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Everyday communication challenges in aphasia: Descriptions of experiences and coping strategies

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RUNNING HEAD: EVERYDAY CHALLENGE IN APHASIA

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Abstract

Background: Everyday communication often occurs in situations that pose high attentional and social demands. People with aphasia have reported perceiving greater challenge communicating in these situations, but more specific information about these challenges could help clinicians and researchers work toward more meaningful intervention outcomes and increased life participation.

Aims: To explore the everyday communication experiences of people with aphasia based on their own perspectives and to identify how they report coping with everyday communication challenges.

Method: Twenty-one participants with mild or moderate aphasia completed semi-structured interviews that immediately followed the experimental arm of a larger project. Interview questions solicited descriptions and examples of communication experiences from participants' everyday life that related to the situations they experienced during the experiment (retelling stories to responsive and unresponsive communication partners and while completing a concurrent tone discrimination task). Interviews were recorded, transcribed orthographically, then coded using thematic analysis.

Results: Qualitative analysis revealed two themes related to participants' communication experiences (i.e., relationships, environmental distractions) and one theme relating to their reactions to challenging everyday communication experiences (i.e., coping). They perceived that they were influenced by their communication partners and the physical environment in which communication took place. Two thirds of participants described implementing behavioral and/or cognitive strategies to cope with everyday communication challenges.

Conclusions: Everyday communication is often challenging for people with aphasia when they feel unsupported by communication partners (even close family members and friends), are exposed to background noise, or are performing a concurrent task. One way that participants coped with challenging communication situations was to regulate their thoughts, attitudes, or beliefs. Future research is needed to understand how to appropriately focus on cognitive strategies in aphasia therapy to improve generalization and social participation.

Introduction

The ultimate goal of aphasia therapy is to help people with aphasia communicate in their everyday life and participate in social situations. Unfortunately, aphasia commonly results in social isolation (Parr, 2007). Everyday communication typically poses greater challenges than communicating in a controlled clinic or research environment (Davidson, Worrall, & Hickson, 2003) and intervention rarely targets strategies aimed at coping with these challenges. As a first step towards learning how to better help people with aphasia cope with the challenges posed by naturalistic communication, the present study qualitatively explored everyday challenges described by people with aphasia and their response to these challenges.

Everyday Communication Challenges

Social isolation is a common consequence of aphasia (Parr, 2007) that should be addressed in treatment (Chapey et al., 2000), but helping people with aphasia transfer gains made in therapy to everyday communication settings, which could reduce social isolation, is difficult. People with aphasia have been shown to participate less in social activities than older adults with no aphasia (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Parr, 2007) and even describe avoiding social settings altogether (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Garcia, Barrette, & Laroche, 2000; Le Dorze, Salois-Bellerose, Alepins, Croteau, & Hallé, 2014). These social settings may be noisy, fast-paced, or involve communication partners who lack knowledge and training about how to support people with aphasia in conversation. Most therapy, on the other hand, occurs in environments that are controlled, quiet, and involve speech-language pathologists (SLPs) who use supportive communication techniques. In this way, one-on-one therapy environments evade many of the attentional and social challenges inherent to everyday communication. To achieve generalization and ultimately impact social participation it would be important to understand the demands of everyday communication and how people with aphasia cope with these demands.

Previous research suggests that people with aphasia identify everyday communication situations as challenging when attentional demands are high (Baylor et al., 2011; Cavanaugh & Haley, 2019; Dalemans, de Witte, Wade, & van den Heuvel, 2010; Harmon, Jacks, Haley, & Bailliard, 2019), but a more comprehensive view of these situations is warranted. Attentional demands increase in distracting environments where background noise, visual distractions, or time pressure are present. These situations have the potential to interfere with communication abilities. For example, participants with aphasia have reported that background noise made it difficult for them to process information and participate in social situations (Baylor et al., 2011; Dalemans et al., 2010; Howe, Worrall, & Hickson, 2008a). Visual stimulation in the background has also been reported by people with aphasia as a barrier to their communication (Howe et al., 2008a, pp. 1103–1104). Another reported barrier is situations where people with aphasia are not provided adequate time for communication or where they perceive a need to communicate information quickly (Howe et al., 2008a; Howe, Worrall, & Hickson, 2008b).

Along with distractions that result from background noise, visual stimulation, and time pressure, being required to communicate while performing an additional task increases attentional demands and interferes with communication for people with aphasia. When having to multitask or do more than one thing at a time, participants with mild to moderate aphasia have reported difficulty communicating (Cavanaugh & Haley, 2019; Harmon et al., 2019). Quantitative findings have confirmed that people with aphasia not only perceive divided attention tasks as more challenging, but also perform significantly worse than their peers when simultaneously performing a spoken language and tone discrimination task (Harmon et al., 2019;

Murray, Holland, & Beeson, 1998). While qualitative and quantitative findings converge to show the difficulty that people with aphasia experience with attentionally demanding communication environments, identifying specific examples from their everyday communication experiences and how they cope with these challenges could inform future research and intervention.

Research has also identified challenging social environments in which people with aphasia communicate. For example, across multiple reports people with aphasia have described interacting with communication partners who they perceive to be dismissive, unreceptive, disengaged, or show signs of annoyance (e.g., sighs, tightening of mouth muscles, shoulder and eye movements; Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Dalemans, de Witte, Wade, & van den Heuvel, 2010; Garcia, Barrette, & Laroche, 2000; Skelly, 1975). These behaviors are generally consistent with those that have been shown to indicate "poor" v. "good" communication partners: less frequent acknowledgment of communicative attempts, less interpersonal coordination during the communicative exchange, and less frequent accommodation to alternative methods of communication (Simmons-Mackie & Kagan, 1999). They have the potential to invoke strong emotional reactions from people with aphasia and may even affect their communicative performance (Cahana-Amitay et al., 2015; Harmon, Jacks, Haley, & Bailliard, 2020). In fact, even people with very mild aphasia describe difficulty engaging in meaningful conversation where they feel respected and accepted by a communication partner (Cavanaugh & Haley, 2019).

In addition to the level of support provided by communication partners, how familiar partners are with aphasia can also impact the degree of challenge people with aphasia experience. People with aphasia have reported that partners who were familiar with them personally and with their language difficulties facilitated their communication (Howe et al., 2008a) whereas partners who lacked general knowledge about aphasia restricted their communication (Le Dorze et al., 2014). A greater awareness of cognitive and social challenges that affect communication for people with aphasia could lead to more meaningful intervention goals and procedures aimed to increase social participation (Worrall et al., 2011).

Coping in Aphasia

While the reality of everyday communication challenges has been established previously (Baylor et al., 2011; Chapey et al., 2000; Dalemans et al., 2010; Skelly, 1975), relatively little is known about how people with aphasia cope with these challenges. Communicating in general can be a source of stress for people with aphasia (Cahana-Amitay et al., 2011), but this is especially true when social and attentional demands are high (Harmon et al., 2020). In general, people with aphasia seem to be more successful and have a better quality of life when they have strong social support and maintain a positive attitude despite challenges (Brown, Worrall, Davidson, & Howe, 2012; Cruice, Hill, Worrall, & Hickson, 2010). Unfortunately, however, previous research has shown that overall coping resources are significantly less for people with aphasia than their peers with no aphasia (DuBay, Laures-Gore, Matheny, & Romski, 2011; Laures-Gore, Hamilton, & Matheny, 2007). DuBay et al. (2011) found that while people with aphasia and their peers did not differ in their perception of the availability of social support, participants with aphasia did report less availability of coping resources related to monitoring their own levels of stress, relaxing and controlling their thoughts, and being accepting of their perceived weaknesses. These *less available* coping resources are centered around attitudes, beliefs, and overall thought patterns of people with aphasia, which we will refer to herein as cognitive strategies.

In addition to having less resources to cope with stress generally, people with aphasia may struggle to cope when faced with a specific communication challenge. We recently found that participants described responding to attentionally demanding dual task and socially demanding unresponsive communication partner conditions by exerting greater concentration. In addition, some described intentionally slowing down, while others described moving forward with their message and trying to get it over with quickly (Harmon et al., 2019, 2020). To date, much of the information we have regarding how people with aphasia cope with challenging communication situations comes from their response to environmental manipulations implemented experimentally. In response, they have primarily identified modifying their communication behavior, which we will refer to herein as behavioral strategies.

Although research regarding how people with aphasia cope with everyday communication challenges is limited, both cognitive and behavioral strategies are important to consider. Social cognitive theory posits reciprocal interactions among environmental, cognitive, and behavioral factors (viz., triadic reciprocity; Bandura, 1977, 1986). In line with this theory, communication environments (i.e., conditions surrounding the communication) affect the thoughts (e.g., attitudes and beliefs about communication) and communicative behaviors of people with aphasia while, simultaneously, their thoughts and behaviors influence one another and the environment. This notion has been integrated into the A-FROM framework, which suggests that the communication environment (environmental factors), personal identity and attitude (cognitive factors), and participation in life (behavior), in addition to aphasia severity, all overlap to account for the experience of living with aphasia (Kagan & Simmons-Mackie, 2007).

Recognition of the impact that these multiple factors can have on living with aphasia has led to a number of psychosocial approaches being applied to aphasia intervention (e.g., life coaching [Holland, 2007], psychoeducation [Ryan et al., 2017; Worrall et al., 2016], personal narratives [Strong et al., 2018]), yet still relatively little is known about methods that SLPs could use to train people with aphasia on cognitive strategies for coping with their communication disorder. Understanding how people with aphasia describe spontaneously coping with everyday communication challenges could lend insight into foundational strategies that could be addressed and trained in therapy and investigated in future research.

The purpose of the present qualitative study was to explore the everyday communication experiences of people with aphasia based on their own perspectives and to identify how they report coping with everyday communication challenges.

Method

The present study was part of a larger mixed-methods project that was approved by the University of North Carolina at Chapel Hill Institutional Review Board. The larger project included both experimental and qualitative arms. The experimental arm investigated quantitative measures of spoken language as well as subjective reactions while participants retold short stories in three experimental conditions: to a responsive communication partner in isolation, to a responsive partner while simultaneously distinguishing between two tones, and to an unresponsive communication partner. The responsive communication partner exhibited backchannel responses that indicated interest and engagement. These included good eye contact, an open body posture, smiles and head nods, and verbal affiliatives (i.e., “mhm,” “ok,” “I see,” etc.; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Simmons-Mackie & Kagan, 1999). In one condition, participants retold the story to the responsive communication partner in isolation; in another, they retold the story while listening for high and low frequency tones. They were asked to push a blue button when they heard a low frequency tone and a red button when they heard a high frequency tone while simultaneously retelling the story. The unresponsive communication partner exhibited backchannel responses that indicated disinterest. These included poor eye contact, closed body posture, and neutral facial expression. Each of these conditions was described in more detail previously (Harmon et al., 2019, 2020). Immediately following the experimental study, a qualitative descriptive study was conducted by interviewing participants about their everyday communication experiences (Sandelowski, 2010). Results from the qualitative study are reported in the present manuscript.

Participants

A convenience sample of people with aphasia was recruited from local community aphasia groups and 21 participated in the study (13 females; 8 males). The mean age of participants was 59 years (range = 32-81) and mean years of education 17 (range = 12-22). All participants reported onset of aphasia at least 19 months prior to participation in the study. All completed the Western Aphasia Battery revised (WAB-R) to assess the severity of their language impairment and type of aphasia (Kertesz, 2006). Based on a WAB-R aphasia quotient (AQ) cutoff of 80, participants were described as presenting with mild (AQ range = 82.8-100) or moderate (AQ range = 52.1-77.8) aphasia. Three participants' AQ was in the normal range, but all three were observed to have word-finding difficulties during conversational speech and complained of aphasia symptoms that prevented them from full participation in everyday life. In addition to the WAB-R, all participants completed the Personal Report of Communication Apprehension (PRCA-24; McCroskey, 1997) and Geriatric Depression Scale (GDS; Yesavage & Sheikh, 1986) questionnaires. Table 1 shows demographic information and assessment results for each participant.

Procedures

Immediately after concluding the experimental arm of the larger project where they retold short stories to a responsive partner in isolation, a responsive partner while performing a concurrent task, and an unresponsive partner, participants completed a semi-structured interview. According to each participant's preference, the testing and interview took place in a research laboratory, a community space used for aphasia group meetings, or the participant's home. We intentionally designed the project so that interviews would occur immediately after the experimental tasks in order to prime participants to think more deeply about environmental influences on their everyday communication; however, participants were given a short break prior to the interview as needed. The author interviewed each participant individually. Interviews lasted approximately 20-30 minutes and were recorded using a Canon Vixia HF R500 camcorder. All participants appeared engaged during the interview and participated appropriately. During the interview, participants were asked to tell about communication experiences in their everyday life that they thought related to the experimental tasks. Specific examples and descriptions of these experiences were elicited (See Appendix A). Consistent with semi-structured interview methodology, the order and wording of questions were not identical during each interview, which allowed questions to be adapted to the individual needs of each participant (Britten, 1995). Similar to previous studies (Harmon, Hardy, & Haley, 2018; Luck & Rose, 2007), one way in which interviews were adapted to meet individual needs was through the use of supported communication strategies to ensure comprehension and verify responses. During the interview, paper and pen were provided to each participant. To support comprehension, the interviewer used simple sentences and gestures and wrote down key words (see Kagan, 1998). Participants with moderate aphasia were also encouraged to use writing to respond when helpful.

Interview recordings were transcribed orthographically by an undergraduate research assistant. Transcriptions included verbal and nonverbal communication that occurred during the interview from both the interviewer and the participant. Interview transcripts were coded qualitatively using thematic analysis. Thematic analysis is a widely used, theoretically flexible approach to analyzing interview data (Braun & Clarke, 2006). The coding was completed by the investigator and two undergraduate research assistants. Both research assistants had completed introductory coursework regarding aphasia. Prior to assisting with the coding, the first author met with both students in three seminar sessions to educate them more explicitly about stroke, aphasia, qualitative research methods, and the aims of the study.

Coding followed a five-step iterative process. First, the author and two research assistants independently read through all transcripts to familiarize themselves with the dataset. While doing so, they took notes to help them process and reflect on the data. Second, the author and research assistants collaboratively drafted an initial codebook with descriptive codes that were based on the purposes of the study and important and/or recurring comments from the dataset. Third, the two research assistants coded the interviews and, in collaboration with each other and the author, revised the codebook in three iterations. This iterative process began with coders using the initial codebook to independently code the interviews while noting missing, ambiguous, or uninformative codes. The coders and author then met together to collaboratively review the coding, discuss discrepencies, and make decisions about how to refine the codebook to improve its informativeness and reliability. After the initial revision, this process was repeated twice until all coders agreed that the revised codebook was adequately specific, defined, and representative of the data. Fourth, the two research assistants used the final codebook to code all interview transcripts. This was done by overlaying new codes onto transcripts that were already marked with original codes. The author also coded 20% of interview transcripts to ensure accurate and reliable coding. After all parties completed their independent coding, the three coders met together to check their coding and resolve descrepencies. This was done by comparing the codes to codebook definitions and establishing consensus among the three coders about which of the listed codes was most applicable. All descrepencies were discussed and resolved by obtaining consensus among the author and both students (even for the transcripts that had only been coded by the students). Across all interviews, five descrepencies were resolved at this time. Fifth, final codes were collaboratively organized into three themes and categories. The themes and categories consisted of natural groupings of participants' coded statements that were labeled according to theoretical constructs consistent with previous research and aims of the present study. Table 2 outlines the final themes, categories, and abridged definitions.

Results

Qualitative coding of interview data revealed three themes: (1) relationships, (2) environmental distractions, and (3) coping. The first two themes relate to participants' communication experiences and challenges that they confront when attempting to communicate in everyday situations. The third theme relates to reactions that people with aphasia described when facing these challenging situations.

Theme 1. Relationships

The relationships theme captured statements from participants with aphasia about their interpersonal communication experiences. These included descriptions of interactions with familiar communication partners (category a), unfamiliar communication partners (category b), and groups (category c). Coding also captured comments about whether participants felt supported (category d) or unsupported (category e) by communication partners during interpersonal communication.

Category 1.a. Familiar Communication Partners. Most participants (62%) commented on everyday communication experiences with people with whom they had previously interacted and who knew about their aphasia. These included family members, friends, and other members of the community. The most commonly described familiar communication partners were family members including a spouse, children, and grandchildren. The most frequent social interactions for these participants with aphasia seemed to be among close family members.

Five participants (24%) described occasional communication with friends, but most of these emphasized that they had fewer friends to talk to than before the onset of aphasia. For example, EC06 explained that after her stroke she didn't hear from many of her friends anymore, and added, “so I don't have a lot of friends.” Similarly, EC07 stated, “I don't have many friends, so I don't have a lot of things… to talk about with one or two or three.” EC16 said, “friends is gone.” Although participants with aphasia described sometimes communicating with small groups of close friends, many of the friendships they enjoyed prior to their stroke had been discontinued.

Six participants (29%) mentioned communication with members of the broader community with whom they had previously interacted, but not as intimately as family members and friends. These included service providers (doctors, speech therapists, and employees at the grocery store), “people from church,” and “neighbor[s].” Two participants talked about communicating with current or previous co-workers. One of these was a participant with mild aphasia who had returned to work part-time (EC08). The other was a participant with moderate aphasia who continued to communicate with his business partner in hopes that he could return to work (EC21). In addition to family and friends, other well-established social groups facilitated important communication opportunities for the participants in this study. In summary, familiar communication partners mostly included members of participants' immediate family, but some participants also communicated with close friends and community members.

Category 1.b. Unfamiliar Communication Partners. A smaller number of participants (33%; 5 moderate, 2 mild) described communicating with partners with whom they had not previously interacted. For example, participants described meeting and interacting with community members in public spaces like parks, shopping centers, and walking trails. One participant (EC15) also described interacting with new people at sporting events and "restaurant[s]." In addition, two participants (EC01, EC09) described communicating with physicians with whom they were previously unfamiliar. Altogether, some participants with aphasia described communicating with unfamiliar partners when in public places or receiving health care services, but less described these interactions than those that described communicating with familiar communication partners.

Category 1.c. Groups. Six participants (29%; 1 moderate, 5 mild) emphasized the challenge of participating in group conversations. For example, EC05 described the difficulties of focusing on more than one speaker and commented that in group situations he feels unable to tactfully "force [his] way into the conversation." Two participants (1 moderate, 1 mild) specifically mentioned their communication experiences at "parties." In this setting, EC11 described "missing a lot of words" and EC13 said, "party; I can't get the words out." Notably, only one participant with moderately impaired language even mentioned an experience communicating in a group setting, whereas all other comments were made by participants with mild aphasia.

Category 1.d. Supported. Eight participants (38%) commented about feeling supported during interpersonal communication. The perception of support came in interactions with both familiar and unfamiliar communication partners, but most felt more supported with partners who were familiar or at least aware that they had had a stroke. A comment from EC20 was representative of the overall sentiment when he described feeling more supported in conversation with people that he knows like family members and friends from church, but added that most of the time even unfamiliar partners are respectful during conversation after learning that he had a stroke. Two participants also mentioned that despite losing most of their friends after their stroke, a small group of family members or friends remained supportive of both their communication attempts and their general well-being by "call[ing]… and check[ing] in." These comments suggest that participants felt most support from close family members and friends; however, others were generally supportive if they understood that the person had aphasia.

Comments about feeling supported during interpersonal communication suggested that participants perceived this support when communication partners were friendly, respectful, and interested during conversation. For example, EC17 described most of the people she talks to as "friendly and nice." EC02 stated, "most people respect me" and then proceeded to explain that people are often willing to help her when she struggles to communicate. EC08 mentioned that he mostly communicates with "pleasant people that at least try… to have expressions of interest."

Category 1.e. Unsupported. Thirteen participants (62%) commented about feelings of unsupport during interpersonal communication. These participants acknowledged that some communication partners were supportive and others were not. They described perceiving partners as unsupportive when they (a) were in a rush to receive information, (b) gave up on participants' attempts to communicate, and (c) showed signs of disinterest or disrespect. Specific examples of unsupportive communication partners mostly included service providers (i.e., healthcare professionals, retail workers), but friends and family members were also mentioned.

Five participants (24%) described feelings of unsupport that were the result of the fast-paced nature of conversations and society. EC14 exemplified this sentiment when she described feeling unsupported in everyday communication because “it’s quick, quick, quick; hurry, hurry, hurry.” She then explained how when she walks her dog and tries to converse with others who are walking their dogs, they are often in a hurry and not willing to take the time needed for her to be able to communicate and get her message across. Similarly, EC18 mentioned feelings of unsupport from her husband when he is in a hurry or has something else to do. EC06 said, “some people have no patience listening to you, so it’s hard.” She considered this lack of patience a sign that her communication partners were “not interested” and even “ignoring” her. This disinterest was described by four additional participants as causing their communication partner to discontinue the conversation. For example, EC13 explained, “the problem is [the] words… All of them, I mean, just, people just go away” and EC07 mentioned that when she tries to speak her communication partners “just move on.” Specific examples of this included a speech therapist who EC07 perceived as not having the patience to maintain a shared conversation topic and acquaintences at a park who would stop talking to EC20 when he was trying to have a conversation. In addition to communication partners giving up on conversation, two participants described people they cared about giving up on their friendship. EC06 said, “friends… they’re all gone” and EC16 said, “friends long ago, it was like boom boom boom and then no one.” Similarly, EC20 suggested that the lack of support in conversation from other adults led him to be lonely.

Eight participants (38%) specifically described feeling disinterest or disrespect from communication partners. This was most commonly described in communication experiences with service providers. For example, two participants (EC07, EC01) described feeling disrespected by healthcare providers and one (EC16) by retail workers. Specifically, EC07 complained that these trained professionals did not care about her as a person or provide her with opportunities to express herself: “They didn’t understand. If they just talked, I couldn’t talk… but if you talk a little bit, I could talk a little more.” EC16 described being treated with impatience and disrespect by staff at clothing stores to the point that she would give up on wanting to talk with them: “for me it’s like I don’t—it don’t matter, be gone.” One participant reported similar experiences with neighbors and another with strangers. Overall, many participants with aphasia described feeling unsupported during their everyday communication because people were impatient, gave up on them, or did not provide adequate support. Participants often did not feel respected when communicating—even, at times, with family members and those who were providing them a service.

During everyday interpersonal communication, participants with aphasia most frequently described interacting with familiar communication partners, but also mentioned communication with unfamiliar partners when in public places or receiving services. A few participants (mostly with mild aphasia) also described the challenge of communicating in group settings. During interpersonal communication, some participants described feeling supported by familiar communication partners, but even more participants described frequent feelings of unsupport. The common experience of feeling unsupported during interpersonal communication related to reports of decreased opportunities for social interactions and feelings of loneliness.

Theme 2. Environmental Distractions

The environmental distractions theme captured statements from participants about aspects of the physical environment that distracted from their communicative performance. These included noise (category a) and multitasking (category b).

Category 2.a. Noise. Six participants (29%; 4 mild, 2 moderate) explained the difficulty they have communicating when there is background noise. Three of these specifically mentioned that background noise makes it hard for them to focus when communicating or performing language tasks like reading. EC03 captured this sentiment when she explained that she needs it "absolutely quiet [to] concentrate." The negative consequences of background noise were highlighted by EC11. He described his difficulty communicating in noisy environments as causing him to become "discouraged from saying anything." The consensus from these participants was that communicating in noisy environments was difficult and discouraged their social participation.

Category 2.b. Multitasking. Eleven participants (52%; 6 mild, 5 moderate) mentioned that doing something else while talking interferes with their communication. Specific examples included talking while (a) driving, (b) working on a computer, (c) controlling the television, (d) writing, or (e) eating dinner with friends. Participants explained that they had to either focus on communicating or the other task. EC10 exemplified this sentiment when he stated, "I can only do my limit of one thing at a time." Several participants also described the increased processing time required when multitasking. For example, when discussing doing something else while talking, EC17 said, "it's just mindboggling, but I can do it myself, but its slow; I mean really slow." Similarly, [A14] stated, "it takes me a while… it gets sort of crazy." Two participants (EC18, EC13) suggested that they felt like they were multitasking whenever they communicated. They explained that they could do fine when they really focused on communication, but not when there were distractions. Overall, the participants with aphasia felt that doing another task while talking interfered with their communication. They suggested that successful communication required concentration and plenty of time.

Theme 3. Coping

The “coping” theme captured comments from participants with aphasia about how they reacted to challenging communication experiences. These reactions included both negative and positive coping strategies and were categorized by negative attitudes (category a), behavioral strategies (category b) and cognitive strategies (category c).

Category 3.a. Negative Attitudes. Nine participants (43%) described negative attitudes associated with their communication experiences. These included negative thoughts about how they are perceived by others and doubts about their ability to communicate. Six participants (3 mild, 3 moderate) expressed negative thoughts associated with what other people think of them because of their aphasia. Four described previous experiences that have reinforced the belief that people will react to them differently because of their aphasia. Participants described feeling lonely, worried, and avoiding talking because of their experiences with being perceived unfavorably by others and anticipation of continued unfavorable perceptions. This sentiment was captured by EC11 who said, “I don’t want to be foolish, you know, so I don’t say too much honestly.”

Three participants (1 mild, 2 moderate) expressed doubts about their ability to communicate. EC17 expressed uncertainties about her general ability to produce spoken language, “I can’t pronounce and I can’t—I can’t—I can’t. The words are hard!” EC05 and EC18 expressed reservations about their ability to communicate in challenging situations, which led to “giving up in terms of trying… to speak” or believing “I can’t do it.” Altogether, many participants with aphasia doubted their ability to communicate successfully and were concerned about what other people would think of them, which they described as leading to anxiety in and withdrawal from social situations.

Category 3.b. Behavioral Strategies. Ten participants (48%; 8 mild, 2 moderate) described concrete behaviors they implement to help manage their aphasia and cope with challenging communication situations. These mostly related to relationship-centered communication, but they also talked about concrete behaviors that help them cope with distracting environments.

Self-advocacy. The most common strategies mentioned related to self-advocacy and most often took the form of disclosing their aphasia or providing instructions to their communication partner. Two participants (EC02, EC16) described verbally telling people "that I have aphasia or that I can't speak that well," or "I stroke." Five participants (3 mild, 2 moderate) described providing instructions or collabotatively identifying a plan with their communication partners to improve the communicative exchange. Three participants (EC09, EC16, EC21) described using this strategy with unfamiliar communication partners by asking them to "listen," "wait," or "slow down." Two participants with mild aphasia (EC10, EC11) described identifying ways with their spouse that he/she could facilitate better communication. For example, EC11 explained that he would often miss a part of the sentence when his wife or daughter asked him to do something. Because of this, they adopted a strategy where he asked his wife "before she said anything to, you know, say [my name] to get my attention."

"Stop talking." Three participants (EC01, EC06, EC10) with mild aphasia noted a different behavioral strategy for coping—specifically with unsupportive communication partners: "Stop talking." EC01 described her "three-time rule." She explained, "if you don't…

ask me or talk slowly within the third time, then I'll try to find somebody else who will listen to me… so I give them three chances to try." EC10 added, "if they're not engaging then I just don't engage."

Focus. Three participants described explicit behaviors they implement to cope with environemental distractions. The behaviors described by all three participants had to do with finding ways to focus. Two (EC08, EC10) described focusing on "do[ing] one [task] at a time" by consciously finishing the task at hand before entering into a conversation. EC06 explained that when communicating in groups or where there is a lot of noise, "I need to close my eyes and relax… I just don't want to hear noise."

Category 3.c. Cognitive strategies. Eight participants (38%; 3 mild, 5 moderate) described strategies for managing their aphasia that relied on positive thoughts, attitudes, and beliefs. Five of the eight participants that described cognitive strategies were more than 9 years post-onset of aphasia. This represented 71% (5/7) of the participants who had lived with aphasia for more than 9 years. Like behavioral strategies, cognitive strategies were most frequently, but not exclusively, mentioned in connection with relationship-centered communication. The strategies that were mentioned included positive perceptions about challenging communication situations, positive beliefs about communication partners, and high self-efficacy.

Challenges as opportunities for growth. Four participants described perceiving challenging communication situations as opportunities for growth rather than threats. For example, EC16 explained that she has learned to not view communication situations as difficult, but "just say, 'this is it'" and do the best she can. Similarly, when explaining her experiences with challenging communication situations, EC14 stated, "I want to myself, um, push… the envelope. Yes. I want to get better!" Later, she added that her aphasia "is a good thing, not a bad thing.” EC09 mentioned that in situations where it is difficult for her to communicate, such as group conversations, she focuses on listening. She added “listening is better than talking… most people doesn’t listen—I mean… I think [I’m] a better listener.” EC08 explained that he can exert a sense of control over the pleasantness of a communicative interaction by being pleasant himself.

Empathy. Two particiapants described curbing negative judgment toward unsupportive communication partners through empathy. EC18 suggested that she gives them the benefit of the doubt by not “worry[ing]” about why they’re unsupportive. EC01 explained, “some people are nice and some people aren’t… I try to remember that you don’t know what other people are going through… because everybody is living a tough life and you don’t know.”

Positive Attitudes. Three participants made comments that demonstrated positive attitudes about their recovery. These included reflections on the progress they had made since the early years after the stroke, hope in continued progress, and positive affirmations about their ability. For example, when talking about communicating in distracting environments, EC17 stated, “it’s slow… but I can do it.”

In summary, participants with aphasia described varied reactions to challenging everyday communication situations. Negative thoughts and attitudes were common, but two-thirds of participants (14/21) used either behavioral or cognitive strategies to cope with these challenges. Behavioral strategies were mentioned more often than cognitive strategies, but included maladaptive strategies (i.e., withdrawing from the communicative exchange). Compared with behavioral strategies, participants mentioned cognitive strategies less often and primarily described thinking positively about the communicative situation and their own abilities. Most participants who described using cognitive strategies had a long history of living with aphasia.

Discussion

Because the ultimate goal of aphasia therapy is to facilitate successful communication in everyday life, the present study aimed to explore the communication experiences of people with aphasia and understand how they react to these challenges. Participants commented most frequently on communication with familiar partners, often described feeling unsupported by their communication partners, and struggled to communicate in noisy environments or while performing an additional task. In response to these challenging communication situations, participants often experienced negative reactions. Many coped by changing their behaviors and some coped by changing their thoughts. Findings suggest that cognitive coping strategies warrant further investigation and possibly more explicit training in aphasia therapy.

Lack of Support during Interpersonal Communication

Findings from the present study confirm that people with mild or moderate aphasia often feel that they lack support from both familiar and unfamiliar communication partners (Dalemans et al., 2010; Davidson et al., 2003; Parr, 2007). They mostly communicate with familiar partners such as close family members and friends (Davidson et al., 2003), but even so are abandoned by many who they deemed as friends prior to the onset of aphasia (Davidson et al., 2008; Parr, 2007). Even the friends and family members who stand by them may become impatient and frustrated when trying to communicate (Dalemans et al., 2010). Several comments in the present study suggested that this lack of communication support led participants to desire to withdraw from the communication experience altogether. Two solutions for overcoming the barrier of unsupportive communication partners are to (a) train partners on supportive communication strategies and (b) train people with aphasia to better cope with unsupportive partners.

Communication partner training focuses on facilitating successful communicative exchanges for people with aphasia by teaching techniques and strategies to potential communication partners (see e.g., Kagan et al., 2001; Turner & Whitworth, 2006). After training, close family members, friends, and healthcare providers have demonstrated more supportive communication strategies (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010). This study confirms the need for such training as friends, family members, and healthcare providers were among those commonly described as unsupportive. Additionally, this study bolsters the recent suggestion that more non-healthcare service providers receive communication partner training (Tessier, Power, & Croteau, 2020). Although some participants in the present study perceived feeling unsupported and even, at times, disrespected by their communication partners, it is likely that most partners do not intend to be unsupportive but simply have not been trained on how to respond appropriately. Despite the benefits of communication partner training, however, it is unrealistic that everyone who interacts with people who have aphasia will be trained and that those who are trained will always be supportive.

Because people with aphasia will inevitably interact with unsupportive communication partners, they should also be trained on strategies that can help them cope with these situations. Consistent with previous research (Cavanaugh & Haley, 2019), an effective strategy that many participants in the present study described was self-advocacy. While we cannot ascertain from the present study whether this strategy was trained or adopted spontaneously, self-advocacy does seem to be a practical strategy for many participants with mild to moderate aphasia. Maladaptive strategies, however, are also common (e.g., withdrawal) and may be the consequence of people with aphasia experiencing feelings of discomfort or other negative emotions. We recently found that when communicating with an unsupportive communication partner, people with aphasia reported more and stronger negative emotions than their neurologically healthy peers (Harmon et al., 2020). We suggested that people with aphasia might benefit from training techniques that incorporate emotion regulation or stress reduction (see also Dickinson, Friary, & McCann, 2017; Marshall, Laures-Gore, & Love, 2018). Ideally, an approach that combines communication partner training and training people with aphasia on coping strategies may best prepare people with aphasia to face the challenges associated with limited support from communication partners during everyday communication. Beyond the communication partner, it is also important to account for complex speaking environments during everyday communication.

Noisy, Fast-paced Communication Environments

Noisy, fast-paced environments, which are becoming more common with increased urbanization (Giles-Corti et al., 2016), seem to distract people with aphasia from having the communication opportunities they desire (Baylor et al., 2011; Dalemans et al., 2010; Howe et al., 2008a). Consistent with previous research, several participants in the present study described feeling unsupported by communication partners because of the fast-paced nature of conversation (Howe et al., 2008a, 2008b); others discussed their difficulty with environmental noises and multitasking (Baylor et al., 2011; Cavanaugh & Haley, 2019; Dalemans et al., 2010). It is important that people with aphasia and their partners recognize the potentially adverse effects of fast-paced conversations and noisy communication environments so that they can take action toward reducing background noise and other distractions when communicating. Several participants in the present study described ways that they were able to accomplish this such as (a) limiting themselves to doing only one thing at a time, (b) asking the communication partner to make sure that they have their attention before transmitting a message, and (c) finding ways to reduce levels of environmental stimulation. Some of these comments were similar to strategies used by people with hearing loss (Middleton, Niruban, Girling, & Myint, 2010), suggesting that drawing upon strategies used by this population might be of value for people with aphasia. Additionally, most of these comments were made by participants with mild aphasia suggesting that people with moderate aphasia may require greater support from communication partners to acheive quiet, distraction-free communication settings.

Training Cognitive Strategies

People with aphasia often learn practical behavioral strategies (like self-advocacy and self-disclosure) to help curb psychosocial effects, but cognitive strategies are rarely trained explicitly—even in psychotherapeutic interventions (Kneebone, 2016; Kneebone & Jeffries, 2013; Thomas et al., 2013). Results from the present study suggest that some people with mild or moderate aphasia do use cognitive strategies to cope with challenging communication situations, but these coping strategies seem to be developed over time as they come to terms with their language impairment.

The cognitive strategies mentioned in the present study may serve as a foundation for investigating whether similar strategies might be effectively trained in people with aphasia—particularly those with more recent onset. First, people with aphasia could be trained to perceive challenging communication situations as opportunities rather than threats. Human beings have evolved to experience stress in response to situations or environments that threaten their physical health or well-being. Laures-Gore and Buchanan (2015) proposed a multifactorial framework for understanding stress reactivity in aphasia. They suggested that how a person perceives and appraises the situation will ultimately affect their stress response and behavioral reactions. A challenging communication situation, then, could be perceived by a person with aphasia as a threat, leading to greater stress, or an opportunity, buffering the stress reaction (see Laures-Gore

& Buchanan, 2015, pp. 693–694). As several participants in the present study coped with everyday communication challenge by embracing the latter perspective, it follows that investigating whether people with aphasia might be trained to attribute more favorable appraisals to such situations is warranted. Such training might apply techniques from psychotherapeutic interventions such as *cognitive restructuring* (changing one's thoughts) used in cognitive-behavioral therapy or *cognitive defusion* (separating one's self from one's thoughts) used in acceptance and commitment therapy (Larsson, Hooper, Osborne, Bennett, & McHugh, 2015).

Second, people with aphasia could be trained to empathize with and take the perspective of others. Previous research has found that people with aphasia desire opportunities to look outside of themselves and focus on the success of others (Worrall et al., 2011). Doing so, however, may be particularly difficult during everyday interpersonal interactions when many people with aphasia experience heightened emotions (Harmon et al., 2019, 2020) and become self-conscious about their impairments (Cavanaugh & Haley, 2019). These feelings can cause people with aphasia to become focused on themselves. Empathizing with or taking the perspective of their communication partner, on the other hand, might be one way for a person with aphasia to refocus on others within the context of everyday communication. This may include recognizing that others are also going through challenges and giving them the benefit of the doubt as exemplified by two participants in the present study. A focus on these skills emphasize relationships over communication function.

Third, people with aphasia could be trained to accentuate the positive. Brown et al. (2012) synthesized qualitative findings from three previous studies and found that people with aphasia and their family members emphasized the importance of a positive attitude for living successfully with aphasia. Similar to findings from the present study, their results revealed that participants with aphasia reflected this positivity by focusing on the improvements they had made and choosing to have hope despite challenges. This positivity has the potential to nurture self-efficacy, leading to improved behavioral outcomes (Bandura, 1997). In aphasia, positive psychology has been promoted and implemented through life coaching and psychoeducational approaches that help teach people with aphasia and their families optimism and hope (Holland, 2007; Ryan et al., 2017; Worrall et al., 2016). Another technique that might be useful for people with aphasia is positive self-talk. Although, to our knowledge, it has not been explicitly applied to aphasia, positive self-talk was previously used in fluency treatment with adolescents who stutter by assigning them to repeat positive, success-oriented statements several times per day and encouraging them to replace negative thoughts with these more positive affirmations (D. A. Daly, Simon, & Burnett-Stolnack, 1995). One criticism of these techniques, however, is that they may not adequately acknowledge the complexity of living with aphasia nor provide opportunities for the negative emotions of participants with aphasia to be expressed and validated (Ryan et al., 2017). Future research is needed to understand how speech pathologists might appropriately help people with aphasia and their families remain optimistic without minimizing the reality of the challenges they face.

Limitations

Unlike previous studies that investigated perceived environmental barriers and facilitators reported by participants with aphasia (Garcia et al., 2000; Howe et al., 2008a; Le Dorze et al., 2014), the present study attempted to contextualize comments from people with aphasia about their everyday communication experiences by conducting an interview shortly after participants had experienced communicating in conditions where environmental factors had been manipulated experimentally. Although this provided an opportunity for participants to think more deeply about their everyday communication experiences by connecting them with a recent experience, it is likely that this approach led participants to comment more about barriers and challenges than facilitators. Given the aims of the study, this emphasis was appropriate and also provided an opportunity for investigating how participants with aphasia describe spontaneously coping with challenging communication situations. It should be noted, however, that had the study been designed differently, more facilitators to communication might have been mentioned. Additionally, it should be noted that data for this study were collected from a convenience sample of participants that were mostly recruited from a community aphasia center. Findings, therefore, should be generalized across the wider aphasia population with caution.

Conclusion

People with aphasia often face challenging communication situations related to relationships and environmental distractions that may cause them to withdraw or disengage. These reactions can contribute to social isolation (Davidson et al., 2003; Parr, 2007). Both concrete behaviors and internal thought patterns and beliefs were reported by people with aphasia as ways to cope with these reactions. Explicit training on thoughts and beliefs may help people with aphasia learn to more effectively cope with communication challenges associated with interpersonal relationships and lead to increased social participation.

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Table 1. Participant Information.

ID	Sex	Age	Education	TPO (yy;mm)	Marital Status	Aphasia Severity	PRCA-24	GDS	WAB	
									AQ	Classification
EC01	F	58	20	14;00	Widowed	Mild	61	1	87.0	Anomic
EC02	F	56	14	4;05	Married	Mild	59	4	90.7	Anomic
EC03	F	81	15	5;07	Married	Mild	46	0	92.7	Anomic
EC04	M	33	16	5;11	Single	Mild	34	5	87.6	Anomic
EC05	M	56	16	2;01	Married	Mild	94	5	100.0	NABW
EC06	F	59	16	1;10	Married	Mild	71	1	89.9	Anomic
EC07	F	65	15	7;07	Married	Mild	44	2	84.3	Anomic
EC08	M	60	22	4;08	Married	Mild	46	3	95.4	NABW
EC09	F	72	18	9;09	Divorced	Mild	70	2	82.8	Anomic
EC10	F	71	16	18;01	Married	Mild	66	1	94.0	NABW
EC11	M	72	18	8;02	Married	Mild	73	4	97.4	NABW
EC12	F	72	12	8;00	Married	Moderate	60	0	72.2	Broca’s
EC13	M	60	18	8;07	Married	Moderate	61	4	75.0	Anomic
EC14	F	48	17	18;04	Married	Moderate	93	2	77.8	Transcortical Motor
EC15	F	32	13	11;11	Single	Moderate	43	0	63.7	Conduction
EC16	F	56	16	12;09	Married	Moderate	80	2	52.1	Broca’s
EC17	F	61	16	11;03	Divorced	Moderate	48	1	74.1	Anomic
EC18	F	61	13	5;04	Married	Moderate	69	5	67.5	Broca’s
EC19	M	61	20	5;08	Married	Moderate	56	3	67.0	Wernicke’s
EC20	M	64	18	3;02	Married	Moderate	57	1	72.7	Broca’s
EC21	M	48	19	1;07	Married	Moderate	36	3	68.2	Broca’s

Note. Age and Education are reported in years. TPO = time post-onset; PRCA-24 = Personal Report of Communication Apprehension (McCroskey, 1997); GDS = Geriatric Depression Scale (Yesavage & Sheikh, 1986); WAB = Western Aphasia Battery-Revised (Kertesz, 2006); AQ = Aphasia Quotient; NABW = Not aphasic by WAB.

Table 2. Final themes, categories, and abbreviated descriptions

Theme and Category	Description
1. Relationships	
a. Familiar Communication Partners	Comments about communication partners who participants with aphasia previously interacted with
b. Unfamiliar Communication Partners	Comments about communication partners who participants with aphasia had not previously interacted with
c. Groups	Comments about communicative interactions in groups
d. Supported	Feelings of support during interpersonal communication
e. Unsupported	Feelings of nonsupport during interpersonal communication
2. Environmental distractions	
a. Noise	Comments about noisy communication environments
b. Multitasking	Comments about doing more than one thing at a time
3. Coping	
a. Negative attitudes	Negative thoughts or beliefs about communication
b. Behavioral strategies	Concrete behaviors used to help manage aphasia
c. Cognitive strategies	Management of aphasia through internal attitudes, thoughts, feelings, or beliefs

Appendix: Semi-Structured Interview Guide

1. Do you think that any of the communication situations you just experienced are similar to those that you experience during day-to-day life? Please describe and give specific examples.

2. *If more prompting is needed…*

    a. Can you describe any experiences communicating in your day-to-day life that seem similar to what you experienced when retelling a story while listening and responding to tones?
    b. Can you describe any experiences communicating in your day-to-day life that seem similar to what you experienced when talking to [name of unresponsive communication partner]?

Probes for Discussion:

- *Awareness of communication partner behaviors*
- *How and why these situations relate to everyday communication*
- *How participants respond to challenging situations during everyday communication*