Original Research

Barriers and Facilitators to Rehabilitation Care of Individuals With Spatial Neglect: A Qualitative Study of Professional Views

Peii Chen, PhD a,b, Jeanne Zanca, PhD a,b, Emily Esposito, MS c, A.M. Barrett, MD d,e

Abstract
Objective: To identify barriers and facilitators to achieving optimal inpatient rehabilitation outcome among individuals with spatial neglect (SN).
Design: Cross-sectional, semistructured focus group discussions.
Setting: Rehabilitation hospitals.
Participants: A total of 15 occupational therapists and 14 physical therapists treating patients with SN on 3 campuses of a rehabilitation hospital system (N=29). Six focus group sessions were conducted and audio-recorded for transcription.
Interventions: Not applicable.
Main Outcome Measures: Not applicable.
Results: Participants identified several patient-related characteristics that posed barriers to treatment, including the symptoms of SN itself, cognitive issues, physical weakness, comorbidities, and reduced therapy engagement. Supportive family members were considered a key facilitator, but lack of preparedness to assume caregiving roles, poor understanding of SN and rehabilitation goals, and inadequate levels of involvement were family-related barriers to successful treatment. Participants expressed that having resources and technologies available at

KEYWORDS
Hemispatial neglect; Neurological rehabilitation; Rehabilitation; Rehabilitation hospitals; Stroke rehabilitation

List of abbreviations: EBP, evidence-based practice; OT, occupational therapist; PT, physical therapist; SN, spatial neglect.
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Spatial neglect (SN) has significant effects on inpatient rehabilitation among patients with stroke or other types of brain injury. Because of damaged attention networks critical to spatial processing and related cognitive and motor functions, affected individuals pay no or insufficient attention (hence, “neglect”) toward the contralateral side of space and demonstrate abnormal bias or deviation toward the ipsilesional side of space. The deficits created by SN disrupt basic self-care activities, impair postural balance, interfere with reading ability, affect spatial memory retrieval and mental imagery, and impede navigation when walking or using a wheelchair. SN also increases the risk of falls and injuries and intensifies burden and stress among family members. Importantly, many individuals with SN are unaware of their own symptoms or the consequences of their deficits, which delays their seeking appropriate treatment or learning compensatory strategies. The disabling consequences of SN may last for a number of years after stroke and long-term outcomes among patients with nonstroke brain injury are not well understood.

Despite advances made in rehabilitation research on SN interventions and identified barriers to evidence-based practice (EBP), recent reports have shown the same poor outcomes associated with SN as reports published decades ago. There remains a disconnection between knowledge of best practices and their implementation. One way to bridge this gap is to examine the real-world context in which treatment is given to people with SN. Greater knowledge of the challenges clinicians face and the supports available to them will inform efforts to facilitate implementation of evidence-based interventions. Therefore, our objective was to identify barriers and facilitators to current SN care in inpatient rehabilitation. We conducted a qualitative study, using the format of focus group discussions, with physical therapists (PTs) and occupational therapists (OTs). PTs and OTs provide treatment daily to patients with SN and usually carry out therapy activities side by side in the same space. They may encounter similar barriers and facilitators to care and treatment delivery even though their scopes of practice differ. The study was conducted and reported following the consolidated criteria for reporting qualitative research.

Methods

Participants

The study was approved by the local Institutional Review Board. PTs and OTs were recruited from 3 campuses of the same rehabilitation hospital system (located in different counties of the same state). This hospital system receives approximately 1800 admissions of patients with neurologic conditions each year, including 1500 stroke admissions. Approximately 80 PTs and 75 OTs are employed in this hospital system. Study invitations were emailed to therapy managers who shared with their staff. The email stated the eligibility criteria and the estimated time of a focus group session (2-3 hours after work). Therapists were eligible if they were currently treating patients with neurologic conditions such as stroke. At the beginning of a focus group session, therapists provided informed consent.

Procedures

Each therapist attended 1 focus group, which took place in a conference room or gym in the rehabilitation hospital where they were employed. A focus group session was scheduled after at least 4 therapists volunteered. A total of 6 focus groups (1 OT group and 1 PT group in each of the 3 hospitals) were held between September 2016 and March 2017. We chose to conduct separate focus groups for OTs and PTs to increase the likelihood that terminology and discipline-specific activities discussed in the focus groups would be familiar to all participants and to provide an opportunity to assess similarities and differences in the perceptions of each discipline.

One of the authors led all the group meetings, using prepared semistructured open-ended questions that covered the following topics: identifying and communicating with colleagues about SN, how treatment planning and implementation is influenced by SN, types of interventions used to reduce or compensate for SN, challenges encountered when treating patients with SN, factors that are helpful in the treatment of SN, and how SN influences outcomes. The latest published guidelines about treatment for SN were briefly discussed at the end of the session as time allowed. Detailed procedures are described in appendix 1.
Data management and analysis

Data were analyzed using a consensus approach to identify themes relevant to barriers and facilitators to achieving optimal rehabilitation outcome in patients with SN. Transcripts were imported and coded into NVivo. Detailed data management and analysis methods are described in appendix 1.

Results

Demographic information and clinical experience of participants, including 15 OTs and 14 PTs, are summarized in table 1. Most OTs had a Master’s degree, whereas more PTs had a clinical doctorate degree (ie, DPT), which reflects the difference in the licensure requirements between the 2 disciplines.

Themes emerged pertaining to patients, family members, clinicians, the rehabilitation hospital, and the health care system (fig 1). Participants identified several patient characteristics that created barriers to treatment, including symptoms of SN, SN-related self-awareness problems, low motivation or poor therapy engagement, physical weakness, and other comorbidities, all of which contributed to poor treatment efficiency (see syntheses and example quotes in table 2). Participants also reported several challenges related to family members, including lack of physical, mental, or emotional preparedness to assist their loved ones; poor understanding of the diagnosis or the goal of rehabilitation; instances of inappropriate behavior; and inadequate levels of family involvement (table 3). Clinician-focused barriers were staff limitations in knowledge and experience in SN care and communication barriers among clinicians because of documentation or disciplinary differences (table 4). One hospital-level barrier was identified, which was facility and equipment limitations (table 5). Lastly, participants identified several health care system–level barriers, including a lack of responsive measures of progress, insurer-related issues, and care discontinuity between transitions such as from inpatient rehabilitation to skilled nursing (table 6).

The facilitators related to patients were the opposite characteristics described in the barriers (see table 2). Positive or successful family involvement was identified as a facilitator (see table 3). Peer support and support staff availability as well as support from managers and physicians were clinician-focused facilitators (see table 4). At the hospital level, 3 facilitators were identified, including facility and equipment resources, research collaborations, and education programs for staff (see table 5). Therapists also discussed the collaboration between inpatient and outpatient units as a good example of a fluid continuum of care, a facilitator at the health care system level (see table 6).

Discussion

The present study identified barriers and facilitators to current SN care in inpatient rehabilitation from OTs’ and PTs’ perspectives. Therapists described SN as a complicated syndrome with motor and cognitive symptoms. They talked about patient characteristics, linked those characteristics to the challenges in treatment provision and interactions with family members, related patients’ characteristics to staff support and clinical communications, and explained the situation in the current health care system. Therapists shared their experience in having access to resources while acknowledging that not all clinical settings had the same level of resources available for SN treatment. Themes identified in the present study align with previous studies that offered reasons for the difficulties in knowledge translation and EBP implementation in stroke care and rehabilitation. However, our specific focus on current SN care shows that these barriers affect not only the implementation of new interventions but all interventions. Investments made in addressing modifiable challenges and enhancing supports in real-world treatment contexts can improve current care and the adoption of EBP.

Patients and family members

SN by itself is a barrier to inpatient rehabilitation because it affects the ability to use certain therapy formats (eg, group session) or devices, to train with the affected limbs, to practice movements on the neglected side (eg, transfer training, dressing and grooming), and to learn compensatory strategies. Patients who participated little in therapies involving affected limbs are denied the benefit of contralesional limb activation, which can ameliorate SN. Patients with severe SN symptoms are likely to have other problems that slow rehabilitation progress, such as hemiplegia, hemianopia, delirium, infections, pain, or fatigue. In addition, patients’ anosognosia for SN, lack of understanding of therapists’ efforts, other coexisting cognitive deficits (eg, memory impairment), or low motivation impede rehabilitation progress from 1 therapy session to the next, which was referred to as “poor carryover” by therapists in the present study. Safety concerns created by SN limit independence even if substantial strength and mobility has been regained. Many patients, regardless of SN severity, are deemed by therapists to need supervision. This means that their level of functional independence is always lower than patients without SN but with similar level of physical abilities, which can be discouraging and burdensome for family caregivers who have little experience in supervising their loved ones in daily life. Therapists in the present study agreed that involving family members early or interacting with them more frequently may help improve health literacy and the understanding of inpatient rehabilitation. Family members may not be prepared for taking the caregiver role although they intend to take the role by learning how to manage SN-related deficits and providing extra supervision. Nonetheless, family members may not share the clinician’s concept of SN and may see symptoms as related to confusion, problems with motivation, or psychological denial. If the symptoms are mild or presented infrequently, family members may find SN a low priority. Thus, family members may be unable to instruct patients effectively to initiate movements toward the neglected side. This can take a toll on the patient-family relationship. If a patient with SN cannot engage in therapy similarly to a patient who does not have SN, family members’ trust on clinical care may be affected, which could be
perceived as a family member–related barrier by the clinician. Family involvement has gained much emphasis in inpatient rehabilitation. 60,61 and 1 study showed beneficial effects of family-mediated exercises on SN improvement.62 Innovative intervention paradigms are needed to cultivate a constructive social support system for patients with SN as well as their family members.

Clinicians, hospitals, and the health care system

Themes related to clinicians and hospitals are aligned with the previous study focused on OTs only.43 OTs and PTs in the present study reported that they had great support from peers and senior faculty, other clinical and service staff, and the management leadership. Therapists reported having access to many if not all facility and equipment resources (eg, specific treatment devices, availability of private space, feasibility of rearranging the physical setup of the room), a flexible schedule to meet individual patients’ needs, the freedom to try new treatment approaches, and various channels to gain knowledge (eg, grant rounds, journal clubs, collaborations with researchers). However, many therapists reported their limitations in experience and knowledge in detecting and treating SN. It is impossible to ask therapists and health care professionals to become experts on every problem that results from brain disorders. As expressed by therapists in the present study, having therapy specialists for SN can greatly help the care and management of patients with SN. The specialist reportedly trained staff on SN assessment and treatment, gave refreshing courses, and facilitated communications among different

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Occupational Therapists (n=15)</th>
<th>Physical Therapists (n=14)</th>
<th>Both (N=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%)</td>
<td>14 (93.3)</td>
<td>10 (71.4)</td>
<td>24 (82.8)</td>
</tr>
<tr>
<td>Age (y), median (IQR)</td>
<td>30 (26-33)</td>
<td>29 (28-30)</td>
<td>29 (27-32)</td>
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<tr>
<td>Race, n (%)</td>
<td></td>
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<tr>
<td>White</td>
<td>12 (80.0)</td>
<td>13 (92.9)</td>
<td>25 (86.2)</td>
</tr>
<tr>
<td>Asian</td>
<td>2 (13.3)</td>
<td>1 (7.1)</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (6.7)</td>
<td>0</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Hispanic, n (%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Level of education, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>0</td>
<td>1 (7.1)</td>
<td>1 (3.4)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>13 (86.7)</td>
<td>0</td>
<td>13 (44.8)</td>
</tr>
<tr>
<td>Doctorate degree</td>
<td>2 (13.3)</td>
<td>13 (92.9)</td>
<td>15 (51.7)</td>
</tr>
<tr>
<td>Clinical experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time in any rehabilitation (y), median (IQR)</td>
<td>2.5 (2-5.5)</td>
<td>5 (4-6)</td>
<td>4 (2.5-5.5)</td>
</tr>
<tr>
<td>Time in inpatient neurorehabilitation (y), median (IQR)</td>
<td>2.5 (2-5)</td>
<td>4 (2.5-5)</td>
<td>4 (2-5)</td>
</tr>
<tr>
<td>Current time in inpatient neurorehabilitation (h/ wk), median (IQR)</td>
<td>32.5 (20-40)</td>
<td>30 (25-40)</td>
<td>32.5 (25-40)</td>
</tr>
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Abbreviation: IQR, interquartile range.

Fig 1 Themes identified pertaining to barriers and facilitators at 5 levels.
<table>
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<tr>
<th>Barriers</th>
<th>Syntheses and Quotes</th>
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| **Symptoms of SN** | • Many therapists described how SN creates impairments of postural control and balance that render them unable to participate in many activities needed for functional improvement, such as gait training or practice of transfers.  
  ○ “They’re going to have the same physical impairments as someone who doesn’t have [SN]. So it’s the same problem plus more. . . . A lot of times you may not be able to address the strength and mobility until you have addressed the vision or neglect enough to make [the therapy] functional.” — PT  
  ○ “. . . if [SN] really affects their midline or their sitting balance, you can’t [train them to] do toilet transfers or wheelchair transfers.” — OT  
  ○ “[Because of problems in] their postural control and sitting balance, I’m probably not going to get that patient on to [the robotic rehabilitation systems we have available].” — OT  
  • One SN symptom discussed in length was distractibility or “attention problems.” Patients with SN would be distracted by stimuli in the ipsilesional side of space, making it more difficult for them to engage in therapy activities.  
  ○ “Their world is so limited that anything on that unaffected side is going to really pull that attention. You have people who are externally distracted . . . or you have the people who are internally distracted—‘pain, pain, pain, I have pain, I have pain.’ You have to kind of overcome some of those barriers before you can even get to them to the point of attending to the left. . . .” — OT  
  • Many therapists conceptualized SN as poor spatial awareness of the contralesional side of space.  
  ○ “They’re sitting there, and they just don’t know. . . . You just can’t leave them at the edge of the mat [because] it’s unpredictable. Their arm could slip off, but they don’t have protective extension reactions, and they just go down.” — PT  
  ○ “They’re not aware. . . . You ask them where’s your cell phone, and they say ‘oh it’s right there on the table’ and then you spin them around [so that the cell phone and table are now in the other side of space relative to their body] and they say ‘well I know it’s on the table, but the table’s not there.’” — OT  
  ○ “. . . getting their arm caught in the wheelchair when they’re sitting down. . . . Decreased awareness of a body part [is] kind of alarming.” — OT |
| **SN-related self-awareness problems** | • In addition to using “awareness problems” or “poor insight” to describe SN symptoms, therapists often used the same terminology to refer to failure to recognize one’s own deficits, a phenomenon known as anosognosia. Therapists reported observing this phenomenon most with patients who had higher function levels, such as the ability to walk, and whose anosognosia became a safety issue.  
  ○ “They don’t realize that they’re missing things on the left.” — OT  
  ○ “[With] those more ambulatory patients, you would think that their awareness is better, but they’re in such denial. They could crash into something 14 times in one lap around the gym, and they’re like ‘I’m fine, I’m fine.’” — OT  
  ○ “The inability to recognize that [SN is] even present is pretty significant.” — PT  
  • “Insight” was also discussed in terms of recognizing one’s own improvement or understanding feedback provided by therapists. This may have led to poor rehabilitation progress, which could be frustrating to therapists as well as patients.  
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| Low motivation or poor therapy engagement   | • Some patients were not interested in doing activities designed to address SN, perceiving them to be unrelated to their personal goals, such as return to walking.  
  ○ “From a patient perspective, we’re whipping out paper and pencil, [but] they want to be up and moving. . . . I had one [patient], and all he cared about was walking. He didn’t realize that doing [prism adaptation treatment] would help him walk in a safer manner, but the only thing on his mind was ‘I wanna walk,’ so anytime I set [prism adaptation treatment] up for him, he didn’t want to do it. So depending on the patient, it might just not be what their priority is.” – OT  
  ○ Therapists also shared that this barrier may result from unrealistic expectations about the short-term outcomes of rehabilitation.  
  ○ “I go into the hospital to get fixed, to get cured.’ [However] this is a type of injury that doesn’t just get fixed. You have to work towards your recovery, it’s going to take a lot of energy and you have to have a commitment of time, energy, and emotion from the patient and their family to recover from it.” – OT  
| Physical weakness                           | • As an SN symptom, many patients pay little or insufficient attention to the contralesional side of their body, which was usually physically impaired. This makes it challenging to address contralesional paralysis in therapy, becoming a vicious cycle.  
  ○ “[I cannot] tap into improving the strength, if [they are] not aware that [the limb] is even there . . . if you’re not aware that your left arm or your left leg is there, you can’t work on improving their range of motion because you don’t know it’s there.” – OT  
  ○ “[If patients had some capability of using their limbs], it’d be easier to incorporate the use and hopefully . . . in the greater scheme of things, improve the neglect over time.” – PT  

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<th>Syntheses and Quotes</th>
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| **Other comorbidities**        | • Therapists frequently mentioned “cognitive” impairments as a coexisting condition that impeded SN care delivery but typically spoke in general terms about the nature of these impairments.  
  ○ “Because neglect is a cognitive [disorder], you often see a lot of cognitive impairments that go with it, and so you’re battling multiple fights that all impede one another.” — OT  
  ○ “It’s really hard when we’re trying to give them [the] learning experience, letting them make errors. But they really can’t reflect on it or they’re not aware. Maybe their cognitive functioning is low.” — PT  
  ○ Therapists reasoned that the existence of memory problems impaired the ability to learn compensatory strategies, to remember steps to complete a task, or to recall educational information.  
    ○ “Compensatory strategies are really difficult as well if memory is a factor. Correctly using a tool that [they have] never used before can be a real barrier.” — OT  
  ○ Patients were described to have difficulty retaining information from one therapy session to the next or applying what was taught in therapies to self-practice outside therapy hours. This was often referred to as “poor carryover.”  
    ○ “We provide the education. Next time you don’t see the carryover as easily as with someone that doesn’t have neglect.” — OT  
  ○ Patients with SN who had a low function level were reported to have a low arousal level as well.  
    ○ “It becomes another problem to just keeping them awake. How would they attend to the other side if they have no arousal? I would do hand-over-hand especially for low-level patients.” — PT  
  ○ Treatment implementation was quite challenging when working with patients with both SN and aphasia or someone who had difficulties communicating in English.  
    ○ “Especially when you get [patients] with right-sided neglect because you usually get some language components going on. Those are really tough.” — OT  
    ○ “When you try to use the interpreter, their translation of [instructions] is a lot harder to explain.” — OT  
  ○ Patients who were medically unstable or had other comorbidities that affected functioning were considered difficult to treat.  
    ○ “If the person is medically unstable, . . . I might hold off on family trainings because you want to make sure that we are maximizing [family members’] time as well.” — OT  
    ○ “Obesity is a huge barrier to even achieving the goals because they might not be able to reach the parts that they need to perform certain tasks.” — OT  
| **Poor treatment efficiency**  | • Patients with SN were perceived to need more assistance, longer set-up time, and a greater number of repetitions to achieve the same result (if possible) as patients without SN.  
  ○ “Their recovery is significantly delayed. The world is just more frustrating when you have neglect. Whether they’re aware of it or not, things happen a lot slower and they just don’t understand why. Whereas you might get like 10 things done in a session with someone without neglect, with someone with that’s definitely cut in half.” — OT  |
### Table 2 (Continued)

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<thead>
<tr>
<th>Barriers</th>
<th>Syntheses and Quotes</th>
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<td></td>
<td>○ “If I’m in another room with them [and need to] pull out an aide from the therapy gym to be with me, which [took the aide] away from the main staff. The time it takes me to find the aide and bring them over also takes [me] away from the treatment as well.” – PT</td>
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<td></td>
<td>• Using group (&gt;2 patients per session) or concurrent (2 patients at a time) sessions were a means of increasing therapy time for patients with neurologic deficits. However, patients with SN were often not considered appropriate for groups because of their need for 1-on-1 assistance and reduced ability to interact with others.</td>
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<td>○ “If you have a concurrent session, you would want to get the two people doing the same task at the same time, throwing a ball back and forth, playing tic tac toe. . . . But if they need that more one-on-one attention [because they] can’t attend to half the field, then it is limiting how much they can interact with the other people. So that is a factor in terms of getting them into groups and treating them efficiently in a concurrent session.” – PT</td>
</tr>
<tr>
<td>Facilitator Quote</td>
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<tr>
<td>Patient characteristics</td>
<td>• Progress was easier to make in patients who had remaining strength in the neglected side of the body and who were cognitively able to self-detect errors and learn strategies. High patient motivation or good therapy engagement was felt to promote better outcomes, too.</td>
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<td></td>
<td>○ “The patient that I was speaking about before. . . . She can stand and walk, but we do really have to draw a lot of attention to the left side. . . . But for her it’s a lot easier because she knows. She has that awareness.” – PT</td>
</tr>
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### Table 3 Family member–focused barriers and facilitators with syntheses and example quotes

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Quotes</th>
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<tbody>
<tr>
<td>Lack of physical, mental, or emotional preparedness</td>
<td>• Therapists expressed concerns about whether family members who had poor physical health could monitor patients’ safety during mobility-related activities or provide necessary assistance to prevent falls.</td>
</tr>
<tr>
<td></td>
<td>○ “Family members’ own medical issues are a big barrier. . . . You know that this patient is going to need physical assistance, and then [the family member will] come in with a walker and your goals change.” – OT</td>
</tr>
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<td></td>
<td>○ “A patient may have a significant other, but if they are both in their 80s, or 70s, it’s not really safe for the significant other to be providing the guarding or the safety that they need.” – PT “[Because of problems in] their postural control and sitting balance, I’m probably not going to get that patient on to [the robotic rehabilitation systems we have available].” – OT</td>
</tr>
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<td></td>
<td>• Readiness for adopting a caregiver role could be problematic. Some family members could get very overwhelmed.</td>
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<td>○ “The family member also has to feel comfortable providing the assistance 24 hours or whatever we’re recommending. Sometimes we may think it’s feasible, and [the patient doesn’t] need that much cueing. But the family member is a little scared and they don’t feel like the patient should go home.” – PT</td>
</tr>
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<td></td>
<td>• The nature of the patient-caregiver relationship might affect willingness to perform intimate care tasks.</td>
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<td>○ “Are they comfortable helping [the patient] in the bathroom, in the shower? If it’s a mother who lives home with her son, you’re going to need someone else there. [Also, consider] a brother and a sister that live together.” – PT</td>
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<th>Barriers</th>
<th>Quotes</th>
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| • Therapists reported the importance of considering the readiness of family members to attempt certain care tasks.  
○ “There are certain things [the family member] is still not comfortable with and goes, ‘I’m just not ready.’ I said ‘that’s fine, you let me know when you are.’ I think it’s about meeting them where they are and not try[ing] to push them into doing things that are outside their comfort zone because that will backfire and ultimately compromise the discharge plan.” — PT  
○ “The concept of SN was not easy to understand, which often led to inappropriate provision of cues, instructions, or assistance to the patient.  
○ “[Family members] sometimes blame the patient, ‘Why can’t you just do this? This is a simple cue. Look at your left.’ They don’t get it. So then we have to educate them more than once, twice, depending on how receptive they are.” — PT  
○ “[Family members would say] ‘why aren’t they turning their head? I’m telling them to turn their head.’ Or ‘why aren’t they looking at me.’ They don’t understand that it’s not under the patient’s control.” — PT  
○ “A lot of times a patient’s spouse will come in. [They would speak in] rapid-fire speech. It’s. . . . It [shows] impatience.” — OT  
○ “It’s extremely distracting and depending on the patient’s or the family’s level of understanding as to what we’re trying to accomplish. . . . You may have a nagging [family member] who’s like ‘Listen, you have to turn, [the therapist] said to turn!’” — PT |
| Poor understanding of the diagnosis or the goal of rehabilitation |  
• Therapists shared their observations about negative family dynamics (eg, problems in the interpersonal relationship between the patient and the family), low level of family engagement in care (eg, no family available to attend family training as scheduled during weekdays, insufficient engagement in care decisions), inappropriate behavior during therapy (eg, playing with the service dog, talking over the therapist, comparing the patient and other patients in the gym), and lack of willingness to take care of the patient (eg, preferring institution over community discharge).  
○ “Just seeing how they interact with each other in the rooms [as] you’re walking by their room. They’re not even attending to the person. They’re outside talking on the phone. Even in the gym, they’re talking on the phone. Then [I wonder]. . . . Are they really truly interested, are they coming forward, or are they just there to bring the clothes in or change the laundry?” — OT  
○ “A lot of [patients] just don’t have family either at all or the family lives far away in another country or another state. It happens more often than not. They don’t have anyone else they can rely on for training. They have like their grandnephew who can come in or cheek in on them. [But] some distant relative is not someone who’s able to be there for them.” — PT |
| Family members’ behavior and inadequate levels of involvement |  
○ “[It] takes a lot longer with regard to family training purposes. Having them become familiar with what the neglect is, how to compensate for it, and all the different strategies that you have to utilize to maintain them.” — PT  
○ “[It] can be equally challenging to try and explain it. Especially when you have somebody who is already emotionally overwhelmed and is having a hard enough time absorbing basic information.” — OT |

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<td>○ “Sometimes culturally, you can run into issues if it’s like male versus female roles in the house and providing assistance for one versus another. Sometimes it’s the female’s job to be the caretaker so if the male is the one that is injured, it’s not so much a big deal. But if it’s vice versa, [I heard one male family member said] ‘that’s not what we do, our job is to not be here to take care of them.’ . . . Then who would be with this person when they go home. . . ?” — PT</td>
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<td>○ “The family members were kind of making the person feel bad about themselves. So when they have negative things, ‘well you can’t do this,’ or ‘why can’t you do that, you should be able to do that, it was so easy for you before.’ Things like that that really lower a person’s morale and ability to thrive so they begin to think ‘well my family says I can’t do it, so I’m not going to be able to do it.’” — OT</td>
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<td>○ “[The presence of] family members can [be] distracting for their loved one. [The patient] might not focus as much in therapy or might not be able to tolerate or want the loved one to help them.” — OT</td>
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<td>● Excessive family involvement was also reported to be problematic, requiring special effort on the part of the therapist to build a productive partnership with family caregivers.</td>
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<td>○ “[I have to] be firm and caring with [them] so that way they know that you care, and that they know that you are trying to serve their family member’s best interests. You are there for them as well, and they have to trust you. But . . . to get that trust takes a lot of time and a lot of energy.” — OT</td>
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<tr>
<td>Facilitator</td>
<td>Quotes</td>
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<tr>
<td>Positive or successful family involvement</td>
<td>● Therapists found supportive family members can make a difference in improving spatial attention and practicing strategies learned in therapy.</td>
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<td>○ “Sometimes families can be very motivating for patients. You can use them to get their attention to [the neglected] side and things like that.” — PT</td>
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<td>○ “A lot of [families] even in the beginning like the first couple days would say ‘Well what can I do to help make this neglect better? What can I do in the room to just try to help?’” — OT</td>
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Table 4  Clinician-focused barriers and facilitators with syntheses and example quotes

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<tr>
<th>Barriers</th>
<th>Quotes</th>
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| **Staff limitations** | Clinicians identified several issues that created barriers to SN treatment, including high staff turnover (ie, a relative great number of new staff members who need to get trained) and infrequent use of new treatments (eg, prism adaptation treatment was not used as often in one rehabilitation hospital than the others). A lack of training or experience pertaining to SN was often mentioned. Many therapists admitted their own limitations in terms of clinical experience and knowledge in implementing recommended best practice and limitations in the knowledge of other disciplines such as nursing staff and therapy aides.  
  - “I know a limitation for myself is that . . . [but] my window of experience is still pretty acute, and I don’t know what this looks like in six months.” – OT  
  - “I would love to collaborate with peers [who treat SN in a later stage]. That’s going to get me better prepare the patient because then I know what [the therapists in other postacute care] are working on later on. This way I can help set [the patient] up for that success, which I don’t really know right now.” – PT  
  - “Part of me would want someone to demonstrate and show me each one of [the recommended treatment options]. . . . Then I would use it. But just reading “neck muscle vibration,” [I can’t just use it]. I’d want to practice it first and see it and go over a protocol for each one about frequency and duration before implementing.” – OT  
  - “Most of the aides are not familiar with [SN]. When doing their ADLs, [the aides] will sometimes let the patient do it one-sided, like wash their hands and do everything on their good side and not facilitate.” – PT |
| **Communication barriers among clinicians** | Between primary and covering clinicians, there may be barriers created by unclear documentation (eg, coverage notes) on the plan of care specifically for SN.  
  - “[When I am covering another OT’s patients, I would like to be] able to understand a patient’s goals, what their focus is, whether it’s transfers, focusing on scanning strategies, walker management, body placement within the walker, rather than [simply] transfers for the plan of care. By the time I’m done with the transfers, [I realize] their vision is impaired, and I’m trying to figure out what the deficit is. By the end of the session, I know what it is but I [am not] able to really hone and focus on [the deficit related to SN].” – OT  
  - “One person might be a max assist towards the right and they’re a contact guard towards the left. But [the primary therapist] just [noted] the max assist. As [the covering therapist], you don’t know [the detail].” – OT  
  - “Especially with weekends when there are usually far more unplanned interactions with family members. People are like ‘oh I’m here, can I try, can I get trained?’ . . . I’ve been in that situation on a weekend where I had a family member who wanted to be trained on how to transfer a patient out of bed. But looking at the plan of care I’m not really sure if this is appropriate, and I don’t know if this is really one of the goals yet.” – OT  
  - Several therapists suggested that not having SN on the assessment template in the medical record and the lack of a standard interdisciplinary protocol for neglect rehabilitation created barriers to raising awareness of SN among clinicians. Even when the communication was displayed clearly with a specific message, it could still fail, especially between the therapy team and the support staff.  
  - “You can try anything. You can try calling the nurse the night before, writing it on [the patient’s] whiteboard, putting a date, time, things like that. They will still get [the patient] dressed. [Then I cannot assess ‘dressing’ for SN.]” – OT |
| **Facilitators** | Therapists praised the interactive and collaborative culture created by and with their peers and support staff. OTs and PTs shared the same space and treated patients side by side, exchanging ideas and making helpful suggestions based on clinical experience or patient-specific observations. Junior therapists appreciated the availability and generosity of senior therapists. In 1 rehabilitation hospital, a senior OT was |

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Table 4 (Continued)

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<th>Facilitators</th>
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<td>Available for extra treatment sessions, and therapists there would refer patients to her to increase therapy time. It was considered resourceful having the majority of OTs trained in the KF-NAP protocol assessing SN and in delivering prism adaptation treatment using the KF-PAT Portable Kit.</td>
<td>“Having everybody trained in all these measures and all these treatments is especially helpful. [Because then] it’s effortless to leave our coverage and say ‘do prisms’ or ‘do KF-NAP.’” — OT</td>
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<td>Support staff, such as therapy aides, were considered very important.</td>
<td>“[Aides] offer a second set of hands or a second set of eyes.” — PT</td>
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<td>— “The nursing aides set up the environment as we had instructed and educated on. They encourage the family to also encourage the patient to look towards that affected side. Even in the dining room, the servers taking orders would approach from that side. If that doesn’t work, then they try the unaffected side. Everybody is part of the rehab, even when they’re not actually in therapy, which I think is really, really good.” — OT</td>
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<td>Support from managers and physicians</td>
<td>Therapists expressed their gratitude toward their managers and considered interacting with specialists as facilitators to SN treatment delivery and care management. Managers provided support in terms of scheduling flexibility and acquiring new equipment requested by therapists.</td>
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<td>— An optometrist and a neurologist provided consultations in certain hospitals. Therapists would interact with them, exchanging information and progress about the patient, and see those interactions as great learning experience.</td>
<td>“I went to [the neurologist’s clinical rounds], and I had gotten some really good intervention ideas from her. That’s just another outlet for more support.” — OT</td>
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<td>— “[The optometrist] is a wonderful teacher. . . . He’s a great resource for the patients, but he’s also a great resource for us, so if we have a question you know we can call him and ask him.” — PT</td>
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### Table 5  Hospital-level barriers and facilitators with syntheses and example quotes

<table>
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<th>Barrier</th>
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| Facility and equipment limitations | • Having a piece of SN-specific equipment was considered a great resource, shared by an OT, but it was a barrier when multiple patients needed it at the same time.  
  • It was important to reduce distraction when treating patients with SN by having private space, which was not always available.  
    ○ “[Speech language pathologists] have their offices, and they can go to quiet places. OT[s] can do in-room therapy in the morning if they wanted to try that, which is still not an easy location, but it’s still like a one-to-one setting, where they can guarantee they can be one-to-one with that patient in the room. In PT, it’s not so easy to have an outlet to get them one-on-one in a private treatment gym at the time when there’s [only] one available.” – PT  
  • Therapists also shared that they wished modification of the setup of a patient’s room, which could help patients continue working on regaining spatial attention toward the contralateral side, outside of therapy sessions.  
    ○ “[Patients are] only in therapy 3 hours a day, but we want to incorporate [what was learned or practiced] as much as we can outside of therapy but of course maintaining a safe environment. But . . . if they’re in the room and everything is on the right all day long—their chairs are on the right, the TV’s on the right . . . a quick change [in orientation] could make a big difference for their downtime in the room where they are still working more or less on those things.” – PT |
| Facilitators | Quotes |
| Facility and equipment resources | • When available, a private room for treatment was considered a great resource. Even the shared therapy gym was considered a valuable resource for its sheer size and flexibility in how it could be used.  
  ○ “[Where we place the patient] for treatment is approachable from both sides, so we can always kind of figure out a way to make it work to patient’s advantage . . . whether it’s making them pay more attention to their neglected side or going towards their unaffected side for safety.” – PT  
  • Therapists praised the various selections of equipment available to them. They had flexibility with sessions to choose different devices or equipment such as tilt table, standing frame, mirrors, prism adaptation treatment equipment, touch screen-based visuomotor exercise, robotic upper limb training devices, harnessed treadmills, etc. Therapists agreed that they were well-equipped. |
| Research collaborations | • Therapists shared that interacting with research staff through studies on SN had increased awareness of SN among therapists.  
  ○ “We’ve become more involved in the study [related to SN]. [The stroke clinical research coordinator] and I do the study with [name of another therapist]. So I think that’s also increased our awareness in patients with neglect.” – OT  
  ○ “We’re lucky enough to have all these studies going on with a lot of our counterparts that are participating in them to really drive these guidelines probably almost on a daily basis with our patients with neglect.” – PT  
  • Keeping up to date on SN-related information helped increase their understanding of the syndrome and encouraged them to try new treatment.  
    ○ “A culture of research . . . makes it much more relevant to our day-to-day treatment. At least for me as a clinician, I feel like I’m actively contributing to the field, and [SN] is an important issue to be addressing.” – OT |
| Education programs for staff | • The rehabilitation hospital system was credentialed to provide a neurophysical therapy residency program for PTs, with 13 months of training and the opportunity to complete requirements for specialty certification. Therapists took this to be a great resource for education because |

(continued)
### Table 5 (Continued)

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<td>the residents were assigned research time and shared what they learned with others. PTs had journal clubs reviewing articles and promoting evidence-based practice. OTs reported online tutorial for neglect assessment to be beneficial.</td>
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<td>“Our neuro resident does so much reading . . . and describing of evidence-based stuff [to us]. So it kind of brings it to the forefront. And [a PT] runs a journal club and . . . get the evidence-based practice stuff in the gyms and . . . keep promoting everyone to keep asking questions.” – PT</td>
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<td>“I did think the [neglect assessment] training online was very helpful with the videos. . . . Seeing [examples] and having to score it is very beneficial.” – OT</td>
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<td>In one of the rehabilitation hospitals, a senior OT’s availability to train new staff was considered a resource for staff training.</td>
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<td>“We have [name of the senior specialist] who has more time allotted to teaching and . . . then being able to train us and our new therapists in using [prism adaptation treatment].” – OT</td>
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### Table 6  Health care system—level barriers and facilitators with syntheses and example quotes.

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<th>Barriers</th>
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<td>Lack of responsive measures of progress</td>
<td>• At the time of the present study, FIM was the measure indicating patient outcome and progress in the rehabilitation hospitals. Many therapists felt that the FIM was insensitive to SN symptoms, related deficits, or improvement. In particular, patients with SN needed supervision even if they were physically strong, leading to a lower FIM score.</td>
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<td>“You can only go up to 5 (supervision) when somebody has like a severe neglect, even they’re functionally recovered because it’s a safety issue. So [patients] don’t reach 6 or 7.” – OT</td>
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<td>“[Patients] are now at midline, they can do this and that that they couldn’t do before, but it’s not going to change their FIM score. Because it’s just not [sensitive] enough in order to capture that.” – PT</td>
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<td>“The FIM is required at admission and discharge, and the KF-NAP and the vision screens are only required at admission. We’re not reassessing any of that at discharge, so we’re not necessarily capturing the improvements [of SN].” – OT</td>
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<td>Insurer-related issues</td>
<td>• A patient’s insurance coverage determines the reimbursement available to cover a specific length of stay in inpatient rehabilitation. Therapists expressed dissatisfaction with the current length of stay being 2 weeks on average for patients with stroke, which gave therapists insufficient time to address SN. They said that insurance reimbursement policies appeared to focus on physical abilities, such as walking, and did not consider SN-related safety concerns when assessing need for ongoing treatment.</td>
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<td>“[Patients] could have a severe, severe neglect but because of what they’re coded as [by the insurer for physical disability], they may not get what they need. That’s a huge barrier to being able to treat the neglect because you’re stuck with that two-week window.” – OT</td>
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<tr>
<td><strong>Barriers</strong></td>
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<td>Discontinuity between transitions</td>
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| ● Clinicians in different settings had different care priorities. Not all therapists in all settings were aware of SN or were capable in treating SN.  
  ○ “For those folks who are perhaps going to another facility like a skilled nursing facility, . . . From my understanding, a lot of therapists there don’t really have a full understanding that [SN] is a need or should be one of their domains of practice.” — OT  
  ○ “I would love to collaborate with peers [who treat SN in a later stage]. That’s going to get me better prepare the patient because then I know what [the therapists in other postacute care] are working on later on. This way I can help set [the patient] up for that success, which I don’t really know right now.” — PT  
  ○ “There [are] a lot of holes in our system collectively that do create these unforeseen barriers. [It is important that we] shift the paradigm of how people look at health and wellness.” — OT  |
| Facility Quotes     |  |
| Continuity of care  |  |
| ● Therapists in one particular rehabilitation hospital discussed the collaboration between inpatient and outpatient units as a good example of a fluid continuum of care. They would share SN-related information about a patient if the patient was going to receive outpatient therapy. If the patient did not complete the entire course of a given treatment (eg, prism adaptation), they could continue in outpatient.  
  ○ “We share the data with outpatient, and they continue on with the [treatment], so that [patients and family members] know there’s a continuum of care.” — OT  |
disciplines. This approach could address staff limitations in knowledge and skills and may warrant more widespread implementation as a strategy to optimize SN care.

Inpatient rehabilitation is multidisciplinary but not always interdisciplinary. An interdisciplinary process relies critically on a mutual understanding of priorities for care and concepts of evidence-based treatment. Consistent with previous reports, therapists stated that communication about SN could be challenging for all members on the care team (clinicians, support and service staff, and insurers) and discussed the importance of formal documentation. A clear and detailed coverage note would help ensure patients or their family members receive adequate care and training. At the hospital level, SN can be added into the templates for progress notes to facilitate intra- and interdisciplinary communications. To document and communicate progress sensitive to SN improvement, it is important to use measures that meet such need, assessing SN at baseline and repeating the assessment periodically to track changes. In addition, SN should always be assigned proper diagnosis and billing codes for the purpose of tracking its public health effect.

Length of inpatient stay is getting shorter, and therapists reported they often had insufficient time to address SN. In the United States health care system, reimbursement for inpatient stay is typically determined by patients’ insurers within the first few days after admission, based on an algorithm taking certain factors into account, such as diagnosis, functional dependence, and age. Frequently, SN and other stroke- or brain injury–induced cognitive deficits are not taken into account. As demonstrated by the present study, including SN and other neurologic deficits in estimates for care utilization and thus length of stay would improve rehabilitation outcome. Therapists expressed their frustration that patients were often discharged prematurely after regaining physical strength and mobility when they were not ready to navigate the real world safely. This concern highlights the critical need to ensure that appropriate assistance is available at home before patients transition from inpatient to outpatient care, that SN status is communicated effectively to outpatient providers, and that clinician training is provided to equip outpatient therapists with the knowledge and skills needed to continue addressing SN.

Post hoc observations

During the data analysis process, we found that therapists used certain words and phrases to describe SN behaviors inconsistently or broadly to indicate different constructs or concepts. The words “attention,” “awareness,” and “insight” appeared to be used differently by different people in the focus groups, suggesting that therapists were drawing from everyday language. For example, the word “awareness” could mean impaired self-awareness of deficits (anosognosia) or awareness of the contralesional side of space (stimulus detection). “Awareness” was also used to describe therapists’ own knowledge about SN. The word “cue” or “cuing” could mean visual stimulation, specific instructions, or short commands indicating a direction. The phrase “cognitive deficits” or “cognitive problems” could be anything associated with the inability to follow commands. Therapists’ use of imprecise language could reflect difficulty distinguishing among different cognitive deficits. For example, a clinician using the word “learning problems” to refer to both spatial movement training and verbal memory lapses in a person with SN may not understand that these are separate symptoms; because only the spatial memory problem is typical in SN, a clinician might overlook important evidence that the patient is developing delirium or depression.

The lack of specificity in the use of terminology contributes to miscommunication among therapists and creates confusion when therapists communicate with other clinical disciplines in rehabilitation, professionals who are in the other fields, and clinical researchers. This may also hinder the development of sound theories to explain treatment mechanisms in people with SN, posing a barrier to both clinical education and research. As rehabilitation becomes truly interprofessional collaboration, it will be pivotal to develop a common vocabulary that describes neurologic and neuropsychological concepts across rehabilitation therapy, psychology, medicine, and nursing. The common vocabulary will enable immediate understanding of terminology that distinguishes between cognitive deficits, physical limitations, and behavioral impairments.

Study limitations

The study was conducted in 3 rehabilitation hospitals under the same institute, where there had been a focus on SN for more than a decade through a long-standing clinical-research collaboration. As a result, training and resources related to SN assessment and treatment were part of clinical practice. The level of knowledge of participating therapists was likely higher than therapists in other hospitals that had less research involvement in SN. Nonetheless, the present study highlights barriers and facilitators to current SN care even in rehabilitation hospitals where many clinicians were experienced in SN research.

A related limitation is sampling bias. Therapists were self-selected and enrolled to the study voluntarily. They might not represent the other therapists in the hospitals, and the results might not easily generalize to other health care institutes. In addition, the findings may only be applicable to OTs and PTs but not to the other disciplines providing care in inpatient rehabilitation. Physicians, nurses, speech-language pathologists, optometrists, psychologists, and other specialists, if invited, may have provided additional valuable information. The focus of the present study was on rehabilitation therapists because these are typically the frontline personnel most involved in the identification and treatment of SN. However, including the perspectives of patients themselves and their family caregivers in the discussion would have contributed to our understanding of the dynamics of current practice. This is an important area for future work.

The same general set of questions was used for all 6 groups, and the analysis was conducted after all groups were completed. Although this allowed us to assess which topics would arise spontaneously in each group, it did not provide opportunities to ask later groups for clarification about ideas arising in the earlier groups. Future studies may consider conducting a second round of discussions with the same groups to clarify themes or seek input on ideas generated in other groups’ discussions.
A limitation stemming from the focus group study design is that we were unable to comment on the relative frequency of any idea expressed by OTs vs PTs or determine why there were more themes of barriers than those of facilitators expressed by therapists. However, the focus group format allows participants to build on each other’s ideas through “piggybacking” and provide candid responses with peer support. Another limitation is that the focus group format (rather than 1-on-1 interviews) may discourage some individuals from speaking in front of coworkers. Although reassurances were given that data would not be associated with names, therapists may have been hesitant to provide negative comments related to their employment environment. However, participants generally spoke without hesitation, suggesting this limitation may not have affected the depth or quality of information shared.

Conclusions

The present study makes a unique contribution in identifying specific needs for innovative interventions that involve family support and training, promote interdisciplinary collaboration, and provide continuous treatment and follow-up assessment for SN through care transitions. Barriers and facilitators to current SN care, identified in the present study, help the understanding of challenges that clinicians face and support that they receive, which may or may not be specific to SN. Importantly, there are promising opportunities to improve SN care by changing current practice. Increasing patients’ self-awareness of their own deficits and improving their engagement and participation in therapy may be an important first step in improving treatment efficiency for this population. Clinicians can benefit from further training specific to EBP for patients with SN. Having a few therapists becoming SN-focused specialists may be an alternative solution to keeping all the therapists consistently updated with new evidence and treatment approaches. Clinicians also need continuous education to provide support, education, and SN-specific training to family caregivers. Clinical leadership should encourage continued mentorships, support interprofessional education programs, and cultivate constructive interdisciplinary teamwork specifically for SN. We suggest using a vocabulary that can be shared across different professions to facilitate interprofessional collaboration in clinical practice. The present study also calls on us as a community of rehabilitation professionals to better educate health care organizations, insurers, and the public about the implications of SN so they may better align expectations of resource utilization to the needs of people with SN and their families.

Supplier

a NVivo Pro 11 for Windows; QSR International Pty Ltd.

Corresponding author

Peii Chen, PhD, Kessler Foundation, 1199 Pleasant Valley Way, West Orange, New Jersey 07052. E-mail address: pchen@kesslerfoundation.org.

Acknowledgments

We thank Kerry Howard and Vitaliya Sobol for transcribing the audio recordings of the focus group discussions and Viktoria Landar and Lauren Heitzhaus for coding the transcripts.

Appendix 1

Two authors (J.Z. and P.C.) were present in each focus group session. J.Z., the discussion moderator, was a full-time PhD researcher with a Master’s degree in PT, who did not have experience in SN care or research but was experienced in conducting focus group discussions with clinicians and qualitative analyses. P.C. was also a full-time PhD researcher, who has had a career in SN research for more than a decade. At the beginning of a focus group session, therapists provided informed consent. Study procedures, risks, and benefits were explained, and clinicians were given ample opportunity to ask questions. During the consent process, it was emphasized that participation was completely voluntary and had no effect on participants’ performance reviews, employment status, or any rights or opportunities to which they were entitled. After completing informed consent, participants completed a form that collected their demographic information, education background, and clinical experience. Audio recorders were turned on as the discussion began. Adjustments in the order or specific phrasing of the preprepared semistructured open-ended questions were made as needed depending on the flow of conversation. Follow-up questions were added by the discussion moderator as needed to clarify ideas expressed by the focus group participants or to obtain additional detail. P.C. took notes of observations and provided assistance when needed.

Audio recordings were transcribed by 2 Master’s level students in programs unrelated to rehabilitation. Names were omitted in the transcripts. The transcripts were compared with the audio recordings for accuracy by P.C. and 1 of the students. Based on their field notes from the focus group discussions, J.Z. and P.C. composed preliminary lists of subthemes and codes (topics) related to the 2 major themes. Two therapist coders (an OT and a PT) independently evaluated the completeness and utility of the preliminary code lists by coding the content of 2 of the 6 transcripts. The therapist coders were currently working with patients with neurologic conditions but were not participants in the focus group discussions. The therapist coders were provided with written and verbal instructions encouraging them to add new barrier and facilitator-related themes to the list as needed, to assign more than 1 code to a particular quote if deemed appropriate, and to note any uncertainties encountered when applying the preliminary codes, so these could be discussed and clarified.

The authors (J.Z. and P.C.) and therapist coders met to identify discrepancies between the therapists’ coding results, revise subthemes and codes, and determine subthemes and codes not represented in the preliminary code lists. Modifications were then made to the phrasing and definitions of subthemes and codes in the lists. Then the therapist coders applied the revised subthemes and codes to 2 additional transcripts. A second meeting was held to
compare coding results and make further revisions. The therapist coders then reviewed all 6 transcripts, applying the final set of subthemes and codes. The therapist coders reported that all content of the transcripts was addressed by final set of codes, without the need to add new codes.

Another author, E.E., compared the 2 therapists’ coding and facilitated in-person discussion between them to resolve discrepancies in coding. Discrepancies were typically attributable to differences in the interpretation of how a code was worded, rather than differences in the interpretation of content being coded. When there were unsolved discrepancies, PC then joined the discussion to reach the final consensus whether a quote was relevant and which code(s) should be assigned to it. Transcripts were imported into NVivo Pro 11 for Windows (QSR International Pty Ltd), and the therapists’ codes (which were noted on hard copies of the transcripts) were entered by E.E. to facilitate review of coded data. J.Z. and P.C. reviewed the coded data and collaborated on the result presentation and example quote selection.

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