Published in final edited form as:

Am J Speech Lang Pathol. 2011 November ; 20(4): 269–287. doi:10.1044/1058-0360(2011/10-0084).

A qualitative study of interference with communicative participation across communication disorders in adults

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Abstract

Purpose—To explore the similarities and differences in self-reported restrictions in communicative participation across different communication disorders in community-dwelling adults.

Methods—Interviews were conducted with 44 adults representing seven different medical conditions: spasmodic dysphonia, multiple sclerosis, stroke, stuttering, Parkinson's disease, amyotrophic lateral sclerosis, and laryngectomy. This paper represents a secondary analysis of qualitative data collected in cognitive interviews during development of the Communicative Participation Item Bank. The data were analyzed to identify themes in participants' experiences related to communicative participation.

Results—Participants described many situations in which they experienced interference in communicative participation. Two themes emerged from the data. The first theme was *Interference is both "functional" and "emotional"* in which participants defined interference as limitations in accomplishing tasks and emotional consequences. The second theme was *"It depends" - Sources of interference* in which participants described many variables that contribute to interference in participation. Participants had limited control of some variables such as symptoms and environmental contexts, but personal decisions and priorities also influenced participation.

Conclusions—Despite different impairments and activity limitations, participants described similar communicative participation restrictions. These similarities may have theoretical and clinical implications in terms of how we assess, treat and study the participation restrictions associated with communication disorders.

Introduction

For many healthcare fields the World Health Organization's (WHO) *International Classification of Functioning Disability and Health* (ICF) (World Health Organization, 2001) has provided a framework and a vocabulary for understanding the different ways that individuals experience health conditions, as well as the range of variables that contribute to those experiences. The ICF has compelled us to broaden our views of health from traditional medical models in which disability is regarded as driven largely by the nature and severity of physical impairments, to biopsychosocial models in which disability is seen as a complex construct influenced by a combination of impairment, activity limitations, participation restrictions, and personal and environmental contexts. This transition has led researchers and healthcare providers to re-examine how well current assessment and intervention practices address each component of the ICF. Comparing current practices to the theoretical framework of the ICF helps us to identify possible gaps where healthcare providers are not adequately understanding or addressing the multifactorial components of health and disability.

Speech-language pathologists (SLPs) have applied the ICF framework to our understanding of the nature of communication disorders as well as current assessment and intervention practices. For example, the ICF has been applied to laryngectomy (Eadie, 2003), aphasia (Simmons-Mackie & Kagan, 2007), dysarthria (Dykstra, Hakel, & Adam, 2007), stuttering (Yaruss, 2007), and voice disorders (Ma, Yiu, & Abbott, 2007) among others. When examining communication disorders within the ICF framework, two trends are evident. First, traditionally the field of speech-language pathology has been similar to other healthcare fields with much of the clinical and research emphasis on the impairments and activity limitations components of the framework, and less attention to participation and contextual variables (Threats, 2007). Second, the ICF typically has been applied separately to different communication disorders with little comparison across disorders. These two trends are probably related. Different communication disorders have been defined largely by their impairments, and many assessment and intervention practices have followed suit. In order to understand the impairments and activity limitations associated with different disorders, different assessment procedures are certainly warranted. For example, the language batteries used to assess the nature and extent of language impairment in aphasia are of little use for understanding the severity and nature of dysphonia due to vocal fold nodules. Much of our intervention also consists of disorder-specific approaches to treat these different impairments and activity limitations. Continuing the previous example, exercises and strategies to assist an individual with aphasia and word-finding difficulties are different than the vocal exercises and techniques required to successfully treat vocal fold nodules.

Recently, SLPs have begun to focus greater attention on participation restrictions. Borrowing from the ICF definition of participation as 'involvement in life situations,' (World Health Organization, 2001), communicative participation has been defined as "taking part in life situations where knowledge, information, ideas, and feelings are exchanged" (Eadie et al., 2006). This definition emphasizes both the reciprocal nature of communication through involvement of more than one person, as well as the situational context in which the exchange of information takes place. In other words, communicative participation describes involvement in communication-related activities as part of fulfillment of life roles in the context in which they occur (O'Halloran, Hickson, & Worrall, 2008). Although more attention is beginning to be directed to communicative participation, at the time of this study there are still few assessment instruments dedicated to the construct of communicative participation (Eadie et al., 2006). Recommendations for participation-focused intervention are available, but most of these are general philosophies or theoretical approaches as opposed to specific evidence-based programs and techniques (Chapey et al., 2000; Worrall, 2006). Emerging programs that are taking a more participation-focused approach only target individuals with aphasia and not other communication disorders (Hinckley & Packard, 2001; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001).

While disorder-specific approaches are appropriate in assessing and treating communication impairments, it is not yet known whether disorder-specific approaches are needed for assessment and intervention related to participation restrictions. If participation restrictions are understood according to the ICF as reduced participation in life roles such as work, relationships and community involvement (World Health Organization, 2001), to what extent might different communication disorders lead to similarly altered participation such as loss of jobs, fewer relationships or reduced community involvement? Understanding similarities and differences in participation restrictions across communication disorders may guide researchers and clinicians in assessment and intervention specifically targeting communicative participation. In particular, having a greater understanding of communicative participation restrictions across disorders may determine the extent to which disorder-specific versus generic approaches in clinical practice, public education and advocacy are warranted.

Currently, studies exploring communicative participation across different communication disorders are limited. For example, in one study Garcia, Laroche and Barrette (2002) explored barriers to work integration for individuals with hearing loss, aphasia, voice disorders, laryngectomy, dysarthria and stuttering. They found many common barriers to employment across multiple disorders such as the attitudes of communication partners, noise levels, phone use, group situations, and the need for rapid communication. Other researchers have found that individuals with either learning disabilities or aphasia face similar challenges with communication and shared decision-making in healthcare encounters (J. Law, Bunning, Byng, Farrelly, & Heyman, 2005; Murphy, 2006), as do individuals with a range of communication disorders related to stroke (Nordehn, Meredith, & Bye, 2006; O’Halloran, Worrall, & Hickson, 2010). Otherwise, the current literature consists largely of studies that describe communicative participation in single populations or within classes of similar disorders (e.g. within voice disorders). Several of these studies will be highlighted in the discussion of this paper. While single-disorder studies provide valuable information regarding communicative participation, the lack of direct comparison across disorders leads to a gap in our understanding about participation restrictions associated with communication disorders. They also limit our understanding of the need for disorder-specific versus generic assessment and intervention strategies for communicative participation. The purpose of this study was to explore the similarities and differences in self-reported restrictions in communicative participation across different communication disorders in community-dwelling adults.

Methods

The data for this paper were collected during face-to-face qualitative interviews with individuals with different communication disorders. The primary purpose of the interviews was to evaluate and revise the format and content of the *Communicative Participation Item Bank* (CPIB) according to cognitive interview methods (Willis, 2005) and is reported elsewhere (Yorkston et al., 2008). The CPIB is an instrument currently under development by the authors (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2009; Yorkston et al., 2008) to provide measurement of communicative participation in everyday speaking situations. It is a self-report outcome measurement tool for community-dwelling adults across a wide range of communication disorders. The items ask about the extent to which a participant’s condition (i.e. health condition or communication disorder) interferes with participation in a variety of everyday speech communication situations (see Table 1 for examples of items and further explanation of item format). Prior work on the CPIB includes cognitive interviews with individuals with spasmodic dysphonia (SD; Yorkston et al., 2008) and multiple sclerosis (MS; Yorkston et al., 2007). Additional information about the CPIB is reported elsewhere (Baylor et al., 2009; Yorkston & Baylor, 2011). Psychometric analyses in multiple populations are currently underway.

This paper presents a secondary analysis of the data from the cognitive interviews, the rationale for which emerged during the study as similarities in the experiences of communicative participation reported by individuals with different communication disorders were observed. All methods were approved by the Human Subjects Division at the University of Washington.

Participants

Data collection occurred over a three-year period from 2006 – 2009. Participants represent a sample of individuals from speech and hearing clinics and hospital clinics serving clients with a variety of communication disorders in the Seattle region. Recruitment was limited to the Seattle region due to the need to meet in-person with the participants for the interviews. Initial recruitment focused on individuals with SD or MS to meet objectives related to broader CPIB instrument development project stages. This accounts for the relatively larger representation of these groups in the sample. Later in the study, recruitment was opened to any adult with a communication disorder in the clinics that were targeted for recruitment. The inclusion criteria were widened to include other communication disorders because the CPIB is intended to be applicable across a range of different communication disorders. For the purposes of guiding future research, the investigators wanted an indication if responses and reactions to the items would vary across disorders.

Inclusion criteria included adults age 18 years and older with a communication disorder who lived in the community and who used speech as their primary method of communication. Participants exhibited communication disorders that ranged in severity from mild to moderate. Judgments about adequacy of communication skills for participation in this study were made jointly by the participants and investigators through a discussion of the nature of the study.

Data Collection

Cognitive Interviews—Participation in the study required a one-time meeting that occurred either at the University of Washington or at a location of the participant's choice – often at home. The interviews were conducted using methods for cognitive interviews (Willis, 2005) which are sometimes also referred to as a "think out loud" process. After providing instructions and obtaining informed consent, participants were presented with approximately 30 items representing the range of topics and situations covered in the CPIB (the candidate item set consisted of over 100 items). Most participants could review the 30 items easily within the session, although the number of items was adjusted if needed for participant comfort. Different participants were given different items to ensure that all candidate items in the CPIB were reviewed by multiple participants. Participants were asked to read and answer each item. If they needed assistance in reading the items or marking their answers, the interviewers provided help.

After the participant chose an answer for each item, the items were reviewed together by the interviewers and the participant. According to cognitive interview methodology, participants were asked to share their thought processes as they read through and answered each item (Willis, 2005). What came to mind when they read the items? What situations did each item call to mind? What experiences had they had related to the situation in the item? Why did they choose the answers that they did? They were encouraged to share any information that they wanted about the item. This included technical aspects of the items such as wording that was difficult to understand or what they liked or disliked about the response options; as well as information related to the content of the item. The interviewers asked follow-up questions to clarify points or to obtain additional information as needed. Participants were also asked to identify any situations that were not included in their questionnaires that they felt were important to describing their communication experiences. This provided the opportunity for participants to introduce new topics or situations to be considered for items in the item bank, or to draw attention to situations that were most salient for them. Each interview lasted about 1 ½ - 2 hours but was shortened if needed for participant comfort. Participants were invited to contact the investigators after the interviews if they had additional comments to add about the CPIB items that came to mind at a later time.

The interviews proceeded iteratively per the recommended methodology for cognitive interviews (Willis, 2005). This means that after each 2-3 interviews the results were analyzed. Any problems identified in the items such as confusing wording or missing content were addressed by modifying or adding items. These were then tested in subsequent interviews. In this manner, all changes to the items were reviewed with participants. The interviews continued until saturation was reached. This was the point at which new interviews were not leading to any changes or additions of items in the CPIB.

There were nine investigators involved in the interview stage of the project, with two investigators attending most interviews. All interviewers were experienced rehabilitation clinicians or researchers and included six SLPs, two occupational therapists and a rehabilitation psychometrician. Four of the investigators had prior experience in qualitative research, including cognitive interviews and provided training to the remaining team. The first author (an SLP and a researcher with prior qualitative research experience) was present at all of the interviews to provide continuity. The other investigators rotated as the second interviewer. In all interviews one investigator was designated as the lead interviewer to facilitate the interaction with the participant. The second investigator focused on taking field notes and also contributed to the interviews by asking follow-up questions or bringing attention to additional details as needed. At least one experienced SLP was present in each interview to provide communication support to individuals with more moderate communication disorders, if needed.

Data Analysis

Data were kept in the form of field notes. The main role of the secondary investigator in each interview was to take detailed field notes, although both investigators took field notes for each interview. Each interviewer had a paper packet that contained the CPIB items for that interview with space below each item for notes. As each item was discussed in the interview, the investigators could make notes on their forms relevant to that item. The investigators did not write down participants' comments verbatim in general because those were not required for the purpose of the cognitive interviews. However, when participants' responses provided particularly unique, interesting or insightful comments, these were written down verbatim. The pace of the interviews allowed for detailed field notes, partly because many of the participants required a slow pace for communication due to their communication disorders, and also because the investigators purposefully kept a slower pace for the comfort of participants as well as for their ability to take accurate notes. Immediately after each interview the investigators compared their field notes for coherence and also discussed the interview together in terms of what they had observed and interpreted from the session. The first author then went through the field notes of both interviewers item by item to compare for continuity of content of the comments. Discontinuity was extremely rare and resolved through comparison of notes by the interviewers. Although not needed, follow-up contact with the participants' could have been used to clarify any discrepancies.

Qualitative analysis—The field notes were entered by the first author into Atlas.ti qualitative software (Muhr, 2009). Atlas.ti allows the investigator to assign codes to text and to then sort and organize text according to the codes, thus serving as a sorting and cataloging aid. Initially, specific situations included in the CPIB items were coded to recognize that participants were asked about these situations in the interviews. Analysis then continued with a careful reading of all field notes. Words or phrases that reflected the main topics or meaning of each section (a section generally being a participant's discussion of an individual item) were assigned to each section of notes as codes. The terms for the codes were not chosen beforehand but instead emerged as different topics were raised in the notes. The codes were rather broad in meaning to identify the overall topic of the participants' comments. For example, if a participant talked about feeling upset by the restrictions imposed by the communication disorder, this passage would be coded with the word "emotions" to reflect that the participant was talking about his or her feelings. A note in which a participant was talking about how communication partners influence participation (either as a barrier or facilitator) would be coded with the term "partner." Multiple codes could be assigned to a single note if multiple topics were addressed in that section.

Consistency in coding was achieved as follows. First, approximately 10% (10/112 pages) of printed notes in Atlas.ti were coded jointly by three authors (CB, MB, KY) who discussed emerging codes and their corresponding definitions. Then investigators MB and KY each independently coded one half of the remaining field notes, while CB coded all of the remaining field notes. After the authors completed their independent coding, the coding was compared and any discrepancies were resolved in discussions involving these three authors. This resulted in the entire set of field notes being coded by at least two investigators, with three investigators participating in discussions of discrepancies.

Once the field notes were coded, the codes provided the tools to sort and bring together sections of text that addressed similar topics. These sections were examined and summarized to reflect the key elements of the reported experiences of participants. For example, participants discussed many variables that they felt influenced communicative participation (e.g. communication partners, environmental features and personal perspectives). These were grouped together under the broad heading of "Sources of interference" with categories under that heading summarizing different sources of interference that participants described. Two key observations guided the development of theme and sub-themes. First, the themes expressed the considerable commonalities across the different disorder groups that were observed in the data. Examples of unique disorder-specific experiences were also reported to reflect the relatively rare occurrences of these observations, but the themes and sub-themes were formed around the experiences that were reported widely across the different disorder groups. Quotes and paraphrases from participants with different disorders were chosen to illustrate how the themes derived from participants' reports. Second, issues that the participants indicated were of most concern to them or most salient in shaping how they viewed their experiences heavily influenced formation of themes and sub-themes. The themes were generated in an iterative manner with discussion among three authors (CB, MB, KY) and rechecks with the field notes. The proposed thematic structure was then returned to the full set of authors along with the raw data for discussion of any needed changes that might be suggested by the perspectives of the rest of the author team. The grouping together of codes and eventual formation of themes and sub-themes was patterned after qualitative content analysis (Graneheim & Lundman, 2004). The appendix provides a list of the final set of codes used in the analysis as well as how they were grouped together to form themes and sub-themes.

Trustworthiness and rigor—The trustworthiness of qualitative data can be revealed through a variety of methods designed to establish credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Credibility, or the extent to which the interpretation of the data reflects the reported experiences of the participants can be established in a variety of ways. In this study, triangulation occurred on two levels. First, the relatively large sample size allowed for comparison and contrast of experiences across many different participants and contributed to saturation in that the investigators were assured that they were ‘hearing the same stories’ across participants. Second, triangulation occurred by the organization of the interview and analysis teams. Two investigators were present in most interviews. The first author was present in all interviews to provide consistency, but the second investigator in each interview rotated which brought in different researcher perspectives. Both interviewers took field notes during the interviews. The two interviewers compared field notes immediately after each interview. This provided a system of checks and balances on the raw data in the field notes to ensure that they represented the information gathered from the interview. Peer debriefing was conducted by dividing the group of five authors who were responsible for data analysis and writing into two groups. One group (CB, MB, KY) was responsible for the primary work of coding and theme development, and the second group (TE, DB) served to check and challenge the emerging thematic structure. Member checking was achieved primarily through the iterative nature of the cognitive interviews. When a participant recommended changes to a CPIB item, the possible changes were discussed with that participant until agreement was reached on a modification that, according to the participant, reflected his or her experiences. Then, those proposed changes were presented to subsequent participants who were asked to comment on the items and the situations reflected in those items. In this manner, participants had the opportunity to endorse or challenge content proposed by prior participants. All participants were also invited to contact the investigators if they had any further input after their interviews. Two participants volunteered to take additional CPIB items home with them for review and returned written comments (one also participated in an in-person follow-up visit). Another participant followed-up with emailed general comments. Otherwise, most participants did not have additional contact with the investigators after their interviews.

Transferability reflects the extent to which the findings for these participants might extend to other similar groups of individuals (Lincoln & Guba, 1985). The primary effort to establish transferability was the inclusion of a range of different communication disorders to document the extent to which reported experiences with communicative participation were similar versus different across different disorders. External audits were not conducted, but the methods described above for credibility also speak to the dependability and confirmability of the findings.

Results

Participants

Forty-four individuals with communication disorders participated in the interviews. These individuals represented seven different diagnostic groups including spasmodic dysphonia, stroke (including a range of communication disorders) (CVA), multiple sclerosis, Parkinson’s disease (PD), laryngectomy secondary to head and neck cancer, amyotrophic lateral sclerosis (ALS) and stuttering. Table 2 provides demographic information for each group. All participants except four presented with mild-moderate communication disorders and were able to convey complex ideas and share their opinions with moderate to high levels of independence. One participant with MS and three participants with stroke had moderate cognitive-communication or language impairments. These participants were able to talk more generally about their experiences living with their communication disorders although they could not answer all of the interview questions in detail. Data obtained from these four participants are included to reflect their experiences to the extent that they were able to convey the information.

Themes

Two themes with corresponding sub-themes emerged from an interpretation of the data. Table 3 presents an overview of the themes and sub-themes. The first theme was *Interference is both "functional" and "emotional"* in which participants defined what interference in communicative participation meant to them. The second theme was *"It depends" - Sources of interference* in which participants described many variables that contribute to interference in communicative participation.

Theme 1: Interference is both "functional" and "emotional" (42 y.o. male, stuttering) [1]—Participants reported that interference in communicative participation had two key dimensions. The participant with stuttering, a 42 year-old male, captured the key elements identified by other participants when he described (a) the "functional" aspect of being able to do a task or not, and (b) the "emotionality" of dealing with the communication disorder. Another participant illustrated the same concepts when she talked about how part of interference was simply "getting the job done" which she often could accomplish with the help of her daughter, but the other part of interference was being "bothered" by her lack of independence with her communication. (47 y.o. female, CVA)

Three sub-themes relating to the "functional" and "emotional" components of interference were identified. The first two sub-themes describe how function is changed by either having to do things differently or withdrawing from situations entirely. The third sub-theme illustrates the "emotional" consequences of the challenges participants experienced communicating in everyday situations

Subtheme 1.1: "I have to do things differently because of my speech." (39 y.o. female, SD): Interference was generally not regarded as an all-or-none phenomenon in terms of either participating or not participating in situations. Instead, interference was usually described as a "degree of change" (66 y.o. female, SD) in how they participated. Participants continued to engage in many of the same situations that they typically would have been in, but they had to adjust what they did to accomplish that involvement. The following sections describe how participants had to 'do things differently' with their communication in order to participate. The following strategies might be regarded in some instances as facilitators of participation by allowing participants to engage in situations, but participants also reported that these strategies embodied the concept of interference as well because they were not the typical or natural way that they would interact with other people. The strategies disrupted the "natural flow" (74 y.o. male, CVA) of communication.

1.1a: "I can make my voice louder if I need to" (68 y.o. male, PD): Some participants felt that, to some extent, they were able to change their speech to be understood better in order to facilitate participation. The ability to change speech was challenging, however, and was one of the few observations that differed across diagnostic groups. For example, several participants with PD, particularly those who had received Lee Silverman Voice Treatment (LSVT) (Ramig, Sapir, Fox, & Countryman, 2001), reported that they could speak louder when needed in various situations. In contrast, other participants, particularly those using an electrolarynx after laryngectomy, reported very little ability to modify speech to facilitate

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[1] In this manuscript quotes will be ascribed to individual participants by noting the age, gender and diagnosis of the participant. The acronyms for the diagnoses are available in Table 3.

participation: "My speech is what it is…it all goes back to if they can understand it [the electrolarynx]." (60 y.o. female, laryngectomy)

1.1b: "Dumbing down" my speech (60 y.o. female, MS): A common strategy for communication was to plan speech carefully, specifically avoiding words that were difficult to say. Choosing words and simplifying sentences was referred to by one participant as "dumbing down" (60 y.o. female, MS) speech and was not an appealing strategy. Participants discussed strategies such as preparing a "script" for conversations so that they had a plan of what to say (particularly on the phone), rehearsing conversations, writing down cues to use during conversations, and then following up with conversation partners to ensure that the message had been understood.

1.1c: "Sparks coming out of my eyes" (67 y.o. male, laryngectomy): When speech could not be modified enough to facilitate participation, participants often chose to use another communication modality. The most common example was the use of email, particularly to replace phone calls. Participants also described greater reliance on body language, gestures, facial expressions and other nonverbal communication.

1.1d: I "lean on" family and friends to communicate for me (50 y.o. male, SD): When participants either experienced or anticipated too much difficulty participating in certain situations, they often accomplished their task by having someone else speak for them. The most common situations included ordering meals in restaurants, making phone calls, talking to social acquaintances outside of the family, and talking to physicians.

1.1e: You "need to be patient with me" (61 y.o. female, CVA): Participants reported that successful participation often depended on informing communication partners about their communication difficulties and making specific requests of communication partners. The most common examples of accommodations they requested included allowing more time for communication, remaining patient during communication and focusing on the content of the words to avoid misinterpreting the sound of the voice or other speech characteristics. For some participants, such as those with laryngectomy using an electrolarynx, very little modulation of speech was feasible to express emotions or to convey meaning. For participants such as those with SD, the voice quality was often misinterpreted as reflecting emotions that the participants were not feeling. In all cases, participants reported how important it was for communication partners to know that they should focus on the content of their words and to not make inferences based on the expression (or lack thereof) in their speech.

Subtheme 1.2: Sometimes the "only way you can change a situation is to avoid it." (50 y.o. male, SD): The prior section summarized modifications that participants used to remain involved in various communication situations. There were times, however, when they simply were not able to, or chose not to remain involved. At that point, interference meant withdrawing from or avoiding certain communication situations. Some participants described withdrawing from major life roles in response to the communication disorder. These included leaving jobs, changing jobs, or modifying responsibilities within current jobs. Participants described giving up involvement, particularly leadership roles, in volunteer or community organizations. Finally, participants described withdrawing from social situations ranging from gatherings with family and friends to dating. At times, withdrawal meant not attending an event, but participants also described many situations when they would attend an event but just not participate in conversations at the event. Instead they would "go into the background and retreat,"(61 y.o. female, CVA) and "do the bare amount of talking," (61 y.o. female, CVA) "keep a low profile," (67 y.o. female, PD) and "drawing back." (66 y.o. female, SD) Participants tended to avoid "unnecessary" (61 y.o. male, SD) conversation. Necessary communication was usually regarded as conversations that were required to address a particular problem, but sometimes participants even chose to leave problems unresolved in order to avoid speaking. The participant with stuttering described the “stuttering tax” as the cost to someone for leaving a problem unresolved in order to avoid speaking. For example, if there was a problem such as an erroneous overcharge on a bill, someone with a speech disorder may choose to simply pay the extra amount instead of trying to resolve the problem because they wanted to avoid having to talk to someone.

Sub-theme 1.3: I feel “like a bystander” (52 y.o. male, SD): While difficulty with the technical aspects of accomplishing tasks was part of interference, as described above, interference was not defined solely by the ability to perform the mechanical aspects of communication or to engage in situations. Many participants talked about the importance of personal feelings in defining interference. Even if they accomplished the task, the frustration or discouragement they felt in getting through the situation was regarded as interference. One of most common feelings associated with interference was feeling left out of conversations and situations. Participants described this as feeling “like a bystander,” (52 y.o. male, SD) feeling “out of the loop,” (64 y.o. female, CVA) or feeling “ignored.” (47 y.o. female, CVA) Participants were also uncomfortable drawing attention to themselves and worried about what other people might think of them. People “will wonder what’s wrong with me – at least in my mind I think so.” (67 y.o. female, PD) Participants used a variety of words to describe their feelings about the impact of their communication disorders on participation including feeling limited, vulnerable, frustrated, nervous, embarrassed, insecure, and discouraged.

Participants described changes in their personalities because of their communication disorder and felt that they had become different people. They described being “more reticent; not like me.” (61 y.o. female, CVA) The participants with SD in this study were all receiving botulinum toxin (botox) injections and some suggested that, to some degree, their self-perceptions varied with their voice quality throughout the injection cycle. For example a 41 year-old female with SD said that when her voice was bad she was less outgoing and more of a “mop in the corner,” whereas when her voice was good after botox injections she had periods of “regaining my sense of self.”

While the majority of participants described feelings similar to those listed above, there were some exceptions. For example, one of the participants with laryngectomy tried to keep an upbeat attitude by saying, “If other people accept me with this, I’m fine with it – being a robot.” (67 y.o. male, laryngectomy) Another participant reported having episodes of feeling “proud” (61 y.o. male, PD) when he was able to do something that was very difficult for him to do in terms of communication.

Theme 2: “It depends” – Sources of interference—When asked if they experienced interference in participation in various situations, the most common answer that participants gave was, “It depends.” They said their participation depended on a wide range of variables that could either facilitate or impede participation. They also described how the influence of any given variable on communicative participation might vary across time or situations. Some variables could be either barriers or facilitators in different situations. The constellation of variables to be discussed below was very consistent across participants, although there was variability in the extent of the influence of the different variables for different participants and in different situations.

A dichotomy emerged when participants described sources of interference. One category consisted of things that were external to the participants or not entirely under their control. The second category was related to their own individual choices and priorities that influenced their decisions about participation. These two types of interference sources are described in the following sub-themes.

Subtheme 2.1: Things "get in your way." (69 y.o. female, PD): Participants identified many variables that created interference in communicative participation that were not entirely under their own control. These variables included their communication disorder symptoms, other health symptoms, and various aspects of the communication task and environment. Examples of these will be presented in the following sections.

2.1a: The "words don't come out right" (64 y.o. female, CVA): Although the participants included individuals with a range of different communication disorders, they reported many similarities in the communication symptoms they identified as sources of interference in participation. Not all of the following symptoms applied to all of the communication disorder categories, but there were representatives from multiple disorders within each of the following categories:

"It is hard to keep my voice up:" (69 y.o. male, PD): Participants with laryngectomy, SD, ALS, PD and MS all reported that they could not project their speech loudly enough to be heard in all situations. However, not all participants reported the same problem of insufficient loudness. For example, a 47 year-old female with a CVA reported that she was too loud in some situations, such as at church and in the library, and that she had difficulty keeping her voice softer as needed for some situations. A 68 year-old male with PD reported that he was aware his louder voice was more understandable but he was uncomfortable "shouting" to people and felt that was a problem for participation. The only participant to indicate that loudness facilitated participation in a positive way was the 42 year-old male with stuttering who said that his speech was sometimes more fluent when it was louder.

'It is hard to show you are angry if all you can do is whisper:' (52 y.o. male, SD): Participants across several disorders including SD, CVA, PD and laryngectomy reported that lack of vocal inflection or difficulties with expressiveness in speech created problems for participation. Communication partners often misinterpreted them because the partners were taking cues from the speakers' tone of voice that was not reflective of the content of what they were saying. Nuances that revealed emotions or subtle meanings were hard to convey, and they could not match the tone of their speech to the situation. For example, when talking about using humor in conversations, one participant reported that without better vocal expression he "had facts but no story telling aspects."(56 y.o. male, CVA) A participant with laryngectomy referred to the limited expressiveness of the electrolarynx as a "barrier" in emotional situations where tone of voice is important. His complaint with the electrolarynx was that it was not subtle: "It's like you are using a microphone and talking to someone in the front row." (88 y.o. male, laryngectomy)

"Mush in my mouth:" (67 y.o. female, PD): Distorted articulation with reduced speech intelligibility was another problematic speech symptom. Participants with PD, CVA and MS reported difficulties making words "clear" and "distinct." (61 y.o. male, PD)

My "mind works like molasses:" (67 y.o. male, CVA): The inability to keep up with the normal pace of conversations was a very common concern across participants. Sometimes the problems were related to slow processing rates for cognitive and linguistic aspects of communication. Other times the problems were related to slow motor production for speech. Some participants purposefully used a slower rate of communication to try to maximize speech intelligibility. Participants with CVA, SD, PD and laryngectomy all reported the need to deliberately slow down to be understood.

"Loss of words:" (69 y.o. female, PD): Several participants with CVA, PD and MS struggled with language formulation, word-finding, memory or information processing even when they had adequate time. Symptoms included, "hard to think quickly," (69 y.o. female, PD) "words will tumble over themselves," (64 y.o. female, CVA) and having to process "one thought at a time." (56 y.o. male, CVA) One participant said that at times she simply "has to stop and look blankly at the person" until she remembers what she wanted to say.(69 y.o. female, PD) For several participants, complex conversations were difficult because of problems with retaining and sequencing information. A 37 year-old female with MS reported that she will simply forget a topic mid-sentence which makes it difficult to continue a conversation. One participant described how he had to "lay it out one step at a time" (67 y.o. male, CVA) when presenting long or detailed information. A 43-year-old male with MS said that having conversations about current events was difficult because he was not able to remember information from news stories well enough to talk about them later.

The communication symptoms listed above were the most common ones across participants. However, there were other isolated examples of ways in which communication symptoms or methods created interference with participation. For example, the electrolarynx was often seen as a barrier by the participants with laryngectomy because of the lack of hands free speech, the hassle of keeping the electrolarynx available when needed, and the "robot" (67 y.o. male, laryngectomy) sound. These participants reported that the electrolarynx was often a barrier to interacting with others: "this machine is a turn-off to almost everyone." (88 y.o. male, laryngectomy)

One of the challenges with several of the communication disorder symptoms described above was fluctuation and unpredictability. Some participants observed patterns such as fatigue at the end of the day that were predictable. However other participants, such as those with MS described overall unpredictability of symptoms. Individuals with SD said it was difficult to make long-term commitments because they did not always know what their voices would be like a week or two in advance. Participants with SD did note, however, that the fluctuation associated with botox injections meant that there would be some periods of good voice quality with the botox, and these were often times when they experienced less interference in participation.

2.1b: The "soup" of symptoms (57 y.o. male, MS): Other health symptoms seemingly unrelated to communication also contributed to interference in communicative participation. These symptoms varied across disorders. For example, individuals with SD or stuttering generally have no other associated health conditions whereas individuals with MS, CVA, ALS, cancer or PD are more likely to experience multiple changes in health. One of the most common examples was mobility problems. Participants with ALS, MS and PD reported that they could no longer engage in the same activities that they used to participate in because of mobility limitations, so they simply did not have the opportunity to interact with friends and acquaintances as they typically would have. For example, a 67 year-old female with PD reported that because of her increasing mobility problems she was having more difficulty keeping her house clean. Because she could no longer keep her housework up to her standards she no longer invited people over to visit – and even turned people away who offered to visit.

Participants reported a range of other health symptoms. For example, participants with ALS and laryngectomy reported that swallowing difficulties created interference with holding conversations at mealtimes. Participants with MS reported that vision problems created interference with eye contact and reading non-verbal cues in conversations. For example, a 57 year-old male with MS and vision changes said that he had difficulty getting the attention of waiters in restaurants because that is often accomplished through eye contact. Participants with laryngectomy reported that their appearance with the stoma and stoma care interfered with their interactions with other people. Participants with MS and CVA reported that emotional lability restricted participation in some conversations because they typically avoided topics of conversation that they knew would trigger their lability. As with the communication symptoms described above, the unpredictability of other health symptoms was particularly troublesome with regards to participation. Participants reported it was very difficult to make and keep social commitments when they did not know what symptoms they would be dealing with when the time of the event arrived.

When describing various symptoms, participants reported that it is sometimes difficult to know exactly which symptoms are influencing communicative participation at any given time. One participant described his experience as the "soup" (57 y.o. male, MS) of MS. He said multiple symptoms such as vision, fatigue, and slow thinking all affect his communication with other people, but he could not necessarily sort out which of those symptoms was most influential at any given time. They were all inextricably combined. There might be fluctuations in 'how hot the soup is" (57 y.o. male, MS) or if he has a "ladle" or other tools to work with to deal with the situation, but the soup is always there.

2.1c: "There is no barrier if you know them well" (88 y.o. male, laryngectomy): Participants described many aspects of the communication environment that heavily influenced communicative participation. Chief among these was the communication partner. In some situations, communication partners were facilitators of participation: "People are usually ok. If they are a real friend they will go along with it – even the spittle running down the chest." (67 y.o. male, laryngectomy) "People understand the problem and don't let it get in the way." (69 y.o. male, PD) In other instances, communication partners were barriers to participation. Partners were described as being "not receptive" (88 y.o. male, laryngectomy) or "dismissive." (50 y.o. female, PD) Several participants reported instances of communication partners ignoring them or walking away from them saying that people "tune me out – look past me." (41 y.o. female, SD)

The familiarity of the communication partner was the key issue in determining if the partner was regarded as a barrier or facilitator of participation. Almost all participants reported that communicative participation was easier with familiar people. "There is no barrier if you know them well." (88 y.o. male, laryngectomy) As with many other variables that influenced communicative participation, however, there were gradations of familiarity. These gradations were related to how well participants knew the communication partners and what the communication partners knew about the communication disorder. In general, communication partners who knew participants well and were part of the "inner circle" (41 y.o. female, SD) facilitated participation because they were willing to do "whatever it takes" (52 y.o. male, SD) to make sure communication was successful. People in the inner circle also often shared similar knowledge and opinions which led to a reduced need to talk: "We both have the same thoughts." (56 y.o. male, CVA) Communication with these partners was "less awkward." (41 y.o. female, MS) Participants noted, however, that the important aspect of familiarity was not always how "close" the relationship was but also the frequency with which people interacted. For example, a 48 year-old female with SD said that while her parents were among her closest relatives, they were not easy for her to talk with because they did not see her very often and they were not familiar with her speech – particularly the fluctuations due to botox. A 52 year-old male with SD reflected the views of many participants when he described three meaningful distinctions in partner familiarity: The most difficult situations were with people he does not know. The next category consisted of people that he knows but they do not know about his communication disorder. The third category of individuals, those who most facilitated participation, were people who not only knew him and knew about his voice, but they also “understand” about his voice – they really have a deeper level of sensitivity for his challenges.

There were isolated examples of participants reporting that communication was not always easiest with familiar people. For example, one participant reported that some communication partners who know about his medical condition make assumptions about his abilities that were not reflective of what he saw as his actual capabilities: “They doubt I can do the activity because of my speech. [I need to] get them to understand how important it is for me to go.” (69 y.o. male, PD) There were also isolated instances of participants preferring interactions with unfamiliar communication partners. For example, a 65 year-old female with CVA reported that it was frustrating communicating with family and friends at times because they are more likely to jump in and try to finish her sentences for her. They assume that they know what she is trying to say. In contrast, unfamiliar partners are more likely to wait and allow her to talk because they do not assume they know what she is trying to say. Another participant reported that communication is “harder with people you know because you care more.” (60 y.o. female, MS) She is more concerned about how she comes across to people she knows.

2.1d: What are my “surroundings” (61 y.o. male, PD): In addition to the variables of communication disorder symptoms, other health symptoms and communication partners described above, participants talked about many other aspects of their “surroundings” (61 y.o. male, PD) that affected participation. These might include features of the physical environment such as background noise, group conversations, situations that demanded speed, and using the phone, as well as issues related to the purpose, topic and length of conversations.

Noise: Noise was a very large barrier to participation for most participants. Indeed, for some participants, noise was the greatest barrier to participation. “Noise is what it is all about” (61 y.o. male, PD) and is the “biggest limiting factor.” (67 y.o. male, laryngectomy) A dichotomy emerged, however, in terms of two different types of noise and their impact on different participants. The two different types of noise were summarized by one participant as “white” noise – the ambient noise such as machinery or traffic in the background and “structured” or “organized” noise such as people talking or music and singing in the background. (67 y.o. male, CVA) Participants regarded the white noise as a “physical barrier” (61 y.o. male, PD) and the challenge was speaking loudly enough to be heard. This was problematic for participants with SD, ALS, PD and laryngectomy. The problem with structured noise was that it was a distraction making language processing and formulation more difficult, and this was an issue for participants with CVA as well as some participants with PD. A few participants reported that noise facilitated participation at times. The participant with stuttering felt that his speech was more fluent in noisy situations and he felt more anxious about having conversations in quiet places. One participant reported that due to difficulties with volume control and excessive loudness, she was uncomfortable in very quiet places like the library or church. (47 y.o. female, CVA)

Groups: Most participants reported that group situations were more difficult to participate in than one-on-one conversations. Participants reported that they often felt “left out” (69 y.o. male, PD) of groups because other people in the group could talk among themselves and did not necessarily need to include the person with the communication disorder. “If there is a group of three people or more, I am the odd man out.” (61 y.o. male, PD) In addition to the challenge of speaking over the noise of the group, the most common difficulties with group situations were getting a turn in the conversation and keeping up with the rapid pace of conversation. This was described as problems “getting a word in edgewise” and “being allowed to say something.” (69 y.o. male, PD). “People go on and on and don’t give you a chance.” (67 y.o. female, PD) Participants tried a range of strategies to facilitate getting a turn in group conversations such as raising their hand to get people’s attention. (56 y.o. male, CVA; 67 y.o. male, laryngectomy; 67 y.o. male, CVA) However, strategies such as these were still regarded as creating interference in participation because they are “unnatural” (67 y.o. male, CVA) and they change the “feel” of the conversation. (60 y.o. female, laryngectomy) Group conversations were sometimes easier in more organized situations such as a club meeting or in a more formal learning setting where turn-taking is more organized as opposed to less structured social situations. (69 y.o. female, PD)

Speed: Speed was another barrier that was pervasive across the participants. Examples of situations in which speed was a problem included humor where timing is critical for punchlines and “quick playing” (62 y.o. male, CVA) with words, brief small-talk types of situations such as passing a coworker in the hall, doctor appointments with doctors who are short on time, talking to clerks in stores and waiters in restaurants, and other “time pressure” (50 y.o. female, PD) situations in which you need to respond quickly, think on your feet, or possibility react to an emergency. The exception to speed as a barrier was with two participants with SD who reported that they were often able to participate in quick, spontaneous comments better than in longer methodical conversations because their voices would be easier in those brief spontaneous moments.

Phone: The phone was a barrier to participation for most participants, and for some the phone “trumps” (52 y.o. male, SD) all other variables as the greatest barrier to participation. One participant represented the view of many others when she said she “hates the phone” (60 y.o. female, laryngectomy) and another said the phone is a source of “anticipation and anxiety.” (42 y.o. male, stuttering) The phone was a barrier to participation not just due to concerns for basic speech intelligibility but also for the loss of nuances of communication. Participants had often been misinterpreted over the phone because the listener would infer something about the situation based on the voice quality or speech difficulty of the participant, and that inference was usually incorrect. Participants reported that with the phone there was no access to body language or facial expression that could help to convey communication intent. There was also no feedback regarding how well the speaker was being understood. Participants chose a range of strategies for dealing with the phone ranging from avoiding phone calls, to having a “script” for use on the phone, to being very explicit with the communication partner to listen carefully to the speaker’s words.

Topic: Participants had mixed opinions regarding the degree to which the topic and purpose of conversations contributed to interference in communicative participation. General trends observed across multiple participants are reported here. Many participants described having difficulty with specific words. Situations that require information to be presented in a very specific sequence, that require specific vocabulary or that require more detail were challenging. One participant described detail as “too much to handle - not just yes and no but something in the middle.” (58 y.o. male, CVA)

Several participants talked about conversations that required question and answer exchanges such as in a doctor appointment. Participants reported that asking questions is generally easier than answering questions, particularly if the questions to be asked can be anticipated or even scripted in advance. Answering questions was more difficult because the content is less predictable and often more complicated, or requires thinking on the spot to formulate a response. Participants were asked about giving advice or instructions. In general, their responses were that the level of interference depended on the situation and how confrontational it was. For example, one participant said there was a difference between giving advice to her granddaughter who is dating someone she does not approve of versus giving advice on “planting spinach.” (she is a gardener)(64 y.o. female, CVA) In a similar manner, asking for help could be more or less difficult depending on who you need to ask for help and whether the help is related to everyday activities versus something related to the medical condition: “Are we asking about getting the salami out of the fridge or falling down and needing emergency help?” (60 y.o. female, laryngectomy)

Using humor was a particularly challenging issue. Participants reported that the difficulty with humor was that often the humorous effect depends on using very specific words or delivering the comments at a very specific time or with a specific expression – all areas where participants struggled. “Timing is off – by the time I get it out it’s too late.” (64 y.o. male, CVA) Only one participant reported that long story-type jokes do work well for him because he can practice them ahead of time and does not have to be spontaneous with them as is required for some types of humor.(67 y.o. male, CVA)

Finally, with regards to topic, there were problems with starting new conversations or changing topics within conversations. Participants commented that starting a new topic was more difficult than participating in a conversation on an ongoing topic, and that they would likely avoid introducing new topics in conversations. They found this to be “limiting.” (52 y.o. male, SD)

Length: For most participants, longer conversations were more difficult than shorter conversations. “One sentence at a time [is] not too difficult. If [it] goes on and on then more difficult.” (67 y.o. male, CVA) Longer conversations were challenging because of the physical effort to talk: “it is hard to keep my voice up” (69 y.o. male, PD) and “exhausting;” (88 y.o. male, laryngectomy) as well as the difficulty formulating long sections of content. Several participants commented that greeting someone briefly such as saying, “hello, how are you” was not difficult, but conversation that extended beyond greetings became difficult.

Subtheme 2.2: “Allowing” (51 y.o. female, SD) interference to happen: When participants described the many variables that influenced their communicative participation, most of their attention was on the variables described in sub-theme 2.1 - variables that were either external to them (environmental variables) or not entirely under their control (health symptoms). However, participants also said that sometimes interference in communicative participation was a “learned behavior” (58 y.o. female, SD) in that they made conscious decisions about participating in situations regardless of what was determined by their symptoms or by environmental variables. This learned behavior could, however, take the form of either increased or decreased participation. Some participants described how they had become accustomed to “holding back” (58 y.o. female, SD) and not participating in situations. In contrast, other participants who had lived with their communication disorders for many years reported they were engaging in situations and participating more than they used to earlier in their experiences with their communication disorders. They reported they had “adapted” (69 y.o. female, PD) or learned to “just live with it” (66 y.o. female, SD) and were “not letting the speech stop me.” (42 y.o. male, stuttering)

Decisions about participation depended heavily on how participants prioritized different situations. Participants reported that they were less likely to allow their conditions to interfere with communication in situations that were important to them. The important situations were the ones that they were more likely to push through regardless of the difficulties. However, different participants had different priorities for communication. Participants in general thought across traditional life boundaries of work, socialization, and other domains, and prioritized the importance of situations in different ways. Some of the ways that participants defined important situations were situations that they “did not want to avoid,” (50 y.o. male, SD) “mission critical,” (42 y.o. male, stuttering) or where you “really want to be heard.” (69 y.o. male, PD) Participants were very clear in saying that the important situations were not necessarily the ones that occurred most frequently, nor were they always situations that required more serious or weighty conversational topics. For example, two participants described how it can be very important to have more casual conversations that involve only small talk with “people who matter” (42 y.o. male, stuttering; 58 y.o. female, SD) such as the boss at work. Participants also emphasized that what they considered to be important might change across time and situation.

While participants reported that they were more likely to try to prevent the communication disorder from interfering with participating in important situations, they also reported that important situations were the ones in which they felt the impact of the communication disorder more keenly and were more likely to report higher levels of interference. For example, one participant reported her highest interference on an item that asks about reading aloud to other people. She said that one of her greatest sources of “disappointment and discouragement” (61 y.o. female, CVA) with her communication disorder was not being able to read to her grandchildren as easily as she had always imagined she would, and the importance of this situation to her led her to rate interference in that situation higher than other situations.

The participant with stuttering described how he prioritized communication situations and made subsequent decisions about participation, and his comments reflect those of other participants as well. He categorized situations into three “buckets.” The first bucket was “safe” situations in which “speech doesn’t matter.” These were situations with family and close friends, and in familiar, comfortable surroundings. Speech did not matter in these situations because there were “no consequences” riding on the speech. The second bucket was “critical” communication situations. These are situations that you simply have to do and/or they have to be done at a specific time and you really do not have any choice. You just have to push through and do the task. The third bucket was “non-consequential” situations. These situations had options as to if, when or how you engaged in the situation. These were situations that you could choose to postpone or change without any consequences. For example, it might not really matter whether you dropped off the dry cleaning today or tomorrow. These situations often involved people that you would see rarely or never again. He explained that in these situations you did not necessarily have to be “honest” with your speech. For example, if there was a misunderstanding or miscommunication that really had no bearing on the outcome or purpose of the situation, you were not obligated to repair the communication breakdown or correct the misunderstanding.

Discussion

The purpose of this study was to explore the similarities and differences in self-reported restrictions in communicative participation across different communication disorders in community-dwelling adults. The questions about interference in communicative participation seemed to resonate with the participants in that they readily had many examples of experiences, and many already had terms that they used to frame their thinking and describe their experiences. When talking about what interference meant to them, participants related that interference had two components. One aspect of interference was restrictions in the ability to accomplish or engage in tasks, and the other component was a range of largely negative emotions about their experiences. When talking about the causes of interference, participants identified variables over which they felt they had little or no control (health symptoms, environmental factors), as well as their own reactions and self-imposed decisions that shaped their participation. All participants reported a wide range of situations in which they had experienced interference in communicative participation.

Although some participants reported that they felt they had adapted to the point at which they were not letting their communication disorders stop them as much as they might, all participants shared evidence of the profound effect that their communication disorders had on involvement in many life roles at some point in their lives.

The most notable observation to come from this study is that despite very different underlying impairments and health conditions, participants overall described very similar experiences in terms of the impact on daily communicative participation. Even when the underlying reasons for reduced participation were different for different disorders, the outcomes for participation were the same. For example, when asked about participating in communication situations in noisy environments, participants presented different reasons for having difficulty depending on their disorders. Participants with speech-related disorders such as SD, PD and laryngectomy tended to report that the problem with noisy situations was being loud enough to be heard over the noise. Participants with language or cognitive concerns (some CVA and PD participants) reported that the problem was the distractions caused by the noise that made it difficult to process and formulate information. However, when it came down to the basic participation question (i.e., whether or not participants could engage in communication in noisy situations), participants across all categories reported that they experienced significant restrictions in these settings. These findings highlight how individuals with very different impairments, and even different activity limitations, can experience very similar restrictions in participating in life roles.

Many of the experiences reported here might be expected for people with communication disorders such as the greater ease of communicating with familiar people or the challenges of talking on the phone. There were, however, some exceptions to these patterns indicating some variability in participants’ experiences. For example, one participant reported that it was almost easier to communicate with unfamiliar people because she did not care as much about what unfamiliar people thought of her as she did about how family and friends regarded her. Another participant reported that unfamiliar people were less likely to interrupt her or try to finish her sentences for her. There were also several examples of nuances of experiences that were meaningful to participants that might not occur to people without communication disorders. Examples reported here include the different types and impact of background noise, and the problems with different types of humor reported by several participants.

Comparisons of this study to existing literature are limited because there is a paucity of studies at this time that have specifically examined communicative participation across different communication disorders. One study focused specifically on participation in employment across communication disorders (Garcia et al., 2002). Many of the identified barriers to employment were similar to participation barriers described in the current study and were expressed by participants who had various communication disorders. Some of the most salient barriers identified by Garcia et al. (2002) included noise levels (reported by participants with hearing impairment, voice disorders, laryngectomy, aphasia, dysarthria), telephone use (hearing impairment, aphasia, voice disorders, dysarthria), group situations (hearing impairment, voice disorders, laryngectomy, dysarthria, stuttering), speed of communication (dysarthria, aphasia, stuttering) and the attitudes and awareness of communication partners (all groups).

One domain that is starting to receive more attention is the impact of communication disorders on participation in healthcare and shared decision-making with healthcare providers. Two studies have included individuals with aphasia or learning disabilities (J. Law et al., 2005; Murphy, 2006), and other studies have included individuals with a range of communication disorders related to stroke (Nordehn et al., 2006; O’Halloran et al., 2010).

These studies document the constellation of variables that influence participation in healthcare settings including the skills and attitudes of healthcare providers, the physical surroundings, the policies of the healthcare setting and the presence of family or friends to help. Similar experiences in healthcare across communication disorder groups are also addressed by O'Halloran et al, (2010) in a recent review

When comparing this study to results from single-disorder studies that have explored communicative participation, many similarities can be found in terms of restricted participation as well as the barriers to and facilitators of participation. Aphasia appears to have been studied more than any of the other disorder populations included in this study. For example, Dalemans, de Witte et al. (2009) conducted qualitative studies of the perceptions of individuals with aphasia and their family members regarding their participation. The results suggested that individuals with aphasia were more concerned about reaching a certain level of feeling involved or engaged in various activities as opposed to focusing on how many activities they performed. Similar to the current study, the participants described a range of variables that influenced their participation including personal factors (e.g. motivation and psychological situation), social factors (e.g. the familiarity and other characteristics of the communication partner) and environmental factors (e.g. noise).

Howe et al. conducted a pair of studies to investigate the environmental barriers to and facilitators of participation for individuals with aphasia. One study sought the perspective of individuals with aphasia through qualitative interviews (Howe, Worrall, & Hickson, 2008a) while the other consisted of observation of individuals with aphasia in their daily environments (Howe, Worrall, & Hickson, 2008b). The results of these two studies were complementary, although not entirely identical, in identifying a range of environmental factors that were considered barriers to or facilitators of participation. Similar to the current study, there were many types of environmental factors including the role of other people in participation, characteristics of the community (i.e. tasks that are common as part of community involvement such as filling out a form or buying a ticket at a machine for public transportation) and physical barriers (i.e., being able to get to needed objects such a pamphlet in a store without having to ask for it). Other studies have gone into further depth exploring aphasia and communicative participation in specific communication situations. These have included exploring the impact on friendships characterized by interactions with fewer friends and smaller social networks (Davidson, Howe, Worrall, Hickson, & Togher, 2008); exploring barriers to use of technology such as cell phones (Greig, Harper, Hirst, Howe, & Davidson, 2008); finding ways to increase the accessibility of art venues such as museums and theaters (Duchan, Jennings, Barrett, & Butler, 2006); and exploring the use of public transit (Ashton et al., 2008).

Dalemans, de Witte et al., (2008) conducted a literature review of 18 studies examining the impact of aphasia on participation. The authors concluded that the literature documented altered participation in various life domains including employment, domestic life and interpersonal relationships. The authors cautioned, however, that it was difficult to form a cohesive picture of participation changes due to aphasia because of considerable variability among the studies in terms of construct definitions and research techniques. This suggests that there is still much to be learned about the participation restrictions associated with aphasia and other communication disorders as we clarify research agendas and approaches.

Several self-report studies have explored the impact of stuttering on participation. Across a wide range of ages in adults, these studies have documented similar findings regarding the impact of stuttering on participation as well as the range of personal, social and environmental variables that influence participation. These studies document the negative self-perceived impact of stuttering on various participation domains including education, employment and social relationships (Klompas & Ross, 2004). They describe a range of variables in common with this study that influence participation including personal emotional reactions, communication partners, cultural or social attitudes and beliefs, the familiarity of situations, and the purpose and content of conversations. The strategies that participants with stuttering report to facilitate participation are also similar to those described in this study including informing communication partners, modifying speech when possible, planning speech and avoiding difficult words, and choosing alternate forms of communication (e.g., email instead of phone) (Bricker-Katz, Lincoln, & McCabe, 2010); (Crichton-Smith, 2002). The challenges associated with telephone use with individuals who stutter has been highlighted, with the negative regard for phone use similar to that found in this study (James, Brumfitt, & Cudd, 1999).

While not yet studied as extensively, there is also documentation of participation restrictions related to other communication disorders examined in this study including communication changes associated with MS (Blaney & Lowe-Strong, 2009; Yorkston et al., 2007; Yorkston, Klasner, & Swanson, 2001), SD (Baylor, Yorkston, & Eadie, 2005; Smith et al., 1993; Smith et al., 1998), PD (Miller, Noble, Jones, & Burn, 2006), laryngectomy (Carr, Schmidbauer, Majaess, & Smith, 2000; Sullivan, Beukelman, & Mathy-Laikko, 1993), and dysarthria due to CVA or other non-progressive etiologies (Dickson, Barbour, Brady, Clark, & Paton, 2008; Whitehill, Ma, & Tse, 2010). Communicative participation in ALS appears to have received little attention except as it pertains to employment and related issues for individuals who use AAC (McNaughton, Light, & Groszyk, 2001). As a group, the single-disorder studies cited above show very similar patterns to the current study in terms of the types of participation restrictions that individuals report as well as the barriers and facilitators. These studies support the current study in that very similar constellations of personal, social and environmental variables interact with communication disorders to impact participation.

While looking across single-disorder studies such as those just described provides evidence that people with different types of communication disorders are sharing similar participation experiences, clearer understanding of these patterns requires direct comparisons of disorders within studies. Researchers and clinicians looking across different studies may come to possibly erroneous conclusions about participation restrictions across disorders due to differences in research methods in different studies. Another research issue that affects our understanding of the challenges that people with communication disorders face in everyday communication pertains to the various constructs, terms and assessment methods that are chosen to explore the impact on daily life experiences. The literature review for this paper focused primarily on studies that conceptualized participation in keeping with the ICF (World Health Organization, 2001) definition of participation in life situations. However, the literature contains evidence of the life impact of communication disorders framed by constructs other than, or in addition to participation. For example, multidimensional evidence of the life impact of SD has been documented through the use of questionnaires such as the *Voice Handicap Index* (VHI) (Benninger, Gardner, & Grywalski, 2001; Courey et al., 2000; Wingate et al., 2005) and the *Voice-Related Quality of Life* (V-RQOL) (Hogikyan, Wodchis, Spak, & Kileny, 2001; Paniello, Barlow, & Serna, 2008; Rubin, Wodchis, Spak, Kileny, & Hogikyan, 2004). Measures of “communication effectiveness” have been used to assess a variety of everyday situations for individuals with ALS (Ball, Beukelman, & Pattee, 2004) and PD (Donovan, Kendall, Young, & Rosenbek, 2008). Examples of other questionnaires that touch on communicative participation, among other topics include the *Dysarthria Impact Profile* (Walshe, Peach, & Miller, 2009) and *Living with Neurologically Based Speech Difficulties* (LwD) (Hartelius, Elmberg, Holm, Lovberg, & Nikolaidis, 2008) for dysarthria; The *Communication Activity and Participation After Laryngectomy* questionnaire (I. Law, Ma, & Yiu, 2009) for laryngectomy, and the *Overall*

Assessment of the Speaker's Experience of Stuttering (OASES) for stuttering (Yaruss & Quesal, 2006). Instruments such as ASHA's *Quality of Communication Life* are geared towards individuals with aphasia (Paul et al., 2004). These and other questionnaires usually contain a mixture of constructs ranging from physical symptoms to emotional impact to activity performance and as such cannot be considered unidimensional measures of participation, although many do contain some participated-related questions (Eadie et al., 2006). In general, these studies reflect an overall negative impact of communication disorders on various constructs that are likely related to, if not identical to participation.

The evidence in this and other studies suggesting similar experiences in communicative participation across communication disorders may encourage us to re-examine how we approach the construct of communicative participation for both theoretical and practical purposes. Traditionally, the discipline of speech-language pathology has been segmented according to type of disorder. Using the terminology of the ICF, the discipline has organized around different types of impairment. This is evident when looking at conference programs, scholarly journals, interest groups, and intervention programs and materials. Aphasia is clearly separated from stuttering which is clearly separated from voice disorders and so forth in many of these venues. These traditional boundaries shape much of how we work in that we frame our questions, choose our methods, interpret our data, assess our clients and recommend intervention strategies within the lens of specific categories of communication impairments. This poses the risk of leading us into thinking that participation restrictions may be dependent upon the type communication disorder, and hence intervention strategies targeting participation might need to be disorder-specific as well. This may obscure important aspects of participation that we could learn about if we looked across communication disorders. An across-disorder approach to studying communicative participation challenges us to further embrace a biopsychosocial framework of communication disorders in recognizing the complex web of physical, personal and environmental variables that shape participation. This view contrasts with an impairment-driven perspective that would suggest that participation is largely determined by the impairment underlying the communication disorder. This study particularly highlights the notable influence on participation of various issues identified in the ICF as contextual factors. The thematic structure that emerged from this data emphasized the roles of both external variables such as the physical and social surroundings (i.e., the ICF 'environmental' factors) and internal variables such as coping and personal emotions (i.e., the ICF 'personal' factors) in shaping how participants experienced interference in communicative participation.

When considering clinical interventions, there may be value in exploring what can be done to facilitate participation for individuals regardless of the type of communication disorder. This may be particularly relevant when considering the environmental and personal factors that have traditionally received less attention than other components of the ICF (Threats, 2007). Addressing environmental factors such as the knowledge and attitudes of communication partners or characteristics of the physical environment such as noise may enhance opportunities for participation for people with a variety of communication disorders. For example, Bloch and Beeke (2008) illustrate how communication partners can facilitate engagement in conversations using similar strategies of co-constructed messages for individuals with aphasia and dysarthria. Clearly, such goals would require a different approach than direct interventions applied with each individual with a communication disorder. Some participation-focused interventions may require more focus on training communication partners. Some environmental barriers / facilitators may require strategies more closely related to public education and advocacy. These participation-related approaches should always augment and never replace efficacious impairment and activity-based interventions, but do warrant consideration to maximize communicative participation.

Some of these clinical implications will take time to implement as more formal participation-focused intervention programs are developed. However, all clinicians can immediately draw on observations from this and related studies to open conversations with their clients about the participation restrictions they may be experiencing, each client's own constellation of contributing variables, and possible avenues for addressing barriers to participation. Clinicians can also be influential in bringing this message to administrators, policy makers, funding sources and even the general public to increase awareness of the participation challenges faced by many with communication disorders.

Several groups of clinicians and researchers have begun advocating for participation-focused assessment and intervention goals and for optimizing the communication environment. Perhaps the strongest efforts have been made in the aphasia area by documenting the participation-focused priorities of individuals with aphasia (Glista & Pollens, 2007; Kagan & Simmons-Mackie, 2007; Worrall, 2006) and advocating for therapy approaches focused on participation and environmental modification such as educating and training communication partners (Chapey et al., 2000; Duchan et al., 2006; Hinckley & Packard, 2001; Kagan et al., 2001). These efforts may be a starting point for exploring how we can implement programs to improve communicative participation for a broader range of individuals with communication disorders.

Limitations of the study

Perhaps the key limitation of the study is that the type of qualitative inquiry used, cognitive interviews, does not allow for the open-ended exploration of participant experiences as well as other qualitative approaches such as phenomenology. The primary purpose of this study was to be a cognitive interview study to address development of the CPIB, and the methods were established according to those aims. The rationale for this secondary analysis emerged after the study was underway based on the observations that were emerging from the interviews, but the cognitive interviewing methods were retained to serve the primary purpose of the project. Participants were asked at the end of each interview if there was additional information they wanted to add such as different situations that they felt were important to include in the questionnaire to reflect their experiences. This did offer a limited opportunity for them to guide a portion of the interview.

A closely related concern is that the format of all of the questions was to ask about 'interference' in participation. This wording of the items comes from participant feedback during the cognitive interviews regarding how participants preferred the items in the CPIB to be framed (Yorkston et al., 2008). Referring to 'interference' may have predisposed participants to think more about barriers to participation than facilitators of participation, however, participants raised many examples of contrasting barriers and facilitators in the interviews (e.g., familiar people facilitate participation whereas unfamiliar people hinder participation). Yet there remains a possibility that to some degree the commonalities observed in the data might be related to the structure of the interview. In order to address this, exploring the same topic through different qualitative approaches such as phenomenology is recommended.

Another limitation that should be noted is the unequal representation of different communication disorder types among the participants. Replication of the study with more representatives across a wider range of disorders including speech, language, cognition, and even hearing impairments is warranted. Interview formats similar to those used in this study may not be fully accessible to individuals with very severe cognitive and language disorders, but modification of interview techniques along with communication support provided by SLPs may allow the perspectives of individuals across a wide range of disorder types and severity to be represented.

Future Directions

This study has identified common self-reported restrictions in communicative participation across adults with varying communication disorders. However, further study is needed to make more extensive statements regarding the nature and extent of these patterns. Future studies should include more even representation of different types and severities of disorders, particularly including both adult-onset and congenital disorders. Future research may also include individuals with medical conditions that do not include communication disorders to better understand the role of other health issues in shaping communicative participation. Different research methods may also provide additional perspectives from which to study this topic. This might include different qualitative and quantitative methods. Additional research should explore the relationships between self-reported experiences such as those identified in this paper with direct observations of the same experiences (e.g., performance of communication tasks and environmental characteristics). While considerable attention is warranted towards how individuals with communication disorders perceive their own participation, comparisons of these subjective accounts with other types of observations would assist clinicians and researchers in understanding how participation experiences are shaped and how to best assist individuals with communication disorders to improve these experiences.

Appendix

This appendix lists the codes used by the investigators to code the field notes and to group meaning units together into the thematic structure.

Code	Code Definition	Theme	Sub-Theme
Interference	How participants define “interference” in participation	Used across themes to inform overall thematic structure	
Behavioral Strategies	Overt behaviors that participants use to try to facilitate participation	1	1
Withdraw	Descriptions of leaving or avoiding situations – not participating at all	1	2
Change	Descriptions of how participation has changed over time (e.g. changes in job, changes in joining social situations)	1	2
Roles	Discussion of how different communication roles are affected i.e. different impact if you are a group leader vs. a group member; if you are a teacher vs. in a social conversation	1	2
Emotion	Emotional reactions to participation changes i.e. feeling sad or left out.	1	3

Code	Code Definition	Theme	Sub-Theme	Category in Sub-Theme
Communication Symptoms	Communication disorder symptoms that influence participation	2	1	a
Other symptoms	Health symptoms other than communication disorder symptoms that affect interactions with other people (e.g. pain, difficulty walking)	2	1	b
Fatigue	Either fatigue as a symptom that might affect participation or the fatigue as a result of attempts to participate.	2	1	b

Familiar	Familiarity of communication partners affects participation	2	1	c
Partner	Characteristics of communication partners that influence participation other than familiarity. (e.g. age or nature of relationship i.e. personal vs. professional)	2	1	c
Attention	The role of attention in communication – primarily problems with other people paying attention to the participant	2	1	c
Noise	Noise influences participation	2	1	d
Groups	Experiences communicating in groups	2	1	d
Turn	Experiences related to joining a conversation or getting a turn in a conversation – "keeping the floor"	2	1	d
Speed	The pace of communication situations i.e. "fast-moving conversations"	2	1	d
Phone	Using (or avoiding using) the phone	2	1	d
Content	The content of conversations affects participation (e.g. topic, level of detail, length, asking vs answering questions)	2	1	d
Environment	Environmental features that participants reported affected participation not covered in the other categories (e.g. not being face to face with people)	2	1	d
Situation	Unique experiences not defined by any other code but represented a confluence of factors to create examples of interference (e.g. ordering a meal through a drive-through window or reading to grandchildren)	2	1	d
Important	How priorities affect decisions to participate	2	2	
Coping	The affective or emotional ways that participants coped with participation restrictions (e.g. "learning to live with it" or "choose to not let it bother me")	2	2	
Stress	Stress or anxiety in anticipation of a situation that affected decisions about participation.	2	2	

Acknowledgments

The authors would like to thank the participants for their generosity in terms of sharing their time and their insights with us. The authors would also like to acknowledge the other investigators who assisted in the interviews: Dagmar Amtmann, Jean Deitz, Brian Dudgeon and Robert Miller, all at the University of Washington. This work was supported in part by the following funding sources: 1R03DC010044-01 (Baylor) NIDCD; 1R03CA132525-01A1 (Eadie) NCI; H133P080008 (Kartin) NIDRR; T32-HD-00742416A1 (Yorkston) NCMRR; 1R21 HD 45882-01 (Yorkston) NCMRR. Thank you to the University of Washington Multiple Sclerosis Rehabilitation and Research Training Center and the University of Washington Speech and Hearing Clinic for assistance in recruitment.

References

Ashton C, Aziz NA, Barwood C, French R, Savina E, Worrall L. Communicatively accessible public transport for people with aphasia: A pilot study. Aphasiology. 2008; 22(3):305–320.

Ball LJ, Beukelman DR, Pattee GL. Communication effectiveness of individuals with amyotrophic lateral sclerosis. Journal of Communication Disorders. 2004; 37:197–215. [PubMed: 15063143]

Baylor CR, Yorkston KM, Eadie TL. The consequences of spasmodic dysphonia on communication-related quality of life: A qualitative study of the insider's experiences. Journal of Communication Disorders. 2005; 38:395–419. [PubMed: 15963338]

Baylor CR, Yorkston KM, Eadie TL, Miller RM, Amtmann D. Developing the Communicative Participation Item Bank: Rasch analysis results from a spasmodic dysphonia sample. Journal of Speech Language and Hearing Research. 2009; 52:1302–1320.

Benninger MS, Gardner G, Grywalski C. Outcomes of botulinum toxin treatment for patients with spasmodic dysphonia. Archives of Otolaryngology - Head and Neck Surgery. 2001; 127:1083–1085. [PubMed: 11556856]

Blaney B, Lowe-Strong A. The impact of fatigue on communication in multiple sclerosis: The insider's perspective. Disability and Rehabilitation. 2009; 31(3):170–180. [PubMed: 18608397]

Bloch S, Beeke S. Co-constructed talk in the conversations of people with dysarthria and aphasia. Clinical Linguistics and Phonetics. 2008; 22(12):974–990. [PubMed: 19031194]

Bricker-Katz G, Lincoln M, McCabe P. Older people who stutter: barriers to communication and perception of treatment needs. International Journal of Language and Communication Disorders. 2010; 45(1):15–30. [PubMed: 19294551]

Carr MM, Schmidbauer JA, Majaess L, Smith RL. Communication after laryngectomy: an assessment of quality of life. Otolaryngology - Head and Neck Surgery. 2000; 122(1):39–43. [PubMed: 10629480]

Chapey R, Duchan JF, Elman RJ, Garcia LJ, Kagan A, Lyon J, et al. Life participation approach to aphasia: A statement of values for the future. The ASHA Leader. 2000

Courey MS, Garrett CG, Billante CR, Stone RE, Portell MD, Smith TL, et al. Outcomes assessment following treatment of spasmodic dysphonia with botulinum toxin. Annals of Otology Rhinology and Laryngology. 2000; 109:819–822.

Crichton-Smith I. Communicating in the real world: accounts from people who stammer. Journal of Fluency Disorders. 2002; 27:333–352. [PubMed: 12506450]

Dalemans R, de Witte L, Wade DT, van dan Heuvel WJA. Social participation through the eyes of people with aphasia. International Journal of Language and Communication Disorders, Early Online. 2009:1–14.

Dalemans R, De Witte LP, Wade DT, Van den Heuvel WJA. A description of social participation in working-age persons with aphasia: A review of the literature. Aphasiology. 2008; 22(10):1071–1091.

Davidson B, Howe T, Worrall L, Hickson L, Togher L. Social participation for older people with aphasia: The impact of communication disability on friendships. Topics in Stroke Rehabilitation. 2008; 15(4):325–340. [PubMed: 18782736]

Dickson S, Barbour R, Brady M, Clark A, Paton G. Patients' experiences of disruptions associated with post-stroke dysarthria. International Journal of Language and Communication Disorders. 2008; 43(2):135–153. [PubMed: 18283594]

Donovan NJ, Kendall D, Young ME, Rosenbek JC. The Communicative Effectiveness Survey: preliminary evidence of construct validity. American Journal of Speech-Language Pathology. 2008; 17(4):335–347. [PubMed: 18957572]

Duchan J, Jennings M, Barrett R, Butler B. Communication access to the arts. Topics in Language Disorders. 2006; 26(3):210–220.

Dykstra A, Hakel M, Adam S. Application of the ICF in reduced speech intelligibility in dysarthria. Seminars in Speech and Language. 2007; 28(4):301–311. [PubMed: 17935015]

Eadie TL. The ICF: A proposed framework for comprehensive rehabilitation of individuals who use alaryngeal speech. American Journal of Speech-Language Pathology. 2003; 12(2):189–197. [PubMed: 12828532]

Eadie TL, Yorkston KM, Klasner ER, Dudgeon BJ, Deitz J, Baylor CR, et al. Measuring communicative participation: a review of self-report instruments in speech-language pathology. American Journal of Speech-Language Pathology. 2006; 15:307–320. [PubMed: 17102143]

Garcia LJ, Laroche C, Barrette J. Work integration issues go beyond the nature of the communication disorder. Journal of Communication Disorders. 2002; 35:187–211. [PubMed: 12036151]

Glista SO, Pollens RD. Educating clinicians for meaningful, relevant and purposeful aphasia group therapy. Topics in Language Disorders. 2007; 27(4):351–371.

Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Education Today. 2004; 24:105–112. [PubMed: 14769454]

Greig C-A, Harper R, Hirst T, Howe T, Davidson B. Barriers and facilitators to mobile phone use for people with aphasia. Topics in Stroke Rehabilitation. 2008; 15(4):307–324. [PubMed: 18782735]

Hartelius L, Elmberg M, Holm R, Lovberg A-S, Nikolaidis S. Living with Dysarthria: Evaluation of a self-report questionnaire. Folia Phoniatrica et Logopedica. 2008; 60:11–19.

Hinckley J, Packard M. Family education seminars and social functioning of adults with chronic aphasia. Journal of Communication Disorders. 2001; 34:241–254. [PubMed: 11409606]

Hogikyan ND, Wodchis WP, Spak C, Kileny PR. Longitudinal effects of botulinum toxin injections on voice-related quality of life (V-RQOL) for patients with adductory spasmodic dysphonia. Journal of Voice. 2001; 15(4):576–586. [PubMed: 11792036]

Howe TJ, Worrall LE, Hickson LMH. Interviews with people with aphasia: Environmental factors that influence their community participation. Aphasiology. 2008a; 22(10):1–29.

Howe TJ, Worrall LE, Hickson LMH. Observing people with aphasia: Environmental factors that influence their community participation. Aphasiology. 2008b; 22(6):618–643.

James SE, Brumfitt S, Cudd PA. Communicating by telephone: views of a group of people with stuttering impairment. Journal of Fluency Disorders. 1999; 24(299-317)

Kagan A, Black SE, Duchan JF, Simmons-Mackie N, Square P. Training volunteers as conversation partners using “Supported Conversation for Adults with Aphasia“ (SCA): A controlled trial. Journal of Speech, Language, and Hearing Research. 2001; 44:624–638.

Kagan A, Simmons-Mackie N. Beginning with the end: Outcome-driven assessment and intervention with life participation in mind. Topics in Language Disorders. 2007; 27(4):309–317.

Klompas M, Ross E. Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: personal accounts of South African individuals. Journal of Fluency Disorders. 2004; 29:275–305. [PubMed: 15639082]

Law I, Ma EP-M, Yiu EM-L. Speech intelligibility, acceptability and communication-related quality of life in Chinese alaryngeal speakers. Archives of Otolaryngology - Head and Neck Surgery. 2009; 135(7):704–711. [PubMed: 19620593]

Law J, Bunning K, Byng S, Farrelly S, Heyman B. Making sense in primary care: leveling the playing field for people with communication difficulties. Disability and Society. 2005; 20(2):169–184.

Lincoln, Y.; Guba, E. Naturalistic Inquiry. Beverly Hills: Sage Publications; 1985. Establishing trustworthiness; p. 289-331.

Ma EP-M, Yiu EM-L, Abbott K. Application of the ICF in voice disorders. Seminars in Speech and Language. 2007; 28:343–350. [PubMed: 17935019]

McNaughton D, Light J, Groszyk L. “Don’t give up”: Employment experiences of individuals with Amyotrophic Lateral Sclerosis who use augmentative and alternative communication. Augmentative and Alternative Communication. 2001; 17(3):179–195.

Miller N, Noble E, Jones D, Burn D. Life with communication changes in Parkinson’s disease. Age and Ageing. 2006; 35:235–239. [PubMed: 16540492]

Muhr T. Atlas.ti: qualitative data analysis (Version 6.1.6): Atlas.ti. Scientific Software Development. 2009

Murphy J. Perceptions of communication between people with communication disability and general practice staff. Health Expectations. 2006; 9:49–59. [PubMed: 16436161]

Nordehn G, Meredith A, Bye L. A preliminary investigation of barriers to achieving patient-centered communication with patients who have stroke-related communication disorders. Topics in Stroke Rehabilitation. 2006; 13(1):68–77. [PubMed: 16581632]

O'Halloran R, Hickson L, Worrall L. Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: a review of the literature within the International Classification of Functioning, Disability and Health (ICF) framework. International Journal of Language and Communication Disorders. 2008; 43(6):601–632. [PubMed: 18608606]

O'Halloran R, Worrall L, Hickson L. Environmental factors that influence communication between patients and their healthcare providers in acute hospital stroke units: an observational study. International Journal of Language and Communication Disorders, Early online. 2010:1–18.

Paniello RC, Barlow J, Serna JS. Longitudinal follow-up of adductor spasmodic dysphonia patients after botulinum toxin injection: Quality of life results. Laryngoscope. 2008; 118:564–568. [PubMed: 18216744]

Paul, DR.; Frattali, C.; Holland, AL.; Thompson, CK.; Caperton, CJ.; Slater, SC. The American Speech-Language-Hearing Association Qualtiy of Communication Life Scale (QCL) Manual. Rockville, MD: American Speech-Language-Hearing Association; 2004.

Ramig L, Sapir S, Fox C, Countryman S. Changes in vocal loudness following intensive voice treatment (LSVT) in individuals with Parkinson's disease: a comparison with untreated patients and normal age-matched controls. Movement Disorders. 2001; 16(1):79–83. [PubMed: 11215597]

Rubin AD, Wodchis WP, Spak C, Kileny PR, Hogikyan ND. Longitudinal effects of botox injections on voice-related quality of life (V-RQOL) for patients with adductory spasmodic dysphonia. Archives of Otolaryngology - Head and Neck Surgery. 2004; 130:415–420. [PubMed: 15096423]

Simmons-Mackie N, Kagan A. Application of the ICF in aphasia. Seminars in Speech and Language. 2007; 28:244–253. [PubMed: 17935009]

Smith E, Nichols S, Lemke J, Verdolini K, Gray SD, Barkmeier J, et al. Effects of voice disorders on patient lifestyle: Preliminary results. NCVS Status and Progress Report. 1993; 4:237–248.

Smith E, Taylor M, Mendoza M, Barkmeier J, Lemke J, Hoffman H. Spasmodic dysphonia and vocal fold paralysis: Outcomes of voice problems on work-related functioning. Journal of Voice. 1998; 12(2):223–232. [PubMed: 9649078]

Sullivan MD, Beukelman D, Mathy-Laikko P. Situational communicative effectiveness of rehabilitated individuals with total laryngectomies. Journal of Medical Speech-Language Pathology. 1993; 1(1):73–80.

Threats T. Access for persons with neurogenic communication disorders: Influences of personal and environmental factors of the ICF. Aphasiology. 2007; 21(1):67–80.

Walshe M, Peach RK, Miller N. Dysarthria Impact Profile: development of a scale to measure psychosocial effects. International Journal of Language and Communication Disorders. 2009; 44(5):693–715. [PubMed: 18821230]

Whitehill T, Ma EP-M, Tse F. Environmental barriers to communication for individuals with dysarthria. Journal of Medical Speech-Language Pathology. 2010; 18(4):141–144.

Willis, GB. Cognitive Interviewing: A tool for improving questionnaire design. Thousand Oaks, CA: Sage Publications, Inc; 2005.

Wingate JM, Ruddy BH, Lundy DS, Lehman J, Casiano R, Collins SP, et al. Voice handicap index results for older patients with adductor spasmodic dysphonia. Journal of Voice. 2005; 19(1):124–131. [PubMed: 15766857]

World Health Organization. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.

Worrall L. Professionalism and functional outcomes. Journal of Communication Disorders. 2006; 39:320–327. [PubMed: 16564054]

Yaruss JS. Application of the ICF in fluency disorders. Seminars in Speech and Language. 2007; 28(4):312–322. [PubMed: 17935016]

Yaruss JS, Quesal RW. Overall Assessment of the Speaker's Experience of Stuttering (OASES): Documenting multiple outcomes in stuttering treatment. Journal of Fluency Disorders. 2006; 31:90–115. [PubMed: 16620945]

Yorkston, KM.; Baylor, CR. Measurement of Communicative Participation. In: Lowit, A.; Kent, R., editors. Assessment of Motor Speech Disorders. San Diego, CA: Plural Publishing; 2011.

Yorkston KM, Baylor CR, Deitz J, Dudgeon BJ, Eadie TL, Miller RM, et al. Developing a scale of communicative participation: a cognitive interviewing study. Disability and Rehabilitation. 2008; 30(6):425–433. [PubMed: 17943516]

Yorkston KM, Baylor CR, Klasner ER, Deitz J, Dudgeon BJ, Eadie TL, et al. Satisfaction with communicative participation as defined by adults with multiple sclerosis: a qualitative study. Journal of Communication Disorders. 2007; 40:433–451. [PubMed: 17125785]

Yorkston KM, Klasner ER, Swanson KM. Communication in context: A qualitative study of the experiences of individuals with multiple sclerosis. American Journal of Speech-Language Pathology. 2001; 10:126–137.

Table 1

Example items from Communicative Participation Item Bank (CPIB) (over 100 candidate items were included in this study).

Sample item format:

Does your condition[a] **interfere**[b] **with**…telling family or friends about your day?

- ___ Not at all
- ___ A little
- ___ Quite a bit
- ___ Very much

Other example items:

- …communicating in a small group of people
- …keeping in touch with family and friends by phone
- …confiding in someone you know well
- …ordering a meal in a restaurant
- …getting your turn in a fast-moving conversation
- …having a friendly debate with someone you know
- …asking a stranger for directions
- …making a phone call for household business
- …talking to a store clerk who is in a hurry

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[a] The wording of the item stem itself derives from the cognitive interviews. The term “condition” was chosen purposefully and after extensive discussions with participants to reflect that their interactions with other people and their communicative participation was influenced by more than the communication disorder. Other aspects of their health conditions such as mobility, vision loss and other symptoms also influenced communication with others. Participants reported that they could not necessarily separate out the specific influence of communication disorder symptoms versus the condition as a whole, and therefore the term “condition” was most acceptable to participants.

[b] Participants were given options to choose or to introduce various terms to use when referring to problems with participation such as “satisfaction,” “restrictions” or “interference.” The term ‘interference’ was the term most preferred. Participants were not provided with a definition of interference but allowed to interpret what interference meant to them (and these definitions were explored as part of this study). This allowed participants to convey the many facets to restricted participation such as the range of functional and emotional consequences reported in this study.

Table 2

Demographic information for each diagnostic group

		SD	CVA	MS	PD	Laryngectomy	ALS	Stuttering
N		13	12	7	7	3	1	1
Age	Mean (sd)	52.8 (9.1)	60.4 (8.3)	50.8 (12.1)	64.0 (6.8)	71.7 (14.6)	71	42
	Range	39 - 71	46 – 74 (1 no report)	37 – 67 (1 no report)	50-69	60-88		
Gender	Male	6	6	3	3	2	--	1
	Female	7	6	4	4	1	1	--
Communication Disorder		ADSD – 11	Aphasia – 4	Negligible impairment – 2	Mild dysarthria – 4	All using electrolarynx with good intelligibility	Mild dysarthria	Mild dysfluency
		ABSD – 1	Aphasia w/ AOS – 3	Mild –mod cognitive – 2	Mod dysarthria – 1			
		ADSD w/tremor – 1	Cognitive w/ dysarthria – 3	Mild cognitive w/ mild dysarthria – 2	Mild dysarthria w/mild cognitive - 2			
		All receiving botox	Dysarthria - 2	Mod cognitive w/ mild dysarthria - 1				
Time Since Diagnosis (years)	Mean (sd)	10.1 (5.9)	8.2 (7.4)	15.4 (5.8)	5.5 (4.1)	5.3 (5.1)	1 year	Childhood onset
	Range	1-21	0.5 - 24	6-20	1.5 - 14	1 - 11		
Work Status	Full time	9	1	1	--	--	--	1
	Part time	3	--	--	1	1	1	--
	Retired	--	3	2	4	--	--	--
	Not working due to condition or other	1	8	4	2	2	--	--

Notes: SD – Spasmodic dysphonia; CVA – Cerebrovascular accident (stroke); MS – Multiple Sclerosis; PD – Parkinsons Disease; ALS – Amyotrophic Lateral Sclerosis; ADSD – Adductor SD; ABSD – Abductor SD; AOS – apraxia of speech; WFL – within functional limits;

Table 3

This table shows the organizational structure of the themes and sub-themes as well as the categories within some sub-themes.

Theme 1: Interference is both “functional” and “emotional”

Sub-themes	**Categories within sub-themes**	
1.1 “I have to do things differently because of my speech.”	**1.1a**	I can make my voice louder if I need to - Try to change speech i.e. speaking in louder voice
	1.1b	“Dumbing down speech” - Simplifying what you say, avoiding difficult words, planning speech
	1.1c	“Sparks coming out of my eyes” – Using different modalities such as gestures, facial expression, writing, email
	1.1d	“Lean on” family and friends to communicate for me
	1.1e	“You need to be patient with me” – Educate people how to communicate with me
1.2 Sometimes the “only way you can change a situation is to avoid it.		
1.3 I feel “like a bystander”		

Theme 2: “It depends” – Sources of interference

Sub-themes	**Categories within sub-themes**	**Sub-categories**	
2.1 Things “get in your way”	2.1a “Words don’t come out right”	*	“It is hard to keep voice up” - difficulty being loud enough
		*	It is hard to show you are angry if all you can do is whisper – lack of expressiveness
		*	“Mush in my mouth” – imprecise articulation
		*	My “mind works like molasses” - difficulty keeping up with conversations
		*	“Loss of words” –problems with language or cognitive processes
	2.1b The “soup” of symptoms		
	2.1c “There is no barrier if You know them well”		
	2.1d What are my “surroundings”	*	Noisy situations
		*	Groups
		*	Speed
		*	Phone
		*	Topic or purpose of conversation
		*	Length of conversation
2.2 “Allowing” interference to happen			