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Understanding Barriers and Facilitators to Participation in People with Aphasia

A Qualitative Approach

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Funding for this paper was provided by a grant from the Livable
Lives Initiative at Washington University in St. Louis

2011

CSD Working Papers

No. 11-38

Campus Box 1196 One Brookings Drive St. Louis, MO 63130-9906 • (314) 935.7433 • csd.wustl.edu



Washington University in St. Louis

Acknowledgements

Funding for this paper was provided by a grant from the Livable Lives Initiative at Washington University in St. Louis. We would like to thank Dr. Frances Tucker, members of the Aphasia Conversation Connection, the study participants, and Kasey Hess, who transcribed some of the interviews.

Understanding Barriers and Facilitators to Participation in People with Aphasia: A Qualitative Approach

Aphasia is an acquired communication disorder that currently affects about one million people in the United States. Although people with aphasia receive rehabilitation services, they often return to the community with barriers that impact participation in activities that are meaningful to them. Few research studies have investigated factors influencing participation in aphasia and people with aphasia are often excluded from research due to their language impairment. The purpose of this exploratory qualitative study was to identify the most common barriers and facilitators to community participation, as perceived by people with chronic aphasia following stroke. Method: Five participants with mild to moderate aphasia due to stroke participated in individual semi-structured videotaped interviews. The interviews were conducted using an aphasia-friendly adapted format, and supportive communication was provided as appropriate for each participant. Living with Aphasia: Framework for Outcome Measurement (A-FROM) was used to formulate questions that explore and measure domains such as personal identity, environment, and participation to fully understand the lived experience with aphasia. All interviews were videotaped and subsequently transcribed and analyzed. Grounded theory was employed in analysis of interview transcripts and emergent themes were identified. Results: Three main themes emerged: the importance of the communication environment, changing social roles, and attitudes about aphasia as a disability. Several components of environment affect participation levels including: face-to-face interactions and personal factors that influenced ability to communicate. In addition, aphasia led to changes in employment status and shifted relationship dynamics to a more dependent role. Changing roles contributed to adjustments in support networks that influenced whether current relationships flourished or ended and how new relationships developed. People with aphasia felt that the general public's knowledge of aphasia was lacking and that employers and the general public did not understand that aphasia is a disability. Conclusion: This study provides preliminary data to understanding the key factors that influence participation.

Key words: *aphasia, stroke, community participation, communication barriers, qualitative research*

Each year, approximately 795,000 people in the United States have a stroke (National Stroke Association, 2010); one-third are estimated to acquire aphasia, with as many as 25% being adults under the age of 65 (Dalemans, de Witte, Wade, & van den Heuvel, 2008b; Wolf, Baum & Connor, 2009). Although there are many causes, such as brain tumor or trauma, the most prevalent cause of aphasia is stroke (Ross & Wertz, 2003). According to the National Institute on Deafness and Other Communication Disorders (NIDCD), aphasia currently affects approximately one million people in the United States (NIDCD, 2010). Despite its name, aphasia does not leave a person speechless, but rather produces difficulty with speech production, writing, reading, and the ability to understand others. Stroke incidence is on the rise (National Stroke Association, 2010); therefore the number of people with aphasia is increasing, producing extensive and wide-reaching affects on people's lives. Several studies have demonstrated that aphasia can have a profound negative impact on self-identity, confidence, relationships, social networks, engagement in activities, and participation in life events (Andersson & Fridlund, 2002; Caporali & Basso, 2003; Cruice, Worrall, Hickson, & Murison, 2003; Dalemans et al., 2008b; Hilari & Northcott, 2006; Parr, 2007). Although people with aphasia receive

rehabilitation services, they often return to the community with communication barriers that have an impact on participation in activities that are meaningful to them (van der Gaag, Smith, Davis, Moss, Cornelius, & Laing, 2005).

Just a few research studies to date have investigated factors influencing participation in people with aphasia (Cruice, Worrall, & Hickson, 2006b; Dalemans, Wade, van den Heuvel, & de Witte, 2009a; Parr, 2007). People with aphasia are often excluded from research due to their language impairment (Dalemans, Wade, van den Heuvel, & de Witte, 2009b; Natterlund, 2010a & b) and their valuable experiences, thoughts, feelings, and concerns about participation remain unexplored (Parr, 2007). Researchers who have included people with aphasia, however, have successfully obtained research data from people with aphasia with minor modifications to stimulus materials and response options (Brennan, Worrall, & McKenna, 2005; Dalemans et al., 2009b; Tucker, Edwards, Mathews, Baum & Connor, in press). To elicit responses from participants, the researchers have used simple vocabulary and grammar, modified question style, increased line spacing, provided supported communication, and used strategies such as encouraging participants to gesture, draw, or write (Brennan et al., 2005, Dalemans et al., 2009b; Hilari, Byng, Lamping, & Smith, 2003; Rautakoski, Korpijaakko-Huuhka, & Klippi, 2008; Rose, Worrall, & McKenna., 2003; Tucker et al., in press). Amongst the limited research that is available, data consistently reflect diminished participation in people with aphasia (Andersson & Fridlund, 2002; Cruice, Worrall, Hickson, & Murison, 2005; Cruice et al., 2006b; Dalemans et al., 2009a; Davidson, Howe, Worrall, Hickson, & Togher, 2008). Aphasia can lead to lower levels of social interaction (Dalemans et al, 2008b; Natterlund, 2010b) and participation in fewer activities outside of the home compared to their peers who do not have aphasia post stroke (Cruice, Worrall, & Hickson, 2006a). Specifically, aphasia decreases the likelihood of participation in more complex occupations such as work, education, community activities, and leisure pursuits (Dalemans, et al., 2008b).

In recent years, a regard for participation and its influence on quality of life has influenced how aphasia is viewed and treated amongst health professionals (Hilari et al., 2003; Simmons-Mackie & Kagan, 2007). Although current approaches to aphasia management and rehabilitation continue to evolve, the traditional clinical approach is derived from the medical model, focusing on treating impairment as a means to restore language function (Ross & Wertz, 2003). A major emphasis in aphasia research is geared toward regaining linguistic competence and language skills (Dalemans, de Witte, Wade, & van den Heuvel, 2008a). Clinicians typically assess speech performance in areas such as the ability to name common objects, follow one-step commands, or comprehend or produce sentences with proper syntactic structure. Interventions tend to focus on increasing linguistic capacity and improving skills necessary for speech with the expectation that it will improve engagement in social activities and quality of life (Andersson & Fridlund, 2002).

Although impairment may provide valuable and predictive information about the person with aphasia's ability to communicate, it may not reflect their ability to fully participate in the activities most meaningful to them (Eriksson & Tham, 2010). Researchers continue to debate whether the majority of aphasia batteries truly measure the effectiveness of language recovery (Bruce & Edmundson, 2009) and whether current outcome measures reflect skills needed to enhance life participation (Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, & McEwen, 2008). In fact, some studies indicate that factors such as social relationships, functional communication, and the

ability to actively participate within the community may have more of an impact on quality of life than therapy-based improvements in language (Larsson & Thorén-Jönsson, 2007).

Since the ultimate goal in aphasia management and rehabilitation is to improve quality of life and participation after rehabilitation is over (Larsson & Thorén-Jönsson, 2007), there is a need to identify the most important barriers and facilitators to participation in people with aphasia. Because so little is known about the nature of participation in people with aphasia, we conducted a semi-structured, supported interview with people living with aphasia in the community to better understand their concerns, supports and techniques they have found to be beneficial to participation, and barriers that they have encountered to resuming the activities that they need and want to do. Learning more about key facilitators and barriers to participation from the point of view of persons with aphasia will contribute to the knowledge regarding the most effective management and rehabilitation possible.

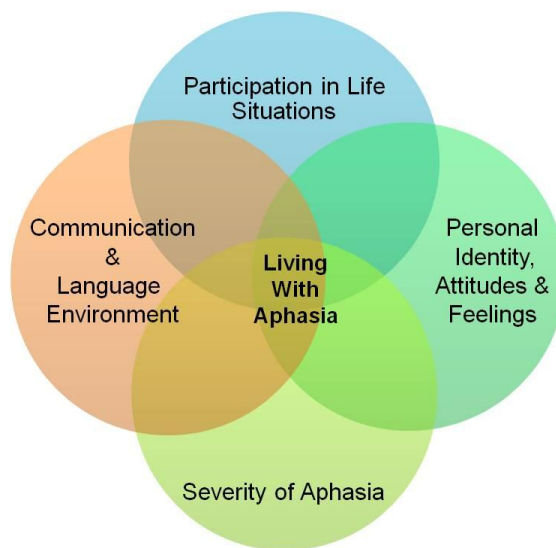
Design and Methods

Design

The study used grounded theory (Charmaz, 2006) and was based on qualitative interviews to capture the perspectives of people living with aphasia due to stroke. Interview questions were developed based on the philosophy of *The Life Participation Approach to Aphasia* (LPAA). The LPAA was developed to promote healthy living with aphasia through engagement in meaningful activities while considering both immediate and long-term needs (LPAA Project Group, 2000). The philosophy of LPAA (Kagan & Simmons-Mackie, 2007) is based on the World Health Organization's International Classification of Function (ICF) that focuses on increasing participation in people with disabilities and chronic health conditions (WHO, 2001). The ICF defines participation as "involvement in a life situation" and is concerned with how factors such as functional impairment, activity participation, and environmental factors influence the ability to live a fulfilling life with disability (WHO, 2001). The LPAA does not propose specific therapy interventions or goals, but rather outlines a system of values for assessment, intervention, research, and advocacy efforts in the field of aphasia (LPAA Project Group, 2000).

Therefore, the concepts of the ICF were used to create: *Living with Aphasia: Framework for Outcome Measurement* (A-FROM); a conceptual framework and valuable tool to frame and guide assessment (Figure 1). The A-FROM can be used to understand how a person with aphasia experiences life by showing how domains such as personal identity, aphasia severity, and environment are all integrated to create the lived experience (Kagan et al., 2008). In this study, the A-FROM was used to help formulate interview questions based on aphasia severity, personal attitudes, language and communication environment, and participation in life activities to explore how a person with aphasia experiences life. A list of the interview questions is provided in Appendix A.

Figure 1. Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008).



Participants

After receiving approval from the Washington University Human Research Protection Office, participants were recruited from The Aphasia Conversation Connection at Barnes Jewish Extended Care (a Barnes-Jewish Hospital affiliate) in St. Louis, Missouri, and from people who had participated in previous studies in our laboratory. Flyers that explained the study were distributed to the group, and prospective participants then contacted the research team if they were interested in learning about the study.

Inclusion criteria for the study were: diagnosis of aphasia of greater than or equal to 6 months duration as a consequence of stroke; mild-moderate aphasia severity; 20-80 years of age; living in the community; and having sufficient cognitive and language abilities to participate in an interview. No restrictions were placed on participation based on race/ethnicity or gender. Participants were offered transportation to the laboratory and compensated for their time.

A total of five individuals met the inclusion criteria and were contacted by phone and invited to participate in the study. The demographics and characteristics of the participants are shown in Table 1. The sample size included three women and two men aged between 46-66 years (mean = 53.4 ± 8.0 years) (Table 1). All participants had mild to moderate aphasia. The mean level of education was 16.8 ± 2.3 years. The majority of the participants were living with either a spouse or family member. All participants had adjusted their work status in some capacity, by either retiring, or working or volunteering in a modified capacity following the stroke. Once participants agreed to enroll in the study, interview questions were mailed to their homes so that they could think about the questions in advance of coming to the lab.

Table 1. Demographic characteristics.

Characteristics	Participants (N=5)
<i>Race</i>	
African-American	1
Caucasian	4
<i>Gender</i>	
Male	2
Female	3
<i>Marital status</i>	
Married	3
Separated	1
Single	1
<i>Living status</i>	
Living alone	1
Living with someone	4
<i>Work status since stroke</i>	
Retired	4
Part-time or modified	1
	<u>Mean (SD)</u>
Age (years)	53.4 (8.0)
Education (years)	16.8 (2.3)
Years post-onset	7.5 (3.0)

Procedure

Before the interview began, informed consent was obtained and participants were examined with the short form of the Boston Diagnostic Aphasia Examination (BDAE: Goodglass, Kaplan & Barresi, 2001) for their verbal expression and comprehension abilities, to characterize their aphasia severity as mild, moderate, or severe. This screening took approximately 20 minutes and was followed by the interview. Scores for the BDAE range between 0-100 with a higher score reflecting better performance (Table 2). Basic demographics for each participant were then acquired through a self-report questionnaire.

Table 2. Performance on measures.

BDAE	Participants' Scores (N=5)				
	1	2	3	4	5
Expression	85.0	82.5	100.0	95.0	90.0
Comprehension	71.7	28.3	100.0	100.0	43.3

A semi-structured interview modified in format to support understanding was conducted with each participant (e.g., Tucker et al., in press). All interviews took place in a private interview room at the Washington University School of Medicine Cognitive Rehabilitation Research Group (CRRG) at a time that was convenient for the participant. To facilitate the participation of a person with aphasia, some of the strategies used included: (1) List of interview questions mailed to participant prior to study; (2) Short and concise questions; (3) One question printed per page in large size font; (4) Interview questions placed in front of the participant as the question was read aloud; (5) Close-ended questions followed up with open-ended questions; (6) Supported communication techniques (e.g. verifying responses and allowing participants to point to response options if necessary).

Close-ended questions were asked first to frame the topic and to provide a specific question to answer. Then, open-ended follow up questions were asked to further explore topics in greater detail. An interviewer trained in supported communication techniques conducted all of the interviews, which were about an hour in length. All interviews were videotaped and subsequently transcribed and analyzed.

Data analysis

Grounded theory (Charmaz, 2006) was the qualitative data analysis technique used to interpret data and extract themes from the interviews. The process involved coding interview data to identify, develop, and relate concepts. Data were analyzed and interpreted through a stepwise process.

First, the videotaped interview sessions were recorded onto audio compact discs and subsequently transcribed verbatim. During this step, the interviews were watched and gestures and body postures were noted on the transcripts.

Second, the transcripts were read and initial line-by-line coding was completed by two individual coders. This method helped break up data into its component parts based on a line-by-line analysis. Transcripts were read, one line at a time, and each line was named with a descriptive code. A code consisted of a short phrase that expressed the meaning of the participant response. Both of the authors completed this step independently. Any discrepancies in coding were then discussed and resolved.

Next, axial codes were derived by comparing codes across the transcripts to identify recurring concepts. This step of the process helped group data together to form relationships between categories. To do this we used codes established from step 2 to identify, develop and relate concepts. The initial codes were grouped on a data spreadsheet to separate data into categories.

This allowed us to see the points participants emphasized during the interviews. After this step was completed, both coders compared codes and began step 5 to determine themes.

Next, themes emerged when concepts that were discussed by all participants were identified. This step involved collaboration between both coders to identify similarities and differences between how data were interpreted. Last, example quotes for themes were selected. This was accomplished through collaboration and comparison of data between coders to select the most descriptive statements that supported the concept of the theme.

Results

The participants in this study were able to answer all of the questions asked during the interview and were open and willing to share their lived experience with aphasia. After using a grounded theory approach to analysis, three *main* themes regarding facilitators and barriers to participation emerged, namely: (1) The importance of the communication environment; (2) Changing social roles; and (3) Attitudes about aphasia as a disability. In many cases, comments about each theme were interwoven throughout the other themes.

Theme 1: Importance of communication environment

The participants expressed that the communication environment can be either a barrier or facilitator to participation. Participants differed in how they discussed environmental influence on communication, yet it remained a prevalent theme amongst all individuals interviewed. Some participants chose to discuss the environmental factors that facilitated communication while others phrased their comments in terms of what environmental factors imposed barriers.

Face-to-face interactions

One of the most prevalent facilitators, face-to-face interactions, helped to provide a context for conversation because facial expressions, gestures, and postures convey feelings and meaning. In fact, participants expressed that telephone calls were problematic because of an inability to see who one was speaking with. One participant expressed, *“I have a difficult time on the phone. It’s very difficult because...they are calling out of nowhere to me,..., the name they tell me, I have no idea. . . they also want to talk about why they called.”* Face-to-face interactions allow the person with aphasia to immediately identify the person they are speaking with and to start to put the conversation into context. Additionally, if the conversation partner is speaking too quickly, it is much easier to ask that person to stop, slow down, or repeat themselves when face-to-face.

Noisy environments and distractions

In contrast, it was stated that the communication environment can be a barrier to participation when the person with aphasia was faced with noisy environments and distractions. Some of the comments included:

“When the place is noisy, when I am tired,..., I think I am more apt, now to, um, in a place that has a lot of people, sit back and listen to conversations, and I was not that kind of person before.”

“Well, the noise is a really big thing, um, it’s become easier but at first when I um, was at the Center taking part in therapy, they always had a um, uh,...radio on and it’s so distracting.”

“Right after the stroke, uh, I’d go out for lunch with some other people in the office and there would be five people there and that’s not a good setting for aphasia because there’s no agenda and people just talk out and they might be talking about what they did over the weekend or uh... one of their kids did or a ballgame. I would understand they probably hit a homerun in the game, and I would guess it was Pujols, but I didn’t know who did it.”

In many cases participants reported that the communication environment had the potential to alter their ability to participate in activities. It was expressed that an environment that involved a lot of activity interfered with the ability to process sounds, express oneself, and comprehend others. Other factors that impeded participation in communication were topic switches during conversations, many people talking at once, and people speaking too quickly.

Theme 2: Changing social roles

The participants also described a change in their social roles which, depending on the individual, was a barrier or facilitator to participation. Changing roles contributed to adjustments in support networks that influenced whether current relationships flourished or dissipated, as well as how new relationships developed.

Within the family unit, interactions shifted to more of a dependent role. Participants relied on family members to assist them in areas in which they were once previously independent. For instance, ordering from a menu and interacting with a waiter/waitress in a restaurant required assistance. *“With restaurants I usually um...I sometimes uh I can’t understand the uh waiter or the waitress uh...and my wife will always say, you won’t want that or he won’t eat that.”* Having a spouse or close friend present was useful for both verbal expression and understanding the menu. Also, having someone to accompany him or her for activities outside of the home helped to facilitate communication with members of the community.

Participants in our study also described that their aphasia facilitated a closer bond with their spouse. *“I think probably I am just as close to my wife...because I am...um more dependent I think. I could survive without that [help] but it wouldn’t be as enjoyable.”* Another participant reported that her husband improved as a partner since the stroke and that he *“used to be a ‘C’ husband and now he is an ‘A’ husband.”* *“My husband is better now...He is just more loving..., He is more protective.”* Another participant stated, *“I’ve been pretty lucky...I have a good partner. Uh...at home it’s uh...I would like to um...if I could do at the same level I did before and I could help with some things.”*

Interactions with friends also changed as some participants explained the loss of friends they had considered their closest companions, or developing strong bonds with other people who were once acquaintances. Many of the participants expressed that some people seemed to emerge with a willingness to help after the stroke. One participant stated, *“you see who your true friends are.”*

As their social roles changed and individuals started attending support groups, new bonds were formed. For example, one participant reported how she enjoyed attending the aphasia conversation group because of the common bond she shared with the other group members. She stated, *“I think*

what has worked for me is the people at that conversation connection group.” I consider them new friends.”

Participants highlighted that having meaningful bonds with others helped to provide emotional support and that engagement in social companionship, or socializing was a meaningful activity.

Theme 3: Attitudes about aphasia as a disability

Lack of knowledge about aphasia

Another barrier was the lack of knowledge of aphasia by the general public. Participants reported how this lack of understanding affected how they were treated by others, including how they were viewed by their employers. Ultimately, these attitudes affected participation in activities and routines they found meaningful.

One participant described less involvement with family because *“people looked at me like I was damaged or something.”* She explained how both family and friends assumed that because she had difficulty with expressing herself through words, that she was incapable of attending various events she would have previously been invited to attend. Another participant expressed, *“Some people treat me like, um, a child. And, um, some people, um, really um, don’t want anything to do with me.”* Participants found themselves excluded from conversations and experienced having their sentences finished for them when they struggled with word-finding. A few participants reported that a lack of understanding about aphasia from family and friends caused frustration for them. *“Members of the families and friends need to have a better understanding of what people with aphasia have to deal with.”* Other comments included, *“I notice people are not very good listeners”* and *“people do not understand aphasia is a disability.”*

Work place attitudes about aphasia

Another of the main barriers discussed was work place attitudes about aphasia and how employers viewed participants. All of our participants were forced to retire, change jobs, or alter their job status to work in a modified capacity. One participant who was forced to retire expressed, *“...my company,..., they wanted to get rid of me never to return because either [they] don’t understand aphasia at all,”...,”I think they may have heard the word stroke and they don’t want to ever see me again.”*

Amongst all participants, having some ability to work or volunteer was a priority. *“I volunteer at a place where they are used to people with head injuries so they are more easy-going. Um, they let you get it [words] out, you know. Now, I think it would be way harder to go to a regular work setting.”* A few participants expressed that they were more comfortable dealing with people who understood aphasia or head injury because those people had more patience, spoke slower, and allowed them to complete their thoughts. Working with others who understand aphasia in some capacity facilitated an ability to work or volunteer successfully.

Discussion

This study explored the facilitators and barriers to participation in five people with chronic aphasia following stroke. The results, though preliminary, are consistent with previous research that suggests that participation in activities is influenced by the environment (Natterlund, 2010b) and that many people with aphasia have barriers to participation in social activities (Andersson &

Fridlund, 2002; Cruice, et al., 2005; Cruice et al., 2006b; Dalemans et al., 2009a; Davidson et al., 2008).

The importance of the communication environment has been acknowledged in a study by Dalemans et al. (2008b). They suggested that participation in community and social arenas is vulnerable in people with aphasia because of the verbal interaction demands required. Further, the results of this study suggest that changing social roles also have ramifications in the lives of those with aphasia. This is consistent with previous findings that the strain on friendships and relationships with others can be extensive, since language impairment affects the skills needed to maintain, create, and enrich social relationships (Cruice et al., 2006a). The relevance of changing social roles is consistent with the LPAA model to aphasia management, which seeks to address the social issues that impact the lives of people with aphasia. The participants in our study have been living with aphasia for many years, yet still experience barriers to participation in activities and roles they find valuable. All of the participants in the study were working age individuals who either chose to retire or were forced to change jobs and work in a modified capacity following their stroke. The majority of the participants reported that employer attitudes played a role in their inability to return to their previous job.

This qualitative study enabled a deeper understanding of the factors that influence participation that may be difficult to quantify, as well as those that may not be represented on currently extant outcome measures. The use of interviews for data collection aided the goal of this study. Specifically, the interview format provided the opportunity for the person with aphasia to express and describe their perspective of the lived experience with aphasia. This study showed that it is possible for people with aphasia to participate in research when provided with a modified format and supported communication.

The recruitment of participants from the Aphasia Conversation Connection and previous studies in our laboratory ensured that we interviewed participants with mild to moderate aphasia. These were also individuals who were accustomed to speaking about their lived experience with aphasia and who could likely tolerate the demands of an hour-long interview. Some of the important factors to highlight about our participants include age, education level, and support systems. The mean age at the time of stroke was 46 years with an average education level of 17 years. At the time of the interview, the mean time post-onset of the aphasia was 7 ½ years. Thus, our participants were a relatively young group of people living with the long term effects of aphasia. Their insights and perspectives on barriers and facilitators to participation offer a basis for understanding the types of services needed to improve quality of life in this population.

We were surprised to learn that most participants seemed to have adequate support systems in place, despite the challenges aphasia may have imposed on their relationships (cf. Cruice, Worrall & Hickson, 2006b; Cruice, Worrall, Hickson & Murison, 2005; Davidson, Howe, Worrall, Hickson & Togher, 2008; Hilari & Northcott, 2006; Parr, 2007). The majority of the participants were living with either a spouse or family member and all reported that they have someone (family or friend) who is able to help them participate in meaningful activities. In addition, we were surprised that strategies such as drawing pictures or writing key words on note paper to communicate were not a large part of their lives (cf., Kagan, 1995; Kagan, Black, Duchan, Simmons-Mackie & Square, 2001; Rose, Worrall & McKenna, 2003). Many participants, however, reported the use of voicemail and computer technology to facilitate comprehension and expression, respectively. For instance,

replaying voicemail messages facilitated understanding of a message, particularly when phone numbers were left on the machine and needed to be written down. In addition, most participants reported the use of Microsoft Word to perform spell check, and email to create drafts of messages that could be proofread by a family member. These strategies helped to improve communication with others.

Limitations

This study had some limitations that included sample size and methodological issues. Because this was an exploratory study, we had a relatively small sample size (N=5). We were unable to achieve true saturation of interview responses with so few participants. Future studies with additional participants, additional interviews, or both may provide more robust results. Also, because only persons with mild to moderate aphasia were included, it is possible that these findings may not extend to those who have severe aphasia.

Further, we have considered the possibility that our selection of interview questions may have imposed themes or ideas that may not have occurred to participants had we not asked. Therefore, we plan to conduct second interviews in the future with the participants that allow for more open-ended responses and elaboration on original responses. For instance, we could perform a member-checking session to confirm the congruence of our data interpretation with participants' original intent. This could occur during a second interview where we would give the participants the opportunity to hear our interpretation of their original statements. The participants could then comment on and correct our interpretations as well as elaborate on their own original responses. This would improve the trustworthiness of our data and improve the rigor of the study methods.

Conclusion

The attitudes and feelings expressed by the participants in our study are useful in building a foundation for evidence-based practice in occupational therapy. The interviews provide preliminary data to understand the key factors that influence participation from the perspective of the person living with aphasia. Knowledge about key factors will help guide appropriate services and interventions needed to improve participation and quality of life. Previous studies support that quality of life of people with chronic aphasia can be enhanced by learning how to increase social participation (Cruice et al., 2003; Ross & Wertz, 2003). Moreover, an increasing body of evidence supports providing long-term treatment in the context of broader life activities (Brown, Worrall, Davidson, & Howe, 2010). This study reveals that aphasia causes an alteration in lifestyle and that long-term services could be needed to address and enable participation goals based on social and environmental contexts.

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Appendix A

Interview Questions

Severity of Aphasia

- | | | |
|--|-----|----|
| 1. How many years have you had aphasia? | | |
| 2. Is it hard to understand what people are saying to you? | YES | NO |
| Hard-----Easy | | |
| 3. Is it hard to find the word you want to say? | YES | NO |
| Hard-----Easy | | |
| 4. Is it hard to write? | YES | NO |
| Hard-----Easy | | |
| 5. Is it hard to read? | YES | NO |
| Hard-----Easy | | |

Personal Identity

- | | | |
|--|-----|----|
| 6. Does not being able to do these things make you feel unhappy or frustrated? | YES | NO |
| 7. Do you tell people you have aphasia? | YES | NO |
| 8. Does aphasia make you feel ... | YES | NO |
| a. Embarrassed? Embarrassed-----Not Embarrassed | | |
| b. Lonely? Lonely-----Not Lonely | | |
| c. Anxious? Anxious-----Not Anxious | | |
| d. Mad? Mad-----Not Mad | | |
| e. Sad? Sad-----Not Sad | | |
| 9. Is there something that you have learned from having aphasia? | | |

Communication and Language Environment

- | | | |
|---|-----|----|
| 10. Does someone always go with you out into the community to help you communicate? | YES | NO |
| a. Store, shopping, post office, bank, bars, restaurants | | |
| 11. If yes, does that person do most of the talking? | YES | NO |
| 12. Do you start a conversation with someone you do not know? | YES | NO |
| 13. Do you join in group conversation with others? | YES | NO |
| 14. What is the hardest part about trying to communicate with others? | YES | NO |
| a. Noise, talking, understanding, others understanding you | | |
| 15. Is there enough information about aphasia available to you? | YES | NO |
| a. Support groups, aphasia friendly material | | |
| Not Available-----Available | | |
| 16. Do you use strategies or supports to communicate? | YES | NO |
| a. Technology, communication books, communication boards, talking devices | | |
| 17. Do you work or go to school? | YES | NO |

18. If so, has aphasia affected your performance? YES NO
Affected-----Not Affected

Participation in Life Situation

19. Are you happy with your level of participation in activities? YES NO

20. Are you happy with your level of participation YES NO
in community happenings?

21. Do you have good support from family and friends? YES NO
Support-----No Support

22. Do your spouse/family/friends use YES NO
specific strategies to help you communicate?

a. Drawing, writing key words, email, pictures

23. In what situations do you use them?

24. Has aphasia affected your romantic relationships? YES NO

a. Dating, marriage, being intimate

Affected-----Not Affected

25. Has aphasia affected your friendships? YES NO

Affected-----Not Affected

26. Do you still have the same friends as before? YES NO

27. Does aphasia make it hard to make new friends? YES NO

Hard-----Not Hard

General questions

28. Are there particular factors or particular places that make it difficult to participate?

29. Are there particular factors or particular places that make it easy to participate?

30. Have we captured your experience with aphasia?

31. Is there something more you want to tell us?