ASHA American Speech-Language-Hearing Association

JSLHR

Research Article

Everyday Barriers in Communicative Participation According to People With Communication Problems

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ARTICLE INFO

Article History:
Received July 13, 2022
Revision received September 28, 2022
Accepted November 23, 2022

Editor-in-Chief: Stephen M. Camarata
Editor: Mary Alt

https://doi.org/10.1044/2022_JSLHR-22-00405

ABSTRACT

Purpose: The purpose of this study was to gain a comprehensive understanding of participation situations that are challenging for people with communication problems, to provide input for the further development of potential items for the Communicative Participation Item Bank (CPIB).
Method: A purposive sampling strategy was used to include a diverse group of people with communication problems. Diaries were used as a sensitizing exercise for inductive in-depth interviews. In these interviews, elements of communicative participation situations (concepts) were elicited that participants themselves experienced as difficult because of their communication problem. A thematic content analysis was used to identify overarching themes. In addition, new items were formulated based on the raw codes of the transcripts and linked to the International Classification of Functioning, Disability and Health Activity and Participation domains to examine the distribution of items across the breadth of the construct of communicative participation.
Results: Eighteen interviews yielded 44 different concepts. They were clustered in six themes, which capture the person, location, topic, mode, moment, and pace of communication. In total, 103 new items measuring communicative participation were formulated. Most of these items relate to International Classification of Functioning, Disability and Health Activity and Participation domains "interpersonal interactions and relationships," "major life areas," and "community, social, and civic life."
Conclusions: This study resulted in an overview of self-reported barriers in daily communicative participation experienced by people with communication problems. These communicative participation situations can be captured within 44 concepts, which are covered by six themes. Future work should investigate if the newly written items can be added to the CPIB. The concepts and the themes can be used in designing and delivering a participation-focused intervention for this population.

Communication is a prerequisite for participation in society (Yorkston & Baylor, 2010). Due to their communication difficulties, people with speech, language, voice, and/or hearing problem experience barriers in participation on a daily basis. Regardless of etiology, these communication problems are all known to affect a person's ability to participate in life, with numerous studies reporting severe negative consequences (e.g., Cruice et al., 2010; Dalemans et al., 2008; Doedens & Meteyard, 2020; Eadie et al., 2006). These limitations vary from person to person and depend on the nature and severity of the communication problem, as well as personal and environmental factors (Baylor & Darling-White, 2020; Eadie et al., 2006; Hughes & Orange, 2007; Threats, 2007; Yorkston & Baylor, 2010).

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The need to directly capture a person's ability to participate is recognized in research and clinical practice (Eadie et al., 2006; Wallace et al., 2017). To support speech and language therapists (SLTs) in designing and delivering a participation-focused intervention, capturing the client's perspective on participation has been a topic of interest over the past few decades (Thompson, 2008; Torrence et al., 2016). Participation problems can only be truly reflected by the persons themselves. Therefore, Patient-Reported Outcome Measures (PROMs) are regarded as the most suitable and adequate format (Brown et al., 2004; Perenboom & Chorus, 2003).

Various PROMs have been developed with the purpose to examine possible problems at the participation level of the client with communication problems (e.g., Speech Handicap Index; van den Steen et al., 2011; Aphasia Impact Questionnaire; Swinburn et al., 2019). Although SLTs acknowledge the value of these PROMs, they do not yet use them consistently in clinical practice. They report several barriers on why this is the case, such as a lack of consensus on what to measure and time investment (Hilari et al., 2015). In addition, it is not feasible in clinical practice to systematically review, select, use, and interpret dozens of disease-specific PROMs (Eadie et al., 2006; Hilari et al., 2015; Simmons-Mackie et al., 2005). Even for research purposes, it proves difficult to decide and agree on which PROMs to use for which population to measure participation outcomes (something the international network in aphasia research has tried to do this for aphasia with the Research Outcome Measurement in Aphasia framework; Wallace et al., 2019).

An instrument that can measure across diseases (i.e., a generic PROM) may provide the solution. People with different communication problems have been described to experience similar participation limitations, regardless of etiology (Baylor et al., 2011). Furthermore, optimizing participation is one of the fundamental elements and guiding principles of the speech and language therapy process for all clients (American Speech-Language-Hearing Association, 2004; Torrence et al., 2016). Although condition-specific PROMs have been argued to have greater face validity, credibility, and responsiveness (Black, 2013), there is increasing evidence that modern generic PROMs are able to combine these advantages with those of generic PROMs (i.e., use for generalizing or comparing across different conditions; Churruca et al., 2021).

These modern PROMs are developed based on Item Response Theory (IRT) models and typically consist of large banks of questions or items (cf. Patient-Reported Outcomes Measurement Information System; Cella, Yount, et al., 2007). They can be administered as a full bank, short forms (which can be made disease or disorder specific), or a computer adaptive test (CAT), for which a computer selects items from the bank based on answers to previous questions. The wide applicability of item banks and their advantage of being adaptable over time means that they are seen as the future and preferred over the use and development of (new) static questionnaires (Cella, Gershon, et al., 2007; Yorkston & Baylor, 2010).

An example of such a generic item bank is the Communicative Participation Item Bank (CPIB) created by Baylor et al. (2013). This item bank can be applied across diseases (Yorkston & Baylor, 2010) and is designed to capture the specific communication difficulties associated with participation, the construct "communicative participation." Communicative participation is defined as "participation in life situations in which knowledge, information, ideas or feelings are exchanged" (Eadie et al., 2006, p. 309). These life situations include several domains as described by the International Classification of Functioning, Disability and Health (ICF) Activities and Participation component, such as personal care, household management, leisure, learning, employment, and community life (Eadie et al., 2006; World Health Organization [WHO], 2001). The CPIB consists of situations involving communication through speech (as opposed to other communication modalities) and can be used in community-dwelling people with mild to moderate communication problems (Baylor et al., 2013; Yorkston & Baylor, 2010).

The CPIB aims to measure communicative participation in adults across a wide range of communication disorders (Baylor et al., 2013). The items were developed largely based on interviews with people with voice disorders as a result of spasmodic dysphonia (Baylor et al., 2005, 2007), and people with voice and/or speech problems as a result of multiple sclerosis (Yorkston et al., 2001). The experiences of people with language or hearing problems were not included in the stage of item development (Baylor et al., 2021). People with language problems were included in a content validity study in which the comprehensibility and comprehensiveness of the CPIB were examined and thus contributed to the final version (Yorkston et al., 2008). The relevance of all items was examined in a population of people with hearing problems. The results showed that 12 of 46 items were not optimally relevant for this group of people. This result is unsurprising, as the items were developed with people with speech output difficulties (Miller et al., 2017). Although the developers, of the CPIB go on to include a variety of groups of participants in the various stages of the assessment of psychometric properties of the instrument (Baylor et al., 2021), in the very early stages of the PROM development, the CPIB was not developed within a sample representing the whole target population. Development and testing within a sample representing the whole target population is an important requirement for adequate PROM development and content validity (see Terwee et al., 2018, Box 1). This is particularly important as the most recent literature on PROM development suggests that content validity is the most important measurement property of a

PROM. Since people with problems in speech perception and language comprehension were not involved in the PROM development, it is questionable whether the items in the current CPIB (Baylor et al., 2013) cover all possible relevant concepts for the whole range of the target population (Terwee et al., 2018).

This study goes back to the beginning of PROM development, and adds to the work of Baylor et al., by conducting in-depth interviews with people covering the full range of speech, language, hearing, and voice problems on situations in which they feel restricted in their communicative participation. This type of study is called a "concept eliciting study" (Terwee et al., 2018) and provides a detailed exploration of what a particular construct entails from the perspective of the participant or patient. No concept elicitation study has been performed for the construct communicative participation, while concepts form an important basis of a PROM (Patrick et al., 2011). This study therefore aims to obtain a complete overview of situations that tap into the construct communicative participation, in order to provide information on the relevance and comprehensiveness of (possible) items in a PROM targeting to capture this construct (Terwee et al., 2018). We aimed to use the results of this concept elicitation study to create new items that could be added to the CPIB, to improve content validity and the general applicability of the CPIB.

Method

Participants and Sampling Strategy

Eligible participants were persons who were 18 years old or older and had a diagnosis of speech problems (dysarthria, stuttering, or apraxia of speech), language or cognitive problems with communication (aphasia or cognitive communication disorders), voice problems, and/or hearing problems. Participants were recruited through three different approaches: (a) via e-mail to the first author's network of SLTs affiliated with rehabilitation centers and hospitals; (b) via messages on websites of networks such as the Dutch Association for Speech and Language Therapy (Nederlandse Vereniging voor Logopedie en Foniatrie), AfasieNet, and ParkinsonNet (both Dutch network organizations for professionals working with people with aphasia or Parkinson's Disease); and (c) messages on social media (LinkedIn and Facebook pages for SLTs). SLTs could register eligible participants (with their consent) via e-mail, after which the first author could contact these people via e-mail or telephone. A purposive sampling strategy was used to include a diverse group of people with communication problems, in terms of gender, age, and diagnosis (including severity reported by the SLT and time since onset of speech, language, voice, or hearing problem). People with severe or terminal comorbidity, severe depression, or no command of the Dutch language (different from aphasia) were excluded from the study. The target sample size was at least 12 participants: three people from each subpopulation (speech, language, or cognitive problems with communication, voice, and hearing) and an equal distribution between people who have perceptive and productive communication problems, to ensure a sample representing the target population (Terwee et al., 2018). The final number of participants depends on when saturation is reached (Patrick et al., 2011).

Ethical Considerations

This study was approved by the Internal Ethical Review Board (Reference Number 108_000_2020) and was conducted according to the principles of the Declaration of Helsinki (World Medical Association, 2013) and in accordance with the Dutch Medical Research Involving Human Subjects Act (Wet medisch-wetenschappelijk onderzoek met mensen). All participants were provided with written information about the study. For people with language problems, the written information was adapted in accordance with the guidelines for accessible information (Stroke Association, 2012). All participants provided written informed consent before participating in the study. Handling and storing of collected data and documents comply with the Dutch General Data Protection Regulation (European Data Protection Board, 2018).

Data Collection

An inductive interviewing approach was used in which diaries were used as a sensitizing exercise for in-depth interviews.

Diaries

People who gave informed consent were invited to keep a diary, in which they noted situations they encountered in daily life that were difficult for them because of their communication problem. The goal of this sensitizing exercise was threefold: (a) to allow participants to reflect on the construct of interest for a longer period of time during which multiple "life situations" are likely to have occurred, (b) for the authors to be able to familiarize themselves with the perspective of the participant prior to the interview, and (c) to inform the topic list (for each individual participant).

People were asked to keep a diary for 2–3 weeks. Gaver et al. (1999) advises to give people a week to fill in the diary. For this study, we chose to give people 3 weeks as we expected that due to COVID-19 pandemic restrictions, people would encounter fewer social situations in 1 week than under normal circumstances. Several COVID-19 restrictions applied at the start of the diary study, including receiving a maximum of two guests per day, shopping by appointment only, and no organized events and outdoor sports with a maximum of four people.

Participants could choose between keeping a written diary or a diary of photos/videos. Three to 5 days after the start of this diary task, the first author contacted the participant to ensure they had understood the assignment and to answer questions if necessary. After 2–3 weeks, the participant was asked to send the diary to the interviewer by mail, e-mail, or by smartphone.

Individual Semistructured Interviews

After the participants had completed their diary, they were invited for an interview. There was a maximum of 1 week between the interviewer receiving the diary and the interview. Interviewers were authors N.W. (PhD-student, SLT) and L.D. (junior researcher, SLT). They received training and coaching in interviewing by a colleague and expert in the field of qualitative research. Both are trained SLTs with vast experience in supported conversations with a range of clients with communication difficulties. NW and LD conducted the first interview together. Subsequent interviews were conducted by one of them.

The interview took place at the participant's home or remotely via Microsoft Teams (Microsoft Windows 365, 2021) based on the participant's preference. The interviews were planned to take between 30 and 60 min and were audio-recorded. Significant others were allowed to be present during the interview, but were asked beforehand not to interfere with the interview, not even to support communication. When supported conversations techniques were required to communicate with the participant, this was provided by the interviewer. Field notes were made after the interview if the participant said something relevant for this study that was not recorded. At the start of each interview, the interviewer introduced herself and provided the participant with an explanation of why this interview would take place, as well as the goal of the study in general. In addition, relevant socio-demographic and clinical variables were collected: gender, age, educational level, living situation, diagnosis and other disorders, and severity of speech, voice, hearing, or language impairment if available (Akense Afasie Test Token Test, Graetz et al., 1992; Grade, Roughness, Breathiness, Asthenia, Strain Scale, Hirano, 1981; Dutch Dysarthria Test for Adults, Knuijt et al., 2014; Cognitive Communication Screening, Stichting AfasieNet, 2016; Diagnostic Instrument for Apraxia of Speech, Feiken & Jonkers, 2012; hearing loss of dB or Stuttering Severity Instrument, Riley, 1972). In addition, the participant rated their own level of perceived communication skills on a 5-point Likert scale (see Appendix A).

The interview guide was informed by the concept elicitation guideline of Patrick et al. (2011). It was focused on situations described in the diaries and other situations one might encounter in daily life, in relation to the construct of communicative participation. It also contained a warm-up question to build rapport with the participant prior to the interview. The interview guide was reviewed by authors L.E., C.T., J.V., and E.G. on flow, redundancy, and terminology before use. In addition, the interview guide was pilot tested with one person with language comprehension and language production problems (aphasia).

First, difficulties in communicative participation were elicited using a "day reconstruction exercise," in which participants were asked to describe a typical day. Then, participants had to describe which situations on that day would be difficult for them, because of their communication problems. Subsequently, participants were asked about the situations from their diary. The diary was available to the participant and the interviewer during the interview. For all participants, except for people with severe language problems, open-ended questions were used. For people with severe language problems, the interview guide was adapted to closed questions, in line with aphasia friendly communication guidelines (Stroke Association, 2012). Furthermore, supported conversation techniques, such as providing the questions and answer options in writing, were used to scaffold the conversation. Examples of open-ended questions about the typical day included "In which situations do you find it difficult to tell something to someone or understand what someone is saying to you?" and "Can you describe what you find difficult about this situation?" In addition, participants were asked about the situations in their diary, such as "Can you explain what you want to tell me with this photo?" After each situation the participant brought up, more specific probing questions were asked to obtain further details about the situation mentioned in terms of the impact of the situation on the participant (e.g., "How difficult is this situation for you?"). The order of topics and questions varied from interview to interview and was determined by the natural flow of the conversations. See Appendix B for the interview guide.

Analysis

The interviews were transcribed verbatim. A summary of each interview was sent to the participants for a member check (a method of returning an interview to a participant to verify or assess the trustworthiness of qualitative data; Doyle, 2007) to confirm the accuracy of the interview results and to allow participants to make changes in case of inaccuracies.

ATLAS.ti (Friese, 2019) was used for the coding process. First, each relevant text fragment received a label (as advised by Brod et al., 2009). A fragment was considered relevant if it described a life situation in which the participant experienced difficulty communicating. This coding process is known as open coding (Holloway & Wheeler, 2010). The first nine transcripts (50%) were dual

coded (by N.W. and L.D.) to evaluate the degree of interrater agreement in the coding process. The other transcripts were coded by one author (N.W. or L.D.).

The open codes were then analyzed in two complementary ways. On the one hand, an inductive approach was used to obtain a complete overview of situations that tap into the construct communicative participation. Therefore, open codes were interpreted and clustered into concepts through axial coding. Each concept refers to an element of a communicative participation situation in which the participants experienced difficulties. This step was performed by authors N.W. and L.D.. Analysis started with the first five interviews that were transcribed, coded, and clustered into concepts. Subsequently, five new interviews were conducted. This iterative process continued until saturation was reached, meaning no new concepts appeared (Holloway & Wheeler, 2010; Patrick et al., 2011). To identify the essence of each concept (Braun & Clarke, 2006), a matrix of the results was created using Microsoft Excel (Microsoft Corporation, 2021), in which each row represented a concept and each column a participant. The concepts were then organized into coherent themes that hinder communicative participation. This was an iterative process going back and forth between transcripts and concepts in the analysis process.

In addition to this inductive approach, a deductive approach was used to (a) ensure the results of this study could be matched to and add to the work of Baylor et al. (2013, 2021) and (b) to provide insight into the extent in which the items cover the breadth of the construct communicative participation. For these purposes, the open codes were used to formulate possible items, as advised by Brod et al. (2009), for the further development of the CPIB. In addition, the basic rules of formulating adequate items were used, such as that items should be written at a basic language level and items should contain only one question (Bradburn et al., 2004). Then, the items were classified in different subdomains to examine the distribution of items across the breadth of the construct of communicative participation. Eadie et al. (2006) describe seven communicative participation domains, based on the ICF Activity and Participation domains. We adhered to the original nine Activity and Participation domains of the ICF itself, because we think that communicative participation is relevant in all of these domains and PROM development guidelines advice to use well-described and used models when available (de Vet et al., 2011). The ICF Activity and Participation domains used in this study are (a) learning and applying knowledge, (b) general tasks and demands, (d) mobility, (e) self-care, (f) domestic life, (g) interpersonal interactions and relationships, (h) major life areas, and (i) community, social and civic life (WHO, 2001). The ICF Activity and Participation domain (c) Communication was not used for classification, as communicative participation cannot be captured by this domain on its own (Baylor et al., 2021; Eadie et al., 2006). Authors N.W. and L.D. independently classified the different items into the different domains. Differences in classification were discussed until consensus was reached. Data are reported according to the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007).

Results

A total of 18 people participated in the study (seven women and 11 men). Their mean age was 60 years (range: 27–85 years). Eight participants were diagnosed with language problems (aphasia), from which one also suffered from speech problems (apraxia of speech). Four people suffered from hearing loss. Four people were diagnosed with speech problems (one with dysarthria as a result of amyotrophic lateral sclerosis, two with dysarthria as a result of Parkinson's disease, and one person with stuttering). Two participants were diagnosed with voice problems (one as a result of Parkinson's disease and one as a result of tumor treatment). The characteristics of the participants are presented in Table 1.

Concepts That Tap Into the Construct of Communicative Participation

Analysis of the interviews resulted in 194 open codes. Within the open codes, a total of 44 concepts were identified. These concepts represent elements of communicative participation situations that participants believe influence participation in these situations. Examples of the process of coding text fragments to concepts can be found in Appendix C. Most of the concepts (70%) were identified in the first set of interviews (Participants 1–5). Twenty-three percent of the concepts were identified in the second set of interviews (Participants 5–10). The remaining 7% of the concepts were identified in the third set of interviews (Participants 11–15), and there were no new concepts found in the fourth set of interviews (Participants 16–18). See Table 2 for a list of concepts and the process to saturation.

Themes Describing the Elements that Influence Communicative Participation

Based on the 44 concepts, six themes affecting communicative participation were identified. The concepts per theme can be found in Appendix D. The themes are listed below.

Theme 1: The Person With Whom One Communicates Largely Determines the Participant's Ability to Participate

Participants mention that the person that they are communicating with largely determines how difficult it is

Table 1. Participant's demographic and clinical characteristics.

Participant	Diagnosis	Communication skills on a 5-point Likert scale[a]	Gender (M/F)	Age (years)	Level of education[b]	Time since diagnosis (years)	Living situation	Other problems related to communication	Severity of speech, voice, hearing or language impairment
1	Language and speech (aphasia, apraxia of speech)	2	M	67	1	6	Partner and kids		
2	Language (aphasia)	5	M	56	2	6	Partner		
3	Language (aphasia)	5	F	39	2	1	By oneself	Mild memory changes	
4	Hearing	5	M		3	5	Partner		25% hearing loss on both ears
5	Speech (dysarthria ALS)	3	F	64	1	0	Partner		
6	Language (aphasia)	4	M	45	1	2	Partner	Slowed processing of information, mild attention problems	AAT TT: 13 (moderate–severe aphasia)
7	Language (aphasia)	3	F	63	1	4	Partner	Slowed processing of information	
8	Hearing	3	F	55	2	15	Partner and kids		10- to 90-dB hearing loss
9	Hearing	3	F	27	2	7	By oneself		
10	Hearing	5	F	78	3	3	Partner		
11	Language (aphasia)	4	F	57	3	11	By oneself		
12	Language (aphasia)	4	M	78	1	1	Partner	Mild attention problems, Fatigue	
13	Speech (stuttering)	3	M	47	2	47	Partner and kids		SSI-4: 38 (very severe)
14	Speech (dysarthria PD)	3	M	65	1	15	Partner	Mild cognitive changes	
15	Voice (tumor)	5	M	85	1	0	Partner		GRBAS: 3–0–3-3-2
16	Language (aphasia)	2	M	58	1	0	Partner and kids		
17	Speech (dysarthria PD)	5	M	67	1	5	Partner		
18	Voice (PD)	4	M	72	3	5	Partner		

Note. M = male; F = female; ALS = amyotrophic lateral sclerosis; AAT TT = Akense Afasie Test Token Test; SSI-4 = Stuttering Severity Instrument–Fourth Edition; PD = Parkinson's disease; GRBAS = Grade, Roughness, Breathiness, Asthenia, Strain Scale.

[a]1 = severe, 2 = moderate to severe, 3 = moderate, 4 = moderate to mild, 5 = mild (see Appendix A). [b]1 = primary school/prevocational secondary education/secondary vocational education, 2 = senior general secondary education/pre-university education/higher professional education, 3 = university education.

Table 2. Saturation table concept elicitation interviews.

Concept codes	Interview Group 1 (Participants 1–5)	Interview Group 2 (Participants 6–10)	Interview Group 3 (Participants 11–15)	Interview Group 4 (Participants 16–18)
Concept first appeared in interview group 1 (n = participants)				
Make appointments (*n* = 4)	X	X		X
Communicate with people without problems (*n* = 1)	X			
E-mail (*n* = 3)	X	X		
Emotionally conversations (*n* = 4)	X		X	X
Party (*n* = 4)	X	X		X
Physical effort (*n* = 1)	X			
Communicate with people with hearing problems (*n* = 4)	X	X		X
One-to-one conversation (*n* = 14)	X	X	X	X
Group conversation (*n* = 10)	X	X	X	X
Way of speaking communication partner (*n* = 4)	X	X		
Strangers (*n* = 6)	X		X	X
Surroundings (*n* = 9)	X	X		X
Unexpected situation (*n* = 1)	X			
Insecurity (*n* = 1)	X			
Personal mail (*n* = 1)	X			
Personal data (*n* = 3)	X	X	X	
Presenting (*n* = 1)	X			
Impressions (*n* = 1)	X			
Sports (*n* = 1)	X			
Language use of communication partner (*n* = 1)	X			
Talk on the phone (*n* = 12)	X	X	X	X
Time pressure (*n* = 2)	X			X
Verbally asking for help (*n* = 1)	X			
Meetings (*n* = 5)	X	X	X	
Fatigue (*n* = 8)	X	X	X	X
Telling how you feel (*n* = 1)	X			
Video calling (*n* = 1)	X			
Work (*n* = 7)	X	X	X	
Text messaging (*n* = 3)	X	X		
Store (*n* = 6)	X	X	X	X
Health care professional (*n* = 3)	X	X	X	
Concept first appeared in interview Group 2				
Attention (*n* = 2)		X		
Administration (*n* = 1)		X		
Facial expression (*n* = 4)		X	X	
Humor (*n* = 2)		X		X
Emergency (*n* = 1)		X		
Politics (*n* = 1)		X		
Space (*n* = 4)		X	X	
Social media (*n* = 1)		X		
Foreign languages (*n* = 2)		X		
Change of topic (*n* = 1)		X		
Concept first appeared in interview Group 3				
To order (*n* = 1)			X	
Family (*n* = 3)			X	
Friends (*n* = 1)			X	
No. of new concept codes appearing in each Interview group	31	10	3	0
% of total new concept codes (total = 44)	70	23	7	0

to participate in social situations. This includes the relationship that the person has with the communication partner, such as being strangers or not:

> "... sometimes I don't find it difficult, but sometimes I don't know what to say, because I don't know those people very well and that is also quite sometimes, yes, difficult." (Participant 3)

In addition, this theme includes characteristics/features of the communication partner, such as the speaking rate:

> "For example, there is one boy, he is also, he is very new and he always talks very quickly. I haven't had a coffee appointment with him yet, but at the team meeting I wouldn't be so quick to say: dude, you have

to be, something, a little slower, because everything you say, I don't understand half of it." (Participant 3)

Finally, communication problems of the communication partner play a role. For example, several people who have problems expressing themselves (speech or voice) describe that they find it difficult to be understood by people with hearing problems:

> "Sometimes when we go to church, we go to X's [wife of participant] mother because she lives nearby, …, to have a chat, but that is often not possible or short on my side. If I want to raise something to my mother-in-law, she looks at X like 'what is he saying'. Then she turns to X." (Participant 17)

Theme 2: The Topic Being Discussed Plays a Role in Being Able to Participate in Social Situation

The content of conversations can also determine whether someone finds it difficult to participate in a certain social situation. This includes engaging in emotional conversations (see also Figure 1):

> "I'm getting emotional now and then I can't speak properly." (Participant 5).

This theme also concerns conversations that are more practical in nature, such as making appointments:

> "Making appointments is already part of that. I find it difficult to understand, especially on the phone." (Participant 8)

Figure 1. Diary photo of an emotional conversation Participant 1.

A person with aphasia described the effect of complexity of the topic of conversation such as discussions on a complex topic such as politics:

> "I was always very political. I don't know if it says but at the FNV (Dutch trade union), etc. I had it extensively, no and has been spoken, for example, and I must say, left and such, that sort of thing, I have an opinion about that and then sometimes I want to tell. […] and then I couldn't tell and [..], and then I want to. Telling it anyway and that is difficult sometimes." (Participant 7)

This theme also includes restrictions in the ability to add a personal communication touch to conversations, such as the use of banter and humor:

> "Remark in between that were humorous […] and now I won't do it anymore, I can't guarantee it anymore... exaggerated what I'm saying, but I'm unsure if it will come through, I'm not actually doing it anymore." (Participant 18)

Theme 3: Fast Pace of the Conversations Hinders People With Communication Problems in Communicative Participation

This theme emerged from situations described only by people with language and speech difficulties. This theme covers the complicating factors of time pressure and (rapid) change of topics:

> "I understand what he is saying, but it takes a long time, he already moves on to the next topic. Or does it go on a bit further and then I think ho ho ho." (Participant 6)

> "So yes, look an example, when I went to a photographer for advice on a new camera. Yes, then I consciously go during the super quiet time and also there, because then you can also give that man space for extensive advice. Look the weekend Saturday, yes, then yes, then you have, then you have none, they have no time for it." (Participant 2)

Theme 4: Communication Disruptors Are Everywhere

For all subpopulations (language, speech, voice, and hearing), the type of location where the conversation takes place plays a major role in experienced participation difficulties. This includes not only the physical location itself but also the type setting and the likelihood of disruptions to occur.

Participant 9 described the following supermarket situation:

> "At the checkout of a supermarket (or other stores) I can hardly understand what they are saying. At the moment I find it even more difficult because of the face masks. . ..and those screens [. . .]. I find it annoying when there are more people around and I still find it difficult when people find out that you have hearing problems." (Participant 9)

Other situations described the impact of environmental factors such as noise:

> "Whether it's the wind or a coffee machine is making some coffee eh. If I am standing next to the coffee machine and the coffee is being ground or the coffee is being poured, then I don't try to make an effort to have a good conversation with someone, because that makes so much noise for me that I don't hear things and that is also eh. I know if you are standing in the wind, for example, it is already difficult to understand others and I now also have the feeling that the wind amplifies that for me. So that sound also comes in louder." (Participant 4)

> "Yes, last Friday there was a church meeting, so i am not going there, because it is too busy. There were children also and then it is too busy in my head and then I spend three weeks with that in my head. that flies through my head. and I keep thinking about that and that is just too much." (Participant 14)

Theme 5: Timing of the Conversation Is an Important Factor in Participation

The current state of mind of the person influences their communicative participation, with fatigue being a major barrier. Half of the participants describe that fatigue plays a role in participation in conversations:

> "A one, a conversation, having a difficult conversation, eh and also look, you notice, when I'm tired, talking is less successful and also when someone answers you [...]. Now I also deliberately reschedule the appointment, because if you say: five, five o'clock, yes, then it is possible, it is possible, but then it is yes, tormenting yourself." (Participant 2)

Theme 6: Communicative Participation Problems Occur in Different Modes of Communication

Conversations can take place in different ways: from a conversation one-to-one to a group conversation, digital or face to face, and all possible combinations of these. Participants mentioned various aspects that are difficult for them within a one-to-one conversation, such as problems following or actively taking part in a conversation:

> "Eh, then I withdraw in the sense that I don't bring up a new topic there while the ladies are still talking [. . .] then I sit there listening and then I don't bring up a new topic myself." (Participant 17)

> "Yes, half, you have to repeat more than half and then you can't even think of it." (Participant 14)

Many participants also find it difficult to participate in a group discussion, including Participant 18:

> "If you are in a large group, there are ten people chatting with each other and then you start talking and then ... you are too late when you start talking actually. You fall behind or you are too slow so that you cannot be understood and then you just keep your mouth shut, you listen to the interesting things they say without bringing in your own experiences of course" (Participant 18)

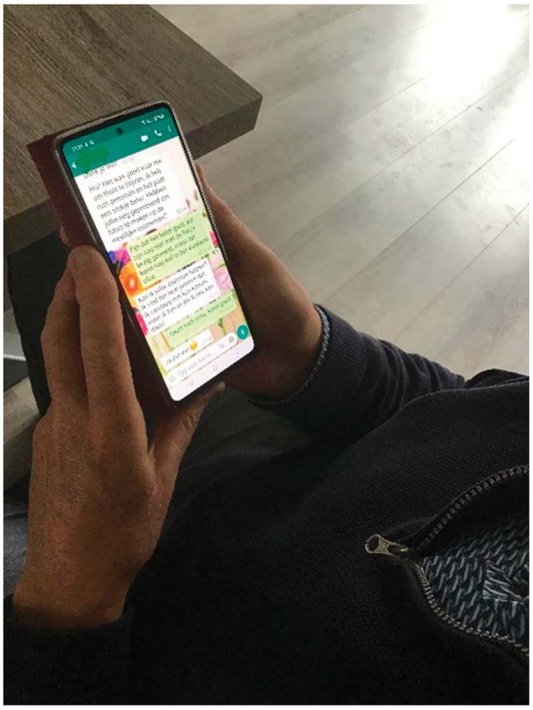
Digital conversations were often more difficult. By digital conversations, we mean conversations that take place via the computer or by telephone, spoken, or written.

> "So why outlined the situation, it's a new managing board, so new faces, er, a er, that's digital too. Yes, you also notice discomfort, no, not for me,but others. So, then you have yes, then the combination is a bit stiff, if you have a new board, physically, that's easy to have a conversation" (Participant 2)

Only people with aphasia mentioned situations in which reading and writing is used, such as text messaging (see Figure 2). It is worth mentioning that participants described situations can be captured by a single theme and concept as well as combinations of themes and concepts. For example, participants mentioned "talking via video calling" in general, but also in combination with a person, such as "to video call a therapist." For a detailed overview of concepts mentioned per participant per theme, see Appendix D.

In addition to these themes, there are a few more general findings worth mentioning: people with aphasia and people with hearing problems both described difficulties with perception of language, but with different underlying causes. People with aphasia describe having difficulty comprehending language, while people with hearing problems describe having difficulty with hearing speech. People with voice and speech problems mainly describe difficulties in situations they want to express themselves.

Figure 2. Diary photo of using text messaging Participant 1.



Item Formulation and ICF Activities and Participation Domain Classification

The 194 open codes led to 103 new items, covering the 44 concepts. Of these new items, 65 items cover the communication modality of speaking and exchange of communication. For the other communication modalities, 27 items were written related to understanding spoken language, four items were written related to writing, and seven items were written related to reading. Items were written with the item stem similar to that of the CPIB: "how difficult is it for you to." Codes that were similar were merged into one item. For example, the codes "talking to a physical therapist is difficult," "talking to a dentist is difficult," and "talking to a general practitioner is difficult," were merged into the item "talking to a healthcare professional." An example of the process from transcript to open coding to item formulation can be found in Appendix C. In addition to the 103 new items, the open codes of this study revealed 11 items that are already part of the CPIB (Baylor et al., 2013). Therefore, we did not write new items for those codes but used the formulation of the CPIB. Examples of the resulting 114 items can be found in Appendix E.

The items of communicative participation identified in this study were related to the ICF-activities and participation domains "Self-care," "Domestic life," "Interpersonal interactions and relationships," "Major life areas," and "Community, social and civic life." Most items relate to the "Interpersonal interactions and relationships" domain (65.9%), followed by "Major life areas" (11.4%) domain, and "Community, social and civic life" (10.5%). Less items relate to the "Self-care" domain (6.1%) and "Domestic life" domain (6.1%). No items have been identified that relate to the domains "Learning and applying knowledge," "General tasks and demands," and "Mobility."

Discussion

The aim of this study was to identify self-experienced restrictions in everyday communicative situations that people with different communication problems encounter, to provide information on the relevance and comprehensiveness of (possible) items in a PROM targeting to capture communicative participation. In total, 194 open codes were found, from which 44 concepts (elements of communicative participation situations) were elicited. These concepts could be captured within six themes affecting communicative participation. One hundred three new items capturing communicative participation were written.

The themes found in this study that cover 44 concepts largely correspond to the four crucial factors of social context as described by Yorkston and Baylor (2010), "where," "when," "why" (topic of communication), and "with whom." The crucial factor "where" corresponds to our theme "location where conversation takes place," the factor "when" corresponds to our theme "moment of conversation," "why" corresponds to our theme "topic being discussed, and "with whom" corresponds to our theme "person with whom communication takes place." Yorkston et al. (2008) added "pace" to the factors described in Yorkston and Baylor (2010), a theme we also found in our study, described as "pace of conversation." A new theme in our study is the mode of communication. This theme includes concepts related to reading and writing. One explanation for finding this new theme is that we included participants with speech perception and language comprehension problems. In addition, finding this new theme may reflect the rapid upcoming and evolvement of digital communication. Five concepts and 12 new items reflect the use of digital communication. Digital (long distance) modes of communication are becoming increasingly important and part of daily life (e.g., due to the COVID-19 pandemic restrictions). Based on our findings, we argue that, in addition to the other themes, mode of communication is an important factor of the social context, which is likely to remain relevant for people and evolve rapidly.

As described above, 103 new items were written. In addition to the 103 newly written items, another 11 items were found, which were already part of the CPIB. For 53 items, the items partially correspond to those of the CPIB; the new item is then worded more specifically or more generally. Because we included people with problems in speech perception and language comprehension, we wrote 38 items reflecting other modalities than spoken language. The results of this study add to the content validity of the CPIB; a large amount of relevant items were identified in a sample representing the target population (Terwee et al., 2018).

The items found in this study were found to cover five of the nine ICF Activities and Participation domains: "Self-care," "Domestic life," "Interpersonal interactions and relationships," "Major life areas," and "Community, social, and civic life." Almost two thirds of the items fell within the third domain: Interpersonal interactions and relationships. None of the concepts were related to the ICF Activities and Participation domains "Learning and applying knowledge," "General tasks and demands," and "Mobility." This is similar to the CPIB, in which only one of the 46 items falls within those domains, although they are described as part of the communicative participation domains (Baylor et al., 2021). It is unclear whether these domains are deemed not important for people with communication problems, or whether the problems in these domains are less obvious and therefore not mentioned by the participants in this study. In order to ensure the full breadth of experiences is taken into account in the development of items, it would be worth explicitly inquiring about the experiences with communicative participation within these domains.

Many of the concepts were identified by multiple participants, regardless of their underlying communication disorder and its severity. Only a few concepts seem to be disorder specific, such as concepts related to reading and writing skills. These concepts were only mentioned by people with aphasia. In addition, only people with aphasia and people with hearing problems described difficulties with speech perception and language comprehension. Furthermore, only people with speech, voice, or language problems describe problems with speaking, and in case of language problems also with writing. Dealing with population-specific participation difficulties in a generic item bank can be challenging. This is one of the reasons why the authors of the CPIB decided to include only situations involving communication through speech (Yorkston & Baylor, 2010). However, recent research on item banks suggests that it is not problematic that items in a generic item bank are relevant for only part of the target group of the generic PROM (Baylor et al., 2021; Miller et al., 2017) as long as all items reflect the underlying construct, in our case, communicative participation. In fact, this is an important benefit of modern item banks; as long as all items within one bank tap into one underlying construct, subsets of questions can and will be more or less suitable for particular patient groups. This could be translated to the development and the use of disease specific short forms (Baylor et al., 2021), or even more person centered: CATs.

There are a few study limitations that should be noted. First, although we asked the participants in a qualitative way about the impact of each situation, we did not use a more quantitative approach (e.g., by asking them to score the frequency or difficulty on a Likert scale). In hindsight, this would have provided useful information for IRT purposes, using this information to determine whether or not an item is distinctive to be included in the measurement instrument. However, this information can also be obtained in a content validity study, the next phase in PROM development.

Second, we failed to reach the target sample size of three people from each "subpopulation," because two people within the subpopulation of voice problems participated in our study. However, this group has already been extensively interviewed by Baylor et al. (2005, 2007) and Yorkston et al. (2001). Therefore, our results can be seen as complementary to those studies, and we did not expect that including more people with voice problems would lead to new insights.

Third, we were unable to find people with cognitive communication disorders for our study. These people experience communication problems that are affected by the disturbance of cognition and are different from language problems. Some of the participants in this study did suffer from cognitive problems in addition to language or speech difficulties, but the lack of participants with only cognitive communication difficulties is a weakness of this study. One possible reason for the difficulty recruiting this population is that it is often the partner or family of the person with the cognitive communication difficulties that experience difficulties in communication, not the patient themselves (Hewetson et al., 2018). It could be that they therefore did not identify with our call for people to participate in a project focusing on (difficulties) with communicative participation.

In conclusion, we gathered a comprehensive picture of the situations that are difficult for people with different communication problems by including people with both expressive and receptive language and communication problems. This study contributes to the current body of knowledge of the construct of communicative participation and supports future research on the further development of outcome measures aimed at this construct. We advocate further testing of the relevance, comprehensibility, and comprehensiveness of the newly written items in a new patient sample in a content validity study. Subsequently, psychometric testing in a large patient sample is

required to examine the added value of the new items in terms of IRT model fit, item difficulty, and discrimination, compared with the existing CPIB items. The concepts and themes found in this study can already be used in designing and delivering a participation-focused intervention in people with various communication problems.

Data Availability Statement

Data available on request due to privacy/ethical restrictions.

Acknowledgments

We are very grateful to all people who participated in this study. In addition, we would like to thank Floryt van Wesel for training and coaching in interview techniques.

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Appendix A

Five-Point Likert Scale Perceived Communication Skills

1. **Severe** – Communicating is very difficult. Person is very difficult to understand for the communication partner. The person hardly understands the communication partner. Communication must be fully supported.
2. **Moderate to severe** – Communicating is difficult. Person is difficult to understand for the communication partner. Person understands the communication partner with great difficulty. Communication should be regularly supported.
3. **Moderate** – Communication is reasonable. Person can convey a simple message intelligibly or understandably within the context. Person understands a simple message within the context.
4. **Moderate to mild** – Communication is reasonable. The person can convey his message to the communication partner, but inquiries about what is meant is still necessary on a regular basis. The person understands the communication partner regularly.
5. **Mild** – Communication is good. The person can convey his message well to the communication partner, inquiring about what is meant is sometimes still necessary. The person sometimes has to ask the communication partner for repetition or clarification.

Appendix B

Topic List Concept Elicitation Study

Warm-up question:

- You kept a diary for this interview; what was it like for you to keep this diary?

Topic 1. Typical day[1]

INFORMATION TARGETED: GENERAL INFORMATION ABOUT EXPERIENCED CONSEQUENCES IN DAILY LIFE AND SITUATIONS ENCOUNTERED BY THE PERSON ON A DAILY BASIS

- What does a typical day look like for you? Can you describe a typical day?
- In which situations do you find it difficult to tell something to someone or understand what someone is saying to you? Can you describe that situation?

If a person does not come up with situations that are difficult for him/her, recap the situations described by the participant in which communication is required and ask: you describe the situation in which . . ..., how do you experience communicating in that situation?

- What does a good day look like?
- What does a bad day look like?
    - Are there differences in bad days/good days?
- Are there any situations you avoid because you have difficulty understanding what someone is saying to you or difficulty telling people what you want to tell them?

Topic 2. Diary content[2]

INFORMATION TARGETED: DETAILED INFORMATION ON COMMUNICATIVE PARTICIPATION SITUATIONS ENCOUNTERED BY THE PERSON

Present the photos/diary and invite the participant to look at their diary with you

- Can you tell me why you took this photo/video/voice memo/described this situation?
    - How difficult is this situation for you?
    - How important is it to you to participate in this situation?
    - How often does this situation occur?
    - In what ways does the situation bother you?

[1]Based on Brédart, A., Marrel, A., Abetz-Webb, L., Lasch, K., & Acquadro, C. (2014). Interviewing to develop Patient-Reported Outcome (PRO) measures for clinical research: Eliciting patients' experience. *Health and quality of life outcomes*, *12*(1), 1–10.

[2]Based on Patrick, D. L., Burke, L. B., Gwaltney, C. J., Leidy, N. K., Martin, M. L., Molsen, E., & Ring, L. (2011). Content Validity—Establishing and Reporting the Evidence in Newly Developed Patient-Reported Outcomes (PRO) Instruments for Medical Product Evaluation: ISPOR PRO Good Research Practices Task Force Report: Part 1—Eliciting Concepts for a New PRO Instrument. *Value in Health, 14*(8). https://doi.org/10.1016/j.jval.2011.06.014.

Appendix C

Process From Transcript to Open Coding, to Concept, to Theme, and to Item

Transcript (translated from Dutch to English)	Open coding	Axial coding (concept)	Theme	Item [literal translation into English, no cross cultural adaptation]
. . .goes, (conversations) mixed up and I, I'd say, but I can't get in, eh, yes, what do we do then, if it works out, then I go with fewer people with, for example, my sister's is not, talk to my daughter alone, that's fine, but everyone, sitting there. That's difficult. (Participant 7)	Conversations with multiple people are difficult	Group conversation	Communicative participation problems occur in different modes of communication	Te praten in een kleine groep mensen [Communicating in a small group of people; CPIB item]
yes and then you get a nice coffee afterwards with a whole group, well, I can shake that too, because I don't understand that either. (Participant 8)	Understanding conversation in group is difficult	Group conversation	Communicative participation problems occur in different modes of communication	Iemand te verstaan in een grote groep mensen [Understanding someone in a large group of people]
Yes, yes, there, I also make myself a bit guilty that you and if several of you want to talk at the same time, it won't work. (Participant 12)	Can't talk to more people at the same time	Group conversation	Communicative participation problems occur in different modes of communication	Te praten in een kleine groep mensen [Communicating in a small group of people; CPIB item] Te praten in een grote groep mensen [Communicating in a large group of people; CPIB item]

Note. CPIB = Communicative Participation Item Bank

Appendix D (p. 1 of 2)

Concepts per Theme per Participant

	Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
	Diagnosis	APH, APR	APH	APH	H	D	APH	APH	H	H	H	APH	APH	STUT	D	V	APH	D	V
	Communication skills on a 5-point Likert scale	2	5	5	5	3	4	3	3	3	5	4	4	3	3	5	2	5	4
Theme	**Concept**																		
Person																			
	Friends											x							
	Family													x	x	x			
	Strangers			x									x	x	x		x		x
	Health care professional	x	x				x												
	Communicate with people with hearing problems					x			x							x		x	
	Communicate with people without problems		x																
	Way of speaking communication partner			x	x				x	x									
	Language use of communication partner			x															
	Facial expression								x	x	x		x						
	Attention									x	x								
	Foreign languages								x	x									
Topic																			
	Emotionally conversations	x				x							x				x		
	Telling how you feel	x																	
	Verbally asking for help	x																	
	Emergency							x											
	Politics							x											
	Make appointments	x	x				x		x								x		
	Personal data			x			x					x							
	Administration							x											
	To order													x					
	Humor									x									x
Pace																			
	Change of topic						x												
	Time pressure		x															x	
Location																			
	Party		x						x	x								x	
	Sports	x																	
	Work			x	x	x	x			x		x		x					
	Store		x			x		x				x	x						x
	Surroundings	x			x	x	x		x	x			x					x	x
	Impressions		x																
	Space								x	x			x			x			

(table continues)

Appendix D (p. 2 of 2)

Concepts per Theme per Participant

	Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
	Diagnosis	APH, APR	APH	APH	H	D	APH	APH	H	H	H	APH	APH	STUT	D	V	APH	D	V
	Communication skills on a 5-point Likert scale	2	5	5	5	3	4	3	3	3	5	4	4	3	3	5	2	5	4
Theme	**Concept**																		
Moment																			
	Unexpected situation		x																
	Physical effort					x													
	Fatigue		x	x		x	x			x			x	x					x
	Insecurity		x																
Mode																			
	E-mail		x	x			x												
	One to one conversation	x	x	x	x	x	x	x			x	x	x	x	x			x	x
	Group conversation				x		x	x	x	x		x	x		x			x	x
	Personal mail			x															
	Presenting		x																
	Talk on phone	x		x		x	x	x	x				x	x	x	x	x		x
	Meetings		x	x						x	x			x					
	Video calling					x													
	WhatsApp	x					x	x											
	Social media							x											

Note. APH = aphasia; APR = apraxia of speech; H = hearing problems; D = dysarthria; STUT = Stuttering; V = voice problems.

Appendix E

Examples of Newly Developed Items and Items From the CPIB Also Found in This Study

International Classification of Functioning, Disability and Health Activities and Participation domain		Item [literal translation into English, no cross cultural adaptation]
5) Self-care		uitleg tijdens therapie te begrijpen [understand instructions during therapy]
		te videobellen met een therapeut [to video call a therapist]
6) Domestic life		te praten met een winkelmedewerker bij drukte [talking to a store employee when crowded]
		iemand achter de kassa te verstaan [hear someone behind the cash register]
	CPIB	. . . met een winkelmedewerker te praten over een probleem met een rekening of iets wat u gekocht heeft [Talking with a clerk in a store about a problem with a bill or purchase]
7) Interpersonal interactions and relationships		iets duidelijk te maken wanneer u praat met familie en vrienden [make something clear when talking to family and friends]
		uw (klein) kinderen te verstaan [understand your (grand) children]
	CPIB	. . . een gesprek te beginnen met iemand die u kent [Starting a conversation with someone you know]
	CPIB	. . . te praten tijdens het ontmoeten van nieuwe mensen [Making new acquaintances]
	CPIB	. . . te praten in een grote groep mensen [Communicating in a large group of people]
	CPIB	. . . te praten in een kleine groep mensen [Communicating in a small group of people]
	CPIB	. . . aan de beurt te komen in een snel verlopend gesprek [Getting your turn in a fast-moving conversation]
	CPIB	. . . grappen te maken met anderen tijdens een gesprek [Making a witty or funny comment in a conversation]
	CPIB	. . . het onderwerp te veranderen tijdens een gesprek [Bringing up a new topic in casual conversations]
	CPIB	. . . een gesprek te voeren over een serieus onderwerp [Having a conversation about a serious topic]
	CPIB	. . . een gesprek te voeren tijden het autorijden [Having a conversation while riding in a car]
8) Major life areas		te telefoneren op het werk [make phone calls at work]
		te overleggen met mensen met een hogere functie [to consult with people in higher positions]
9) Community, social and civic life	CPIB	. . . een maaltijd te bestellen in een restaurant [Ordering a meal in a restaurant]
		eten te bestellen in een drive-thru [ordering food in a drive-thru]
		een sportleraar te verstaan bij een groepsles [understand a sports instructor at a group class]