A qualitative study of adult AAC users’ experiences communicating with medical providers

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Abstract

Purpose: To study the experiences of adults who use augmentative and alternative communication (AAC) systems and methods when interacting with medical providers, specifically primary care providers. Method: Individual face-to-face interviews were conducted with 12 participants, four of whom also participated in an online focus group. Diagnoses of the participants included cerebral palsy, undifferentiated developmental disability, head and neck cancer, amyotrophic lateral sclerosis and primary lateral sclerosis. Transcripts from the interviews and the focus group were analyzed to create a list of codes. From these codes themes that captured particular concepts discussed were identified. Results: Participants described multiple frustrations in communicating with medical care providers. Themes that arose included: planning and preparing for the appointment, time barriers, inappropriate assumptions, relationship building and establishing rapport, medical decision making and implementing the plan. All but one participant reported bringing a caregiver with them to their appointments and this person, whether a family member, friend or paid aide, had a substantial role throughout the appointment. Conclusions: The participants’ stories highlight important barriers they experience when communicating with medical providers. These barriers bring attention to the need for education for physicians, caregivers and patients with communication disabilities, along with increased research to improve patient–provider communication.

Keywords

Augmentative and alternative communication, communication disabilities, health disparities, patient–provider communication

Implications for Rehabilitation

• Patients with communication disabilities face multiple barriers to communicating with medical care providers.
• Patients, caregivers, and medical care providers all play a role in effective and ineffective communication during appointments.
• Education for medical care providers, caregivers, and patients with communication disabilities, along with increased research is needed to improve patient–provider communication.

Introduction

Effective patient–provider communication and positive patient–provider relationships are critical in successful medical encounters. When patients and providers engage in effective communication, patients are more invested in their medical care and have a better understanding of their treatment, leading to better adherence, self-management and self-reported medical outcomes [1–4]. Effective communication is also associated with increased patient satisfaction and decreased medical costs [3,5,6]. A physician’s communication and interpersonal skills have been linked to reduced blood pressure, improved pain control and reduced anxiety levels of patients [7,8]. In addition, effective patient–provider communication has also been reported to produce more realistic expectations and decrease conflict during medical decision making [9,10]. Finally, effective communication has been shown to increase the number of patients who participate in decision making and reduce the number of individuals who are undecided about a plan of care [9,10]. While communication is important in all medical interactions, it is particularly important when the patient has a disability [11,12]. Patients with disabilities face greater barriers in accessing quality care as compared to those without disabilities [13]. A study in Kansas found 40% of individuals with disabilities reported that their health was fair to poor while only 11% of the non-disabled population reported this level of health [14]. Studies have shown that individuals with disabilities are less likely to have access to or receive primary care or preventative care services, despite the fact that they are more likely to have conditions requiring health interventions than compared to non-disabled individuals [14–21].
Not only do individuals with disabilities report lower quality of health, they also report less satisfaction with communicating with their medical care providers; namely providers not adequately explaining their medical care or answering all of their questions [16]. Lawthers et al. [13] reported that communication barriers between providers and patients are a major contributor to lack of access to quality care for individuals with disabilities.

Patient–provider communication is particularly challenging among patients with communication disabilities. Physicians have described feelings of anxiety, inadequacy and fear when working with patients who have communication disabilities [22]. In one study, physicians reported difficulty diagnosing and prescribing treatments for those with significant communication and cognitive disabilities [11]. They felt unable to adequately gather a medical history and current medical information, which in turn caused them to be cautious in making definitive diagnoses. In this same study, physicians expressed concerns in conducting invasive, complex, or time-consuming examinations because they felt they had inadequate evidence to support the examination and did not know how the patient would react to the examination [11]. This attitude can result in providers being described as making decisions for individuals with communication and cognitive disabilities and excluding them from discussions, negotiations or decisions relating to their care [22].

While patients with communication disabilities receive care from a variety of providers, encounters in primary care are particularly important and challenging. First, visits for primary care services are common. There is no specific data on people with disabilities use of primary care services, although, 50.6% of outpatient visits in the United States are general care visits (this includes primary care, internal medicine and pediatrics) [23]. Second, primary care providers are likely to have less awareness and training in how to communicate effectively with individuals who have communication disorders [11]. Finally, communication in these medical encounters is inherently demanding [24].

Methods
Participants
All participants had a diagnosed communication disability and were using AAC systems and methods for at least six months. AAC was broadly defined to include high-tech devices and other low and no-tech options such as gestures and writing. Participation was not restricted by diagnosis or severity of speech disability. Individuals with acquired disabilities such as amyotrophic lateral sclerosis (ALS) and individuals with developmental disabilities such as cerebral palsy (CP) were recruited. Purposeful sampling, or sampling of certain diagnosis groups, occurred to obtain a diverse participant pool. To participate, participants were required to be their own legal medical decision makers (which we determined by self-report). This was used as an indication that the participants had adequate language and cognitive abilities to be able to participate in the study.

A total of 12 individuals participated in the study. All participants took part in individual face-to-face interviews, with four participating in an online focus group. Of the 12 participants, half were female and half were male. Five had a diagnosis of CP, one with undifferentiated developmental disability, one with head and neck cancer who had undergone surgery, three with ALS and two with primary lateral sclerosis (PLS). Participants with CP and the undifferentiated developmental disability will be described as the developmental disability group, and the participants with head and neck cancer, ALS and PLS will be described as members of the acquired disability group. See Table 1 for a list of the participants' diagnoses, time since diagnosis, age and years of education.

All participants lived within suburban or urban areas in the Pacific Northwest in the United States and lived in the community either by themselves or with family. The age of the participants ranged from 31 to 69 years with a mean age of 47.4 years. For the developmental group, the mean age was 45.7 [31–69] years and for the acquired group, the mean age was 49.2 [36–58] years. All participants had at least 12 years of education. Of the participants with acquired disabilities, the time since diagnosis ranged from 1 to 10 years with the mean length being 5.2 years. All but one participant owned a high-tech AAC dedicated device. The participant who did not have a dedicated AAC device used his phone and a speaking program on his laptop computer to communicate. The participants had been using AAC devices between eight months and more than 12 years.

Participants were asked about their methods of communication with both familiar and unfamiliar communication partners. See Table 2 for a summary of the communication methods they used (and do not use) during what they perceive as successful and unsuccessful medical care interactions.
Table 2. Number of participants who used different types of communication methods.

<table>
<thead>
<tr>
<th>Method</th>
<th>Familiar listener</th>
<th>Unfamiliar listener</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Writing</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Gestures</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Low-tech AAC</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>High-tech AAC</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Other*</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

*Other methods included using devices such as laptop computers and smart phones.

reported using. During the interviews participants used a range of communication methods. Four participants were unable to produce any vocal sounds. The other eight participants used some speech and were judged to have severe dysarthria with reduced speech intelligibility. All participants used gestures to assist in communication. Eight participants used either low-tech or high-tech AAC devices and one participant used writing and two participants used either a laptop computer or smart phone to communicate during the interview.

**Procedures**

To explore the patient–provider communication experiences of individuals who use AAC, a qualitative study that used phenomenological methods was conducted. Phenomenology is a method in which the focus of study is on the experiences of a group of individuals [27–30]. Meaning of a phenomenon is derived from how individuals describe their experiences [28]. The use of a phenomenological method informed all aspects of the research process including the conception of the research question, the design of the methods and the analysis of the data. A set of semi-structured questions consistent with phenomenological methodology was created to explore the experiences of communicating during a medical encounter (see Table 3). All methods were approved by the Human Subjects Division at the University of Washington in Seattle, WA.

Participants were recruited through multiple sources. Advertisement flyers were provided to speech-language pathologists who serve AAC users, AAC device representatives and other rehabilitation providers who have contact with AAC users. In addition, word of mouth and social networking sites were used.

Face-to-face interviews were scheduled at a place and time that was convenient for the study participants and lasted approximately one hour. The participants were provided a copy of the semi-structured interview questions at least one week prior to the interview. This allowed the participants to compose messages and responses to the questions prior to the face-to-face interview if they desired. Each interview was recorded using video and audio digital recorders. Video recording of the interviews was necessary to capture the nonverbal communication strategies used by participants. All identifiable information was masked or coded for confidentiality; such as names, addresses and names of physicians or hospitals. Interviews were transcribed and descriptive memos were written to capture narrations and expressions.

Following the completion and preliminary analysis of the face-to-face interviews, an online focus group via a discussion board was implemented. The discussion board served as a way to member check, or to confirm the preliminary impressions of the experiences described in the face-to-face interviews and to ensure that no other major topics or areas had been overlooked [31]. All 12 of the participants were invited to participate in a focus group. Eight participants did not participate for the following reasons: one had passed away since his interview, one was dealing with serious medical illness, two had difficulty accessing a computer and four were either not interested or too busy by the time the focus group began. Four individuals who had completed face-to-face interviews took part in the focus group: one with ALS, two with PLS, and one with head and neck cancer. Because it was used to member check and no other themes were explored in the online focus group, the researchers believed it was not necessary for all 12 participants be involved in the focus group.

GoPost software from Catalyst Tools at the University of Washington was used for the discussion board. It was a secure, password protected site managed by the researcher. The discussion board was moderated by the same researcher who conducted the face-to-face interviews. Participants who agreed to participate in the focus group were sent information on how to create an account with a unique login name for the board and also instructions on how to use the discussion board including posting a new conversation and replying to others’ comments.

The focus group lasted three weeks and a new topic for conversation was started every three to five days. The participants were asked to respond to the proposed topic question and to each other’s ideas and topics. The participants were able to participate in the discussion board at a time and at a computer of their own choosing. Participants were asked to post at least three times during the course of the discussion board.

**Data analysis**

The video and audio recordings for each participant were viewed at least three times by the researcher who conducted the interviews to accurately transcribe what the participants had communicated during the interview. Recordings were transcribed word for word with nonverbal communication described and included in the transcripts.

The transcripts of both the face-to-face interviews and the online focus groups were independently read and coded by at least two researchers. Responses from both formats were combined for analysis. For the participants who participated in both an interview and the focus group, their transcripts were not linked. The transcripts were entered and coded in NVivo 8, a software program for managing qualitative data. Transcripts were analyzed within and across participants to develop codes. The interviews were analyzed as a whole and no one diagnosis, age or gender group was analyzed separately. It should be noted that no differences were observed between the stories or experiences of participants with developmental disabilities versus participants with acquired disabilities and it was because of this, the data was combined. A list of codes, or descriptors that captured the concepts and ideas discussed in the interviews, was developed from multiple rounds of reading the transcripts [28].

Initially, four of the transcripts were read by two researchers independently who created a list of codes [28]. The researchers then met and discussed their respective codes and the definitions of these codes. The two lists of codes were combined and similar codes were condensed [28]. This list of codes was then applied to another four interviews and additional codes that were not captured in the original list were added by each of the researchers [28]. Again the researchers met and combined and condensed the list of codes. Then the list of codes was then applied to the final four interviews. No other codes were added in the final round of code development. The list of codes were discussed and reviewed with two other members of the research team, who had also read the transcripts and focus group texts. They offered suggestions and comments to the list of codes, in particular how codes with similar concepts and meanings could be consolidated. The focus
Implementing the plan: Participants "fired" physicians when the physicians could not answer their questions, did not talk directly to them, or if they had to prove themselves as cognitively competent.

Relationship building and establishing rapport:
Participants felt as though they were not included or their opinions were not acknowledged.

Decision making:
Participants feel they are not included or their opinions are not acknowledged.

Planning and preparing for the appointment:
The duration of the appointment.

Table 3. Sample questions asked during face-to-face interviews.

<table>
<thead>
<tr>
<th>Themes and subthemes</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Planning and preparing for the appointment</td>
<td>Participants prepared for appointments by rehearsing the appointment in their head, or making a mental checklist.</td>
</tr>
<tr>
<td>Time barriers</td>
<td>Physicians demonstrated that they were rushed and did not have enough time by looking at their watch, talking to the caregivers for a quicker answer, or asking simpler questions to keep the responses by the patients shorter.</td>
</tr>
<tr>
<td>Inappropriate assumptions</td>
<td>Participants with acquired and developmental disabilities equally reported inappropriate assumptions about their cognitive levels.</td>
</tr>
<tr>
<td>Relationship building and establishing rapport</td>
<td>Physicians often began communicating the &quot;wrong&quot; way and with time and more interactions, many eventually learned how to effectively communicate.</td>
</tr>
<tr>
<td>Decision making</td>
<td>Participants were given options when making decisions and often felt as though they were in charge of their care.</td>
</tr>
<tr>
<td>Implementing the plan</td>
<td>Participants &quot;fired&quot; physicians when the physicians could not answer their questions, did not talk directly to them, or if they had to prove themselves as cognitively competent.</td>
</tr>
</tbody>
</table>

Other types of physicians and nurses. These experiences were included in the analysis and reported results.

With each of the six themes three parties were involved: the patient, physician and a third person. All but one of the participants reported bringing someone else into the appointment with them. Typically this third person was a family member, friend or paid aide. This third person was always involved in the patients’ care to some degree, so the inclusive term “caregiver” will be used to refer to this third person.

Participants frequently discussed how caregivers were integral to all parts of the appointment. Participants with acquired diagnoses were asked how roles had changed since diagnosis. They stated that while the physicians’ role and their own had not changed, their caregivers’ role had changed. Caregivers now needed to be available throughout the appointment to physically assist the patient, to serve as an interpreter and to participate in decision making.

The following is a description of the themes and the roles of the players (patient, physician and caregiver) for each theme. Quotes are provided to give examples and highlight the voices of the participants. The quotes are from both the face-to-face interviews and the online focus groups. The original spelling and punctuation
is preserved with the focus group quotes. Descriptions of the participants including gender, age and diagnosis are included as well as if the quote was from the focus group.

Planning and preparing for the appointment

Patients

Many participants reported some type of preparation for their appointments. This could involve rehearsing the appointment in their head, or making a mental checklist of what they would like to cover in the appointment. Several participants reported writing messages, either on paper or in their communication device, for the physicians: descriptions of why they were at the appointment or topics they wanted to discuss. This decreased the energy required to communicate and also saved time in the appointment. One participant created a document that she would bring to all of her appointments. It was a one page sheet with the first paragraph being a quick description of her diagnosis, and her current limitations, including her mobility status and how she would like people to communicate with her. The second paragraph was a list of her current medications. The last paragraph would change for each appointment and was a description of why she was at the appointment and questions she had for the physician. See the appendix for a mock example of the form the participant had created.

Physicians

A majority of participants did not think physicians did anything specific to prepare for their appointments. One participant reported that a physician, well known to her, would ensure that the participant would have appointments at the end of the day or a double appointment, as the physician knew the appointment would likely last longer due to slowed communication. Another participant felt that as physicians became familiar with him and his communication style, including knowing that communication required more time, they seemed to be more conscientious of starting appointments in a more timely manner.

Caregivers

The caregiver was often a part of the preparations for the appointment, including assisting the patient in brainstorming and creating a list of issues to be addressed in the appointment. Caregivers also helped schedule appointments and would call ahead to ensure that necessary equipment was available during the appointment.

Time barriers

Time was a theme that was discussed by all the participants and could be split into three categories: the duration of the appointment, the amount of time dedicated to communication in the appointment and finally the perception of not having enough time conveyed by the physician’s nonverbal communication or language.

Patients

Participants acknowledged that it takes longer for them to communicate than the general population. It physically took longer to express a message and participants stated they need more time in the appointments to think of questions and make decisions. One participant described:

> It takes time for me to type. Waiting is important even when I go on and on. Because I have to type, sometimes it actually takes longer to formulate what I am going to say as opposed to when I could speak. (male, 48, HNC)

Participants varied in their opinions about whether they had adequate time to communicate what they needed during an appointment. When there was not enough time in appointments, participants thought this resulted in insufficient discussion of their concerns and questions. This occurred more often with physicians who were new to them. Participants thought it was the physicians' responsibility to make more time during the appointment for communication.

One participant acknowledged physicians' time pressures, and that longer appointments might not be possible. She reported that even with short appointments, having enough time devoted to communicating within the appointment led to higher quality appointments. In other words, the quality of the interaction often depended on the time available to communicate during the appointment.

Physicians

Almost all participants described feeling as though their physicians were rushed and gave the impression that they did not have enough time to communicate. Physicians demonstrated this by looking at their watch or clock, looking repeatedly at the door, talking to caregivers for a quicker answer, asking simpler questions to keep the responses by the patients shorter or looking over the patient’s shoulder while the patient composed a message. When asked to describe what gives her the impression that the physician does not have enough time, one participant reported:

> You know, kinda fidgety [...] where you can tell they are crawling out of their skin and really, really wanting out. There’s a certain physicality that portrays boredom, and ‘‘oh god I need to be somewhere.’’ [...] You can tell someone wants out. And it is not just looking at their watch repeatedly. You can tell when they’re not really listening and kind of distracted. (female, 44, ALS)

Participants described a multitude of feelings related to the rushed nonverbal and verbal cues physicians gave them, including frustration and anger. The following is a quote from a participant about her feelings, ‘‘When a Doctor is in a hurry or preoccupied looking out the hall for someone else or takes a phone call, then yes I want to scream who’s appointment is this????’’ (female, 56, PLS, focus group).

Several participants felt that it was their responsibility to rush through the appointment when the physicians did not seem to have enough time. Rushing placed pressure on them and made it harder for them to communicate what they wanted or needed. One participant reported that when the time pressure is too much, she will not even try to communicate. ‘‘Rushing doesn’t work. You just get frustrated or decide it will take too long, so you don’t even try.’’ (female, 44, ALS).

Participants felt that often physicians who were not rushed were in specialty clinics or physicians whom they had seen for a long time, as described by one participant:

> She makes extra time so we can communicate, because she knows it takes me longer to get what I have to say put into my communication device. I do feel like I am heard by my primary doctor and I feel good after my appointment with her. (female, 69, CP)

Caregivers

Participants reported that caregivers could be either a help or a hindrance when it came to time barriers. Caregivers often assisted in making conversations more efficient. Participants would turn to...
the caregiver to speak for them in a variety of situations, for example, when the physician did not understand them, when they were asked to repeat statements to multiple providers (e.g., nurse and then the physician) or if there was something complicated to communicate and the caregiver was familiar with the issue. This would increase the rate of communication and require less effort on the part of the patient.

She talks faster. So they ask me about sleep apnea. If you ask me right now to describe a night, the equipment, I would call her in and say ‘‘answer that’’. She gets 200 to 300 words out in the space that takes me 20. (male, 58, ALS)

Nevertheless, some participants reported that the caregivers were not always accurate when communicating for them, and so the patient would have to correct them, which would then take extra time.

Inappropriate assumptions

Patients

Every participant reported experiences of physicians and other providers making inappropriate assumptions about them, typically about their cognitive abilities. Assumptions about cognitive levels were one of the most common themes discussed by the participants and were also the most frustrating and upsetting. Only one participant denied that his cognitive level was questioned. That participant had head and neck cancer and was the only participant who did not also have a mobility disability. He did, however, report experiencing assumptions about him being deaf.

Participants wanted to be treated like other patients, or in the case of participants with acquired disabilities, the way they were prior to their diagnosis. In response to assumptions, participants felt they had to assert themselves and educate the physician. Participants saw it as their responsibility to educate the physician about themselves and their communication system or methods. When the participants felt that they were ignored or disregarded in the appointment, they reported jumping in or ‘‘pushing’’ themselves into the conversation. They discussed taking control of appointments, including ensuring that they were in charge and the driver of the interactions.

Physicians

Participants with acquired and developmental disabilities both reported that physicians and staff would make assumptions about their cognitive and education levels. The physicians assumed that the patients did not understand, could not produce answers or did not have opinions.

Inappropriate assumptions made patients feel frustrated, angry and disrespected. Participants felt as though they were not treated like ‘‘normal’’ patients. They felt as though they were invisible, not in the room and not accepted as a competent patient. As one participant stated, ‘‘if they don’t recognize that you are cognitive or competent, then you may as well not be present in the room.’’ (male, 58, ALS). Then when asked how he felt when the physician speaks to his wife instead of him, he replied, ‘‘Like I am not there.’’

Caregivers

Again the caregiver was often spoken to first in appointments because physicians made inappropriate assumptions about the patient’s capacity. Participants with acquired disabilities discussed how this became more common when they became harder to understand. One participant stated, ‘‘As I get slower they ask me simpler questions. Questions you would ask a kid. Turning to my caregiver for answers that are lengthy or complex.’’ (male, 58, ALS).

Relationship building and rapport establishing

Patients

Participants felt that communication in an appointment is a partnership, and both the physician and patient have communication responsibilities. Participants reported that it is their role to come in with an established method of communication and then, in some cases, to teach the physician how to effectively communicate with them. The following is an excerpt from a participant’s description of their communication responsibilities in an appointment.

As far as ‘‘teaching’’ or ‘‘adapting’’ is concerned, I believe it is everyone’s responsibility involved in a communication setting to seek out and meet the needs of the listener in order to have successful communications. To me this means that I try to go out of my way to make sure that I know that the doctor understands my concerns or issues and that the doctor goes out of his/her way to make sure that their message is understood by me. (male, 48, HNC, focus group)

Participants reported frustrations with themselves when they perceived the communication was not effective, or not all of their questions were answered. Participants stated that it was their responsibility to ask questions and make sure that all of their concerns were met. Additionally, they needed to remember all of the reasons for the appointment and to set the agenda. Some reported that it was their responsibility to ensure that physicians understood them. Not only did the physicians need to be patient with them but they needed to be with the physicians as well, especially when the physicians were having a hard time understanding them.

Participants thought it was their role and responsibility to take charge of their health and healthcare, including being an advocate for themselves because no one else would do this. One participant had the following statement about his responsibilities: ‘‘Along the decline I have learned that I need to take my health into my own hands because they are not there to fight for me. That’s my job.’’ (male, 36, ALS).

When participants were asked what advice they had for other AAC users, they reported that AAC users need to be advocates for themselves, know that they are competent, talk as much as they can in appointments, ask lots of questions, be considerate with the physician and the situation, and finally, be positive.

Physicians

Participants reported that physicians had a learning curve when initially interacting with them. Physicians often began communicating the ‘‘wrong’’ way and then with time and more interactions, many physicians eventually learned how to effectively communicate with them. The following is one participant’s description of visiting a new physician and the emotions she feels with these appointments.

It is always hard if it is someone new to me. First time appointments. So I just have accepted that it will be what happens. Then in certain instances I react badly after wards. […] when I leave it hits me, I am exhausted, cry/laugh non stop till I feel better. (female, 56, PLS, focus group)

Physician behaviors that frustrated the patients included looking at a caregiver and not the patient or not looking at the
patient while the patient was communicating. When a patient was using an AAC system, physicians would also look over the shoulder of the patient and read what he/she wrote or would move on to a different topic before the patient had finished composing his/her message. Physicians were also inflexible and did not attempt to learn or adapt to the way the patient communicated, which included adapting how they interviewed the patient and the types and format of questions they asked. Participants wanted physicians to ask at the beginning of the appointment how the patient would like to communicate and then throughout the appointment, admit or stop the patient when they did not understand what the patient said. Patients did not expect perfection from the physicians, but a willingness to learn and work with them.

Caregivers

Participants reported relying on the caregiver to help formulate and ask additional questions. Caregivers again served as an interpreter, especially when the patient was becoming tired from communicating or the physician could not understand them. One participant reported that he would become fatigued from communicating, so his wife would assist with ensuring that appointments did not last too long and she would negotiate the communication time.

Caregivers could be a hindrance in that some physicians seemed to prefer talking with the caregiver rather than with the patient, thus not allowing for their relationship or rapport to build with the patient. Several participants reported the importance of taking a caregiver who knew them well and was knowledgeable about their care and their current medical issues.

Decision making

Patients

Despite almost all participants describing assumptions being made about their cognitive levels, almost all reported feeling as though they were their own decision makers and that decisions they made were respected. Participants felt that the physicians gave them options when making decisions. As one participant reported, he felt as though he was in charge of his care and that the providers worked for him.

Two participants shared stories of when they felt that their position as a decision maker was questioned, and their thoughts and opinions were not respected. One participant stated her medical team and friends (who were involved in her care) wanted her to move to a long-term care facility, which she was opposed to for multiple reasons. According to her, they “conspired” to make her move, but ultimately it was her decision whether or not to move.

Another participant told the following story of when he was admitted to the hospital, and was voicing that he wanted to go home, but felt that this was not respected or even heard by the physician.

He was only using the medical data to decide, um, whether to keep me or not, and I was saying ‘send me home, send me home.’ And they wouldn’t listen at all. And that was extremely frustrating. Because of that, I will never allow myself an overnight in the hospital again. […] I think it falls down to people in my condition are not viewed as people at the same level as healthy people. (male, 36, ALS)

Physicians

Participants appreciated hearing a physician’s opinion about their medical care when a decision needed to be made, but they did not want the physician to make the decisions for them. Participants were frustrated when physicians would assume that the caregivers were in control and primarily talked to them about decisions.

Caregivers

Almost uniformly, participants stated that caregivers were involved in their decision-making process. These people were heavily involved in their lives and care and, according to the participants, knew them best. Participants also reported that their families, including young children, were involved and reported a sense of responsibility to consider all members of the family in their decisions.

Participants reported that often caregivers were co-processors, would help them reason through options and assisted in the final decision making. One participant gave the following description about how he viewed his wife’s role in the decision-making process:

My spouse is there to help me remember all of my (our) questions, to come up with and ask more questions as information is provided that sheds new light on whatever the issue is. Then I expect my spouse to give me her input and wishes are, but I have to make my best decision based on all the input provided by all involved and then it is the providers responsibility to help carry out that decision. (male, 48, HNC, focus group)

Implementing a treatment plan

Patients

Participants described two potential outcomes of appointments. First, they reported going home satisfied with the care they received, including the communication interaction, and were able to implement the treatment plan discussed in the appointment. The second outcome resulted in them feeling that the communication was not successful, and so they would reject the care and/or not return to the physician or medical care facility.

Participants reported sometimes not returning to physicians or ‘firing’ physicians when the physicians could not answer their questions, if the physicians did not talk directly to them, if they had to prove themselves as cognitively competent, if they had to teach the physicians about themselves and their disability, and finally, if they perceived the physicians to be uneducated about disability issues, such as adaptive devices. Participants reported ‘shopping around’ to find a physician who knew how to communicate with them.

One participant described going to see a specialist about Botox injections in her legs. When she went to the appointment, she felt that the physician was unwilling to talk with her or answer her questions, and she had the following reaction:

I was going to try Botox on my left leg because it is bent, so I made an appointment and went. The doctor would not allow me to ask questions and he kept saying that he knew all he wanted to know. […] I didn’t go back to him and I didn’t do Botox. (female, 69, CP)

Physicians

Overall, the participants did not describe any issues or concerns with physicians in the implementation phase of their care, except that it was voiced by several participants that physicians did not have time to provide follow-up care.

Caregivers

Participants stated that it was important for their caregivers to help remember what was discussed in an appointment,
including writing down information, so they could assist in the follow-up care.

Discussion

Twelve individuals who use AAC systems and methods to communicate were recruited to share their experiences communicating with physicians. Participants shared similar stories and experiences about the frustrations and successes of communicating with their physicians. There was unanimous consensus that inappropriate assumptions were made about them and their cognitive level. These assumptions led to a series of behaviors in which the physician appeared to ignore them, and be impatient, rushed and/or disrespectful. Participants reported that these behaviors occurred more frequently with physicians who were new to them. Providers who knew them or had experience communicating with people with communication disabilities, tended to treat them with respect and like other patients (or in the case of acquired disabilities, treated like they were prior to their diagnosis).

The results of the study are consistent with previous research studies that have examined the satisfaction of people with communication disabilities with their medical care. As Hoffman et al. [32] reported, Medicare beneficiaries with communication disabilities reported decrease satisfaction with their medical care [32]. The present research study provides more granular and descriptive data on what may be contributing to the dissatisfaction of this population, specifically how communication barriers during patient–provider communication negatively impact appointments. The experiences of the participants in this study are similar to the experiences of participants in several other studies. Murphy [15] conducted a qualitative study with people with aphasia and learning difficulties to learn about their perceptions of communication in a general practice. In this study, participants discussed the importance of a caregiver assisting with communication during the appointment. Ziviani et al. [11] in their qualitative study that involved people with cognitive disabilities, their caregivers and primary care physicians who see patients with cognitive disabilities, reported themes of time pressures, physicians being unaware or inexperienced with how to interact with patients with cognitive disabilities, and patients wanting to be looked at and spoken to during the appointment; again themes and concepts that were discussed in the present study. The participants’ descriptions of how they were treated were quite similar to how the participants in this study reported being treated. This highlights again the physicians’ inappropriate assumption that patients with communication disabilities also have cognitive disabilities.

Limitations of this study include the purposeful sampling of the participant population. All of the participants lived in urban or suburban locations with access to medical care. All had medical insurance and social supports in place. The participants also all had established effective communication systems. The participants were all excellent advocates for themselves which included asserting themselves and feeling as though they were in control of their health and healthcare. This profile might not be typical for all individuals with communication disabilities. The study population was self-selected and each participant was required to have computer and Internet access to participate in the online focus group. The results cannot necessarily be generalized to all individuals with communication disabilities. The results of this study have implications for physicians and providers, patients with communication disabilities, especially those who use AAC systems and methods, and finally, for caregivers, both paid and unpaid, who attend appointments with patients with communication disabilities. The implications could be immediately implemented and potentially have a considerable impact on the quality of care of patients with communication disabilities.

Patients with communication disabilities can contribute to effective and efficient communication in appointments by preparing for appointments. As was described by one participant, patients can prepare by creating a sheet with their medication list, a description of their disability and goals of the appointment. Preparing for appointments is an effective strategy for all patients with or without communication disabilities. It was evident that a key component of the success of an appointment was the patient’s willingness to be their own advocate. Patients, both with or without communication disabilities, should know that they are in charge of their health and their bodies and need to advocate for what they need and want. This includes letting the physician know how they want to communicate, insisting that the physician talks with them directly and not to a caregiver, and switching providers if they feel as though they will not be able to obtain satisfactory care from a physician.

Caregivers need to be educated about their roles and how they can help make the appointment efficient and successful. For example, when they serve as interpreters they need to understand that they are simply repeating what the patient said and that if they would like to interject their own opinion (which might be appropriate and welcomed depending on the patient and situation), they need to indicate that it is their own opinion and they are not speaking for the patient. Study participants reported that caregivers need to come prepared to the appointment as well; for example, bringing any documentation to the appointment and a pen and paper to take notes, as they will be assisting in implementing the plan following the appointment.

A major complaint of the participants was that primary care physicians were not knowledgeable about how to interact with them, whereas specialty physicians, such as neurologists, were prepared and experienced with whatever communication system they used. Specialty physicians who have experience working with these types of patients need to take a leadership role to advocate for their patients by educating their medical care peers. One simple method to do this would be to include a statement in the appointment documentation about the patient’s communication disability with a brief description of how the patient communicated during the appointment. Included in this should be a statement about whether a caregiver was present and what his/her role in the medical encounter was.

Multiple participants thought that during medical school, providers should be taught communication skills, particularly skills in communicating with patients who have communication disabilities. Once considered a minor subject, communication skills are now an essential part of medical school curriculum [33–35]. There has been little attention and research focused on methods to teach general communication skills to physicians [36]. Nevertheless, research has shown that training programs in medical school are effective in improving communication skills, but the skills can be forgotten if not reinforced throughout the medical education system [34]. The typical model is to teach communication skills during the first years of medical school, but not reinforce them during clerkship or residency years [34]. Therefore, communication training programs that include skills to communicate with patients with communication disabilities should be integrated into all levels of
education, and throughout all years of medical school and residency.

Training needs to occur not only for new physicians, but also for those who are currently practicing. Studies have shown that communication skills do not necessarily improve with experience [37]. Unfortunately, the majority of continuing medical education courses focus on technical and biomedical aspects of medical care rather than communication skills [35]. When physicians participate in training courses for communication skills, research has shown it can make a difference in both physicians’ behavior and patient outcomes [33]. Because no curriculum exists that targets teaching practicing physicians how to communicate with patients with communication disabilities, curriculum needs to be developed for practicing physicians and other medical care providers.

Improving patient–provider communication requires a team approach in which each player, the patient, physician and caregiver contributes. Through education and improved methods, these players can contribute to patient–provider communication that will be respectful, inclusive and timely, which will ultimately lead to effective patient–provider communication and improve the quality of care received by patients with communication disabilities.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Appendix: mock form based on participant’s form for physicians

About me:
I was diagnosed with ALS in 2004. It has progressed and has affected my speech and my walking. I use a walker to help me get around in my house, outside, and in the public. I type in messages into my iPhone and make it speak for me when people have a hard time understanding me. I still like to use my speech sometimes to communicate, so if you are having a hard time understanding me, let me know what you did and did not understand and I will repeat it with my iPhone. My ALS has not affected my thinking abilities.

Current medications:
- Rilutek (10 mg)
- Lorazepam (5 mg)
- Protonix (40 mg)
- Multivitamin

Why I’m here:
- I am having trouble sleeping at night.
- I have questions about non-medication ways to treat my heartburn.