



The Open Journal of Occupational Therapy

Volume 8
Issue 2 *Spring 2020*

Article 6

April 2020

Assessing Unmet Needs of Caregivers after Stroke: Occupational Therapist Practices and Perspectives

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Recommended Citation

Clymer, D. R., Fields, H. A., & Kniepmann, K. (2020). Assessing Unmet Needs of Caregivers after Stroke: Occupational Therapist Practices and Perspectives. *The Open Journal of Occupational Therapy*, 8(2), 1-13. <https://doi.org/10.15453/2168-6408.1653>

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Assessing Unmet Needs of Caregivers after Stroke: Occupational Therapist Practices and Perspectives

Abstract

Background: Family caregivers of stroke survivors often feel unprepared and overwhelmed post discharge with numerous unmet needs. Occupational therapists can play an integral role in addressing family caregivers' needs. Limited research exists on assessment practices of occupational therapists in identifying caregivers' needs poststroke. This study explores the practices and perspectives of occupational therapists in assessing unmet caregivers' needs.

Method: A cross-sectional, mixed methods research design was used to electronically survey 15 occupational therapists. Part 1 of the survey explored participant methods for identifying caregivers' needs and their views on using formal caregiver assessment tools. Part 2 gathered participant perspectives on three selected caregiver assessments. Descriptive statistics and thematic analysis were used to interpret the data.

Results: The participants perceive formal assessments as beneficial. However, they use informal strategies to assess the unmet needs of caregivers rather than formal assessment. Reimbursement challenges, productivity pressure, and questionable necessity are barriers to conducting formal assessments. Advantages and disadvantages of each assessment are discussed.

Conclusion: Occupational therapists face barriers to conducting formal assessment across settings. Implementation of recent policies is needed to further support occupational therapy's role in addressing caregivers' needs. This study can inform future development of assessment tools tailored to occupational therapy.

Comments

The authors report that they have no conflicts of interest to disclose.

Keywords

caregiver assessment, caregiver needs, caregiver preparedness, family caregivers, occupational therapy, stroke

Cover Page Footnote

We thank all occupational therapists who took the time to participate in this study. We would also like to thank others in Dr. Kniepmann's Family Caregiving Lab who contributed to this study while they were graduate students. Some of the information from an earlier version of this manuscript was shared in a poster at the American Occupational Therapy Association 2019 Annual Conference and Expo on April 5, 2019.

Credentials Display

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DOI: 10.15453/2168-6408.1653

Stroke is a leading cause of long-term disability in the United States (Benjamin et al., 2019). Most stroke survivors return home after a short length of stay in a hospital or rehabilitation facility with continuing physical and emotional challenges (Cameron et al., 2013; Palmer & Glass, 2003). Successful reintegration of the stroke survivor into the community is dependent on the comprehensive preparation of the family caregivers (MacIsaac et al., 2011). Family caregivers, defined as unpaid family members assisting loved ones, may require education on functional limitations and care needs of their loved ones as well as coping strategies to manage the unexpected responsibilities of caregiving (Alexander & Wilz, 2010; AOTA, 2007; Young et al., 2014).

Family caregivers rarely receive adequate preparation for the full extent of caregiving responsibilities (Greenwood et al., 2016; Lutz et al., 2017). They often have numerous and diverse unmet needs across the care continuum (Hafsteindóttir et al., 2011). Families report feeling rushed through discharge preparations while practitioners describe having limited time to address the individual needs of caregivers (Andrew et al., 2018; Creasy et al., 2013; MacIsaac et al., 2011). Lack of preparedness is associated with higher burden, increased depression and anxiety, and lower levels of hope (Henriksson & Årestedt, 2013; Scherbring, 2002). Caregivers who have unmet educational needs at discharge are more than twice as likely to experience an injury because of caregiving activities when the stroke survivor returns home (Hinojosa & Rittman, 2009). The ability and preparedness to provide care and the psychological health of caregivers are predictors for the stroke survivor's health-related quality of life and discharge destination (Klinedinst et al., 2009; Meijer et al., 2004).

Supporting family caregivers is in the scope of occupational therapy. Occupational therapists are well qualified to address the diverse needs and concerns of family caregivers by applying occupational performance expertise in addressing the physical, psychosocial, cognitive, sensory, and contextual elements that affect caregiver occupational performance (AOTA, 2007). Many family caregivers report mental and physical health challenges and decreased satisfaction in performance of leisure and social activities for months and years poststroke (Alexander & Wilz, 2010; Cameron et al., 2013; Haley et al., 2015; Kniepmann & Cupler, 2014). However, caregiving is not always a negative or stressful experience. Many caregivers report positive aspects of caregiving, such as improved relationships, a sense of fulfillment, feelings of pride and mastery, and new perceptions of "togetherness" (Arntzen & Hamran, 2016, p. 48). Learning new skills, managing the situation, and overcoming difficulties together are also associated with positive caregiving experiences (Mackenzie & Greenwood, 2012). Occupational therapists can use their expertise to equip caregivers for assisting the relative who had a stroke and to facilitate caregivers' engagement in their own occupations independent of providing care, thus promoting a healthy and balanced lifestyle.

An increasing body of literature recommends that health care practitioners use assessment as the first step to efficiently identify unmet needs and concerns of caregivers and to inform client-centered family practice. Moghimi (2007) suggests that occupational therapists conduct caregiver assessment because they have expertise in occupation, analyzing role demands, and understanding patient function. In addition to screening for physical and psychological health issues, Cameron et al. (2016) recommend caregiver assessment to determine specific unmet needs and to integrate knowledge and training into daily activity at each care transition. Lutz et al. (2017) also recommend systematic and comprehensive assessment of caregivers prior to discharge to promote successful transitions home. Lutz et al. (2011) found that the ability of the caregiver to meet the needs of the stroke survivor influences the success of the family's transition home. The ability of the caregiver to successfully perform the caregiving role is

dependent on their own needs being met. Often these needs include knowledge and training of care provision skills, physical and psychological health concerns, access to resources, and social support.

While assessment of the caregiver is shown to be an important part of the therapy process, several studies indicate that systematic assessment of caregiver preparedness, commitment, and ability to provide care is generally overlooked (Feinberg, 2003; Young et al., 2014). This may be because caregivers are viewed by health professionals as a resource for the patient and not as individuals who need support and personalized assistance for themselves (Caro et al., 2018; Young et al., 2014). Occupational therapists may benefit from using assessment tools to minimize unaddressed needs and to guide intervention planning that meets caregiver needs. There is limited literature, however, that describes the extent to which occupational therapists assess caregivers, formally or informally, in their current practice. There is also limited information on occupational therapists' perspectives on the use of available standardized caregiver assessment tools.

This study was designed to explore how occupational therapists identify the unmet needs of family caregivers poststroke across the continuum of care. The first objective is to identify current assessment practices of occupational therapists. The second objective is to investigate clinician views on using formal assessment tools to identify caregiver needs, exploring both perceived benefits and barriers to using formal measures. The third objective is to gather clinician perspectives on the use in occupational therapy practice of three formal assessment tools: The Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and Expectations Tool Short Version; and the Perceived Change Index.

Method

Research Design

This research used a cross-sectional design. Such a design is used to study “a stratified group of subjects at one point in time and [draw] conclusions about a population by comparing the characteristics of those strata” (Portney & Watkins, 2015, p. 280). A mixed methods approach can provide a more thorough picture than either a qualitative or quantitative approach alone (Creswell, 2014). The study instrument was a survey. According to Portney and Watkins (2015), surveys are efficient and “particularly useful as a research method for examining phenomena that can be assessed through self-observation, such as attitudes and beliefs” (p. 326). Surveys also provide a means to gather data anonymously, promoting honest and candid responses. Thus, a cross-sectional, mixed methods survey was determined to be the appropriate research design for this study.

Participants and Procedures

In order to be included in the study, participants had to have at least 1 year of experience as a registered occupational therapist working with clients and family caregivers poststroke, access to a computer to complete an online survey, and fluency in English. Participants were recruited through email and distribution of fliers. Recruitment emails were sent to 55 occupational therapists from the greater St. Louis region. Snowball sampling was encouraged. It was not known how many clinicians were working with clients and families poststroke, so a number of clinicians may have been ineligible. Because a snowball technique was used, it is impossible to determine a response rate. The recruitment emails were sent in February and March of 2019.

Potential participants received an email describing the purpose of the study, information on informed consent, and directions to open a survey link and read an attached document describing the three assessment tools if they agreed to proceed. This study was reviewed and approved by the

university human resources protection office (HRPO) at Washington University in St. Louis before any recruitment began.

Instrument

The survey was developed by the researchers in the Family Caregiving Research Laboratory in the Program of Occupational Therapy at Washington University in St. Louis. They first met to discuss what topics the survey should cover to answer their research questions. One author wrote an initial draft of the Qualtrics survey. The other two authors reviewed the survey individually and generated a list of edits. The researchers again met to compare and contrast notes. Two graduate students in the laboratory also reviewed the survey and provided feedback. Local occupational therapists provided input throughout development of the instrument. The survey went through multiple rounds of vigorous edits until all contributors agreed the survey would satisfactorily address their research questions.

Potential participants were informed they could skip any survey questions or discontinue the study at any time. Part 1 of the survey consisted of seven closed-ended questions. The first two questions gathered demographic information, asking the participants how many families of stroke survivors they see per month and in what setting(s) they worked. The participants were asked if they assess family caregivers, using a Likert scale ranging from *definitely not* to *definitely yes*. If the participants reported they do assess caregiver needs to any extent, they were asked what assessment methods they use. The participants were then asked specifically if they use formal tools to assess caregivers. The participants who indicated that they did not use formal tools were asked why not. The participants who reported that they do use formal tools were asked to list them. The participants were asked what benefits, if any, they saw in assessing caregivers. They were provided with the option to select *other* and the opportunity to write in their own responses throughout Part 1 of the survey.

The participants were then directed to review a brief, one paragraph description on the purpose, use, and cost of each of the following assessment tools: The Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and Expectations Tool Short Version; and the Perceived Change Index (see Appendix). The participants who chose not to review this document could submit Part 1 of the survey without completing Part 2.

If the participants chose to review the assessment tool information, they could complete Part 2 of the survey. Part 2 gathered information on the participants' perspectives on the three assessment tools: The Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and Expectations Tool Short Version; and the Perceived Change Index, through five open-ended questions. The questions inquired into the perceived advantages and disadvantages of using each tool. The survey concluded with an opportunity for the participants to write down any remaining thoughts about assessing the caregivers' needs.

The Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and Expectations Tool Short Version; and the Perceived Change Index (see Table 1), were chosen for analysis as they have been found to be useful in identifying the caregivers' needs and addressing factors that influence caregiver well-being (Archbold et al., 1990; Gitlin et al., 2006; Keefe et al., 2008). The Preparedness for Caregiving Scale is a self-report measure usually administered in the acute and inpatient settings to assess how prepared caregivers believe they are for taking on caregiver responsibilities, such as providing physical care and coping with the stress of caregiving (Zwicker, 2018). Psychometric analysis reveals the Preparedness for Caregiving Scale to be valid and reliable (Cronbach's alpha = 0.94) (Pucciarelli et al., 2014). Construct and content validity have been demonstrated between caregiver

worry and lack of resources in the Preparedness for Caregiving Scale (Archbold et al., 1990). The Caregivers' Aspirations, Realities, and Expectations Tool Short Version is usually administered in home health or outpatient therapy settings. It thoroughly addresses areas such as the physical and emotional health of the caregiver, service support needs, and financial concerns (Guberman et al., 2007). It has been found to increase "practitioner understanding of many aspects of caregiving and enables practitioner understanding of many aspects of caregiving and enables practitioners to identify and address key areas of concern efficiently" (Keefe et al., 2008, p. 301). While psychometric testing revealed varied results among the subsections of the full version of the assessment, further research is needed to determine the psychometric properties of the short version of the Caregivers' Aspirations, Realities, and Expectations Tool Short Version (Keefe, 2008). Finally, the Perceived Change Index measures caregiver appraisal of improvement or decline in areas of their own well-being (Gitlin et al., 2006). Psychometric analysis found the Perceived Change Index to be valid and reliable (Cronbach's $\alpha = 0.90$) (Gitlin et al., 2006). Pearson correlational analyses of the Perceived Change Index revealed that perceived improvement in well-being was significantly associated with more social participation, increased reports of positive aspects of caregiving, and fewer depressive symptoms (Gitlin et al., 2006).

Table 1

Description of Standardized Assessment Tools that Address Caregiver Preparedness and Needs

Name	Description	Administrative Time (m)
PCS	8-item self-rated survey. Screens how prepared caregivers believe they are for the caregiving role.	15-20
CARE Tool SV	13-page short answer questionnaire. Assesses in-depth information about caregiver needs and concerns.	45-60
PCI	13-item self-rated survey. Assesses perceived changes in caregiver well-being over a 1-month period.	15-20

Note. m = minutes. PCS = Preparedness for Caregiving Scale. CARE Tool SV = Caregivers' Aspirations, Realities, and Expectations Tool Short Version. PCI = Perceived Change Index.

Data Analysis

This was a cross-sectional, one-time online survey. A quantitative approach was used for Part 1 of the survey and a qualitative descriptive approach was used for Part 2 of the survey.

Quantitative data from the close-ended questions were analyzed using descriptive statistics to calculate frequencies and percentages of the answers from Part 1 of the survey. Thematic analysis was used for the qualitative data obtained from Part 2 of the survey (Stanley, 2015). Two of the authors individually open coded the lines of responses from the participants and interpreted categories based on their codes. The researchers then reviewed their categories with each other, comparing and contrasting findings to generate mutually agreed on themes. The themes were triangulated with the quantitative data and discussed with the third author to ensure accuracy.

Results

Fifteen participants completed the one-time, cross-sectional survey. See Table 2 for their demographics.

Table 2
Participant Demographics

Clinical experience	Total (n = 15)	%
Caregivers seen per month		
>20	1	7
10 to 19	4	27
5 to 10	6	40
1 to 4	4	27
None	0	0
Practice setting(s) ^a		
Acute	4	25
Subacute	2	13
IPR	5	31
OPR	1	6
Extended care	3	19
Home health	1	6

Note. % were rounded up at .5; IPR = inpatient rehabilitation; OPR = outpatient rehabilitation.

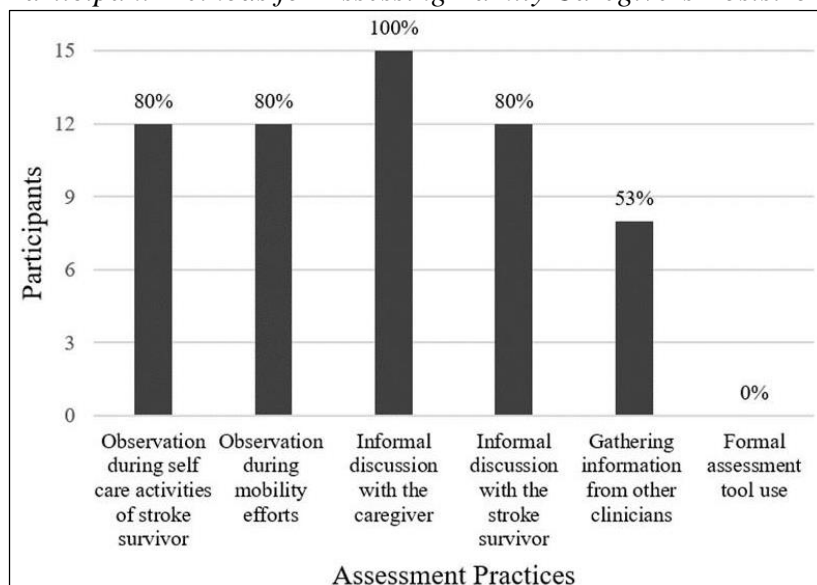
^aThere were 16 responses for practice settings as the participants were asked to select all that applied.

Current Assessment Practices

The participants were asked if they assess the needs of family caregivers in any way. Of the participants, 33.3% reported they *definitely* assess the needs of family caregivers after stroke. Twenty percent of the participants reported they *probably* assess their needs, and 26.7% of the participants reported they *may or may not*. Twenty percent of the participants reported they *probably do not* assess their needs, and 0% of the participants *definitely do not* assess the needs of caregivers. Figure 1 shows the methods the participants use to assess caregivers. None of the participants reported use of formal assessment tools with caregivers. Rather, all of the participants reported informal methods for identifying caregivers' needs.

Figure 1

Participant Methods for Assessing Family Caregivers Poststroke

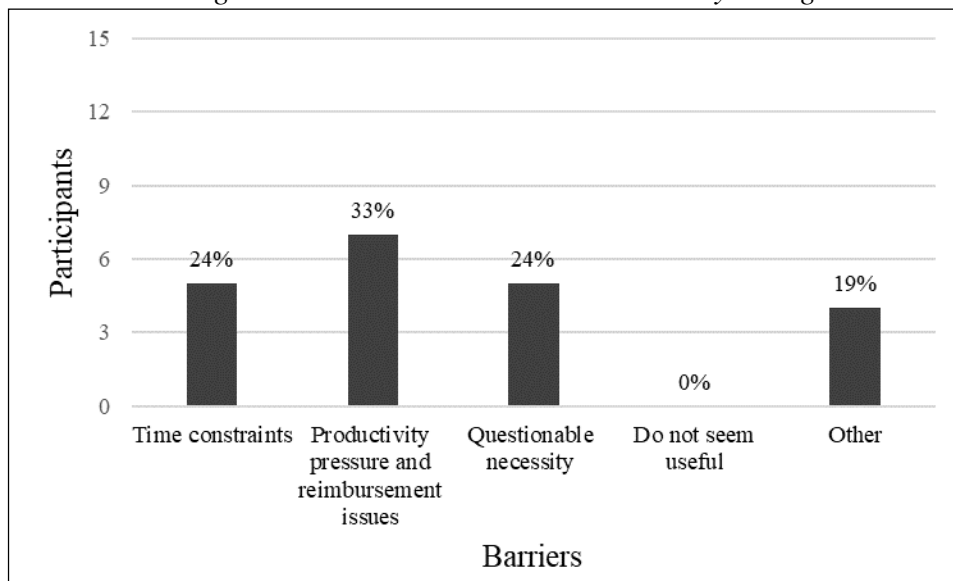


Benefits and Barriers to Formal Assessment

Although zero participants reported current use of formal assessment in their practice, all of the participants indicated that use of formal caregiver assessments could be beneficial. Thirteen of the participants indicated formal assessment could help them create family-centered, realistic goals. Ten of the participants reported that formal assessment could help to identify learning needs and determine the family's need for connection to community resources. The participants also identified numerous barriers to formal assessment (see Figure 2). Productivity pressure and reimbursement challenges were identified as the top barrier. One participant wrote, “[There is] pressure from work to meet certain productivity standards. [I] may not be able to bill for administering caregiver assessments.”

Figure 2

Barriers to Using Formal Assessment Tools with Family Caregivers



Occupational Therapists' Perspectives on the Preparedness for Caregiving Scale

Four participants chose to complete Part 2 of the survey, reporting both perceived advantages and disadvantages of the Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and Expectations Tool Short Version; and the Perceived Change Index. The participants were not asked to use the assessments in their practice but solely review the tools and share their views.

Reported advantages of the Preparedness for Caregiving Scale included free access, availability online with no training required, its nature as a quick and thorough assessment, and the ability to provide occupational therapists with insight into the caregivers' perceptions of their own caregiving abilities. Minimal analysis of cultural implications, lack of depth, and information on caregiver perceptions instead of true abilities were identified as disadvantages of the Preparedness for Caregiving Scale.

Occupational Therapists' Perspectives on the Caregivers' Aspirations, Realities, and Expectations Tool Short Version

A reported advantage of the Caregivers' Aspirations, Realities, and Expectations Tool Short Version is that it is a comprehensive assessment with detailed questions in each of the eight domains. However, the Caregivers' Aspirations, Realities, and Expectations Tool Short Version warrants 45 to 60 min for administration and requires training.

Occupational Therapists' Perspectives on the Perceived Change Index

The participants reported the quick administration and free access as advantages of the Perceived Change Index, which is similar to the Preparedness for Caregiving Scale. Additional advantages included gathering insight into caregiving experiences over the past month to gain a broad understanding of performance and capabilities and allowing caregivers to see their progress on a second administration of the Perceived Change Index. Reported disadvantages include minimal consideration of everyday stressors as well as the generic nature of the questions.

Discussion

The first aim of this study was to determine current practices of occupational therapists with regard to assessment of the needs of caregivers of stroke survivors. This study highlights that the extent to which occupational therapists assess caregivers of stroke survivors varies extensively from *definitely* assessing caregiver needs to *probably not* assessing their needs. The study indicated that informal methods, such as informal discussion and observation, are currently used by these occupational therapists while formal assessment tools are not used.

The second aim was to identify clinician perspectives on benefits and barriers of using formal assessment tools. The participants indicated several reasons for not using formal assessment tools. The most commonly stated barrier related to productivity pressure and reimbursement issues. This concern aligns with Moghimi's (2007) findings that "health policy, reimbursement practices, time constraints, and traditional medical approaches" (p. 270) influence occupational therapy practice to focus on the care recipient over the caregiver. Currently, reimbursement for caregiver assessment is uncommon, though this may vary between settings. Legislators and family caregivers are advocating for increased involvement of health care practitioners with family caregivers that includes assessing caregiver needs and the ability to provide care (Badovinac et al., 2019; Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017, 2018). The Caregiver Advise, Record, Enable Act, for example, is a law that has been enacted in 36 states at the time of this writing; it requires hospitals to identify and include family caregivers during admission and in preparation for discharge (Anthony, 2018). The Recognize, Assist, Include, Support, and Engage Act of 2017, passed into law in 2018, requires that a federal advisory board develop a strategy to recognize and support family caregivers. The law requires that part of this strategy include recommendations for the "assessment and service planning" of family caregivers and care recipients across the care trajectory, including care transitions, in a manner that reflects the diverse needs of family caregivers (The Recognize, Assist, Include, Support, and Engage Act of 2017, 2018, p. 24). Further clarification, implementation, and advancement of policy change, however, is needed to ensure reimbursement for the assessment and training of caregivers (Badovinac et al., 2019; Meyer et al., 2019).

While no participants currently use formal assessment in practice, all of the participants indicated potential usefulness of the three assessment tools. Development of realistic client and family-centered goals, identification of specific learning needs, and referral to appropriate community resources were identified as potential benefits. Lutz et al. (2011) also found that addressing specific learning needs and creating informal community support networks can increase self-efficacy in caregivers and stroke survivors.

The third aim of the study was to gather perspectives on the use of three formal assessment tools for use in occupational therapy practice. Four of the participants chose to review and respond to questions about the Preparedness for Caregiving Scale; the Caregivers' Aspirations, Realities, and

Expectations Tool Short Version; and the Perceived Change Index. Two themes were identified: (a) the use of assessment tools to measure perceptions of performance rather than actual performance and (b) considerations of the length versus comprehensiveness of the tools.

Perceptions versus Performance

An advantage of the Preparedness for Caregiving Scale is that it can be used as a tool to identify caregiver perceptions about how prepared caregivers believe they are for discharge. However, a disadvantage of the Preparedness for Caregiving Scale is that it only measures caregiver perceptions of preparedness and does not measure actual level of performance. One participant described various factors that could influence one's perception of preparedness, including socioeconomic status and cultural factors. An advantage of the Perceived Change Index is that it allows caregivers to see their own progress and compare ratings over time. While the Preparedness for Caregiving Scale and the Perceived Change Index are not performance-based tools, clinicians may find these helpful in measuring caregiver perceptions and fostering insight into progress over time.

Length versus Depth

The participants indicated that the short length of the Preparedness for Caregiving Scale and the Perceived Change Index was an advantage, whereas a disadvantage of the two tools was a lack of specificity. However, the participants indicated that the comprehensive nature of the Caregivers' Aspirations, Realities, and Expectations Tool Short Version was an advantage, but its lengthiness was a disadvantage. One participant wrote that the Caregivers' Aspirations, Realities, and Expectations Tool Short Version may be "difficult to complete in entirety in many settings." The applicability of the tools will be determined, in part, by the amount of time occupational therapists have to administer formal caregiver assessment tools in their respective settings.

Limitations and Future Directions

This study had several limitations. The study had a small sample of 15 participants with only four of the participants choosing to complete Part 2 of the survey. The potential implications and generalizability of these findings is therefore limited and difficult to assess. The settings in which the participants worked were primarily inpatient rehabilitation (31.3%) and acute care (25%), whereas only 4.8% of the participants worked in either an outpatient or home health setting. The findings, therefore, may be more representative of therapists working in acute or inpatient settings rather than home health or outpatient clinics.

An issue was discovered in the wording of the open-ended questions regarding the Caregivers' Aspirations, Realities, and Expectations Tool Short Version. The tool name was abbreviated in the survey to the CARE Tool, leading one participant to misinterpret the abbreviation to mean the Continuity Assessment Record and Evaluation (CARE) Item Set. This participant thus described the benefits and barriers of the incorrect tool. In a future study on use of caregiver assessment tools, more refined and specific questions could help to better identify additional implications of formal assessment tool use.

The amount of contextual information of the participants obtained from our survey was limited; therefore, the discussion on current legislation and policies was broad. Further investigation of the context of the participants and a more in-depth application of policies in their respective areas of practice may enrich the understanding of the challenges occupational therapists face in addressing the needs of caregivers and further the conversation of how these barriers can be addressed.

The three assessment tools were selected based on which tools the authors believed would address caregiver needs across the continuum of care. The tools were not designed for use by occupational therapists specifically, but rather were developed for interdisciplinary use among health care professions. Another future direction would be the development of formal caregiver assessment tools tailored to occupational therapy practice. When developing formal assessment tools specific to occupational therapy in the future, the time required to administer the assessment and opportunities for observation should be considered.

Future research on the effectiveness of formal assessment tools and the impact on caregiver and stroke survivor outcomes is warranted. An important next step for further investigation into the effectiveness of these three selected tools would include occupational therapists incorporating the use of these tools in their practice. The occupational therapists would then be able to report on their actual experiences with the tools. Further, a larger sample of therapists using these assessments would provide valuable information on the generalizability and use of the tools in occupational therapy practice.

Conclusion

This study was created to contribute to current research on occupational therapists' practices and perspectives regarding caregiver assessment. The results from this study demonstrate that assessment practices vary across settings, but use of formal assessment tools is still a challenge across the continuum of care. Challenges to tool use include reimbursement and productivity concerns, measuring perception rather than performance, and the time-consuming nature of comprehensive assessment. This study suggests formal assessment tools are perceived by occupational therapists as useful and can aid in the creation of client and family-centered treatment plans. Implementation of recent policies is needed to further support occupational therapy's role in addressing caregivers' needs. Future development of assessment tools tailored to occupational therapy is warranted.

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Appendix

Description of Assessment Tools

1. Preparedness for Caregiving Scale (PCS)

Link to access: <https://consultgeri.org/try-this/general-assessment/issue-28.pdf>

Cost: Free

Utility: “Internal consistency has been reported as moderate to high with alphas of 0.88 to 0.93 reported (Carter et al., 1998; Hudson & Hayman-White, 2006). Construct and content validity have been demonstrated between caregiver worry and lack of resources (Archbold et al., 1990). In caregivers of stroke survivors, the Cronbach alpha was 0.94 and test-retest reliability 0.92 (Pucciarelli et al., 2014)” (Zwicker, 2018, para. 4).

Description: “The PCS (Archbold et al., 1990) is a caregiver self-rated instrument that consists of eight items that asks caregivers how well prepared they believe they are for multiple domains of caregiving. Preparedness is defined as perceived readiness for multiple domains of the caregiving role such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving” (Zwicker, 2018, para. 2).

2. Caregivers’ Aspirations, Realities, and Expectations (C.A.R.E.) Tool–Short Version

Link to access: <https://www.msvu.ca/site/media/msvu/ShortCAREToolEnglishWatermark.pdf>

Cost: Free. Permission from authors is required before using. Training is usually required. The training is offered to practitioners in the form of an online workshop.

Utility: The full C.A.R.E. Tool has been used in research to determine utility. “Seven sites in Quebec and Nova Scotia involving 40 assessors tested the [C.A.R.E.] tool with 168 caregivers. Results suggest that this comprehensive tool enables practitioners to understand caregivers’ needs and situations. Focus groups with assessors and interviews with home care administrators revealed that the tool increased worker understanding and awareness of what it means to be a caregiver, ascertained the key caregiver concerns, and identified these needs in rapid succession” (Keefe et al., 2008, p. 286). The C.A.R.E. Tool Short Version “contains the same 10 sections as the full C.A.R.E. Tool . . . but with fewer questions and without user information. The Short Version was developed in response to concerns about the time required to administer the original C.A.R.E. Tool (2001)” (Mount Saint Vincent University, 2019, para. 2).

Descriptions: “The C.A.R.E. Tool Short Version is designed to be used by home care practitioners with family caregivers to help understand Caregivers’ Aspirations, Realities, and Expectations (C.A.R.E.). It assists practitioners in gathering information related to caregivers’ support needs and helps to identify key areas of concern” (Mount Saint Vincent University, 2019, para. 2). “It contains 10 sections: demographic information of the caregiver and care receiver, caregiving work, informal and formal support, living arrangements, other responsibilities, financial contribution, physical and emotional health, family relations, crisis and long-term planning, and service support needs. The final section summarizes the caregiving situation, allowing for the identification of areas of difficulty experienced by the caregiver and key areas of concern to be addressed in the future” (Mount Saint Vincent University, 2019, para. 1).

3. Perceived Change Scale (PCS)

Link to access: <https://nadrc.acl.gov/sites/default/files/uploads/docs/Perceived%20change%20scale.pdf>

Cost: Free

Utility: The authors suggested that it may have use in practice as it “is easy and quick to administer and feasible to use in care settings to identify and monitor fluctuations in well-being” (Gitlin et al., 2006, p. 310). Perceived improvement in well-being was found to be “significantly associated with fewer depressive symptoms, higher scores on perceived positive aspects of caregiving, and more participation in social activities” (Gitlin et al., 2006, p. 304).

Description: The PCS is a “a 13-item scale that measures caregiver appraisals of self-improvement or decline in distinct areas of well-being” (Gitlin et al., 2006, p. 304).