

Prior to your scheduled surgery, did any healthcare provider talk to you about risks of confusion or memory problems after surgery or anesthesia?

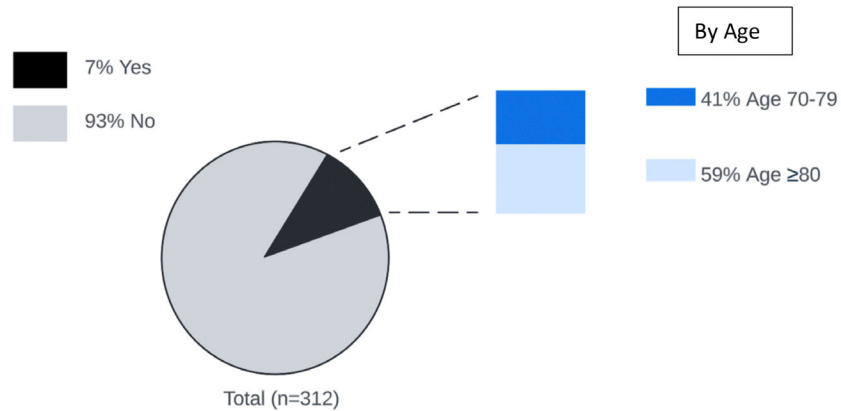


FIGURE 2 |.

Respondents who had conversations with healthcare providers regarding the risk of perioperative neurocognitive disorders. Respondents who had conversations with healthcare providers regarding the risk of perioperative neurocognitive disorders. The 7% who responded yes were stratified based on their age.

Symptoms Brain fog Anesthesia fog Problems concentrating Memory issues after surgery Not myself after anesthesia Why can't I remember things? What is happening to me?	Expectations How long will memory issues last after anesthesia? Am I going to be ok? How long will this last? Is this permanent? Can this happen again?	Risk of Dementia Dementia after surgery Alzheimer's risk after general anesthesia
Cause What caused this? Did anesthesia cause my memory problems?	Treatment What can be done to help me? What should I do? What should I avoid?	

FIGURE 3 |.
Patient internet search terms. The terms used by respondents to search the internet when they experienced symptoms of perioperative neurocognitive disorders.

TABLE 1 |

Demographics.

A. Survey participants (n = 312)				
Characteristics	Total (n = 312)	English (n = 186)	NELP (n = 126)	p
Age, n (%)				
65–69	180	111 (60%)	69 (55%)	0.67
70–79	75	42 (23%)	33 (26%)	
≥ 80	57	33 (18%)	24 (19%)	
Female, n (%)	168	103 (55%)	65 (52%)	0.51
Education, n (%)				
High school graduate or greater	276	168 (90%)	108 (86%)	0.30
Previous surgery, n (%)	194	117 (63%)	77 (61%)	0.75
Subjective memory changes, n (%)	66	34 (18%)	32 (25%)	0.13
Language preference, n				
Armenian			11	0.11
Chinese			23	
English		186		
Farsi			16	
Korean			4	
Spanish			51	
Tagalog			13	
Vietnamese			8	
B. Interview participants (n = 10)				
Characteristics	Total (n = 10)	English (n = 6)	Spanish (n = 4)	
Age, mean (SD)		74.8 (4.4)	74.2 (7.3)	
Female, n (%)	5	3 (50%)	2 (50%)	
Education, n (%)				
High school graduate or greater	7	6 (100%)	1 (25%)	
Surgical setting				

Community hospital	5	2	3
Academic hospital	3	3	0
Private hospital	2	2	0

Abbreviation: NELS, non-english language preference.

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TABLE 2 |

Topics and representative quotes for patient interviews.

Topics	Representative quotes
Knowledge and beliefs about PND	“Honestly, no. Like I said, my whole family. All the women, they are sharp. They have endured so much. Plus was more worried about the surgery itself, you know, whether it would go smoothly and how long it would take to get back on my feet. The thought of memory issues never really crossed my mind until it hit me.” [PE001] “Doctor, know people who never recovered their memory. Mrs. [name] fell and broke her hip. She lost her memory. She became invalid and died within a year. Mr. [name], he had a heart attack and the same thing happened. He lost his memory, they had to put a tube for him to eat, and within a year, he passed away. Of course, was worried about memory decline. But my heart was failing. One has to try to do something, right?” [PS010]
Information seeking behavior after PND symptoms appeared	“I searched the internet... just looked for things that sounded like me. Things that sound credible. There were some videos, some of them were doctors I think, and then there were some news articles, those were very helpful. But sometimes you go down a rabbit hole and who knows where it will lead you.” [PE005]
Counseling from healthcare providers regarding management of PND	“I talked to my geriatrician. He told me that there is this thing called P.O.C.D. he said some people, the brain, it just doesn’t tolerate the anesthesia so then they start to develop these memory problems. That’s what’s happened to me. The more anesthesia symptoms I have, the worst it has gotten.” [PE005] “[Surgeon]... but you lose trust when they make you feel like it’s just you, like it’s no big deal. So mostly have managed myself. go on the internet, read, and manage day by day.” [PE001]
Themes	Representative quotes
Lack of formal diagnosis	“I don’t know what delirium is... My son, he said they kept on asking me my name, they kept on asking if knew where was. So think they knew was confused... [the doctors did not say]... I had to tell them. told my doctor that was having problems” [PS010]
Lack of discharge instructions or next steps	“[My daughter]... she knew was delirious, was not acting myself, and she talked to the doctors. They told her what was going on. But they didn’t give her any information about what to do next. That is why she talks about it at every doctor’s visit, with every doctor, but none of them give her the information she wants.” [PE003] “I don’t recall receiving any specific information about [delirium]. They probably just assumed everything would go back to normal once was home.” [PS009]
Inability to have meaningful conversations with healthcare providers	“They don’t let you talk. They talk to you. You go, they ask you the questions. Are you taking your medications? Are you doing your rehabilitation? Are you walking? Are you drinking? Are you smoking? answer their questions but they don’t leave room for you to say anything. You are done, you are out.” [PS006] “I made sure to let them know loud and clear. But don’t think they took me seriously.” [PE007]

Abbreviation: PND, perioperative neurocognitive disorder.