Occupational Therapists' Expanding Role in Preparing Stroke Caregivers for Patient Discharge

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Introduction

The life-changing event of a stroke affects 775,000 U.S. citizens per year (Benjamin et al., 2017). Stress associated with stroke caregiving presents challenges to rehabilitation and successful home transitions for the caregiver and for the patient. Because of caregiver strain due to daily stress, caregivers experience an increased risk of adverse health events (Hayes, Chapman, Young, & Rittman, 2009). Previous research done on this subject only addresses the initial event of the stroke and progress long after the patient and caregiver are released from rehabilitative care. This leaves a significant gap in the information available on stroke recovery, particularly for the moment of discharge and transition into the home environment. Caregivers report feelings of anxiety and stress at this loss of support and feel overwhelmed and underprepared to take on the caregiving role (Lutz et al. 2016).

Previous research has documented a crisis of discharge following release from care due to loss of support systems and lack of appropriate preparation for caregivers (Lutz, Young, Cox, Martz, & Creasy, 2013). This crisis puts both caregiver and patient health at risk, as the mental and physical health of the caregiver is closely tied to patient outcome (Hayes, Chapman, Young, & Rittmann, 2009). Caregiving challenges post-discharge include a lack of comprehensive education for the caregiver (Smith, Lawrence, & Langhorne, 2004), mental and physical strain and lack of respite services, and injuries on caregiver due to the physical toll of caregiving (Hays, Chapman, Young, & Rittman, 2009). This research addresses the crisis of discharge and how occupational therapy can help prepare the caregiver as they transition into life in the home environment.

By conducting a preliminary survey of occupational therapists and occupational therapy assistants within the Southeast United States who were working with stroke patients, we were able to find areas where occupational therapy could potentially be integrated into the process of transitioning the caregivers into home life. Caregiver feelings about their level of preparation vary, which indicates a need for comprehensive, realistic education for caregivers prior to

discharge. Caregivers do not know what to expect on the return home and often have unique circumstances that are challenging to address with a single standard of practice. (White, Brady, Sucedo, Motz, Sharp & Birnbaum, 2014).

We found that occupational therapists felt that caregiver involvement was important and necessary for the patient's recovery and quality of life for both parties following the event of a stroke. But there were significant gaps in caregiver education, particularly in preparation before discharge and post-discharge follow up and support. The aim of this study was to expand the practice of occupational therapy to improve caregiver readiness specifically for the moment of discharge and return home.

By expanding occupational therapy's role in rehabilitation to include digital home health evaluations, beginning caregiver education and home preparation early, sharing outside resources, and making support groups part of the transition home, there is a potential for improving caregiver health and reducing caregiver strain, which could potentially lead to reduced re-hospitalization rates for stroke patients (Richards, Latham, Jette, Rosenberg, Smout, & DeJong, 2005) and better outcomes for caregivers.

Hypothesis: Occupational therapy has a role in better preparing caregivers for the transition home after discharge from therapy through preparation and education beginning during therapy, and through continuing support during the transition home.

Methods

We conducted a survey of occupational therapists and occupational therapy assistants working with stroke patients in care facilities across the Southeast United States. A University of Florida Department of Occupational Therapy provided contact list of occupational therapy site supervisors was used. Some names from the list were eliminated based on certain criteria (pediatric, school facilities, universities, and government programs were not included). The first round of emails was sent to only locations in Florida, but the range was expanded to include the Southeast United States based on the initial number of responses.

The survey was sent to 154 facilities via email. The 17 question survey was based on the model for caregiver tasks (Lutz et al, 2012). The survey completed by occupational therapists and occupational therapy assistants working with non-pediatric stroke patients with family caregivers.

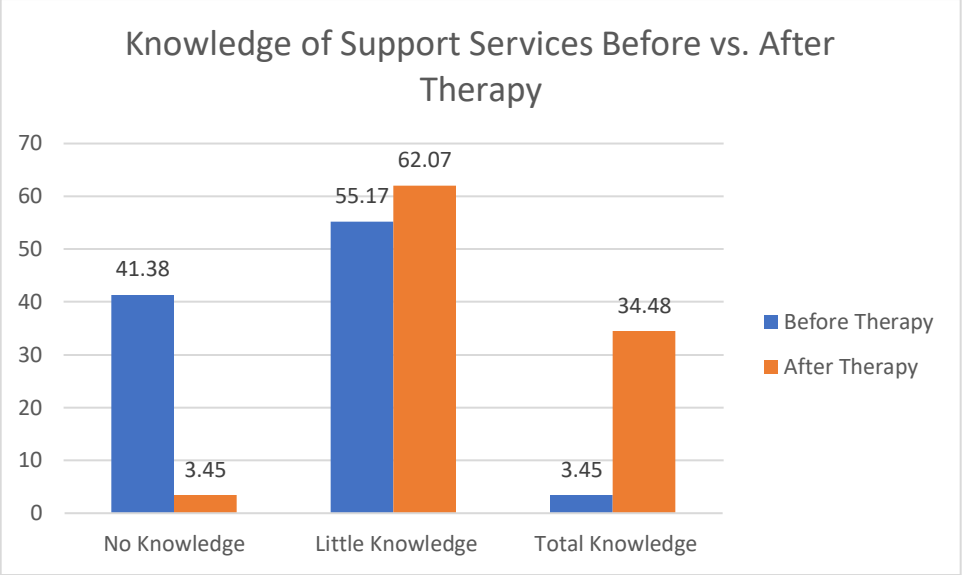
Participating facilities were contacted via e-mail and asked to distribute a digital flyer to occupational therapists and occupational therapy assistants working with stroke patients. Participants volunteered by responding anonymously to the survey linked in flyer. The survey was done through a University of Florida provided Qualtrics program. Questions were intended to identify areas where occupational therapists can better prepare caregivers for discharge and the immediate transition home. The survey and procedure were approved by the University of Florida IRB Board (IRB201701895).

Results

Ultimately, the survey received a total of 47 responses with 29 complete responses. Of the complete surveys, 93% were completed by occupational therapists and 7% were completed by occupational therapy assistants. Of the respondents, 14 worked in an acute inpatient setting, 2 worked in subacute inpatient, 19 worked in an inpatient rehabilitation facility, 5 worked outpatient, 4 worked home health, and 6 selected "Other." The average number of years working in occupational therapy was 13 years.

The first three questions on the survey gathered data quantitatively on therapist’s use of in home or digital media evaluations and assessed the level of caregiver knowledge about support services before and after therapy.

Ranking of caregiver knowledge of support services.



At the beginning of therapy, about 41% of caregivers were rated by occupational therapists as having no knowledge of support services, 55% were rated as having little knowledge of support services, and just 3% were rated as having total knowledge of the support services available to them as caregivers. After therapy, there was a slight change yet 65% of family caregivers did not have total knowledge of the support services and resources available to them.

Next, therapists were asked to rank tasks for the caregiver in respect to three categories: importance for caregiver preparation for discharge, adequacy of caregiver training, and contribution to caregiver strain. Tasks were ranked individually, and for each task the therapist was asked to give a ranking from 1 being a low score to 10 being the highest score. Means are all listed out of a possible 10.

Tasks in order of importance for caregiver preparation from most to least important

Tasks	Mean
Training to perform safe transfers	9.10
Recommending appropriate equipment, supplied, and accessible transportation options	8.83
Training how to provide physical care and management	8.77
Training in fall prevention strategies	8.70
Training to provide hands on therapy	8.40
Recommending home modifications	8.07
Referring for further rehabilitation therapy (OT, PT, SLP)	8.03
Identifying resources	7.41
Training in coordinating care across settings	6.96
Identifying strategies for caregiver respite	6.83
Supporting other caregiver responsibilities	6.76
Problem solving and management of behavioral and emotional issues	6.70
Identifying caregiver health maintenance strategies	6.67
Problem solving in management of multiple appointments	6.00
Referring caregiver to individual or family counseling	5.86
Teaching medication management	5.80

“Training to perform safe transfers” was ranked as most important with a score of 9.10 out of 10, and “Teaching medication management” was ranked least important with a score of 5.80. It is well known that caregiver strain does exist, “Identifying strategies for caregiver respite” was ranked low in terms of importance, and “Referring caregiver to individual or family counseling” was ranked even lower at a 5.8.

There is a significant drop in ranked importance between “Referring for further therapy” (8.03) and “Identifying resources”(7.41). Caregivers require preparation as to where to find respite services, home modifications, and assistance in dealing with insurance issues, these tasks are important for ensuring a successful transition back home.

Along with “Problem solving and management of behavioral or emotional issues” (6.70) and “Identifying caregiver health maintenance strategies” (6.67), tasks that would help to decrease caregiver strain and improve caregiver health were ranked at the bottom. Caregivers are well prepared to take care of their loved one, but less prepared to care for their own health.

Tasks in order of adequacy of caregiver training listed from most adequate to least adequate.

Task	Mean
Training to perform safe transfers	8.80
Recommending appropriate equipment, supplies, and accessible transportation options	8.50
Training how to provide physical care and management	8.27
Referring to further rehabilitation therapy (OT, PT, SLP)	8.07
Training in fall prevention strategies	7.90
Training to provide hands on therapy	7.83
Recommending home modifications	7.73
Problem solving and management of behavioral and emotional issues	5.73
Identifying resources	5.67
Training in coordinating care across settings	5.24
Teaching medication management	5.10
Supporting other caregiver responsibilities	4.83
Identifying caregiver health maintenance strategies	4.57
Identifying strategies for caregiver respite	4.04
Problem solving in management of multiple appointments	3.83
Referring caregiver to individual or family counseling	3.81

Caregivers were most adequately trained in how to perform safe transfers (8.80), yet they were the least adequately trained in access to resources such as management of appointments for the person in their care (3.83) and access to counseling (3.81). Caregivers were ranked as being less adequately trained compared to the importance of their training.

There was another significant drop in ranked adequacy of training between "Recommending home modifications"(7.73) and "Problem solving and management of behavioral and emotional issues"(5.73). Caregivers are less adequately trained to deal with any behavioral and emotional issues they may encounter with their loved one.

Tasks in order of contributing to caregiver strain- highest contribution to lowest contribution

Task	Mean
Providing physical care and management	8.76
Problem solving and management of behavioral and emotional issues	7.79
Performing safe transfers	7.62
Completing home modifications	7.25
Attention to other caregiver responsibilities	6.97
Implementing strategies for caregiver respite	6.93
Acquiring appropriate equipment, supplied, and accessible transportation options	6.78
Coordinating care across settings	6.52
Implementing caregiver health maintenance strategies	6.48
Implementing fall prevention strategies	6.41
Management of multiple appointments	6.28
Providing hands on therapy	6.15
Identifying resources	5.52
Obtaining further rehabilitation therapy (OT, PT, SLP)	5.23
Obtaining individual or family counseling for the caregiver	5.00
Medication management	4.75

"Providing physical care and management" caused the most caregiver strain (8.76), and medication management caused the least caregiver strain (4.75). Tasks in order of importance did not line up with tasks in order of causing caregiver strain. "Problem solving and management of behavioral and emotional issues" is ranked high in terms of contributing to caregiver strain (7.79), yet in terms of adequacy of preparation, it was ranked low (5.73).

This shows that there is a disconnect between what is causing caregivers the most challenges post-discharge and what OTs are focusing their education on while in rehab.

The final part of the survey consisted of four open response questions. Selected responses to these questions from the survey are shown here.

How does your level of caregiver education change as the Functional Independence Measure (FIM) score of your patient changes?
I will continue to address caregiver education/training even though the patient is making improvements based on their FIM score.
A patient that is total assist would require us to begin hand over training and as the FIM score and comfort level of the CG changes so would our approach. Tactile cues then verbal cues.
If the individual is becoming more independent it should be focused more on them and not the caregiver
Depends a lot on the family and patient. I do a lot of education to family either telling them that it is okay to let go and let a patient shower by themselves for example or reminding them that even though a patient is making progress with independence, they may not be ready to be left alone yet or return to work.
The more safe and independent the client, the less caregiver education is warranted/needed.

The selected quotes indicate that therapists tend to base education on caring for the patient, there is little education for caregivers on self-care or guidance with accessing resources for home modifications. The caregiver is primarily guided on how to care for the patient in therapy, there is little done to address caregiver needs post-discharge or available resources.

Describe any other aspects of occupational therapy that could improve the caregiver's abilities to help stroke patients after rehabilitation.
I think safety is key, is the patient going to be safe at home with the caregiver? Is the caregiver going to be able to safely assist the patient? You do not want patients to fall at home, or not to be cared for properly. It could cause readmission to the hospital, falls, DCF involvement, or death.
[Discharge] planning, caregiver training, and education should start ASAP. I would suggest a checklist or some type of written information in an easy to read (not overwhelming) format be given and spoken about at every visit... Often times, a patient's family is not ready for full time caregiving services and try to get everything done right when the patient gets home instead of focusing on parts of "to-do" list as patient is still in inpatient rehab.
Give them resources like stroke.org where they can find an extensive amount of information. Have sessions that the caregiver joins in on at regular intervals so that they can be taught specific strategies you want them to help the client with.
Caregiver health is critical in order to provide good care of the patients after rehab. Providing them with support, counseling and respite is an important part of my care.
Accessibility to outside resources, importance of respite care, and knowledge/understanding of body mechanics is so important.

The common themes in this question were using support groups continuing after therapy, starting home modifications while in therapy, providing support to caregivers, and focusing on caregiver health maintenance. Support groups were mentioned by occupational therapists as being helpful to caregivers.

However, caregivers often need to provide 24/7 care to their loved one, and were unable to attend support groups or felt burdened trying to find time to attend support groups or find care for their loved one during that time (Young, Lutz, Creasy, Cox, & Martz, 2014). This shows the disconnect between OT recommendations for care and what is actually needed by caregivers.

In your opinion, what is the importance of in-home evaluations or digital media home evaluations during therapy?
Barriers that cannot be assessed in a "sterile environment"; pets, carpets, furniture in close spaces, cabinets, TV remotes that are not attached to walls
Provide realistic accommodations or recommendations for improved functioning at home.
Caregivers often have little grasp of what changes will need to be made upon return to home. In the hospital setting, they are getting assistance and respire from staff and "think" they can handle it upon return home. I think it's a HUGE adjustment once they actually get home with their loved one.
Home assessments are very important in order to carry over the necessary skills to the home environment.
It would be nice to see what the pts home actually looks like instead of assuming what the home is like from their description.

According to the survey, 60% of occupational therapists do not perform in-home or digital media evaluations, yet acknowledged the importance of doing in-home evaluations for patient safety and caregiver adjustment.

Using digital media- such as Skype or FaceTime- and in-home evaluations allows OTs to better assess the home for safety risks and any needed modifications. This helps caregivers better understand any safety risks to mobility in the home and what changes or equipment will be needed before their loved one returns home.

How does caregiver availability during rehabilitation influence your approach to therapy?
It is important from the start of therapy to get the family involved with clear expectations of family and level of care the patient will require upon discharge home.
Patients whose caregiver is present show better progress and prognosis, as compared to those who have to deal with CVA by themselves.
[Caregiver availability] is the most important part of therapy if a patient wants to return home.
Highly influences. Usually recommend more supportive setting when lack of caregiver availability.
Caregivers are encouraged to participate/observe in as many treatment session as possible, schedule is rearranged to accommodate caregivers schedule as needed/possible.

The responses were consistent in that caregivers are an essential part of the recovery process. OTs need caregivers to be present, as they will be responsible for the care and safety of their loved on after therapy. Therefore, it is necessary to also educate the caregiver on how to care for their own mental, physical, and emotional health, and give them realistic expectations for what life will be like after discharge.

Discussion

Other research has found that caregivers do feel unprepared and face a crisis at the moment of discharge (Young, Lutz, Creasy, Cox, & Marts, 2014). Caregivers felt alone and isolated after discharge, and struggled with managing responsibilities in their role as caregiver and obligations in their other roles. With limited time in therapy occupational therapists focus more on the patient's safety at discharge, with little time available for comprehensive preparation of the caregiver. Averages in terms of adequacy of caregiver training were consistently ranked lower than tasks in terms of importance of training.

In addition, there is a disconnect between what occupational therapists are preparing caregivers for and what caregivers feel they need. The tasks caregivers struggled with most were training to provide physical care and management, identifying resources, managing their other responsibilities, identifying health maintenance and respite strategies, and seeking out personal or family counseling (Young, Lutz, Creasy, Cox, & Martz, 2014),(Lutz, Young, Cox, Marts, Creasy, 2013),(Creasy, Lutz, Young, Ford, & Martz, 2013). With the exception of providing physical care and management, these tasks were all ranked low by occupational therapists in terms of importance to caregiver training.

There are three areas in which occupational therapy can be utilized in order to better support caregivers during the period post-discharge- using telehealth programs to accurately

assess the home environment, beginning home modifications in acute care to reduce stress on the return home, and assisting caregivers with accessing outside resources available to them after therapy.

Telerehabilitation

Telerehabilitation is defined as the use of telecommunication technology to allow healthcare providers to serve patients at a distance. Occupational therapists could use telehealth strategies to better assess home modification needs (Carson, 2012), and if needed, provide education and support to caregivers remotely (Chi & Demiris, 2014). Smartphones with applications such as Skype or FaceTime could be used to better assess the home environment and to more accurately gauge the assistive equipment and modifications needed for the home for safety and ease of mobility (Hoffmann & Cantoni,2008).

Caregivers struggled with confidence in transferring skills learned in therapy into the home, and frequently struggled with correctly identifying the needed home modifications. Telerehabilitation can provide real-time, remote support from occupational therapists to caregivers directly in the home, and offer guidance for caregivers (van den Berg, Crotty, Liu, Killington, Kwakkel, & van Wegen, 2016). However only 40% of occupational therapists are doing in-home evaluations, digitally or in-person.

Beginning Home Modifications in Therapy

Most caregivers are concerned about falls and their loved one's mobility at home, and require necessary home accommodations as soon as possible (Krishnan, Pappadis, Weller, Fisher, Hay, & Reistetter, 2017). With limited time in therapy, it is almost impossible to have the home adequately prepared in time. Caregivers struggle with being there for their loved one while at the same time making the necessary arrangements for safety at home.

"So we weren't really prepared and we wished it could have been at least another week before he came home so we could have had a chance to set things up and had some of the stress taken off us."

(Lutz et al, 2016) Caregivers felt unprepared to find and access services for home modifications. "Completing home modifications" was given a score of 7.25 in terms of contributing to caregiver strain.

This rush is in part caused by caregivers not knowing what home modifications will be needed or where to get these things done. Occupational therapy can provide assistance in showing caregivers what will be needed, either through digital media evaluations or in home therapy, and guiding them through the process of acquiring these modifications.

Assistance with Accessing Outside Services

Caregivers are not just there to support the patient, they need education on how to care for themselves and their needs as well. They could benefit from family or personal counseling, but often are not able to seek out these services or are unaware that counseling services are available to them (Bakas, Jessup, McLennon, Habermann, Weaver, & Morrison, 2016).

Caregivers were often overwhelmed trying to find the resources they were given in therapy (Bakas, Jessup, McLennon, Habermann, Weaver, & Morrison, 2016). They struggled with making appointments, finding home modifications, and locating and using support and community services. In addition, caregivers struggled with medication management, ranked low by OTs, and proper care for their loved one in the home environment (Young, Lutz, Creasy, Cox, & Martz, 2014).

"[Discharge] was horrible. It's a terrible, terrible experience. I had no one to guide me, no one to help me."

Outside resources, such as care management services would help caregivers with accessing resources, scheduling appointments, and navigating insurance issues. OT can be of assistance to caregivers by providing this information along with coaching throughout the process.

Caregiving is a full time role and it does cause strain, so there is a place for occupational therapy in reducing that strain and assisting caregivers with the transition. Caregivers frequently reported a need for guidance in accessing support services. They were given the phone numbers and names, but needed help with making the calls, managing appointments, and being proactive in getting the services they needed. Occupational therapy can offer guidance and support to caregivers throughout this process.

Future research can address the disconnect between what caregivers feel they need to be supported and what occupational therapists are doing in therapy. “Caregiver care” is important to the health and safety of the patient and the health of their loved one, and needs to be addressed in therapy. With occupational therapy’s emphasis on success in life roles, there is a place for caregiver guidance and help with adjustment to discharge within the profession.

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