Subjective Communication Difficulties in Very Mild Aphasia

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Abstract

Purpose: In comparison to the large literature on moderate to severe aphasia, very little is known about aphasia of the mildest severity and whether intervention may be warranted. The purpose of this pilot study was to characterize challenges experienced by people who have recovered to the point that they score normally on aphasia batteries, yet report they continue to have aphasia.

Method: Five people with aphasia who scored above the Western Aphasia Battery – Aphasia Quotient (WAB-R, Kertesz, 2007) cutoff for aphasia participated in a semi-structured interview. Descriptive qualitative design was used to analyze subjective descriptions of difficulties in everyday communication situations within a framework for living with aphasia.

Results: Participants reported salient communication difficulties, reduced social participation, difficulties returning to work, a continual need to concentrate when engaging in language tasks, and a keen awareness of persisting impairments.

Conclusion: People with very mild aphasia experience salient language difficulties and these difficulties have an adverse effect on multiple domains of living successfully with aphasia. Further investigation towards better methods of assessment and intervention are warranted.

Introduction

It is estimated that more than 2 million people have aphasia in the US alone (Simmons-Mackie, 2018). Persistent language impairments have unequivocal effects on

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This is the accepted version of an article which has been published in the American Journal of Speech Language Pathology.

Cavanaugh, R., & Haley, K. L. (2020). Subjective communication difficulties in very mild aphasia. American Journal of Speech-Language Pathology / American Speech-Language-Hearing Association, 29(1S), 437–448. https://doi.org/10.1044/2019_AJSLP-CAC48-18-0222

Disclosure: The authors have declared that no competing interests existed at the time of publication.

communication through all language modalities and, as such, may require resources in the form of speech-language therapy, modified life circumstances, and social support for the remainder of people's lives. In this study, our interest is in people who have a documented history of aphasia, but have since recovered to the point that language impairments are no longer evident on aphasia batteries. Yet, when asked, they maintain that they still do have language difficulties. It is unclear how common these experiences are, but it is a potentially large and certainly poorly understood subset of stroke survivors. For example, evidence from one prospective study indicated that about 40% of people who were diagnosed with stroke-related aphasia at hospital admission scored above the cutoff for aphasia one year after stroke onset (Pedersen, Vinter, & Olsen, 2004). By better understanding lingering complaints and their potential effects on productivity and life satisfaction, interventions and community resources may be offered to this essentially unserved population. The purpose of this pilot study was to contribute to understanding the range of subjective communication difficulties and potentially identify areas worthy of deeper inquiry. We employ the term "very mild" aphasia to describe the phenomenon of aphasia that is no longer detected on formal testing but remains a subjective complaint.

Language Impairment Above the Cutoff

Scoring above a cutoff on an instrument developed to characterize and estimate severity of aphasia is, of course, not the same as not having language difficulties. Experienced speech-language pathologists recognize that most aphasia batteries have limited sensitivity in the milder aphasia range and they routinely accept their clients' own impressions of their disability. The literature on more in-depth assessment of language and other cognitive domains in mild aphasia remains sparse, with a limited number of studies suggesting quantifiable impairments in areas such as word finding (Armstrong, Fox, & Wilkinson, 2013; Fox, Armstrong, & Boles, 2009), processing speed, attention capacity or allocation (Murray, Holland, & Beeson, 1997, 1998), and executive function for people with mild aphasia (Frankel, Penn, & Ormond-Brown, 2007).

Recent research has reported that people with very mild aphasia demonstrate abnormal performance on discourse measures, which are more comparable to communication in common life settings and potentially better aligned with the personal experience of very mild aphasia than standardized aphasia batteries. A study by Dalton and Richardson (2015) included 25 participants who were regarded as having aphasia within the Aphasia Bank protocol (http://talkbank.org/AphasiaBank/), but scored above the cutoff (93.8) on the WAB-R aphasia quotient (Kertesz, 2007). For this subgroup, scores on main concept and core lexicon discourse measures differed both from neurotypical control participants and from participants with varied aphasia profiles. Furthermore, upon inspecting the fifty most frequently produced lemmas in the "broken window" narrative task, the authors observed that participants who scored above the WAB-R cutoff for aphasia "performed similarly to persons with anomic aphasia" (Dalton & Richardson, 2015, p. 935). In another study, Fromm and colleagues (2017) compared 28 people who scored above the WAB-R cutoff for aphasia to 92 participants with anomic aphasia and 177 control participants on a number of discourse measures. Again, the "Not Aphasic by WAB" group demonstrated differences from both neurotypical control participants and people with anomic aphasia. Differences included communication speed, vocabulary access, utterance productivity, information content, and word error frequency (Fromm et al., 2017).

Whereas research is beginning to demonstrate quantifiable difficulties in discourse production for people with very mild aphasia, aphasia batteries remain the standard for demonstrating recovery. When used as outcome measures, these tools may indicate that the aphasia has resolved (e.g., Lazar, Speizer, Festa, Krakauer, & Marshall, 2008), even though salient life consequences may remain. To better understand recovery with very mild aphasia and what type of intervention may help, a critical next step is to characterize the communication difficulties people experience in real life.

Living with Very Mild Aphasia The Aphasia-Framework for Outcome Measurement (A-FROM) conceptualizes life with aphasia as the intersection of four snapshot domains (Kagan et al., 2008). These domains are: (1) language and related impairment (2) participation in life situations; (3) communication and language environment; and (4) personal identity, attitudes, and feelings. Each domain can be analyzed from the perspective of both strengths and weaknesses and a number of variables that are potentially responsive to intervention. To understand communication difficulties that people with very mild aphasia experience, each of these snapshot domains may offer insight about potential barriers and lingering difficulties. Having already established that a small number of studies have reported evidence of language impairment during high level formal testing (Armstrong et al., 2013; Fox et al., 2009; Hickin, Mehta, & Dipper, 2015), cognitively demanding tasks (Frankel et al., 2007; Murray et al., 1998), and discourse that is similar to everyday conversation (Dalton & Richardson, 2015; Fromm et al., 2017), we turn now to the other three A-FROM domains of participation in life situation; communication and language environment; and personal identity, attitudes, and feelings. Unfortunately, the extent of research focused on people with very mild aphasia is very limited in these domains. Thus, for background purposes, we consider a combination of personal accounts, individual data from larger studies, and a handful of studies that addressed mild aphasia.

A number of recent studies have observed that aphasia of varying severity has direct effects on life participation. Hickin, Mehta, and Dipper (2015, p. 1043) describe a case study with a person with mild aphasia who scored near ceiling on the Comprehensive Aphasia Test (Swinburn, Porter, & Howard, 2004), but reported that she “was no longer able to participate in discussion with friends about films in the same way. . . consciously limiting her language to avert the possibility of it breaking down, and the potential embarrassment that might ensue from this.” In designing a conversational treatment approach for mild aphasia, Fox and colleagues (2009, p. 953) reported on the communication between a person with very mild aphasia and her husband, noting that the couple described conversations as “less frequent and less satisfying.” Subsequently, Armstrong et al. (2013, p. 270) characterized a similar couple where the spouse with very mild aphasia reported less frequent communication, “because it’s just not worth it.” Taken together, these studies suggest that standardized assessment does not require or elicit the complexity of everyday communication and may fail to capture the impact very mild aphasia has on communicative life participation (Armstrong et al., 2013; Fox et al., 2009; Hickin et al., 2015).

Avoidance of life participation can also be triggered by feelings of uncertainty or anxiety. In a qualitative study of coping after mild stroke, Carlsson, Moller, and Blomstrand (2009) interviewed 18 people after mild stroke, nine of whom had a left hemisphere stroke. They concluded that people with mild stroke experience uncertainty in daily living and may avoid situations when they do not feel 'secure.' They observed that participants were often "considered to have recovered, and thus faced expectations they could not live up to" (Carlsson et al., 2009, p. 780). Similarly, Niemi and Johansson (2013) interviewed 6 participants with mild to moderate aphasia about their everyday occupations, including one with mild aphasia and one with mild-moderate aphasia. Responses suggested that confidence is often a prerequisite for participation in social situations, and may be perceived as particularly important by people with aphasia (Niemi & Johansson, 2013). While it is apparent that the latter study included individuals with relatively mild aphasia, it is not clear that they were representative of the population we have in mind; those who do not show evidence of aphasia on standard aphasia batteries. There is also evidence that potential barriers in the communication and language environment affect communication. Previous studies have demonstrated the importance of communication partner knowledge and competence in facilitating successful communication (Simmons-Mackie, Raymer, & Cherney, 2016) and some of the observations have included mild aphasia. In the same qualitative study by Niemi and Johansson (2013, p. 1831), people with mild to moderate aphasia reported that familiarity with communication partners improved confidence and that "others lacked an understanding of the aphasia" or that "feedback from others was discordant with their own view of their capacity." Conversely, "Laura," the participant with very mild aphasia studied by Fox et al. (2009, p. 953), "expressed particular frustration that friends did not acknowledge her aphasia as problematic" and that they questioned her need to attend therapy. Broadly speaking, difficulties specifically related to complex communication, such as professional or group conversations, indicate that the behaviors and expectations of conversation partners can have powerful effects on communicative success even when the aphasia may be barely noticeable to others (Armstrong et al., 2013; Carlsson et al., 2009; Fox et al., 2009; Hickin et al., 2015; Niemi & Johansson, 2013).

Finally, within the A-FROM domain of personal identity, there have been reports that attitudes and feelings can impact everyday communication negatively for people with mild aphasia (Armstrong et al., 2013; Fox et al., 2009; Hickin et al., 2015; Niemi & Johansson, 2013). Niemi and Johansson (2013) noted that communication attempts were often a reminder of communication ineffectiveness and that participants experienced feelings of deficiency and frustration about limitations in their communication abilities. The authors quoted one participant in saying "at least 50 percent of me vanished when speech vanished that that's how I think about it" (p. 1831). The authors also reported that participants connected communication ability with perceptions of their own competence in their daily occupations, "such as being a considerate hostess at a dinner party" (2013, p. 1831).

Purpose

There is a clear need for more information about the impact of very mild aphasia on people's lives. Because these individuals are not systematically referred for speech-language pathology services and are often discharged based on their objectively "within-normal" functioning, clinicians have limited experience and research evidence from which to derive treatment methods. The purpose of this study was to better understand the subjective experience of living with aphasia despite scoring in the non-impaired range on an aphasia battery. Specifically, we sought to identify a range of self-reported communication difficulties as preparation for further exploration of their dimensions and potential responsiveness to intervention.

Method

Participants and clinical testing

Participants were recruited from a stroke registry, local hospital and rehabilitation centers, and by disseminating study information to participants in other allied health sciences research studies at the university. Recruitment materials called for participation by people who had a stroke and aphasia and had “gotten much better,” but still had “some trouble communicating.” Inclusion criteria required participants to be medically stable and at least six months after a single neurological injury. It was further required that all enrolled participants score above the 93.8 aphasia quotient cutoff for aphasia on the Western Aphasia Battery-Revised (Kertesz, 2007). This meant that a profile of “mild aphasia” based on an aphasia quotient between 76.0 and 93.8 was considered too severe for study inclusion. Past medical history in relation to aphasia was documented if available. Comorbid diagnosis of apraxia of speech or dysarthria was permitted, provided that it was characterized as mild.

Five participants with a diagnosis of aphasia as a result of cerebrovascular accident (n=4) or focal traumatic brain injury (n=1) were enrolled in the study. All five had a history of aphasia that was verified through review of the medical record, though a description of one participant’s initial aphasia presentation was not available at the time of the study. Time post-onset ranged from 21 months to 115 months. WAB-R aphasia quotients ranged between 94.7 and 99.2. Comorbidities included right hemiparesis (3/5 participants), mild dysarthria (3/5), right homonymous hemianopsia (1/5), and mild apraxia of speech (1/5). Age ranged from 31 years old to 64 years old and education ranged from some college to a doctoral degree. All participants were fluent English speakers, passed a hearing screening, and reported functional vision. No participant had a medical history of dementia or any other neurological condition. Two volunteering participants were excluded from the study. One indicated a subjectively high level of fatigue, which was judged to hinder her ability to complete the experimental protocol. For the other we were unable to verify a diagnosis of aphasia after his stroke.

For descriptive purposes on overall quality of life, all five participants completed the Stroke and Aphasia Quality of Life Scale (SAQOL-39; Hilari, Byng, Lamping, & Smith, 2003). The total score on the SAQOL-39 can range from 1 to 5, expressing low to high health-related quality of life, Scores for our participants were at the higher end of this range (3.8 to 4.7), indicating high subjective quality of life levels compared to the group of 83 people with aphasia of varying severity who completed ratings for the initial scale psychometrics (Hilari et al., 2003; M = 3.3, SD = 0.7). Demographics and clinical test results for our participants are presented in table 1.

Table 1. Demographic information, etiology, aphasia test results, and scores on the Stroke and Aphasia Quality of Life Scale (SAQOL) and analog rating scale.

Participant	Age	Education	Months Post-Onset	Etiology	Initial Aphasia description	Other Comorbidities	WAB AQ	SAQOL Total	"How much is aphasia a factor in your life?" (0-100 mm)
1	48	Bachelor's	25	L internal carotid artery dissection leading to left MCA infarct	Not available	Right hemiparesis and mild dysarthria	94.7	4.7	63 mm
2	58	Ph.D	115	Left internal carotid artery dissection leading to infarct	Word finding difficulties	Right hemiparesis and mild dysarthria	96.1	4.7	12 mm
3	58	Ph.D	29	Left distal MCA, likely atherothrombotic	Trouble expressing himself on day of admission. Word finding difficulties and some replacement errors.	Right hemiparesis, facial droop and mild dysarthria	95.2	4.2	81 mm
4	64	Some College	25	Left MCA likely embolic	A bit of word searching, difficulties with word association and getting his words out	Right homonymous hemianopsia	98.9	3.8	50 mm
5	31	Master's	21	depressed skull fracture L temporoparietal region, subarachnoid hemorrhage, craniectomy	Mute initially, then aphasia for two weeks, then predominantly AOS	Mild apraxia of speech	99.2	4.6	21 mm

[a] WAB-AQ = Western Aphasia Battery–Aphasia Quotient; L = left; MCA = middle cerebral artery; AOS = apraxia of speech.

Semi-structured interviews

Participants were engaged in semi-structured interviews (Arthur & Nazroo, 2003) designed to reveal experienced communicative challenges in relatively typical communication and then identify characteristics associated with those perceived as most challenging. They were prompted to consider all modalities of communication skills but were not asked to distinguish among specific disorders (aphasia, apraxia of speech, dysarthria). First, they were given 20 cards with descriptions of daily situations (See Appendix A) and asked to sort the cards into four categories in response to the question "How difficult is communicating when. . . ?" The four categories were: difficult, somewhat difficult, not difficult, and not applicable/I don't do that anymore.

The purpose of the sorting task was to focus the questioning on areas and factors that were perceived as particularly difficult. Accordingly, once all cards had been sorted, the experimenter placed cards that were sorted into the "difficult" category side by side in front of the participant. If the participant did not place any cards in the difficult pile, the experimenter started with the "somewhat difficult" category. The participant selected the order in which to talk about each of these cards based on subjective importance. For each card, the experimenter asked the question: "How is communicating difficult when. . . " Each interview included 10 cards. If this meant the interview had to progress to cards placed in the "not difficult" category, participants were encouraged to discuss communication more broadly in regard to the importance of that situation. If the interview included cards placed in the "not applicable/I don't do that anymore" category, the experimenter asked if language impairment was in any way related to that card.

We developed this sorting procedure for the purpose of the study, to provide structure and balance between interview focus and flexibility. Because the study purpose was to better understand the nature of experienced communication difficulties, the prompts were also focused on the idea that communication is sometimes difficult. The four level scale and categories follow recommendations from Miles, Huberman, and Saldana (2014), matching word choice with the topic or experimental context. The scenarios on the cards were created based on the research team's clinical experiences with people with mild aphasia and accounts of mild aphasia in the literature, as discussed above. Some activities of daily living (e.g. "When you go shopping") were also chosen to provide contrast with situations that had relatively low predicted difficulty for people with very mild aphasia.

At the end of the interview, participants were asked if they currently worked or volunteered and to comment on any experienced barriers to their ability to work or volunteer. The interview concluded with the question: "How much is aphasia a factor in your life?" which participants answered by marking a 10 centimeter visual analog scale with "100%" at the top and "0%" at the bottom. Responses for the visual analog scale rating were measured by hand and are reported in Table 1. Participant 2 responded somewhat differently to this question by choosing to interpret it as "how much do you let aphasia affect your life?" The other participants' ratings ranged from 21 to 63 mm from the 0% anchor. We included comments work, volunteering, and the analog scale in the qualitative analysis.

Throughout the interviews, the experimenter asked follow-up questions about the answers to elicit expanded and more specific responses via general and open-ended questions such as "Can you be more specific" or "what do you mean by that?" Responses were transcribed live and also audio recorded for subsequent transcription and verification. Due to technical difficulties, the audio recording for participant 1 could not be completed. Instead, the interview was transcribed by hand by the experimenter and an observer.

Thematic analysis

Descriptive thematic analysis was completed using open and focused coding for general patterns and determination of interview themes (Saldaña, 2012).The first author or a research assistant transcribed interview recordings and each transcript was read and coded multiple times with respect to the research question. In vivo coding, using a word or short phrase directly from the participant's response, and descriptive coding, summarizing the participants response, were used. Initial open coding was broad, using both in vivo and descriptive coding, while focused coding was used to condense number of codes to a manageable size for analysis. A codebook was created and codes then were condensed multiple times with regards for common patterns across transcripts. Trustworthiness and reproducibility were enhanced by review by the second author and by two colleagues who were not otherwise involved with the study. One was a colleague with expertise in adult neurogenic communication disorders; the other was a researcher with expertise in qualitative methodology within a different rehabilitation profession and basic familiarity with aphasia. As a final step, the codes and themes were organized according to the domains of the A-FROM model.

Results

After open and focused coding, 24 codes and 10 themes (table 2) were identified. There were three themes within the language and speech impairment domain ("need for preparation," "need for focused attention," "salient difficulties"), two themes within the life participation domain ("reduced social participation," "struggle to engage in meaningful activities"), two themes in the environmental domain ("attitudes are influential," "self-advocacy to modify environment"), and two themes within the personal identity and attitude domain (self-consciousness about impairments," "more emotional)." One additional theme ("typing difficulties") was mentioned by all five individuals, but did not fit clearly into any A-FROM domain. Please refer to tables 3-6 for quotes to illustrate the themes within each of the domains.

Language and Related Impairments

Three themes and 11 condensed codes were conceptually synergistic with the language impairment domain. Participants reported a variety of difficulties: the need to write things down, the need to prepare more for communication, increased response time, anomia/getting stuck, difficulty explaining complex ideas/arguing/debating, increased effort for communication, increased fatigue with work, more mistakes if not focusing on speech, and memory problems.

Table 2. Themes and condensed codebook sorted within the Aphasia-Framework for Outcome Measurement (A-FROM) domains.

A-FROM Domain	Themes	Condensed Codebook
Life Participation	• Reduced social participation • Struggle to engage in meaningful activities	• "Used to do" • Speak less because of aphasia • Difficulty reentering professional world • Difficulty finding appropriate & stimulating activities • Desire to do something meaningful • Participate less in group/social situations
Personal Identity and Attitudes	• More emotional • Self-conscious about impairments	• Dislike of identity as stroke survivor • More emotional/easily bothered by emotional stimuli • Bothered/frustrated by expressive language • Critical, aware, and/or self-conscious of expressive • Low Self-Esteem or confidence • Concern re: other people think about me
Environment	• Self-advocacy to modify environment • Attitudes are influential	• Ignorance of aphasia/condition affects communication/perception of PWA
Language & Speech Impairment	• Salient difficulties • Need for preparation • Need for focused attention	• Need to write things down • More mistakes if not focusing on speech • Need to prepare more for communication • Need to do one thing at a time • Slower to respond • Anomia/getting stuck/jammed up • Difficulty explaining complex ideas/arguing/debating • Increased effort for communication • Work more tiring • Memory Problems
Other	• Typing Difficulties	• Difficulty typing

Four of the participants reported the need for increased preparation to communicate, whether for daily conversation or specific events. One reported that conversations and presentations required more effort and concentration. Another reported preparing more for work presentations to large groups than before his stroke. However, he was more concerned about communication he could not anticipate beforehand, specifically the questions after his prepared remarks. A third participant also reported increased preparation for meetings to make sure communication was clear and "I don't get stuck being unclear." Similar to needing preparation, participants also reported that language use required focused attention. Multiple participants commented on inability to multi-task since the stroke.

Beyond the relatively broad themes of needing more time and focus for successful communication, participants reported a variety of salient difficulties with language use. One participant described difficulties with word selection and dissatisfaction with dysfluencies in speech output. Two participants commented specifically on the struggle to express themselves clearly and effectively when arguing or debating.

Table 3. Selected quotes from the life participation domain.

Theme	Quotes
Reduced social participation	"If I try to speak to a lot of people at once, then I say I get held up on myself so I don't do this. And I definitely, I don't go much to parties for the very same reason." "I find myself, especially with my Yankee friends who all talk fast, less able to keep up and therefore, well not necessarily shy away, but I tend to only answer certain questions."
Struggle to engage in meaningful activities	"...So I have debated can I go back [to work]? Where am I compared to where I was before I had the stroke? So that's kind of like...I don't know I really don't know. And I've had a lot of boredom so I'd kind of like to do something. I'd really like to go back to work and do something kind of meaningful even if I couldn't go back to work if I could just do some volunteer work. At one time I was going [to go back to work]...but the jobs they were going to have me doing seemed so mundane. Like taking books and sorting. Pretty mundane stuff. I think I'd have to have a certain amount of interest level. I could go stock shelves at [local store]. I don't really want to stock shelves at [local store]."

Life Participation

The 6 condensed codes within the life participation domain included comparisons to premorbid communicative competence ("used to do"), reduced communication due to aphasia, difficulty with work re-entry, difficulty finding appropriate and stimulating activities, a desire to do something meaningful, and reduced participation in group and social situations. Frequently, challenges included a keen self-awareness of communication challenges.

Participants reported limited involvement in social events and group conversations. They reported feeling hesitant or less interested in pursuing these situations because they were concerned they could not participate successfully. A similar theme was reported with regards to reentering the workforce or finding meaningful activities. One participant expressed a desire to return to meaningful settings such as discussion groups for his academic topic of interest, but conveyed inability to participate due to aphasia. Despite difficulty with work re-entry, three of the five participants did report returning to work. Of these three, only the youngest had returned full time. Another reported success returning to work with a slightly reduced workload, but needing to take more time off due to personal priority for speech-language therapy and for family time.

Table 4. Selected quotes from the personal identity and attitudes domain.

Theme	Quotes
Self-advocacy to modify environment	“I try not to excuse away my abilities or inabilities. And if I run into a point when I am having trouble, that that point I say, pardon me my aphasia is kicking in a little bit so I will have difficulties with certain words and if you give me a second or two ill answer your question.”
Attitudes are influential	“If somebody knows what is truly aphasia, they give you all the leeway that you ever need... ” “A lot of people still think that anything that has to do with the brain being damaged must affect intellect... When I go places where I don’t know anything its hard to make contact with people. And it’s hard to get people to accept my language as just being a physical thing, not a mental thing. So its hard for me to talk with them because they wont accept my... my reasoning. I’ll say I know what I’m talking about here, they’ll say yeah sure. Sot that’s not really good.... I’m having trouble saying it like I want to, I’m having trouble having people accept it, accept my spoken language.”

Personal Identity and Attitude

The six condensed codes in the personal identity, attitudes, and feelings domain included dislike for identifying as a stroke survivor, greater emotionality, frustration with expressive language, self-criticism and self-awareness of expressive language, reduced self-esteem or confidence, and concerns regarding perceptions of communication partners. Participants’ self-awareness of their speech and language abilities was frequently mentioned throughout the interview. They reported keen self-consciousness of required effort, errors, and communication breakdowns during many of the situations presented in the interview. Some also linked awareness of communication difficulty to identity and confidence with communication. One expressed concern with how colleagues perceived the speech output, but did not believe participation was reduced because of this concern. Finally, two participants reported that they reacted more emotionally to events that would not have previously invoked an emotional response.

Table 5. Selected quotes from the language and community environment domain.

Theme	Quotes
More Emotional emotional	“Emotional issues get to me. I get so emotional with people like I never did before.”
Self-conscious about their impairments	“People try to tell me that they really and truly can’t hear my aphasia. I can hear it immensely just in my verbiage and the more I have to talk the more I know that eventually everybody is going to know that I have a problem. . . .and so I do become self-conscious, self-aware of my words. And become a little more leery of having to talk very long off the cuff.” “I think. . . talking with work colleagues is somewhat difficult because I feel that pressure to be perfect in what I’m saying so it’s a little bit different. . . I want to speak-what’s the word-not be someone who’s had a stroke. I want to talk like I did before. That’s the key thing.”

Typing troubles

One last pattern that was apparent with all participants, though for a variety of reasons, was difficulties with typing and/or electronic communication. Three participants reported difficulty typing due to hemiparesis. Another, who did not have hemiparesis, reported “hunting and pecking” for the keys whereas before the stroke typing was quick and fluid. The fifth participant reported misspelling words because “my brain thinks faster than I can clearly type.”

Language and Community Environment

Two participants reported that a lack of knowledge of aphasia impacted communication exchanges adversely. In response to the communicative scenarios, two described difficulty with communication partners who were not familiar with aphasia. Another relayed much more successful experience when the communication partner was familiar with aphasia. This same participant also felt that self-advocacy improved communication success. Presentations to large groups were common before his stroke, and since the stroke when there were occasional opportunities to present, the participant expressed that it often felt helpful to discuss aphasia with the audience at the beginning.

Table 6. Selected quotes from the language impairment domain.

Theme	Quotes
Salient difficulties	“So I go to the [conference] and I presented my research. And what I had prepared was very easy. But what I didn’t prepare for was other people’s questions. And so I ran into small difficulties.”

Theme	Quotes
	"My words are not fluent, the language is not nice. . . It comes out in parts and pieces." "Well I can get a message across no problem, but I can't argue a point. I can't try to make, I find it hard to stick to a point and make an argument."
Need for preparation	"I have to think about what I'm going to say and the words I'm going to use. . . I have to slow down and I have to write down what I'm going to say. Can't just say it. I have to do dry runs all the time when before I never had to do it."
Need for focused attention	"I used to be pretty good at multitasking and keep several things going on at the same time. Now, if I don't concentrate on what I'm doing, I'm going to forget and then slip off to the side and then an hour later I'm like oh yeah I'm supposed to be doing this." "If I'm going to convey something clearly, I need to be fairly focused on it. Not to say that I can't multi-task but more so than before. For example, if I were watching TV and I'm on the computer and [my partner] asks me a question, I really have to listen to him in order to answer it. So that's a definite change."

Discussion

We set out to establish a better understanding of the lives of people with very mild aphasia in order to identify directions for further research. Qualitative analysis of semi-structured interviews revealed that our five participants with very mild aphasia experienced salient language difficulties and that these difficulties had adverse effects on several aspects of their lives. In the following, we discuss potential clinical implications for intervention and life outcomes.

Using the subjective experience to customize rehabilitation

Evidence from this preliminary study suggest that residual communication difficulties have a substantial impact on living with aphasia, regardless of severity. Further research is warranted to address not only communication impairment, but also participation, environment, and personal factors, as all four domains in A-FROM were notably impacted for our participants.

The codes and themes we identified parallel those in a previous qualitative study that explored adjustment processes in stroke-induced chronic aphasia for three people with mild to moderate aphasia (Mumby & Whitworth, 2013). In that study, barriers to quality of life included "impairment", "internal emotions"," isolation", "inaccessible systems", and "ignorance". Similarities to our findings suggest that the WAB-R cutoff does not distinguish between very mild aphasia and mild to moderate aphasia with regards to psychosocial factors. One theme from Mumby and Whitworth (2013), "inaccessible systems," was not identified in this study. Though it is possible that our participants were able to engage more fully in desired interests than the participants with mild to moderate aphasia, it is also likely that the communication scenarios offered for discussion in our interviews did not address this topic or their interests sufficiently.

In a prospective cohort study, Worrall, Hudson, Khan, Ryan, and Simmons-Mackie (2017) followed people with aphasia at three month intervals after stroke to explore factors that predicted living well with aphasia. Mild severity was positively associated with participation, but aphasia severity was a "less significant predictor" of successfully living with aphasia in comparison to social and psychological factors (Worrall et al., 2017, p. 239). We suggest that our study is consistent with this finding. Though the participants were engaged in professional, social, and community activities and events, they reported salient communication difficulties, dissatisfaction with current communication abilities, and a meaningful impact on overall quality of life. We conclude that very mild aphasia severity does not have very mild effects on daily communication and that scoring above the WAB-R cutoff has little relation to daily experiences with communication or identity as someone with or without aphasia.

One explanation for this discrepancy is that our participants placed a high value on the quality of their communication. Even subtle differences in communication ability may be obvious to the person with very mild aphasia, given their ability to self-assess language accuracy and effectiveness compared to people with more severe aphasia. Thus, communication difficulties may have an outsized impact on self-perceived communication ability and desire to pursue meaningful activities. These findings suggest that assessment and intervention should include elements that address the perception of communication abilities. In many situations, patient-reported outcome measures, such as confidence and self-perception (e.g., Babbitt, Heinemann, Semik, & Cherney, 2011), may be more sensitive indices of recovery than impairment-based assessments.

The participants in this study described difficulties that were consistently apparent in more complex psychosocial settings, such as group conversations or arguments. Increased demands on attention, linguistic precision, clarity, and efficiency in these situations is likely to illuminate mild deficits and require the adaptations mentioned by participants, notably taking more time and increasing preparation for communication. Mild deficits in conversational discourse, such as those previously described (Dalton & Richardson, 2015; Fromm et al., 2017) may also be associated with strategic and effortful mediation.

These results suggest that addressing conversational discourse should be a high priority for clinical assessment and intervention. If standardized discourse measures can be integrated into conventional clinical assessment, they may provide additional justification for services for payor-sources and validate the salient concerns of this population. Further development of functionality and psychometric properties is likely to improve the distinction between very mild aphasia and communication at the lower end of the normal language continuum.

Prior treatment studies have demonstrated value in addressing spoken language production, cognition, and personal strategy use in individuals with mild and very mild aphasia (Fox et al., 2009; Frankel et al., 2007; Murray, Keeton, & Karcher, 2006). For example, Fox et al. (2009) used conversational therapy to address goals for a person with mild aphasia to improve the content and clarity of her conversational speech. The treatment was also designed to encourage this woman to acknowledge communication difficulties with strategic metalinguistic statements (e.g. “give me a minute”) to obtain more time for putting her thoughts together. Hickin and colleagues (2015) found some success improving sentence complexity and metalinguistic skills with a patient, BM, using an ‘eclectic approach’ that encouraged a greater variety of discourse connectives to reduce dependence on the conjunction ‘and’ to increase overall sentence complexity. They noted difficulty measuring outcomes for the protocol due to the lack of sensitive assessments available. While these studies illustrate that successful intervention is feasible for people with very mild aphasia when customized to individual complaints, further research is clearly indicated. For example, future studies might implement interventions that target particularly challenging aspects of communication, such as increasing sentence complexity, addressing coherence and/or cohesion, or placing limitations on time or preparation.

Modifying avoidance and anxiety

The degree of self-consciousness described by our participants merits further investigation. Though communication challenges may not be readily apparent to communication partners, they are reportedly painfully obvious to people with very mild aphasia. A keen self-awareness of errors, dysfluencies, circumlocutions, reduced speed, and increased effort to communicate appears to impact interactions with communication partners. It is not clear whether the degree of self-awareness is helpful or disadvantageous to recovery, communication competency, or life participation. On the one hand, strong self-awareness skills can improve information transfer. On the other hand, awareness of anomia, dysfluency, and imprecision may induce anxiety or social avoidance. Cahana-Amitay et al. (2011, p. 603) termed this phenomenon “linguistic anxiety,” as “one in whom the deliberate, effortful production of language involved anticipation of an error, with the imminence of linguistic failure serving as the threat.” In response, the authors suggested self-guided relaxation programs for augmenting traditional language intervention. Recent findings by Laures-Gore and colleagues demonstrate the potential for mindfulness practice for people with aphasia (Laures-Gore & Marshall, 2016; Marshall, Laures-Gore, & Love, 2018). These interventions may be particularly beneficial for people with very mild aphasia.

While we did not systematically collect information about therapy history, all participants reported that they had previously participated in speech-language therapy. It is possible that some of this treatment included coaching to self-monitor language production for imperfections and may have magnified self-consciousness of errors. Another possibility is that past communication experiences and negative interactions in the community reduced self-perceived communicative competence. All participants reported concern for how they are perceived by others and several expressed a desire to, if possible, mask any sign of impairment. They commented on negative interactions, often characterized by unfamiliar communication partners’ unhelpful reactions or perception of reduced intelligence. We suspect adverse communication experiences may heighten self-consciousness and anticipation of potential failure and thereby reduce social life participation.

One distinction between the participants with very mild aphasia and people with more moderate aphasia is the possibility of hiding the aphasia from communication partners, since there is an outwardly small gap between typical and minimally impaired communication. The desire and potential to be perceived as someone without aphasia may increase attention on the success of verbal communication, pulling needed attention resources away from accurately formulating and conveying information.

Disclosure of aphasia appears to improve communication for some people with very mild aphasia, but not all. While one participant reported positive outcomes of disclosing aphasia to communication partners, another reported that disclosure did not impact how communication partners perceived his communication. Differences in communication partners may explain the contrasting reports of listener reactions to self-advocacy. People with aphasia may also make different assumptions about listener reactions that affect perceptions of communication interactions. The relationship between perceptions of listener reactions and social participation is another area that warrants future exploration.

Therapeutic methods for stuttering provide one source for potential intervention in this context. For example, people who stutter are often counseled to understand that communication partners may have poor understanding of stuttering, that they should inform communication partners on the need for additional time, and that the person who stutters has the ability to promote awareness of stuttering and its ramifications (Montgomery, 2006). Furthermore, comprehensive approaches to stuttering intervention may include promoting increased understanding and acceptance of stuttering and “reframing assumptions about listener reactions” (Montgomery, 2006, p. 189). A similar approach may be effective for people with very mild aphasia: they may benefit from a better understanding of listener reactions, improved communication partner competence, and a general acceptance of dysfluency. Overall, these approaches may be helpful in lessening personal and environmental factors that adversely impact communicative life participation. If the goal is to improve life participation in social settings and enhance their ability to return to work or become more involved in meaningful activities, intervention should account for the influence of all factors affecting life participation.

Returning to work

Returning to work was a clear and meaningful challenge for several participants in this study and aphasia played a significant role in their current decisions not to work. Meeting the demands of past work environments or finding similarly challenging or meaningful work were expressed as salient barriers. Past reports on factors affecting return to work for people with aphasia include aphasia severity, workplace flexibility, social support, motivation, and motor impairment (Graham, Pereira, & Teasell, 2011; Hinckley, 2002). The potential to return to a comparable level of employment seems to be additional factor for this population. Given the importance participants placed on the desirability of employment, further study should focus on the relationship between these factors and their interrelated effect on vocational outcomes.

Limitations

In reflecting on the qualitative interview process, a number of factors may have influenced the study. Our category choice of “difficult,” “somewhat difficult,” and “not difficult” may have been suboptimal. Many times, a participant placed a situation into the “not difficult” category because they did not ascribe any level of difficulty to the scenario even if it was more challenging than before. Instead, we might ask participants to simply rank scenarios from easy to difficult and then discuss the most difficult scenarios.

Second, our small group of participants who volunteered for the study is not likely representative of the larger population of people with very mild aphasia. They were relatively well-educated and relatively young. While Worrall et al. (2017) did not find age to be associated with quality of life outcomes on the Assessment for Living with Aphasia, higher levels of education were negatively associated with participation, possibly because of the importance of communication for people with graduate or postgraduate education. That potential effect should be taken into account for our study. It is also worth noting that our participants demonstrated high quality of life scores on the SAQOL-39 compared to Hilari et al. (2003). Our limited sample size prohibits statistical analysis of this variable in the current study, but the overall trend does suggest a need to further explore the effect of very mild aphasia on quality of life.

Finally, our interviews did not explicitly address the potential role that cognitive deficits may play. Increasingly, studies have shown that people with aphasia can demonstrate cognitive deficits in areas such as attention or working memory (Martin & Reilly, 2012; Murray et al., 1998, 2006). These deficits may account for at least some of the difficulty with language and communication experienced by our participants as shown by previous studies (Frankel et al., 2007; Sinotte & Coelho, 2007). Future work should incorporate measures of cognitive abilities as a potential contributor to communication difficulty in very mild aphasia.

Conclusion

Five participants with very mild aphasia reported meaningful difficulties in all aspects of communicative life participation, despite scoring in the nonimpaired range on the WAB-R (Kertesz, 2007). Reduced social engagement, difficulty returning to work, and keen self-consciousness of impairments were common themes. Practicing clinicians should be aware of the substantial impact of subtle language impairments when designing intervention for people with very mild aphasia and consider how these subtle impairments interact with personal identity and environmental factors to affect communicative life participation. Further research should seek to identify more sensitive assessment instruments and develop effective methods for identifying and eliminating barriers to overall life participation and return to work outcomes that are specific to living with very mild aphasia.

Acknowledgements:

Many thanks to Adam Jacks, Antoine Bailliard, and Lucy Hardy for their assistance on this study.

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Appendix

Appendix A: The complete list of interview scenarios presented to each participant during the semi-structured interview.

1. When you do several things at once
2. When you argue or debate
3. When you write letters, emails, or notes
4. When you read letters, emails, or notes
5. When you feel sick or tired
6. When you talk with people you don't know
7. When you attend social gatherings or parties
8. When you talk with several people at once
9. When you are in a new or unfamiliar situation
10. When you talk with children
11. When you go out to restaurants
12. When you attend religious services
13. When you exercise
14. When you talk one on one with family
15. When you ask for help or directions
16. When you talk with former or current work colleagues
17. When you go shopping
18. When you talk with healthcare staff (doctors, nurses, and therapists)
19. When you give a speech or presentation
20. When you talk about important or emotional issues