

**Early Caregiver Training in Stroke  
Capstone Project**

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### **Abstract**

Cerebrovascular accidents (strokes) have a widespread and profound impact on survivors and caregivers, their quality of life and their ability to engage in occupations. Shortened hospital stays, limited access to post-acute rehabilitation, and often drastic changes in an individual's functioning, can leave caregivers untrained and unprepared at discharge. The focus of acute care is limited to medical stabilization and discharge of the patient, resulting in a missed, and sometimes sole, opportunity to support and prepare caregivers through education and training.

The current healthcare climate and review of the literature support the need for an early, standardized education program for caregivers that is clear, systematic, and readily accessible to clinicians and caregivers. The establishment of a formalized program in the acute care setting provides an opportunity for improved outcomes in functioning and quality of life and health for caregivers and survivors of stroke. Benefiting stakeholders, this program serves as a template for other settings. In addition, this program contributes to the scholarship of occupational therapy (OT), positioning the profession as a visible leader in hospital discharge planning and preparation.

## Introduction

In the United States (U.S.), strokes occur approximately once every forty seconds, and are a leading cause of death and serious, long-term disability (American Heart Association, 2020; Blanton et al., 2018; Cameron, 2013; CDC, 2020; Lawson et al., 2015). As a result of improving emergency treatment and survivorship of stroke, an estimated 78% of patients with stroke will return home upon completion of an inpatient hospitalization or rehabilitation stay (Cameron, 2013). Up to 40% of survivors of stroke experience a moderate disability, and up to 30% suffer a severe disability. These disabilities can present significant physical, mental, and social challenges, many of which are not fully realized until the survivor is home (Duncan et al., 2017). These challenges result in approximately 70% of stroke survivors requiring assistance with activities of daily living well into the first-year post stroke or beyond (Duncan et al., 2017; S. Smith et al., 2008). Most often, this assistance is provided by family members or friends who rarely receive adequate preparation to support their new life role (Knecht-Sabers et al., 2017).

Family members, who assume the responsibility of caregiver, play a key role in the facilitation of recovery (Tosun & Temel, 2017), with the reliance of stroke survivors on their caregivers being critical in the ability to continue engaging in life to their full capacity (Hong et al., 2017; Lawson, 2015). Despite this, family members are often unaware and overwhelmed by the level of care required, experiencing the transition home to be as traumatic as the stroke onset itself. The role requirements of these caregivers are complex and fluid throughout the recovery process. Caregivers are tasked with the management of medications, appointments, and health care coordination; the provision of physical assistance for self-care and mobility; and communication assistance for speech and language problems. Providing cognitive assistance for safety, emotional support, and the addition of increased household responsibilities are often the norm. Even patients with mild post-stroke disabilities can have undetected physical and

cognitive deficits. Upon returning home, these deficits become evident by interfering with function and management of risk factors, (Duncan et al., 2017) further compounding the caregiver burden.

In trying to meet the needs of their loved ones with stroke, caregivers report a great degree of physical strain, fatigue, depression, and feelings of incompetence. Many caregivers report prominent levels of anxiety, social isolation, and stress (Tosun & Temel, 2017). The challenges faced by caregivers often result in an inability to meet their own physical and emotional needs (Lawson et al., 2015), can decrease their ability to continue the caregiving role, and increase their own mortality (Blanton et al., 2018; Hong et al., 2017; Lawson et al., 2015). To lessen these negative outcomes, and increase the chance of success, it is imperative that caregivers be educated, informed, and supported in meeting their own needs (Tosun & Temel, 2017). Individualized training and education can play a pivotal role in mitigation of these negative outcomes.

## **Background**

The setting of this program is a 176 bed acute care hospital entering its third year as a Det Norske Veritas-Germanischer Lloyd (DNV-GL) Primary Stroke Center. This designation results in an average of twelve patients with stroke per month being admitted and treated. This designation also sets standards for excellence in treatment of these patients. The inpatient therapy department, however, has yet to create a systematic way to educate patients and their loved ones. New caregivers of patients with stroke currently receive only the opportunistic education that is determined to be necessary by, or is available to, their treating therapists. This education can vary, depending on the experience and consistency of the therapist, the availability of the family members, the number of missed visits due to testing or medical instability of the patient, and the patients' length of stay. While this usual training may be

sufficient in some cases, it is anticipated that a more formalized and comprehensive approach would serve to improve outcomes for both patients and their caregivers.

Growing economic pressure and reform within the healthcare climate mandates shorter hospital stays, and decreased access to post-acute rehabilitation, with nearly one half of patients with stroke discharging directly home (Caswell, 2017). In trying to meet the needs of their loved ones, caregivers report physical strain, fatigue, depression, feelings of incompetence, high anxiety, social isolation, and stress (Tosun & Temel, 2017) that can be further compounded by lack of training. In addition, the literature clearly indicates that lack of caregiver training in stroke can increase health care costs including emergency department use and readmissions (Cameron, 2013; Hankey, 2004; Hong et al., 2017; Koenig et al., 2011, Mudzi et al., 2015). Inpatient therapists provide a first, and sometimes *only*, opportunity to provide such training. As a profession committed to improving quality of life, occupational therapists are called to empower and best prepare caregivers for success by providing consistent, clear education and support at every opportunity. The existing reliance on varying and opportunistic caregiver education creates a gap in this setting that must be filled.

### **Research Question**

Considering the limitations presented in our current healthcare climate, and the impact that caregiver training is shown to have on outcomes with patients with stroke and their caregivers, how can clinicians better prepare our caregivers of stroke for their new life role, thereby improving physical and emotional outcomes for both patient and families?

### **Literature Review**

In preparation for this project, a review of the literature to inform the occurrence, benefit, barriers, and best methods of stroke caregiver education delivery was conducted. The literature clearly indicates that adequate training in stroke can decrease health care costs, as well as

improve the mental and physical health of the caregiver. Proper education can decrease negative outcomes, emergency department use and hospitalization for the recipient (Cameron, 2013; Hankey, 2004; Hong et al., 2017; Koenig et al, 2011; Mudzi et al., 2015). In spite of this support, Andrew et al., (2018) found that only a fraction of patients and caregivers received all measured aspects of discharge care planning, and that most often caregiver needs were not met (Andrew et al., 2018; Eames et al., 2010; Hafsteinsdottier et al., 2010; O'Connell et al., 2003; Smith et al., 2008).

With growing economic pressure to reduce and shorten admissions, the average acute care hospital stay for stroke survivors is between four (ischemic) to seven (hemorrhagic) days (Caswell, 2017). Furthermore, nearly half of patients with stroke will discharge directly home, never experiencing inpatient rehabilitation. This new reality contributes to the increased demands, acuity, and complexity of tasks that families are expected to perform (Reinhard et al., 2019). The abrupt nature of stroke and limited access to medical and community resources post-discharge add further complexity to the burden (Reeves, 2017). In recognition of caregivers' need for support, The Caregiver Advise, Record, Enable (CARE) Act became law in 40 states within just four years (Reinhard et al., 2019). Signed in Texas in 2017, the CARE Act requires hospitals to allow patients to formally designate a caregiver and requires hospital workers to provide patient-designated caregivers with instruction or training on how to perform tasks for the patient at home. This legislation gives legal weight to the importance of acknowledging and preparing caregivers before leaving the hospital setting.

While it is found that therapists across the United States provide some degree of training to caregivers of stroke survivors, few do this in a systematic way (Lawson et al., 2015). Even fewer report having a formalized protocol to provide training. Acute care therapists in this country specifically report lack of resources (education binders or videos, support in scheduling groups of caregivers for training) as barriers for providing training. Formal identification and

availability of the caregiver is also noted to be a limiting factor, indicating a need for a more flexible and conducive training schedule (Cameron et al., 2013). Transitional care for stroke patients in the United States is highly fragmented, poorly organized and is rarely patient centered (Reeves, 2017). International resources such as the Canadian Stroke Best Practice Recommendations may serve as a valuable reference for U.S. therapists, recognizing the lived experience in providing evidence-based guidelines and resources on all aspects of stroke (Heart and Stroke Foundation of Canada, 2018). The London Stroke Carers Training Course (LSCTC) provides a 14-item structured competency-based training program designed to help develop knowledge and skills essential for the management of stroke survivors and may also prove a useful resource (Clarke et al., 2014) for therapists in this country and for this project. Despite the fast paced and urgent atmosphere, lack of resources, and absence of an established program, therapists in the acute care setting provide a first opportunity to engage and educate caregivers of stroke, serving as mode of application in my capstone project.

## **Methods**

### **Project Purpose**

This project aimed to offer consistent, formal, and early education to caregivers in the acute care setting. The need for such a program in this setting was first recognized by the changing healthcare climate, and then established through extensive literature review and feedback from clinicians and caregivers. Barriers and facilitators of caregiver education in stroke was a focus, as was its impact on outcomes.

### **Key Elements**

In addition to the clinical experience and research performed by the program author (an OT), consultation with an outpatient physical therapist, inpatient physical therapist, inpatient speech language pathologist and hospital stroke program coordinator within the setting was utilized to determine need and topics that would be included. Additional guidance was obtained

through printed questionnaires completed by 11 current caregivers of loved ones with stroke and resources such as American Heart Association, Stroke Engine and Stroke.org.

All feedback and information were compiled to create a printed, interdisciplinary booklet. The purpose of this booklet was to empower caregivers with immediate, digestible information on stroke impact and management in a time of profound and sudden change in their life role. Specifically, the booklet contained introductory information regarding the cause and effect of strokes, mobility, activities of daily living, emotional changes, swallowing, cognition, communication, safety, durable medical equipment, levels of therapeutic intervention, stroke prevention and support resources. In addition, information was provided regarding caregiver stress management and self-care.

Careful attention was given to ensure the content was clear, concise, and usable to the intended reader (informal caregiver/ family). Also included was a pre and post Likert scale questionnaire to be completed by the caregiver receiving this education. The booklet design was aligned with existing hospital system booklets and the supply of booklets was maintained through the hospital's marketing department. Electronic copies of these booklets were made available when needed.

In addition to the information booklet, a second element was the establishment of a therapy stroke resource center. The intent of this resource center was to provide immediate access to additional, more specific, stroke topics and resources that were not included in the booklet. The resource center provided information on topics such as visual deficits, emotional changes, and area support groups. This was done by providing and maintaining a supply of printed materials held within a clearly labeled, wall mounted brochure holder on the hospital's stroke unit. Replenishment of materials was ensured by the inpatient therapy department's staff.

## **Implementation**

Upon initial completion of the project booklet, its contents were introduced and reviewed with the treating inpatient therapy team to ensure carryover and understanding. The evaluating OT for any patient with a confirmed stroke was instructed to provide a copy of the booklet to the designated caregiver/family member. Each treating discipline (occupational therapy, physical therapy, and speech language pathology) was then asked to review their specific topics with the caregiver at their earliest convenience, preferably within the first or second treatment session. Opportunity for hands on practice and questions was noted to be an important part of training and was encouraged. Pre-arranging a training course with caregivers was suggested. In the absence of a caregiver at the bedside, contact was to be made by phone. Documentation of booklet provision and review of information was to be entered into the patient's medical record.

Therapists and nurses were asked to direct family members to the therapy stroke resource center, where printed materials are immediately accessible. Educational videos may be added to the resource center going forward.

### **Results**

A short pre- and post-training Likert scale questionnaire was included in the booklet. This questionnaire indicated caregiver knowledge/preparedness before and after training. Refer to Figure 1 to view pre/post training questionnaire. Questionnaire results were used to determine success of the program's initial, partial trial. In this trial, portions of the project were presented to two caregivers of patients with stroke. It should be noted that the content included in the trial was limited to emotional changes post-stroke, caregiver self-care tips, identification of caregiver burden and provision of resources. In both instances, post-training scores increased, indicating an improved sense of caregiver preparedness. See Figure 2 for graph of results.

### **Limitations**

Some limitations exist. The number of patients with stroke, family/ caregiver availability and response rate (two patients discharged before surveys were returned) contributed to the small sample size. Staff productivity expectations and time constraints limited opportunity for inpatient therapists to contribute feedback toward content. The setting required facility approval for program implementation, necessitating that the program trial only include portions of the program. This also contributed to the small sample size.

Pending project approval, further success will be indicated by the number of caregiver booklets distributed to caregivers and the documentation of booklet review with caregivers in the medical record. The number of therapy stroke resource center materials needed to maintain supply will indicate frequency of use, or retrieval, by family members. Data collection sheets for this information are maintained by therapy staff. Additional anticipated means of evaluation include any decreases in preventable readmissions of patients with stroke, decreased caregiver burden (as indicated on follow up surveys) and the adoption of this program by not only the initial setting, but by the hospital system, following a presentation to system decision makers. This data will be available following implementation of the program in its entirety.

## **Discussion**

A review of the literature revealed that the amount of education received by caregivers in stroke is rarely adequate, leaving them untrained and ill prepared (Blanton et al., 2018; Hong et al., 2017; Lawson et al., 2015). Inadequate caregiver training contributes to increased health care costs and decreased mental and physical health of the caregiver. Conversely, proper education is found to decrease negative outcomes, emergency department use and hospitalization for the recipient (Cameron, 2013; Hankey, 2004; Hong et al., 2017; Koenig et al, 2011; Mudzi et al., 2015).

Caregivers need targeted, timely, client-centered, and understandable training that is specific to their needs and situation. This training should begin at the time of admission and continue throughout the stay (Cameron, 2013; Koenig et al., 2011; Hafsteinsdottir et al., 2010; Walder & Molineaux, 2009, Winstein et al., 2016). Caregivers report a need for improved availability of training information; a conducive environment for obtaining information; clarity and coordination regarding who to ask for information, and clear, comprehensive, and succinct information (Cameron, 2013; Cameron et al., 2013; Eames et al., 2010; Hoffman & Cochrane, 2009; D. Smith & Hudson, 2012). Caregivers prefer multimedia methods of delivery; printed and verbal training, facility-specific information; and the opportunity for repetitive, active practice (Danzl et al., 2016; Hafsteindottir et al., 2010; Hoffman & Cochrane, 2009). Including two key elements (a stroke unit-based resource center and a multidisciplinary caregiver booklet) this project addresses identified needs and barriers, and a lack of resources reported by acute care therapists across the United States.

Surveys completed by 11 current caregivers of patients with stroke confirmed a gap in training at the acute care stage. Caregivers identified 19 topics (see Table 1) which they wish had been addressed prior to discharge. This information was used to build content of the program. Limitations of this data that should be considered is that the severity of the loved one's stroke, nor the length of time one served in the caregiver role, were reported. Future research might include caregiver surveys that may inquire about these factors to further inform appropriate topics to be covered.

**Table 1**

*Training Needs by Topic as Indicated by Caregiver Responses*

<b>Education Topics</b>	<b>Total Responses</b>
Emotional Changes/ Concerns	5
How to Avoid Another Stroke	5
Exercises	4
Cognition/ Thinking	3
Support Programs for Patient	3
How to Manage Your Own Stress/ Caregiver Self-Care	3
How to Avoid/ Assist Loved Ones if They Fall	3
Activities of Daily Living	2
Transfers	2
Fatigue Following Stroke	2
Going Out into the Community	2
Positioning	2
Swallowing/ Feeding	1
Speech/ Communication	1
Visual Changes	1
Equipment (walkers/wheelchairs/ Bathing Equipment etc.)	1
Differences in Rehab/Skilled Nursing/Home Health	1
How to Recognize Another Stroke	1
Support Programs for Caregivers	1

*Note.* Eleven current stroke caregivers were asked to indicate in which areas (from those listed above) they wish they had received training prior to hospital discharge. No limit on number of topics was given.

Considering the setting is a DNV Primary Stroke Center, the adoption of this project in its entirety is anticipated to be positive. Interest, need, and support was demonstrated by our facility when first proposed two years ago. Upon approval by the initial setting, a future goal would be adoption by the entire hospital system, reaching seven inpatient entities. With system wide and marketing backing, sustainability is reasonable. Utilization of this project can easily be documented in the electronic health record and monitored the hospital's stroke and readmission committees.

The uniquely holistic lens of OT lends itself to the development and implementation of an interdisciplinary educational program that aims to improve the quality of life, engagement, and well-being of those impacted by stroke. In addition to contributing to my setting and hospital system, its clients, and caregivers, this project will contribute to the profession of OT by upholding a commitment to client-centered care. It will serve to mitigate negative outcomes (Reinhard et al., 2019) that are reflective of shortened hospital stays and increased caregiver burden in our current healthcare environment. Consistent with the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2020) and Code of Ethics (AOTA, 2015), this project will promote the profession of OT, highlighting its commitment to advocacy, education, occupational justice, empowerment, and advocacy. In a setting where patient education and recommendations often hinge on mobility alone, OTs are primed to promote education in all facets of functioning (elevating our contribution, visibility, and value to the team) and further recognizing our client-centered focus. This project brings OT to the forefront of acute care stroke caregiver education and serves as a catalyst for improved interdisciplinary intervention and well-being for those who are served.

### **Conclusion**

This capstone project aimed to address a void in resources currently available to therapists, patients, and caregivers within the acute hospital setting. By providing a formalized stroke caregiver education program (to be implemented immediately upon evaluation in the acute setting) training opportunities are maximized, rather than delayed to the next level of care, or omitted all together. Current literature, clinicians and caregivers indicate a need for early, consistent, and coordinated education following stroke (Cameron, 2013; Koenig et al., 2011; Hafsteinsdottir et al., 2010; Walder & Molineaux, 2009, Winstein et al., 2016), and our current healthcare environment mandates it. While this project is designed to fill a gap in a specific

hospital setting, it may provide a template for additional acute care settings within the system, extending its contribution to improved outcomes for all stakeholders.

## References

- American Heart Association (2020). *2020 Heart Disease and Stroke Statistical Update Fact Sheet at a Glance*. [https://www.heart.org/-/media/files/about-us/statistics/2020-heart-disease-and-stroke-ucm\\_505473.pdf?la=en](https://www.heart.org/-/media/files/about-us/statistics/2020-heart-disease-and-stroke-ucm_505473.pdf?la=en)
- American Heart Association/American Stroke Association. *Stroke*, 47(6), e98–e169. <https://doi.org/10.1161/STR.0000000000000098>
- American Occupational Therapy Association (2015). Occupational therapy code of ethics. *American Journal of Occupational Therapy*, 69, Article 6913410030. <https://doi.org/10.5014/ajot.2015.696S03>
- American Occupational Therapy Association (2020). Occupational therapy practice framework: Domain and process (4th Edition). *American Journal of Occupational Therapy*, 74, 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>
- Andrew, N., Busingye, D., Lannin, N. A., Kilkenny, M. F., & Cadilhac, D. A. (2018). The quality of discharge care planning in acute stroke care: Influencing factors and the association with postdischarge outcomes. *Journal of Stroke and Cerebrovascular Diseases*, 27(3), 583-590 <https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.09.043>
- Blanton, S., Dunbar, S., Clark, P., & Blanton, S. (2018). Content validity and satisfaction with a caregiver-integrated web-based rehabilitation intervention for persons with stroke. *Topics in Stroke Rehabilitation*, 25(3), 168–173. <https://doi.org/10.1080/10749357.2017.1419618>
- Cameron, V. (2013). Best practices for stroke patient and family education in the acute care setting: A literature review. *MEDSURG Nursing*, 22(1), 51-55.

<http://search.ebscohost.com.libux.utmb.edu/login.aspx?direct=true&db=rzh&AN=85176682&site=ehost-live>

Cameron, J., Naglie, G., Silver, F., & Gignac, M. (2013). Stroke family caregivers' support needs change across the care continuum: A qualitative study using the timing it right framework. *Disability and Rehabilitation*, 35(4), 315–324.

<https://doi.org/10.3109/09638288.2012.691937>

Caswell, J. (2017). *What Happens Next? Making the Best Decision at Discharge after Stroke*.

<https://strokeconnection.strokeassociation.org/Summer-2017/What-Happens-Next-Making-the-Best-Decisions-at-Discharge-After-Stroke/>

Center for Disease Control and Prevention. (2020, January 31). *Stroke Facts*.

<https://www.cdc.gov/stroke/facts.htm>

Clarke, D. J., Hawkins, R., Sadler, E., Harding, G., McKevitt, C., Godfrey, M., Dickerson, J., Farrin, A.J., Kalra, L., Smithard, D., & Forster, A. (2014). Introducing structured caregiver training in stroke care: Findings from the TRACS process evaluation study. *BMJ Open*, 4(4). <https://doi.org/10.1136/bmjopen-2013-004473>

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>

Duncan, P., Bushnell, C., Rosamond, W., Jones Berkeley, S., Gesell, S., D'Agostino, R.,

Ambrosius, W., Barton-Percival, B., Bettger, J., Coleman, S., Cummings, D., Freburger, J., Halladay, J., Johnson, A., Kucharska-Newton, A., Lundy-Lamm, G., Lutz, B., Mettam, L., Pastva, A., Sissine, M.E. & Vetter, B. (2017). The Comprehensive Post-Acute Stroke

- Services (COMPASS) study: Design and methods for a cluster-randomized pragmatic trial. *BMC Neurology*, 17(1), 133–13. <https://doi.org/10.1186/s12883-017-0907-1>
- Eames, S., Hoffmann, T., Worrall, L., & Read, S. (2010). Stroke patients and carers' perception of barriers to accessing stroke information. *Topics in Stroke Rehabilitation* 17(2), 69-78. <https://doi.org/10.1310/tsr1702-69>
- Hafsteinsdottir, T.B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counseling*, 85(1), 14-25. <http://dx.doi.org/10.1016/j.pec.2010.07.046>
- Hankey, G. (2004). Informal care giving for disabled stroke survivors. *BMJ (Clinical Research Ed.)*, 328(7448), 1085–1086. <https://doi-org.libux.utmb.edu/10.1136/bmj.328.7448.1085>
- Heart and Stroke Foundation of Canada (2018). <https://www.strokebestpractices.ca/>
- Hoffman, T., & Cochrane, T. (2009). What education do stroke patients receive in Australian hospitals? *Patient Education and Counseling*, 77(2), 187-191. <http://dx.doi.org/10.1016/j.pec.2009.03.009>
- Hong, S-E., Kim, C-H., Kim, E-J., Joa, K-L., Kim, T-H., Kim, S-K., Han, H-J., Lee, E-C., & Jung, H-Y. (2017). Effect of a caregiver's education program on stroke rehabilitation. *Annals of Rehabilitation Medicine*, 41(1), 16-24. <https://doi.org/10.5535/arm.2017.41.1.16>
- Knecht-Sabres, L., Shiffer, C., Krol, E., & Case, E. (2017). After a stroke: Addressing the needs of caregivers. *American Occupational Therapy Association SIS Quarterly Practice Connections*, 2(3), 22–24. <https://www.aota.org/Publications-News/SISQuarterly/Physical-Disabilities/8-17-mental-health.aspx>

- Koenig, K., Steiner, V., & Pierce, L. (2011). Information needs of family caregivers of persons with cognitive versus physical deficits. *Gerontology & Geriatrics Education*, 32(4), 396–413. <https://doi.org/10.1080/02701960.2011.611713>
- Lawson, S., Rowe, A., & Meredith, 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>
- Mudzi, W., Stewart, A., & Musenge, E. (2015). Caregiver strain and associated factors 12 months post stroke: Impact of caregiver education. *Physiotherapy*, 101, e1055–e1055. <https://doi.org/10.1016/j.physio.2015.03.1935>
- O'Connell, B., Baker, L., & Prosser, A. (2003). The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience Nursing*, 35(1), 21–28. <https://doi.org/10.1097/01376517-200302000-00006>
- Reeves, M., Hughes, A., Woodward, A., Freddolino, P., Coursaris, C., Swierenga, S., Schwamm, L., & Fritz, M. (2017). Improving transitions in acute stroke patients discharged to home: The Michigan stroke transitions trial (MISTT) protocol. *BMC Neurology*, 17(1), 115–15. <https://doi.org/10.1186/s12883-017-0895-1>
- Reinhard, S., Young, H.M., Ryan, E., & Choula, R. B. (2019). The CARE Act implementation: Progress and promise. *Spotlight*. <https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf>
- Smith, D., & Hudson, S. (2012) Using the person–environment–occupational performance conceptual model as an analyzing framework for health literacy, *Journal of Communication in Healthcare*, (5)1, 11-3. <https://doi.org/10.1179/1753807611Y.00000000021>

- Smith, S., Gignac, M., Richardson, D., & Cameron, J. (2008). Differences in the experiences and support needs of family caregivers to stroke survivors: Does age matter? *Topics in Stroke Rehabilitation*, 15(6), 593–601. <https://doi.org/10.1310/tsr1506-593>
- Tosun, Z., & Temel, M. (2017). Burden of caregiving for stroke patients and the role of social support among family members: An assessment through home visits. *International Journal of Caring Sciences*, 10(3), 1696–1704.  
[https://www.internationaljournalofcaringsciences.org/docs/65\\_8\\_tosun\\_10\\_3.pdf](https://www.internationaljournalofcaringsciences.org/docs/65_8_tosun_10_3.pdf)
- Walder, K., & Molineux, M. (2019). Listening to the client voice-A constructivist grounded theory study of the experiences of client-centered practice after stroke. *Australian Occupational Therapy Journal*, 00, 1-10. <https://doi.org/10.1111/1440-1630.12627>
- Winstein, J., Stein, R., Arena, C., Bates, J., Cherney, L., Cramer, E., Deruyter, J., Eng, J., Fisher, G., Harvey, D., Lang, D., Mackay-Lyons, D., Ottenbacher, D., Pugh, D., Reeves, D., Richards, D., Stiers, D., & Zorowitz, D. (2016). Guidelines for adult stroke rehabilitation and recovery: A guideline for healthcare professionals from the

## Appendix

### Figure 1

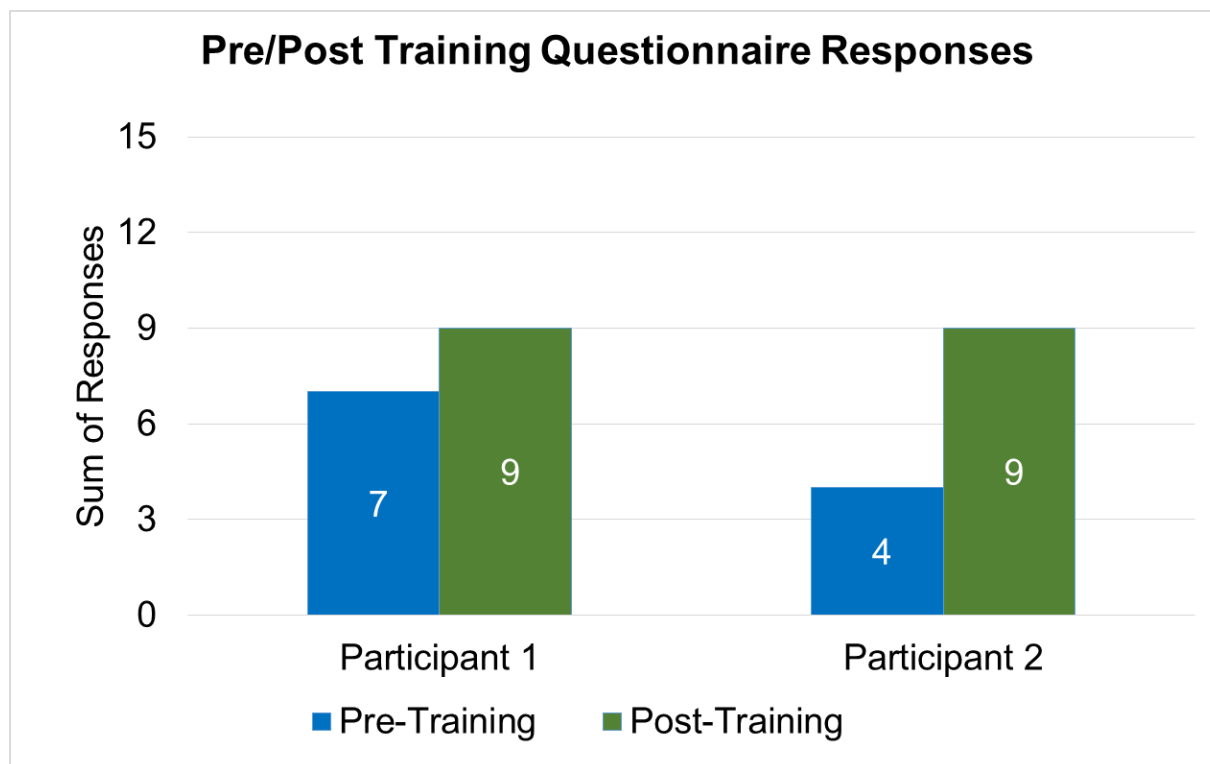
#### *Caregiver Pre/Post Training Questionnaire*

Pre/Post Training Questionnaire	
Please answer the questions below so that we may determine the benefit, and how we can improve upon, the enclosed information.	
Please circle 1 through 5, with 1 being the least and 5 being the most. These questions should be answered BEFORE, and then again AFTER, you review this booklet.	
How much information have you received regarding stroke and the therapy process?	1   2   3   4   5
How confident are you that you know where to find support, resources, and information regarding any questions that you have?	1   2   3   4   5
How prepared do you feel as a caregiver?	1   2   3   4   5

*Note.* Identified caregivers of hospitalized patients with new strokes responded to this questionnaire before and after provision of printed educational materials.

**Figure 2**

*Comparing Caregiver Preparedness Pre and Post Training*



*Note.* A score of 3 indicates the caregiver is “least prepared” while a score of 15 indicates the caregiver is “most prepared.” This graph demonstrates that the degree of preparedness perceived by each participant increased after participating in program trial.