



January 2022

## Occupational Therapists' Perspectives on Caregiver Education of Stroke Survivors

Elinor Pastore

*Midwestern University – USA, epastore12@midwestern.edu*

Daniel Ryan

*Midwestern University – USA, dryan98@midwestern.edu*

Lisa J. Knecht-Sabres

*Midwestern University – USA, lknech@midwestern.edu*

Follow this and additional works at: <https://scholarworks.wmich.edu/ojot>



Part of the Occupational Therapy Commons

### Recommended Citation

Pastore, E., Ryan, D., & Knecht-Sabres, L. J. (2022). Occupational Therapists' Perspectives on Caregiver Education of Stroke Survivors. *The Open Journal of Occupational Therapy, 10*(1), 1-16. <https://doi.org/10.15453/2168-6408.1881>

This document has been accepted for inclusion in The Open Journal of Occupational Therapy by the editors. Free, open access is provided by ScholarWorks at WMU. For more information, please contact [wmu-scholarworks@wmich.edu](mailto:wmu-scholarworks@wmich.edu).

---

# Occupational Therapists' Perspectives on Caregiver Education of Stroke Survivors

## Abstract

*Introduction:* The objective of this research study was to gather a greater understanding of how occupational therapists provide education to caregivers of stroke survivors and how they address the needs of caregivers throughout the rehabilitation process.

*Methods:* The researchers used a convergent mixed methods design. RedCap electronic surveys containing both open-ended and closed-ended questions were completed by 90 participants from multiple states. A focus group (n = 8) and a one-on-one interview (n = 1) were conducted to gather qualitative information regarding occupational therapists' perspectives related to their experiences on educating caregivers in the acute rehabilitation setting. Descriptive statistics were used to analyze quantitative survey data. The focus group and the one-on-one interview were recorded and transcribed verbatim. Qualitative data were thematically analyzed. Interviews were coded individually and re-coded until consensus was reached. The results across data were compared to identify themes. Rigor was enhanced through the use of multiple coders, member checking, expert review, and triangulation of the results.

*Results:* The survey results (n = 90) revealed the occupational therapists' top five topics for caregiver education for stroke survivors: toileting (94.4%); dressing (94.4%); bathing (94.4%); functional mobility (91.1%); and hygiene/grooming (75.6%). Yet, 22% of the occupational therapists surveyed indicated they provided education only during the week of discharge, and 37.8% specified they only spent 15 min of education during an intervention. Five themes emerged from the qualitative data: (a) caregivers and stroke survivors have different needs, (b) occupational therapists must hurdle a variety of barriers when providing education, (c) access to various supports at the workplace is beneficial when providing caregiver education, (d) occupational therapists use a variety of methods to administer caregiver education, and (e) occupational therapists tend to prioritize ADL tasks during education.

*Conclusion:* Clients and caregivers have a plethora of educational needs related to enhancing safety and independence with daily occupations prior to discharge from inpatient rehabilitation. Occupational therapists play a vital role in educating the caregiver as a means to enhance an individual's quality of life and in easing the transition into the home environment after inpatient rehabilitation. The findings from this study highlight the common methods used for education by occupational therapists, as well as the challenges faced when providing caregiver education.

## Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

## Keywords

occupational therapy, caregiver education, stroke survivors

## Credentials Display

Elinor Pastore, OTD; Daniel Ryan, OTD; Lisa Knecht-Sabres, DHS, OTR/L

Copyright transfer agreements are not obtained by The Open Journal of Occupational Therapy (OJOT). Reprint permission for this Applied Research should be obtained from the

---

corresponding author(s). Click here to view our open access statement regarding user rights and distribution of this Applied Research.

DOI: 10.15453/2168-6408.1881

Stroke, or cerebrovascular accident (CVA), is highly prevalent across populations worldwide and there is a vast amount of research regarding stroke prevention, care, and recovery. In the United States, stroke is the leading cause of serious, long-term disability, with other prominent causes of long-term disability including cancer, diabetes, musculoskeletal disorders, heart disease, and mental health issues (CDC, 2020). Because of the impairments that can occur after a stroke, survivors must often turn to their family members for their caregiving needs. As advances in medical treatment, as well as survival rates, continue to improve for stroke patients, more family members will be called on to provide assistance post discharge (Young et al., 2014). Henceforth, caregivers are, and will continue to be, integral members of the rehabilitation teams.

Caregivers are people who provide care to individuals who require assistance with everyday tasks on a regular or daily basis (CDC, 2020). Occupational therapists play a vital role in educating the caregiver as a means to enhance the client's quality of life and to ease the transition to the home environment after inpatient rehabilitation (Wolf et al., 2015). Numerous researchers have investigated caregivers' perspectives regarding their experiences related to the provision of caregiver education. However, minimal research has explored the topic of caregiver education from the perspective of occupational therapists. The current literature regarding caregiver education, as it relates to stroke survivors, highlights the following points: (a) caregiver needs are not viewed as separate from those of the client, (b) timing is a major factor toward providing intervention, (c) occupational therapists tend to prioritize certain topics when educating the caregiver, and (d) efficient communication in the multidisciplinary team is imperative when providing caregiver education. Thus, the objective of this study was to gather a greater understanding of how occupational therapists provide education to caregivers of stroke survivors and how they address the needs of caregivers throughout the rehabilitation process.

## **Literature Review**

### **Caregiver Needs Are Not Viewed as Separate from Those of the Client**

Based on the current evidence, caregivers of stroke survivors are not being fully considered throughout the rehabilitation process. Unfortunately, caregivers often do not feel fully prepared or confident to take on their roles once the patient is discharged (Camicia et al., 2018; Chen et al., 2015; Young et al., 2014). One reason behind these feelings of uncertainty is that therapists do not see the caregiver as a separate entity from the stroke survivor. Therefore, the caregiver is not consistently viewed as having separate needs that must be addressed during therapy sessions (Ekstam et al., 2015; Roy et al., 2015). Unfortunately, the caregiver is not given enough training and/or information to fully grasp their new role, which impacts the care provided to the stroke survivor immediately post discharge, as well as the mental health of the caregiver as their emotional needs are not being met (Camicia et al., 2018; Lutz et al., 2011). As the caregiver is a critical part of the recovery process, they must be provided with the proper information and understanding of how to perform all tasks associated with their new role.

### **Barriers Related to Timing**

It is imperative for occupational therapists to evaluate whether or not the caregiver fully understands the provided information, can apply this information, and can effectively perform various tasks associated with the role of a caregiver; however, various barriers can impede this process. One major barrier to effective and efficient caregiver education revolves around the concept of time in which schedules of both the occupational therapist and caregiver line up for an individual caregiver education

session. For example, constraints placed on how long a therapist has with a patient and their caregiver can limit when, where, and how the therapist can provide the necessary education (Chen et al., 2015; Liu et al., 2013; Roy et al., 2015). Henceforth, this can result in the therapist having inadequate time to properly teach the caregiver. In addition, restrictions to caregivers' schedules have been identified as a barrier to caregiver education as their limited availability impacts the amount of time caregivers are present during therapy and educational sessions (Rochette et al., 2014). Stroke survivors are frequently required to stay in an inpatient hospital for a series of weeks, resulting in fluctuating involvement from their family members (Rochette et al., 2014). In addition, stroke survivors heavily depend on their family to handle many aspects of their care, both pre and post discharge (Lutz et al., 2011). Yet, the majority of the research indicates that caregivers do not receive assistance throughout the entirety of this process (Roy et al., 2015). Therefore, prior to discharge, the therapist must provide a plethora of information to caregivers when they are present. Unfortunately, this often occurs immediately before discharge, which can significantly limit the opportunity for the caregiver to practice and apply new knowledge and skills. Thus, caregivers are frequently left feeling overwhelmed by the large influx of new information they receive in a short period of time (Roy et al., 2015; Ryan et al., 2017), especially because caregivers are receiving information from providers in a wide range of disciplines, not just occupational therapists (Liu et al., 2013). Other barriers to the provision of educational information to the client and caregiver include resources, funding, and language barriers (Roy et al., 2015).

### **Type of Instruction and Priorities During Education**

Studies investigating how occupational therapists provide education to caregivers suggest that the majority use verbal instruction and demonstration and observation while educating (Banford et al., 2001; Gustafsson et al., 2009; Liu et al., 2013). These methods were also believed to be the most effective in terms of providing information and evaluating understanding from the caregiver (Banford et al., 2001). While the majority of health care professionals prefer delivering information verbally, recipients often find this method to be overwhelming (Danzl et al., 2016). Conversely, caregivers and stroke survivors have indicated they prefer visual and written methods during education (Danzl et al., 2016). They also expressed a need for information to be provided throughout the recovery and rehabilitation process, rather than receiving a heavy load of information at one specific time (Danzl et al., 2016). Other research studies have revealed the most prevalent methods used in practice for caregiver education were hands-on/face-to-face and written modes of information delivery (Lawson et al., 2015). Caregivers have suggested that hands-on education is very helpful; yet, occupational therapists are expected to be efficient with their time, which can limit their ability to build strong relationships with their patients and/or caregivers or result in occupational therapists needing to cover significant material immediately before discharge (Ryan et al., 2017). Unfortunately, health care professionals have indicated they often do not adapt their educational practices to align with the needs of their clients and their caregivers (Roy et al., 2015). Even though caregiver education is seen as a standard and vital part of the stroke rehabilitation process (Young et al., 2014), only 52% of occupational therapy respondents in one study received education on how to perform caregiver training (Naguwa et al., 2010). Moreover, most of the respondents (74%) stated they would like to have more training on caregiver education (Naguwa et al., 2010). Thus, occupational therapists believe caregiver education is important, but they may not have been adequately trained on how to provide it. Ultimately, the evidence shows there is a disconnect between occupational therapists' and caregivers' views on education and on what the optimal type of instruction should be (Chen et al., 2015).

## **Communication Between Caregiver, Therapist, and Other Health Care Providers**

The reviewed studies revealed the importance of communication between the caregiver, therapist, and other health care providers. The perspectives of all members of the rehabilitation team should be taken into consideration during caregiver education to make a smooth transition from the hospital to the home (Baxter et al., 2018). Research shows a common trend in which occupational therapists give more information and attention to the stroke survivor because the caregiver is not always present for the sessions. This trend can make caregivers feel disconnected from the recovery process and can result in the caregiver needing more information regarding their new role before the stroke survivor is discharged (Danzl et al., 2016; Gustafsson et al., 2009). Effective communication between the caregiver and health care professionals is highly important, especially during discharge planning. At this time, there should be an emphasis on patient care and giving caregivers greater roles of involvement in the discharge process (Waring et al., 2016). Methods to improve caregiver involvement in the discharge process consist of including caregivers when teaching discharge instructions; providing clear, written instructions; and delivering education to caregivers earlier in a patient's hospital stay (Hahn-Goldberg et al., 2018). Lastly, developing a connection between the caregiver and the survivor is important because survivors with the highest perceived social support tend to have a better recovery and improved functional ability at the time of discharge from the inpatient facility (Mirkowski et al., 2016). Therefore, forming a good relationship and communicating with the caregiver at the start of the rehabilitation process should promote caregiver involvement, understanding, and competence in therapy (Mirkowski et al., 2016).

Occupational therapists play a vital role in educating the caregiver as a means to enhance quality of life for the stroke survivor and to help ease the transition into the home environment after the rehabilitation process. Because minimal research has investigated the topic of caregiver education from the perspective of the occupational therapists, the purpose of this study was to gain a better understanding of: (a) how occupational therapists provide education to caregivers of stroke survivors and (b) how occupational therapists address the needs of caregivers throughout the rehabilitation process.

## **Method**

### **Research Design**

This study used a convergent mixed methods design, which allowed the researchers to bring together the strengths of both quantitative and qualitative methodology (Creswell & Plano Clark, 2011). A mixed methods design was chosen for this study because it enabled the researchers to understand the research question more comprehensively and because it is known to enhance credibility (Creswell & Plano Clark, 2011). More specifically, collecting both sets of data allowed the researchers to gather a greater understanding of how occupational therapists provide education to caregivers of stroke survivors and how they address the needs of caregivers throughout the rehabilitation process. RedCap electronic surveys containing both open-ended and closed-ended questions were distributed to gather qualitative and quantitative information. Additional qualitative data were gathered by a focus group and an individual interview to gather more in-depth information and to obtain a better understanding regarding occupational therapists' perspectives related to their experiences on educating caregivers in the inpatient rehabilitation setting.

## Measures

A researcher-developed survey (see Appendix A) was created to obtain data regarding education provided by occupational therapists to caregivers of stroke survivors. The researcher-developed survey was informed by the literature and modified according to expert opinion. The survey included questions regarding basic demographic information as well as closed-ended and open-ended questions related to caregiver education. The closed-ended survey questions inquired how often the occupational therapists provided caregiver education, time spent educating caregivers, occupations addressed during caregiver training, methods used to provide education, and how often caregivers were present. The open-ended survey questions allowed the participants to describe challenges and barriers to caregiver education, as well as the perceived needs of both the caregivers and occupational therapists. The survey also invited the participants to partake in an in-person or virtual focus group, depending on the location and availability of the participant(s). If interested, the participants were asked to contact the researchers via email.

To gain a more in-depth understanding of the occupational therapists' perspectives on caregiver education in an inpatient setting for stroke survivors, qualitative data were gathered from a semi-structured focus group and a semi-structured interview (see Appendix B). The semi-structured focus group and interview questions were informed by the literature, responses to the open-ended survey questions, and expert opinion. The focus group and individual interview were audio-recorded and transcribed verbatim. The focus group lasted approximately 1 hr, and the individual interview lasted approximately 30 min.

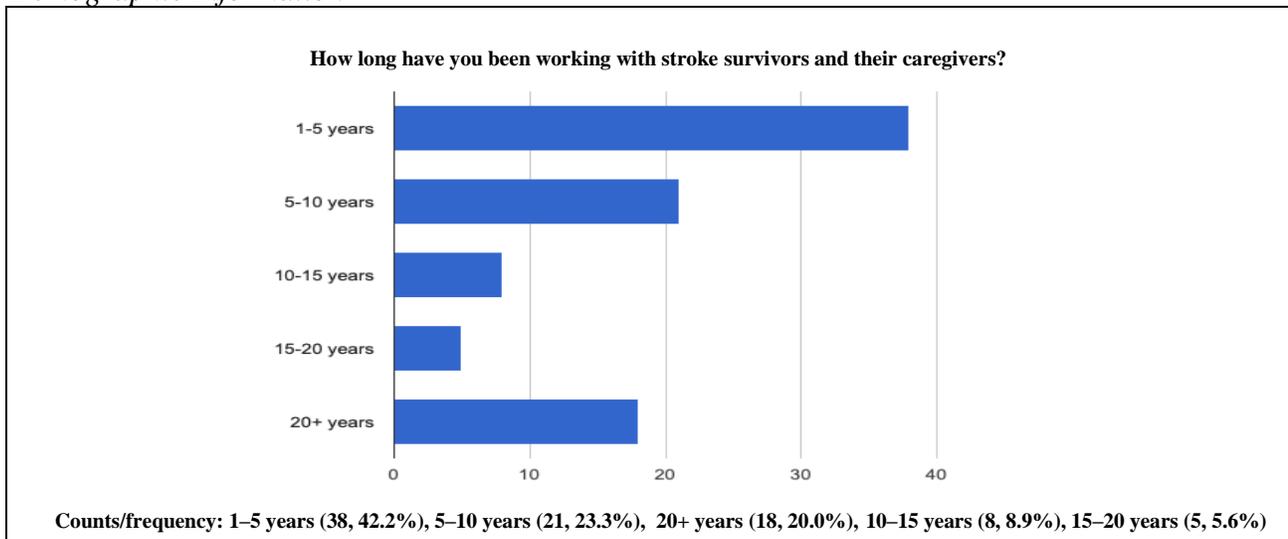
## Participants and Procedures

The participants in this study consisted of licensed occupational therapists who had at least 1-year experience in working with stroke survivors and their caregivers in an inpatient setting. Convenience sampling and snowball sampling were used to recruit all participants of this study. The researchers obtained consent from all individuals who participated in the study. This study was approved by the university's institutional review board.

The survey participants were obtained through the distribution of the survey via the American Occupational Therapy Association discussion forum and mass emails sent through the Illinois Occupational Therapy Association membership list and the university's occupational therapy alumni list. Ninety participants responded to the online survey. The majority (90.9%) of the survey respondents were female. The median age of the participants was 33.5 years, with a range of 25 to 64 years of age. Of the 90 participants, 42.2% ( $n = 38$ ) had an entry-level master's degree in occupational therapy, 31.1% ( $n = 28$ ) had a post-professional master's degree, 13.3% ( $n = 12$ ) had a bachelor's degree, 11.1% had a post-professional doctorate degree ( $n = 10$ ), and 2.2% ( $n = 2$ ) had an entry-level doctorate degree. The majority of the survey participants had over 5 years of experience working with stroke survivors and their caregivers (see Figure 1).

Because one out of state survey participant expressed interest in partaking in a focus group, the researchers conducted an individual virtual interview with this participant. In an attempt to gather more qualitative data, the researchers collaborated with a local inpatient rehabilitation hospital, which agreed to help recruit participants ( $n = 8$ ) who met the inclusion criteria for a focus group. The focus group met in a reserved, private conference room which provided privacy for the participants to share their experiences.

**Figure 1**  
*Demographic Information*



### Data Analysis

The quantitative data obtained from the closed-ended questions of the online survey were analyzed using descriptive statistics. The frequencies, percentages, and graphs were generated through the Redcap platform and analyzed by the researchers. Both the quantitative data and qualitative data results obtained from the survey were used to inform and create the focus group and individual interview questions based on observed trends in responses.

The qualitative data obtained from the focus group and individual interview were individually coded using inductive coding and cross-checked until inter-coder agreement was reached by the first two researchers. Inductive coding is a process of analysis in which themes or concepts emerge from participants' discussion (Fereday & Muir-Cochrane, 2006). Codes and themes were then reviewed by the third researcher. Revisions to codes and themes were made until all of the researchers came to a consensus. Peer debriefing and expert examination were used throughout the data collection and analysis process. As a result, both rigor and trustworthiness were enhanced through individual coding with multiple coders, peer review, and expert examination. Triangulation occurred via a mixed methods design and by having the researchers compare and contrast both quantitative and qualitative findings during the data analysis and interpretation process. Member checking or respondent validation was used with the focus group participants to better ensure credibility and to increase the overall rigor of this study. Finally, the results of this study were compared with the existing literature as another means to enhance the meaning and trustworthiness of the findings.

### Results

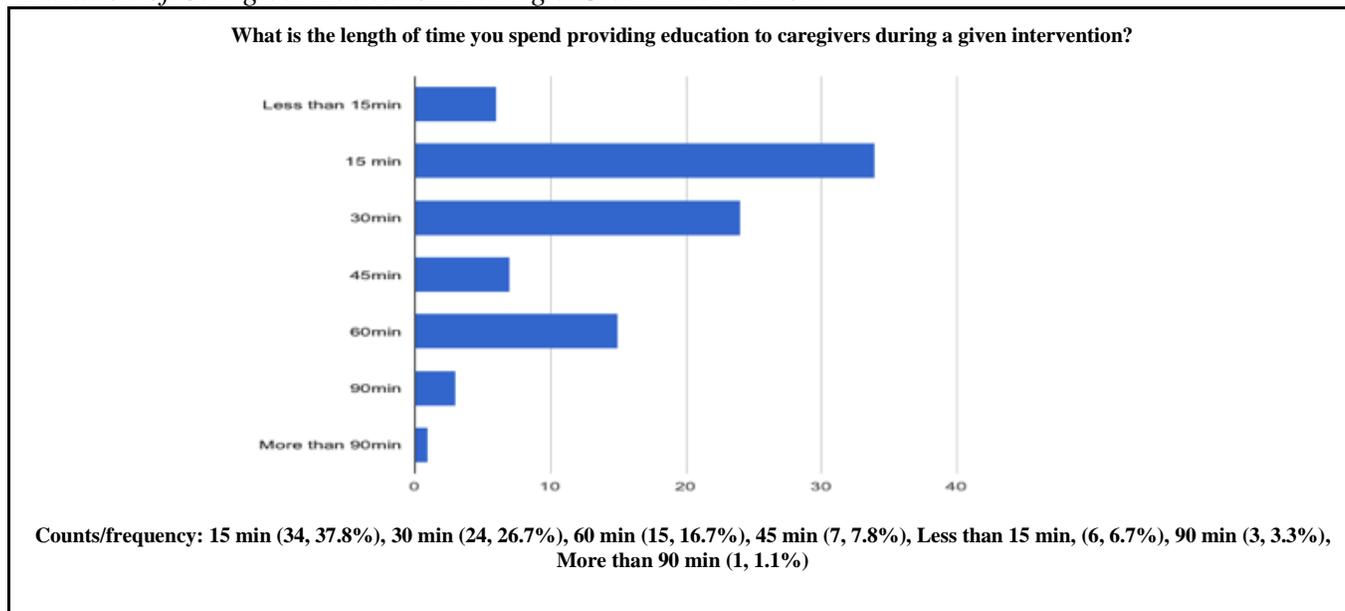
#### Quantitative Data

The results of the quantitative data revealed the majority (~65%) of the occupational therapists in this study typically spend between 15-30 min providing education to caregivers of stroke survivors before discharge from inpatient rehabilitation (see Figure 2).

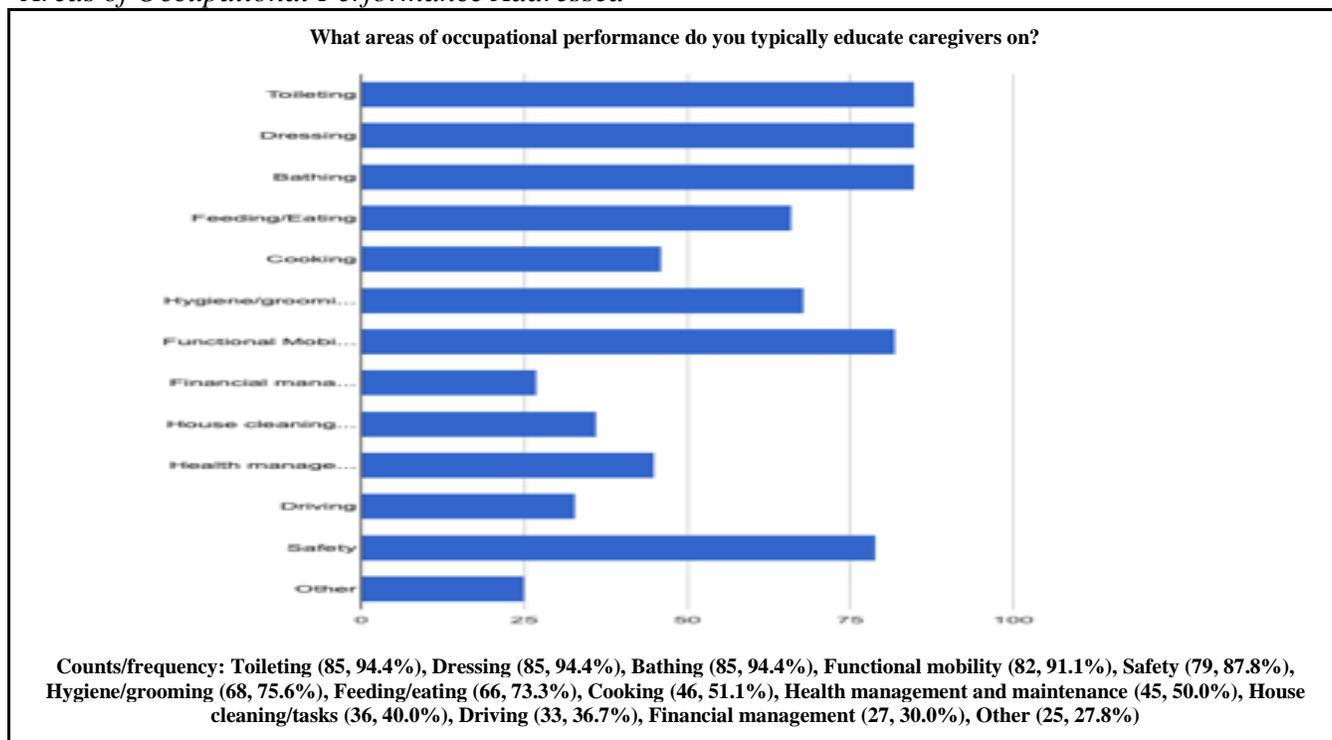
The participants reported providing caregiver education on a variety of basic activities of daily living and instrumental activities of daily living skills, with toileting, dressing, bathing, and functional mobility being the most frequent topics for caregiver education (see Figure 3). In regard to the specific method

used during caregiver education (see Figure 4), the respondents reported using all modes fairly equally during caregiver educational sessions (verbal [98.9%], written information [87.8%], observation [88.9%], and hands-on practice [96.7%]). In terms of how often the caregivers were present throughout the rehabilitation process (see Figure 5), the participants’ responses varied in frequency between daily, usually the week of discharge, twice a week, usually twice before discharge, and usually once a week.

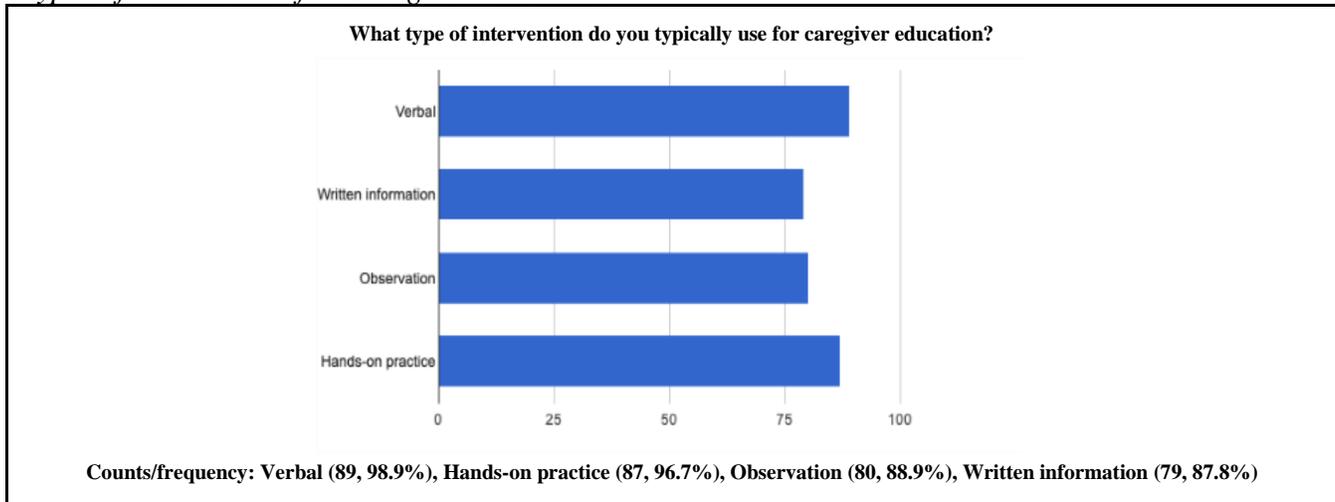
**Figure 2**  
*Duration of Caregiver Education During a Given Intervention*



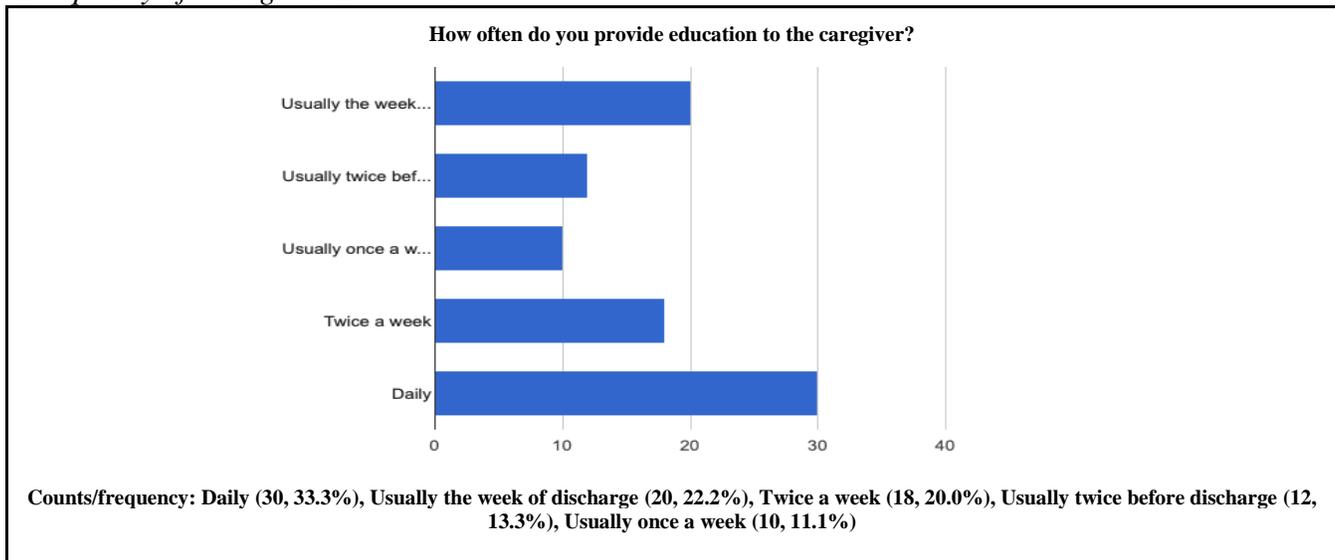
**Figure 3**  
*Areas of Occupational Performance Addressed*



**Figure 4**  
*Types of Intervention for Caregiver Education*



**Figure 5**  
*Frequency of Caregiver Education*



## Qualitative Results

Analysis of the qualitative data gathered from the focus group, one-on-one interview, and open-ended survey questions revealed the following five themes: (a) caregivers and stroke survivors have different needs, (b) occupational therapists must hurdle a variety of barriers when providing education, (c) access to various supports at the workplace is beneficial when providing caregiver education, (d) occupational therapists use a variety of methods to administer caregiver education, and (e) occupational therapists tend to prioritize ADL tasks during education.

### *Caregivers and Stroke Survivors Have Different Needs*

Occupational therapists in this study expressed that the caregivers and stroke survivors have different needs, both of which must be taken into account during caregiver education. One occupational therapist emphasized it is important “to make sure you’re talking to [the caregiver] but to the patient as well, so you’re including everyone in the conversation.” Whereas another occupational therapist stated

that their education style “depends on the comfort level of the caregiver.” The occupational therapists revealed the caregiver’s level of comfort often influences which areas of need are prioritized during the session as well as the style of education provided by the therapist. One of the participants stated it is important to “educate [caregivers] on self-care and burnout because they often come [to therapy] and they are super burnt out and so they’re not taking in the information very well.” While another occupational therapist talked about differences in family dynamics during caregiver education therapy sessions. Specifically, emphasis was placed on the fact that each family is different, so forming connections with them is important, with one participant stating, “It’s not the ability to teach the transfer, it’s the dynamic of who you’re teaching and the family; it could be two of the same transfers but two totally different families and you might approach it differently.” Addressing these needs is important to the occupational therapists, but they do face some barriers that can make it difficult when providing education.

### ***Occupational Therapists must Hurdle a Variety of Barriers when Providing Education***

The data show occupational therapists face multiple barriers when trying to provide education to caregivers, including timing and schedule limitations; patient and caregiver motivation; hospital limitations on education; and insurance coverage. The amount of time occupational therapists spend on providing education can be limited by the caregiver’s schedule. Thus, if the caregiver can only come in for one education session, they may need to schedule another session to increase their confidence related to their ability to care for the stroke survivor’s needs. One of the occupational therapists in the focus group stated, “In my experience, 30 minutes of training for a higher-level stroke patient is typical. Someone who needs a lot of help physically and has a lot of deficits, then it could be a whole hour session and maybe another session after that.” It can be difficult for occupational therapists to provide the caregiver with the necessary amount of information in a 30- to 60-min session while still addressing the needs of the caregiver and making sure they feel confident in what is being taught. If the caregivers are only there for one education session, they will likely also be receiving information from other health care providers. For example, one therapist said, “usually it is not just coming in for an OT session, it is them coming in for certain time periods so they get to go to OT, PT, and then speech if they also have it. So, they may get work from all of us.” Another therapist indicated feeling frustrated at times in stating, “There’s so much more we could do but don’t have the time or the funding because the time we have really has to be focused on the person with the stroke because that’s where the money is and that’s what insurance will reimburse.”

### ***Access to Various Supports at the Workplace is Beneficial when Providing Caregiver Education***

Occupational therapists identified numerous supports that had a positive impact on the provision of caregiver education. These included communication between fellow occupational therapists and multidisciplinary team members, established protocols and checklists, and caregivers being present throughout the rehabilitation process. All of the participants indicated a team approach was very useful in enhancing caregiver education. In fact, these occupational therapists expressed they were “good at bouncing ideas off of one another and asking each other for feedback. For example, one occupational therapist said, “It might be my patient, I might be the primary occupational therapist, but that doesn’t mean I’m not bouncing ideas off of the rest of the team about different approaches and different ideas.” The participant who volunteered for the individual interview mentioned their hospital offered helpful resources, such as a discharge checklist for the occupational therapists to use to guide the discharge process. However, the participant added, “the only real caregiver-focused thing would be approving

them to provide transfers in their room and get them to the bathroom if it's safe at that time, more of the hospital checklist that we coordinate with the PT." Therefore, even though supports were present, and the participant acknowledged it is necessary to have resources available, one of the participants strongly asserted that their resources need to be more caregiver-centered and offer better ways to address the individual needs of the caregivers. The majority of the participants expressed that the provision of education to caregivers throughout the rehabilitation process was an essential component to enhancing comfort, confidence, and skills with the caregiver's roles. When asked about how often caregivers are present, a participant responded, "It is nice to have [caregivers] there more." The participant further explained, "I try to include [caregiver education] into the treatment session, so if we're doing some range of motion and stuff, I try and get the caregiver involved." This is beneficial for the caregiver to observe what is happening in therapy to understand what the patient is capable of doing.

### ***Occupational Therapists use a Variety of Methods to Administer Caregiver Education***

The data demonstrate occupational therapists call on a wide arsenal of techniques when providing education to caregivers. These methods primarily include written information, demonstration, observation, verbal feedback, and hands-on training. The most preferred method overall is hands-on training. One participant summarized this perspective by stating, "It's generally hands-on training and then we have them teach back, especially if it's for transfer training, so they can show us they can get the person in and out of the tub safely." The strategy of having the caregiver demonstrate back to the occupational therapists is beneficial in terms of allowing the occupational therapists to evaluate whether or not the caregiver has a clear grasp on what they are being taught. As one participant stated, "I don't think we can really know [caregiver understanding] until they show us, and they are not doing it correctly." Hands-on training can be effective for the caregiver to understand how their body mechanics are impacted when assisting in activities, such as transfers, "You got to get them hands-on and show them, 'No, put your hand here. No, block their knee here.' And, we have to correct them and show them and have them safely be able to complete the job." In this way, verbal feedback and hands-on training are used in conjunction with each other to instruct and correct the caregiver when necessary. None of the participants indicated written information was used to educate the caregiver on the process of how to perform a task. Instead, written information was most commonly used when providing the caregiver with general education on topics, such as information on cognitive deficits or certain equipment they might need. Lastly, observation techniques were used to increase the caregiver's awareness of the client's abilities and/or deficits in carrying out tasks, "We always try to get family in earlier for observation if we know [the stroke survivor] is more complex to see what they're going to have to face when they get home." In this way, the occupational therapist's role in providing caregiver education encompasses preparing the caregiver based on the level of functioning the client is exhibiting.

### ***Occupational Therapists Tend to Prioritize ADL Tasks During Education***

The participants reported spending the most time on ensuring the caregiver and client were able to safely perform activities of daily living (ADL) tasks in the inpatient setting. Specifically, occupational therapists tend to spend the most time with caregivers and clients on functional mobility training (i.e., transfers), toileting, and bathing. In describing her reasoning, one participant stated, "It's usually transfers, just because that's usually the hardest thing for people to help with." The focus on functional mobility was a common trend among the majority of participants to ensure safety and reduce any subsequent injuries in the home environment upon discharge. The participants within the focus group and interview reported highly similar views. For example, one participant stated, "Generally our primary

focus for in-patient will be to make sure we can check them off for safety to get to the bathroom, for safety to get into the shower, anything [involving] mobility around the house, like navigating the environment.” The data shows there is less focus on IADLs and greater emphasis on ADLs which appears to stem from family caregivers often having no previous exposure to assisting another individual in functional mobility tasks. Therefore, occupational therapists provide caregivers with this training in the inpatient rehabilitation setting so that there is carryover once the patient is discharged from the hospital.

### Discussion

Clients and caregivers have a plethora of educational needs related to enhancing safety and independence with daily occupations prior to discharge from inpatient rehabilitation. Occupational therapists play a vital role in educating the caregiver as a means to enhance an individual’s quality of life and in easing the transition into the home environment after inpatient rehabilitation (Wolf et al., 2015). The findings from the current study highlight the common methods occupational therapists use for education, as well as the challenges faced when providing caregiver education.

The quantitative and qualitative findings suggest occupational therapists recognize the importance of addressing the needs of both the patient and the caregiver, but the patients’ needs often come first as they are viewed as the primary client. The qualitative results of this study indicate challenges such as time constraints, limited resources, and lack of caregiver knowledge influence the education provided by occupational therapists. This supports the findings from previous research regarding the constraints placed on how long a therapist has with a patient and their caregiver can limit when, where, and how the therapist can provide the necessary education (Chen et al., 2015; Liu et al., 2013; Roy et al., 2015).

The results from this study show not only that the occupational therapists have a limited amount of time for caregiver education but also the limited amount of time occupational therapists need to educate caregivers on multiple topics. The quantitative results of this study were consistent with previous research findings (Chen et al., 2015; Danzl et al., 2016; Liu et al., 2013; Roy et al., 2015; Ryan et al., 2017) that suggest that the extensive amounts of areas to cover is a barrier in caregiver education. Moreover, these studies demonstrate that caregivers often report feelings of being overwhelmed because of all of the information they receive in a short period. The findings of this study supported this notion as 94.4% of the participants answered that they educate caregivers on toileting, dressing, and bathing. Yet, over half of the participants stated they only spend 15–30 min providing this education, while 37.8% answered 15 min, and 26.7% answered 30 or more min. Unfortunately, some of the participants in this study stated time limitations for caregiver education were hard to work around because of lack of funding or insurance reimbursement. For example, one participant indicated that there are times in which occupational therapists would like to provide more caregiver education but feel as if they are held back by policies enforced by their place of work or insurance companies.

Although the literature suggests occupational therapists do not take the caregivers’ needs into account while providing caregiver education (Camicia et al., 2018; Lutz et al., 2011), the results from this study indicate they do make an effort to address the needs of both the caregivers and patients separately. Occupational therapists are trying to take the needs of the caregivers into account while providing education. As seen in the qualitative results, one participant stated, “It’s not the ability to teach the transfer. It’s the dynamic of who you’re teaching and the family. It could be two of the same transfers, but two totally different families and you might approach it differently.” This is also evident in

the quantitative survey results in which over 85% of all of the participants stated they use either verbal (98.9%), written information (87.8%), observation (88.9%), or hands-on practice (96.7%) as methods for providing caregiver education (see Figure 4). Hence, each modality is used for different purposes. The occupational therapist's choice to use specific methods to provide caregiver education depends on what both the needs of the caregiver and the client require. Health care professionals should communicate among themselves to ensure the caregivers feel supported and that the caregivers are receiving information in an effective manner, especially because they are receiving information from a wide range of disciplines, not just occupational therapists (Liu et al., 2013).

It should also be noted that not all patients are discharged from inpatient rehabilitation to a home setting. There is some evidence to suggest that approximately 20% of stroke patients are discharged to a skilled nursing facility after inpatient rehabilitation for either continued rehabilitation or long-term care (Nguyen, et al., 2015). Thus, the amount and type of caregiver education and/or results of this study could have been influenced by place of discharge from rehabilitation. For example, if the discharge plan is for admission to a skilled nursing facility, the occupational therapist may have limited training because of feeling that it may be irrelevant.

### **Study Limitations**

Because this study consisted of a small sample size and the focus group only consisted of occupational therapists from one rehabilitation facility in the Midwest, it is unknown if saturation has been reached and if these findings are transferable. Another limitation of this study is that the survey was not pilot tested, which could have resulted in the misinterpretation of the survey items and affected the results.

### **Areas for Future Study**

Future studies should include a larger participant pool with individuals from various geographical locations. In this way, data saturation can be determined with greater certainty and the results can be transferred. The results can then be used to improve the experiences of all clients, caregivers, and occupational therapists, not just of those interacting with stroke survivors.

More information on communication styles and preferred ways of educating from the occupational therapists will be beneficial for the profession because the barriers faced can then be addressed and aligned with the caregivers' needs. Finding out what supports and barriers health care practitioners face during family/caregiver education will increase awareness throughout the profession. Hopefully, the supports can be emphasized and the barriers addressed.

Future studies should continue to focus more on understanding caregiver education from the occupational therapists' point of view so that research can unveil what is necessary to improve on to make caregiver education most effective for all parties involved- the client, the caregiver, and the occupational therapist. Future studies could additionally investigate whether or not occupational therapists are using audio-visual means (i.e., videotapes) to enhance caregiver comfort and skill to understand if it is a viable option for caregiver education. This study occurred before the pandemic. However, given the current global state of health, it seems imperative that future studies also investigate the impact of this pandemic on caregiver education as the role of technology in caregiver education has become an essential part of the caregiver education process as no, or limited, visitation is/was allowed. Thus, future studies should consider the strengths and limitations of advanced technology in caregiver education.

## Implications for Occupational Therapy Practice

The participation from the occupational therapists in both the survey, as well as the focus group and individual interview, offered a unique perspective on caregiver education. The results will be used to inform others in the profession about the information obtained and to help create better outcomes related to caregiver education from occupational therapists as well as other health care providers. This research shows there can be more collaboration between occupational therapists and caregivers as well as more opportunities for occupational therapists to address the caregiver's individual needs during an education session. There are opportunities to create resources for both caregivers and occupational therapists to use to help with the education process and address the time constraints as well as other barriers faced during practice.

The findings also imply additional training may be necessary to properly identify if the information is being transferred to the caregiver in a coherently and/or presented in a format that would best ensure understanding and future application. Occupational therapists should take into consideration the entire process of educating caregivers on stroke units. Occupational therapists should identify the main caregiver, involve the caregiver by having them observe treatment, assess the competency of the caregivers to learn new technical skills and their willingness to participate in training, and determine if the patient and family member(s) are ready to be safely discharged from the hospital (Sadler et al., 2017).

---

### References

- Banford, M., Kratz, M., Brown, R., Emick, K., Ranck, J., Wilkens, R., & Holm, M. B. (2001). Stroke survivor caregiver education: Methods and effectiveness. *Physical & Occupational Therapy in Geriatrics, 19*(1), 37–51. [https://doi.org/10.1300/j148v19n01\\_03](https://doi.org/10.1300/j148v19n01_03)
- Baxter, R., O'Hara, J., Murray, J., Sheard, L., Cracknell, A., Foy, R., Wright, J., & Lawton, R. (2018). Partners at care transitions: Exploring healthcare professionals' perspectives of excellence at care transitions for older people. *BMJ Open, 8*(9). <https://doi.org/10.1136/bmjopen-2018-022468>
- Camicia, M., Lutz, B. J., Markoff, N., & Catlin, A. (2018). Determining the needs of family caregivers of stroke patients during inpatient rehabilitation using interview, art, and survey. *Rehabilitation Nursing, 1*. <https://doi.org/10.1097/rnj.0000000000000129>
- Centers for Disease Control and Prevention. (2020, January 31). *Stroke facts*. <https://www.cdc.gov/stroke/facts.htm>
- Chen, L., Xiao, L. D., & Bellis, A. D. (2015). First-time stroke survivors and caregivers' perceptions of being engaged in rehabilitation. *Journal of Advanced Nursing, 72*(1), 73–84. <https://doi.org/10.1111/jan.12819>
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Sage Publications.
- Danzl, M., Harrison, A., Hunter, E., Kuperstein, J., Sylvia, V., Maddy, K., & Campbell, S. (2016). "A lot of things passed me by": Rural stroke survivors' and caregivers' experience of receiving education from health care providers. *Journal of Rural Health, 32*(1), 13–24. <https://doi.org/10.1111/jrh.12124>
- Ekstam, L., Johansson, U., Guidetti, S., Eriksson, G., & Ytterberg, C. (2015). The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: A mixed methods study. *BMJ Open, 5*(2). <https://doi.org/10.1136/bmjopen-2014-006784>
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 80–92. <https://doi.org/10.1177/160940690600500107>
- Gustafsson, L., Hodge, A., Robinson, M., McKenna, K., & Bower, K. (2009). Information provision to clients with stroke and their carers: Self-reported practices of occupational therapists. *Australian Occupational Therapy Journal, 57*(3), 190–196. <https://doi.org/10.1111/j.1440-1630.2008.00765.x>
- Hahn-Goldberg, S., Jeffs, L., Troup, A., Kubba, R., & Okraimec, K. (2018). "We are doing it together"; The integral role of caregivers in a patients' transition home from the medicine unit. *PloS One, 13*(5), e0197831. <https://doi.org/10.1371/journal.pone.0197831>
- Lawson, S., Rowe, A., & Meredith, Y. Y. (2015). Survey of Stroke Caregiver Training provided by OT, PT, and SLP across practice settings. *Physical & Occupational Therapy In Geriatrics, 33*(4), 320–335. <https://doi.org/10.3109/02703181.2015.1089970>
- Liu, C., Pape, S., Ferrell, J., Turner, E., & Johanningsmeier, K. (2013). Gerontic Occupational Therapy and Patient Education: Perceptions, Barriers, and Needs. *Physical & Occupational Therapy In Geriatrics, 31*(2), 140–147. <https://doi.org/10.3109/02703181.2013.782383>
- Lutz, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: Experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation, 18*(6), 786–797. <https://doi.org/10.1310/tsr1806-786>

- Mirkowski, M., Pereira, S., Janzen, S., Mehta, S., Meyer, M., McClure, A., Speechley, M., & Teasell, R. (2016). Caregiver availability for severe stroke results in improved functional ability at discharge from inpatient rehabilitation. *Disability and Rehabilitation*, 40(4), 457–461. <https://doi.org/10.1080/09638288.2016.1260652>
- Naguwa, K. (2010) Addressing the needs of caregivers: Self-reported practices of occupational therapists in the U.S. [Master's thesis, University of Puget Sound]. [https://soundideas.pugetsound.edu/ms\\_occ\\_therapy/4/](https://soundideas.pugetsound.edu/ms_occ_therapy/4/)
- Nguyen, V. Q., PrvuBettger, J., Guerrier, T., Hirsch, M. A., Thomas, J. G., Pugh, T. M., & Rhoads, C. F., 3rd (2015). Factors associated with discharge to home versus discharge to institutional care after inpatient stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation*, 96(7), 1297–1303. <https://doi.org/10.1016/j.apmr.2015.03.007>
- Rochette, A., Racine, E., Lefebvre, H., Bastien, J., & Tellier, M. (2014). Actual and ideal services in acute care and rehabilitation for relatives post-stroke from three perspectives: Relatives, stroke clients and health professionals. *Journal of Rehabilitation Medicine*, 46(1), 16–22. <https://doi.org/10.2340/16501977-1228>
- Roy, D. E., Gasquoine, S. E., Caldwell, S., & Nash, D. (2015). Health professional and Family perceptions of post-stroke information. *Nursing Praxis in New Zealand*, 31(2), 7–24. <https://doi.org/10.36951/NgPxNZ.2015.004>
- Ryan, T., Harrison, M., Gardiner, C., & Jones, A. (2017). Challenges in building interpersonal care in organized hospital stroke units: The perspectives of stroke survivors, family caregivers and the multidisciplinary team. *Journal of Advanced Nursing*, 73(10), 2351–2360. <https://doi.org/10.1111/jan.13313>
- Sadler, E., Hawkins, R., Clarke, D. J., Godfrey, M., Dickerson, J., & Mckevitt, C. (2017). Disciplinary power and the process of training informal carers on stroke units. *Sociology of Health & Illness*, 40(1), 100–114. <https://doi.org/10.1111/1467-9566.12625>
- Waring, J., Bishop, S., & Marshall, F. (2016). A qualitative study of professional and carer perceptions of the threats to safe hospital discharge for stroke and hip fracture patients in the English National Health Service. *BMC Health Services Research*, 16, 297. <https://doi.org/10.1186/s12913-016-1568-2>
- Wolf, T. J., Chuh, A., Floyd, T., McInnis, K. & Williams, E. (2015). Effectiveness of occupation-based interventions to improve areas of occupation and social participation after stroke. *American Journal of Occupational Therapy*, 69(1), 6901180060p1–6901180060p11. <https://doi.org/10.5014/ajot.2015.012195>
- Young, M. E., Lutz, B. J., Creasy, K. R., Cox, K. J., & Martz, C. (2014). A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation. *Disability and Rehabilitation*, 36(22), 1892–1902. <https://doi.org/10.3109/09638288.2014.881565>

## Appendix A

### Researcher-Developed Survey

Confidential

Page 1 of 2

# OT Practitioners' Perspect Survey: Caregiver Education for Stroke Survivors

Please complete the survey below.

Thank you!

- 
- 1) Age \_\_\_\_\_
- 
- 2) Gender  Male  
 Female
- 
- 3) What is your highest level of education obtained?  Bachelors degree  
 Entry-level masters  
 Post-professional masters  
 Entry-level doctorate  
 Post-professional doctorate
- 
- 4) How long have you been working with stroke survivors and their caregivers?  1-5 years  
 5-10 years  
 10-15 years  
 15-20 years  
 20+ years
- 
- 5) How often do you provide education to the caregiver?  Usually the week of discharge  
 Usually twice before discharge  
 Usually once a week  
 Twice a week  
 Daily
- 
- 6) What is the length of time you spend providing education to caregivers during a given intervention?  Less than 15min  
 15 min  
 30min  
 45min  
 60min  
 90min  
 More than 90min
- 
- 7) What areas of occupational performance do you typically educate caregivers on? (Check all that apply)
- Toileting
  - Dressing
  - Bathing
  - Feeding/Eating
  - Cooking
  - Hygiene/grooming
  - Functional Mobility
  - Financial management
  - House cleaning/tasks
  - Health management and maintenance
  - Driving
  - Safety
  - Other
- 
- 8) \*Optional\*  
If selected "other" for the question above, please explain. \_\_\_\_\_

04/29/2019 4:57pm

www.projectredcap.org



Confidential

Page 2 of 2

- 
- 9) What type of intervention do you typically use for caregiver education? (Check all that apply)
- Verbal
  - Written information
  - Observation
  - Hands-on practice
- 
- 10) How often are caregivers present during survivors' therapy sessions?
- Usually the week of discharge
  - Usually twice before discharge
  - Usually once a week
  - Twice a week
  - Daily
- 
- 11) Describe any challenges or barriers you typically face while providing education to caregivers.
- \_\_\_\_\_
- 
- 12) What are the most common questions caregivers ask while receiving education/training?
- \_\_\_\_\_
- 
- 13) Do you feel you would benefit from further training on methods to enhance caregiver education?
- Yes
  - No
- 
- 14) If yes, what specific topics would be considered helpful?
- \_\_\_\_\_

## **Appendix B**

### **Examples of Focus Group/One-on-one Interview Questions**

- How often are caregivers present during stroke survivors' therapy sessions?
  - How long do you get to spend educating them during the session?
- How involved are caregivers throughout stroke survivors' recovery process?
  - Are they there daily, weekly, just at discharge?
- Is there a specific area/activity you address first? How do you prioritize?
  - What might those be and why?
  - What methods do you use to educate caregivers?
- How do you recognize when a caregiver is struggling to understand a concept during education?
  - What strategies might you use to help them through the difficulties they are having?
  - How do you separate client needs from caregiver needs?
- How do you evaluate whether a caregiver understands what you're teaching and if they can apply that on their own?
- What are the most common questions caregivers ask while receiving education/training?
- Do you feel you would benefit from a training session on methods to enhance caregiver education? If so, what specific topics would be helpful?