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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.

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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.

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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.

Table 1
Example items from Communicative Participation Item Bank (CPIB) (over 100 candidate items were included in the 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
...coniding in someone you know well
...ordering a meal in a restaurant
...getting your turn in a fast-moving conversation

[Table 1](#)

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

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 ([Muh, 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.

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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.

		SD	CVA	MS	PD
N		13	12	7	7
Age	Mean (s.d)	52.8 (9.1)	60.4 (8.3)	50.8 (12.1)	64.0 (6.8)
	Range	39 - 71	46 - 74 (1 no report)	37 - 67 (1 no report)	50-69
Gender	Male	6	6	3	3
	Female	7	6	4	4
Communication		ADSD -	Aphasia - 4	Negligible	Mild

[Table 2](#)

Demographic information for each diagnostic group

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"	
Sub-themes	Categories within sub-themes
1.1 "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, slowing 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

[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” (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 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)