Preferred Communication Strategies for People with Communication Disabilities in Health Care Encounters: a Qualitative Study

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ABSTRACT

BACKGROUND: People with communication disabilities (CDs), which includes disabilities in speech, language, voice and/or hearing, experience health and healthcare disparities. A barrier to accessing high-quality, equitable care is the lack of effective communication between patients and their providers.

OBJECTIVE: In designing a patient-prompted tool to facilitate communication, we analyzed qualitative feedback on communication strategies and the experience of people with CDs, caregivers, and providers in healthcare encounters. We aimed to describe communication strategies that patients with CDs find most useful and optimize a tool for patients to share their communication strategy preferences during clinical encounters. While patient-provider communication is paramount in every interaction, we aimed to highlight the intricacies of optimizing communication for this population.

DESIGN: We performed a qualitative study utilizing focus groups and interviews with patients with CDs, their caregivers, and healthcare providers.

PARTICIPANTS: A total of 46 individuals participated in focus groups or interviews; 26 participants self-reported a CD, nine were caregivers, and 11 were providers. Participants represented diverse types of CDs, including stuttering, aphasia, hearing loss, and people with autism or cerebral palsy who use assistive technology to communicate.

APPROACH: Analysis of qualitative interview and focus group data was guided by a qualitative content analysis approach.

KEY RESULTS: We identified three themes: (1) While communication strategies should be individualized, participants agreed upon a consolidated list of best strategies and accommodations. We used this consolidated list to finalize tool development. (2) Patients and providers preferred disclosure of the CD and desired communication strategies before the appointment. (3) Providers often do not use communication strategies and accommodations during clinical encounters.

CONCLUSIONS: For patients with CDs, it is critical to acknowledge and document the CD and individualize communication strategies during healthcare visits to facilitate communication. Studies are needed to evaluate whether improved communication strategy usage leads to improved health outcomes for this population.

KEY WORDS: communication disabilities; strategies; caregiver; primary care

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INTRODUCTION

In the USA, approximately 14% of adults report having a communication disability (CD), which includes speech, language, voice, and/or hearing disabilities. [1–3] This heterogeneous group includes many types of disabilities both acquired and congenital, for example, older adults with aphasia resulting from stroke and younger adults with a developmental stutter. Research demonstrates that people with CDs experience significant disparities in health and health outcomes.[3–6] In nationally representative surveys, people with CDs are more likely to have chronic conditions, such as hypertension and diabetes, than those without a CD.[3,7] People with CDs also report higher levels of difficulty accessing healthcare services, including having more trouble finding a physician and being more likely to delay or forgo care as compared with people without CDs.[3]

While multiple factors influence the quality of care and health of persons with CDs, one potential major contributor is poor patient-provider communication. In general populations, effective patient-provider communication is associated with improved patient outcomes and satisfaction.[8–11] Yet, in numerous qualitative studies, patients with CDs describe being excluded from conversations and decisions about their healthcare, inappropriate assumptions being made about their cognitive levels, lack of age-appropriate language being used during clinical visits, and providers not taking the time or effort to adapt to their communication needs.[12–21]

Prior Presentations We are appreciative of the opportunity to present the preliminary findings of this work as a poster at the Society of General Internal Medicine 2023 conference.

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Previous studies have shown that if communication partners use evidence-based communication strategies and accommodations, persons with CDs have improved comprehension and expression during conversations.[22,23] Examples of strategies include not interrupting, and looking at the person with a CD while they are speaking.[14,24,25] Communication accommodations can consist of communication boards and sound amplification devices. A study by Morris et al. (2014) video-recorded clinical encounters of patients with aphasia and found that physicians rarely used the evidence-based communication strategies that patients desired.[26] Patients with CDs included in this study also reported that their healthcare provider never asked them about their communication needs and preferences.

Given these gaps, there is a need for research to identify how to increase providers' use of evidence-based communication strategies. Our team sought to address this need by developing a patient-prompted tool to facilitate communication between providers and patients with CDs. We engaged patients with different types of CDs, caregivers, and primary care providers to (1) aggregate the communication strategies that patients with CDs find most useful and (2) identify the best mechanism for patients to share their communication strategy preferences with providers during clinical encounters.

METHODS

Study Design

Our primary goal was to develop a tool to facilitate communication between providers and patients with CDs during clinical visits. To begin, we conducted a series of qualitative semi-structured 1:1 interviews and focus groups with patients, caregivers, and providers to elicit input on the communication strategies to be included in the tool. Using participant feedback, we developed a draft tool and refined it through patient cognitive interviews. We then tested this tool in our parent study (PCORI-funded clinical trial AD-2019C1-15642). This study was approved by the University of Colorado Institutional Review Board (Protocol # 20-1884) and verbal informed consent was obtained before study enrollment.

Study Setting and Participants

We partnered with local and national disability advocacy organizations to recruit participants with CDs and caregivers of persons with developmental or progressive CDs. We purposefully sampled participants representing a wide range of CDs. Since communication strategies relate to the type of disability (e.g., hearing, speech, language, and voice disabilities) rather than diagnosis, we loosely organized participants by type of disability to encourage some homogeneity among participants. We recognize that some individuals had multiple types of CDs, so the organization of the groups was fluid. We recruited outpatient primary care providers via email from four academic medical centers. Recruitment and data collection continued until preliminary analyses indicated that saturation, or no new themes, was reached.[27]

Data Collection

We developed the interview and focus group guides with input from our stakeholder advisory board.[27] To begin, the interviewers showed participants a list of evidence-based communication strategies (Supplementary Table 1) identified by the research team from relevant literature.[12–14,16,17,19,22,23,26,28–32] Participants then provided feedback on the strategies, including commenting on ones that they typically use and ones that were missing. Next, the interviewers introduced the proposed functionality of the tool: on an electronic tablet, a patient would select three preferred strategies from the list of communication strategies, which the patient would then share with their provider at the start of the visit. The proposed functionality was based on the "Ask Me 3" intervention.[33]

The study team included individuals with personal experience with family members who have CDs and/or were trained in qualitative methods and engaging persons with CDs in qualitative research. Two authors (MAM and SL) trained in conducting qualitative interviews and focus groups and led all virtual focus groups and interviews between November 2020 and March 2021. If a participant was unable to attend the focus group, they were offered an individual interview. Focus groups lasted 60–90 min, and interviews lasted 30–45 min. Participants received a gift card as compensation.

Analysis

Guided by qualitative content analysis methodology, the team analyzed the data using an iterative team-based process.[34] The analysis team included the principal investigator (MAM), a speech-language pathologist with expertise in qualitative methods, two physicians (EH, BM), a trained qualitative analyst (SL), and a research assistant (KH). The team developed the codebook inductively by reading and rereading transcripts and creating initial codes that emerged from the data. All transcripts were independently read, double-coded, and merged prior to analysis. Throughout the analytical process, the study team met regularly to discuss emergent codes, themes, and preliminary and final results. ATLAS.ti v9 was used for data management.

Cognitive Interviews

Preliminary findings were integrated into an initial draft of the tool. The tool and the following cognitive interview framework were developed by a study team member trained in user-centered design (JD). During the cognitive interviews (virtual or in-person), participants selected communication strategies and accommodations using the tool and were encouraged to use a "think-aloud" approach.[35] Specifically, they provided feedback on the tool's design, layout, and functionality, as well as the communication strategies and accommodations listed (Supplementary Table 2). After 2–3 interviews, the tool was refined based on participants' feedback and then presented to 2–3 more participants. This process continued until no additional modifications were needed and the tool was finalized by the study team.

Rigor and Quality

We used multiple approaches to ensure the rigor and trustworthiness of data collection, analysis, and findings.[36] Our multidisciplinary research team had targeted conversations about members' biases, and assumptions and all team members were encouraged to practice self-reflexivity.[37,38] Team-based coding assured confirmability, maintaining the reliability of coding processes needed to ensure a close connection between the data and the codes.[27] During the analysis, we kept an audit trail and analytical memos. Findings from the data collection and the developed tool were presented to the stakeholder advisory board for additional feedback.

RESULTS

Our study team conducted six focus groups, five interviews, and eight cognitive interviews. A total of 46 individuals participated in focus groups or interviews; 26 participants self-reported a CD, nine were caregivers of persons who have a CD, and 11 were providers. Additionally, eight individuals participated in cognitive interviews. (See Table 1 for participant demographics.) While the interview and focus group guides specifically focused on providing feedback on the communication strategies and the proposed tool, all participants provided rich descriptions of their experiences interacting during clinical encounters. In these descriptions, we identified three major themes for facilitating effective communication between patients with CDs and their providers.

Theme 1: While communication strategies should be individualized, participants agreed upon a consolidated list of best strategies and accommodations.

Participants solidified a list of 16 communication strategies and 9 accommodations (Table 2). Specifically, they

Table 1 Characteristics of Participants in Focus Groups and Interviews

Age group, years			
18–24	2		
25–34	4		
35–44	9		
45–54	13		
55–64	9		
65 or older	9		
Gender			
Men	15		
Women	28		
Non-binary	3		
Race/ethnicity			
Non-Hispanic White	34		
African American	3		
Hispanic	2		
Asian	3		
Hawaiian/Pacific Islander, multi-racial, or other	4		
	Number of participants in each focus group (*n*=6)	Number of cognitive interview participants	Number of interview participants
Type of CD			
Aphasia	8	0	
Autism or cerebral palsy	5	3	
Deaf or hard of hearing	6	2	
Stutter	7	3	
Caregiver	9	0	
Provider type			
Physician	5		4
Advanced practice provider			1
Psychologist			1
Provider specialty			
Geriatrics			6
Internal medicine			5

Table 2 List of 16 Communication Strategies and 9 Accommodations Commonly used for Facilitating Communication with People with Communication Disabilities

- Communication strategies
  - Look at me when either you (the provider) or I are talking.
- When you, the provider, are talking...
  - Use words that are respectful and appropriate for my age.
  - Speak in short phrases and sentences.
  - Ask questions that I can answer with yes or no.
  - Speak clearly and at a medium pace.
  - Frequently check that I understood what you said.
  - If I do not understand, rephrase what you said.
  - Let me know when you are switching topics.
  - Use printed words or pictures for me to point to when answering questions.
  - Write down key words.
  - Use meaningful gestures.
- When I am talking...
  - Provide me extra time to think about what you said.
  - Provide me extra time to talk.
  - Do not interrupt or guess what I am saying.
  - Ask for permission to guess what I am saying.
  - Let me know when you don't understand and ask me to explain.
- Accommodations:
  - Assistive listening device (example: pocket talker)
  - Picture or word book
  - White board
  - Augmentative communication device
  - Electrolarynx
  - Phone
  - Voice-to-text apps
  - CART transcription
  - Hearing aids

provided feedback on the wording of the strategies and the number of strategies.

Patient and caregiver participants across and within different types of CDs described a range of preferences for the strategies they desired their healthcare team to use. For example, some individuals with comprehension difficulties preferred people to slow down, while others who lipread preferred people to speak at a normal pace. Some participants who stuttered wanted the provider to ask permission to guess what they were saying, while others who stuttered felt one should never guess what they were saying. Similarly, some participants across CD types designated a preference for eye contact, while one in the autism or cerebral palsy focus group said, "I want people to talk to me/in my direction, but I don't want eye contact."

Among and between groups, there was earnest discussion about whether doctors should use simple and clear language, or whether the practice of over-simplifying language is offensive and leans into the stigma that someone with a CD needs to be spoken to like a child. An individual with hearing loss highlighted the need to "build the awareness that every hearing loss is different. Every person is different, the accommodation that [they] may use is different."

Patient participants stressed the importance of having their provider speak directly to them rather than to a support person present. One caregiver relayed, "She is so brilliant, but the doctors always looked at me, [laughter] and she would get so mad for good reason... Saying, 'I'm the patient! Look at me!' However, patient and caregiver participants also highlighted that the caregiver should not be ignored and that their roles should be clarified and, based on the patient's preferences, incorporated into the visit. One participant described that, as the caregiver, they do not want to be ignored by providers, "but then they ignore me as the wife and that's not okay either. We're a team and what happens to him impacts on me as well."

Again, because patients have different preferences, even within the same type of CD, it was important for the healthcare team to elicit each patient's individual preferences. When asked how many strategies they wanted their healthcare team to use, many patient participants requested that most of the strategies be applied. Conversely, the provider participants requested that they focus on only one or two of the strategies during the clinical encounter.

Development of the Tool. Based on the findings from the focus groups, interviews, and cognitive interviews, the research team developed a tool for patients to complete before a clinical encounter to indicate the top three strategies they would want their primary care team to use with them. The patient would then share the tool with the provider at the start of the clinical encounter. Based on feedback from participants, we developed paper and web-based versions of the tool. The web-based version has videos of the communication strategies and audio recordings of all the text. Furthermore, if a patient is unable to complete the tool, we created a proxy version of the tool that a caregiver can complete.

Theme 2: Patients and providers prefer disclosure of communication disability and desired communication strategies prior to the appointment.

The majority of participants with a CD reported welcoming a discussion about their CD with their healthcare team. Many felt that disclosing a CD was an important first step to improving communication with their healthcare team and desired their CD to be acknowledged.

> *I think it's helpful once it [the communication disability] gets out in the open, it breaks the ice, and I feel more ease to talk at that point when it's already out there. If there was any boxes to check here, if you were to—what do I need, maybe you would want to disclose maybe even before the meeting with the doctor that, 'hey, sometimes, I stutter and require a little bit more time.' That would break the ice there. I think I would feel more at ease to talk at that point.* (stuttering focus group)

Several participants with aphasia reported showing people a card that they carried or an app on their phone disclosing their CD and communication preferences. Participants across all CDs believed that a similar tool sharing both their CD and preferred communication strategies would be beneficial to use with their healthcare teams.

> *I was thrilled because without my saying a word, I was apparently red flagged as having hearing loss in the EMR. He was equipped with a clear mask and put it on right away, so that was wonderful.*

Participants noted a lack of questions about CDs on health intake forms and that providers would often not clarify or confirm their disability status. Participants across all CDs stated the desire to have their disability acknowledged rather than ignored, with one participant in the autism or cerebral palsy focus group saying: *"Don't use euphemisms around or pretend to not notice my disability."*

Participants with CDs noted that providers sometimes seemed uncomfortable with patients' CDs. One participant with a stutter described his physician uncomfortably "chuckling" when the patient spoke. Many other patient participants also reported experiencing stigma when interacting with their healthcare team. Patient participants noted feeling that the team often had false assumptions about their intelligence. Participants believed that having an upfront conversation about their CDs and communication needs would address these concerns. Finally, some participants noted fear or concern about communicating or using assistive devices during clinical encounters, which impeded communication.

> *I have a tendency to speak softly and mumble and don't use AAC [augmentative and alternative communication] much at doctor appointments because I am too scared. Then, you add to that a really thick cotton mask, and it's super hard to hear me. (Autism or cerebral palsy focus group)*

Provider participants stressed the desire to know ahead of time whether a patient has a CD. They described feeling as though they are often left guessing when a patient does not disclose, potentially leading to missed opportunities for effective communication during the appointment. Many providers reported that knowing patients' preferred communication strategies before the visit, including a reminder on the electronic medical record, would optimize the time during the clinic visit.

> *There's been a couple of times where I realize a little bit into the appointment that there is a comprehension issue. They're nodding along like anyone would [...] Then, when I ask for [the patient] to repeat it back, it's obvious they did not understand. [...] It'd just be nice to remember that ahead of time. Then, those patients, "yes, give a longer pause if they're trying to get their words out and don't speak over them and allow them to make their point because I know they will at some point."*

Theme 3: Providers often do not use communication strategies and accommodations during clinical encounters due to lack of time, training, and resources.

Many participants from the patient and caregiver groups discussed that providers often seem unaware of how to use communication strategies and assistive devices such as clear masks. Additionally, many described situations where the healthcare team did not know the communication accommodations mandated under the Americans with Disabilities Act (ADA). One participant with hearing loss reported being told by her provider to stop using an app on her phone that provided real-time captioning when she could not understand what her provider was saying.

> *...this woman wanted to use Otter [app that provides real time translation] and they said, "No it's against policy." Well, when we talked to the people at that hospital, they said, "Oh, no. She can use Otter," so there also has to be a way to let the providers know what's available and to make sure they'll have the pocket talker [sound amplification device] in their office when the patient shows up.*

Patient and caregiver participants reported the need for providers to be trained on how to implement strategies and accommodations, as well as be flexible and learn with patients. As one caregiver stated,

> *Docs have to be fearless. They just have to jump in there and be comfortable with that. I think obviously the more they do it, the more comfortable that they get.*

Multiple provider participants acknowledged that they have a limited understanding of what it is like to navigate the healthcare system for patients who have a CD. Despite interest in using communication strategies during visits, most stressed that lack of time was the most significant barrier to using communication strategies or accommodations. For example, some providers felt that there was not enough time to try new communication methods, and preferred to "stick to what works" or improvise.

> *I just try to individualize best I can, you know, because that's all we're really supposed to do every day is communicate with people, so any way you can do it, you try.*

Providers reported having numerous concerns to address during the visit and "adding another thing, even if small, can be a lot." Some providers felt there was not always enough time to confirm a patient's comprehension. While some providers reported already using various strategies and spending additional time augmenting their communication with patients with CDs, many expressed a lack of knowledge of what communication strategies or accommodations were preferred by their patients.

> *Nothing's ever been introduced to me as a provider, saying: "if a person has this issue, use this. If a person finds that they have this issue, use this." So I'm not even sure what the options are.*

Finally, providers described a need for more accommodations/accessible equipment, such as communication boards, available at their clinics, and relied on patients to bring their own accommodations.

> *I don't have the resources. If someone comes to me with their board, then I can use it. For me to need to provide a board, I can't do that. […] If this is a, "I'd like you to use this board to help us communicate," that's different. That could be a priority, and we could that. For us, as the primary care team, to need to provide the board is beyond our capacity.*

DISCUSSION

While all patients are at risk of inadequate patient-provider communication, people with CDs are at a greater risk for ineffective patient-provider communication due to the inherent nature of their disability. Communication challenges can be exacerbated and compounded when a patient has a CD. For instance, while it is always a recommended practice for the provider to avoid interrupting patients, it is more likely for the provider to interrupt if the patient has a stutter and is taking two to three times longer to speak about their concerns. Highlighting the unique needs of people with CDs, some of the identified strategies that are effective for patients with CDs, such as asking questions with a yes or no answer, are different from how providers are trained to engage in effective patient-provider communication. For these reasons, extra attention and intervention are needed to promote effective communication with patients with CD.

Consistent with existing literature, we found that, across different types of CDs, patients reported that their healthcare team is unprepared and untrained in how best to communicate with them.[12–19] While multiple factors contribute to poor communication, such as inadequate time during clinical encounters, increasing providers' use of evidence-based communication strategies is one potential solution. We identified 16 strategies patients across different CD types desired, all of which healthcare teams could easily implement with little to no training. As a result of the study, we developed a web-based and paper tool with which patients and caregivers can select up to three preferred communication strategies for their provider to use during the encounter. The tool alerts the provider to the CD and the patient's preferred strategies, hopefully initiating a conversation about the ways the provider can best support the patient's communication.

While providers in our study reported being willing and interested in using communication strategies during visits with patients with CDs, most voiced concern about needing more time to use every communication strategy requested by their patients. Communication with patients with CDs often takes longer, but the use of the strategies may result in more effective and efficient communication during clinical encounters by, for example, decreasing providers' need to repeat themselves. Many providers reported already spending extra time trying to meet their patients' needs without knowing what specific strategies their patients would benefit from.

Many patient participants reported experiences with stigma when interacting with their healthcare team. Patients noted that providers seemed uncomfortable interacting with them and felt that the team often had false assumptions about their intelligence. This is concordant with existing literature demonstrating provider discomfort with disability in general. In a recent national survey of practicing physicians, only 56% reported strongly welcoming patients with disabilities into their practice, and 40% felt they could provide the same level of care to patients with and without disabilities.[39] It is likely that providers' negative attitudes and uncertainties about caring for patients with disabilities affect their interactions with patients with disabilities, resulting in patients' experiences of stigma. Increased medical education is needed from undergraduate medical school curriculum to continuing medical education for practicing providers.

The ADA requires that healthcare teams provide "effective communication" to all patients with disabilities. This includes the provision and use of disability accommodations, such as a sound amplification device for people with hearing disabilities. In our study, many patients and caregivers were aware of their rights. In contrast, some of the provider participants described not having the resources in their clinic to provide accommodations. Therefore, they relied on patients with CDs to bring their own. This is a violation of the ADA. This finding is unsurprising given a recent qualitative study that found physicians incorrectly placed the responsibility for providing accommodations on the patient.[29] Additionally, the aforementioned survey of practicing physicians found that 71% answered incorrectly about who determines reasonable accommodations and 20% were incorrect in identifying who pays for accommodations.[40] Physicians and healthcare leaders need improved education to know their responsibilities under the ADA for providing equitable care to patients with disabilities.

An important finding of this study was that patients across and within different types of CDs had varying preferences in communication strategies; this means that one cannot assume, based on the kind of CD, what methods a patient prefers. Consequently, providers should ask all patients with CDs about their preferred communication strategies. All our study participants stated the need for collecting patients' disability status and accommodation requirements prior to a clinical encounter and storing this information in the electronic health record (EHR). This is consistent with existing literature demonstrating that patients with disabilities want their disability status and accommodation needs documented in the EHR.[13,41] Additionally, this is supported by current national policy. In July 2022, the Office for the National Coordinator of Health Information Technology released their new standards for EHR interoperability, which included standardized disability data elements.[42] A national standard for documenting disability status in the EHR will hopefully facilitate the collection and recording of disability status in the EHR by healthcare team members.

This study is not without limitations. First, while we aimed to engage a diverse group of study participants, we had a limited number of focus groups so it is possible that we did not capture the experiences and preferences of all individuals with CDs. We also recruited individuals with CDs from support and advocacy groups. As such, we likely had a more empowered and activated patient and caregiver group of participants who may be more likely to advocate for themselves and know their rights under the ADA. Finally, our provider participants represented a limited group of primary care providers from academic centers. Despite the limitations, the study contributes to the literature by identifying communication strategies primary care providers can use with patients with CDs during clinical encounters.

Providing equitable care to patients with CDs will likely require a multi-faceted solution. Despite this, healthcare teams can make meaningful changes today. Through the routine collection of disability status and accommodation needs, including communication strategy preferences, and then integration of those strategies into healthcare communication, healthcare teams will have a significant impact on ensuring equitable care for patients with CDs. The skills that we hope providers will learn to improve their communication with patients with CDs specifically will also lead to improved communication with all patients regardless of disability status.

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Data Availability *The data includes identifiable information and thus cannot be made publicly available.*

Declarations

Conflict of Interest *Jennifer Duffecy is a consultant for Healent Health, MyAlloy, and Chorus Health. The other authors have no conflicts of interest to disclose.*

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