"At times avuncular and cantankerous, with the reflexes of a mongoose": Understanding Self-Expression through Augmentative and Alternative Communication Devices

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ABSTRACT

Amyotrophic Lateral Sclerosis (ALS) is a disease that causes individuals to lose their ability to control their muscles, eventually leaving them unable to speak or write. People with ALS often transition to using an augmentative and alternative communication device (AAC), which requires both the AAC user and their conversation partners to adjust to new and different communication patterns. We conducted interviews with seven individuals with ALS and their partners, focusing on how AAC use has impacted their communication and personal expression. Our participants experienced a range of communication difficulties, including conversational pacing, personality expression, and interacting with unfamiliar conversational partners. Participants worked to adapt their communication behaviors to the AAC device, but still experienced challenges in expressing themselves, and sometimes felt compelled to withdraw from social interaction. By improving our understanding of how people transition to using AAC, we may inform improved designs for future AAC devices.

Author Keywords

AAC; speech generation; gaze interfaces; ALS; locked-in syndromes; paralysis; communication disabilities.

ACM Classification Keywords

K.4.2. Computers and society: social issues – *assistive technologies for persons with disabilities*.

INTRODUCTION

ALS is a neurodegenerative disease that affects approximately 1 in 50,000 people worldwide [1]. Over months or years, ALS reduces an individual's ability to move their muscles until they become unable to walk, speak, and breathe. As people with ALS lose the ability to speak, they often turn to augmentative and alternative

communication (AAC) devices to supplement or replace written and spoken communication [5]. People with ALS typically retain movement in their eyes while losing control over other voluntary muscles; thus people with advanced ALS typically control AAC devices using eye gaze [4].

Individuals who adopt AAC systems face many challenges, and must adapt their communication strategies to their new abilities. Perhaps most salient is the incredibly slow speed of eye gaze input. In practice, eye gaze keyboard input allows users to communicate at 10 to 20 words per minute (wpm) [27], as opposed to a rate of 180 wpm for spoken speech [47]. Furthermore, eye tracking user interfaces can be error prone, especially in environments with significant infrared light, such as outdoors [26]. Even with perfect eye tracking accuracy, the theoretical maximum throughput of an eye tracking keyboard has been estimated to be only 46 wpm [19]. Thus, we should expect that eye gaze AAC users will continue to lag significantly behind others in communication speed. In addition to slow input, most AAC devices produce flat and unarticulated speech and use generic voices that may not match the user's preferred voice, which can impair face-to-face conversations [31].

With medical advances prolonging the lives of those with ALS [1], and the availability of eye tracking technology to support communication even when individuals lose control of other body movements, people today may spend more time living with ALS than in previous generations. This means spending more time living with AAC as the primary means of communication. Thus, designing effective AAC devices can significantly improve quality of life for people with ALS. As prominent ALS advocate Steve Gleason notes on his foundation's website, "until there is a medical treatment or cure [for ALS], technology can be a cure" [13].

In this paper, we explore the challenges of maintaining authentic communication while using an AAC device, and during the transition from unmediated to AAC-mediated speech. Using AAC can affect many aspects of communication, including emotional expressivity, responsiveness, and communicating in ways that represent the user's personality before ALS. To explore how communicative abilities change with the onset of AAC use, and how individuals with ALS currently adapt their behavior to overcome communication limitations, we

conducted interviews with seven People with ALS (PALS) and their close communication partners. Our interviews explored how PALS and their partners perceived their personality and communication style, how their ability to express themselves has changed over time, and how they have adapted to these changes. Our findings illuminate the gaps present in current communication aids, and identify areas where AAC technology could better support people with ALS and related conditions in communicating authentically and expressively.

The contributions of this work are: 1) insights from interviews with PALS and their caregivers about the transition from independent communication to AAC, and the effects of that transition on communication and self-expression; 2) holistic metrics for assessing AAC use to support people with ALS and related conditions; and 3) design recommendations that may address communication issues as individuals transition from independent to AAC-supported communication.

RELATED WORK

AAC Devices for People with ALS
The majority of people with ALS will experience difficulties with speech, and many will rely upon AAC to support communication. As ALS is typically acquired during adulthood and does not generally impact cognitive function, most PALS will use AAC devices that involve typing out phrases with a keyboard, rather than using more simple symbolic AAC systems [5]. People with ALS may first operate AAC devices with their hands, but many will transition to slower and more error-prone eye-gaze AAC systems as they progressively lose motor control [17].

Improving the speed of AAC output has been a primary focus of gaze-based AAC research. Because eye-gaze users often cannot click a key to select it, they instead must hold their gaze on a key for a fixed time period (known as *dwell*) to select the key. Typical dwell times range from 450-1000 milliseconds per key, but with well-calibrated dwell times and accurate eye trackers, gaze-based typing systems can approach 20 wpm, although this performance has been reported only for users without disabilities [25]. "Dwell-free" eye keyboards [19] promise to improve typing speed by considering the user's gaze path over an entire word without dwelling, much as stroke-based keyboards can enable faster text entry on mobile devices by enabling users to write an entire word with one gesture [48]. However, current dwell-free eye gaze keyboard implementations have not shown performance benefits beyond dwell-based keyboards [20,32]. Non-traditional text entry techniques, such as Dasher, have reported between 23 and 25 wpm for eye-gaze based text entry, which presents a marginal improvement over dwell-based typing but requires mastering a new text entry method [38,43]. Predicting and suggesting words as they are typed can reduce the number of selections needed to enter a word: predictions can be based on language models [37], and may also be enhanced

with information about the user's task [16] or location [11]. However, none of these techniques can raise the rate of eye typing to even half that of spoken conversation, and thus the AAC user's conversation partner must often pause and wait for the AAC user to complete their sentence.

Another way to improve the speed and responsiveness of AAC is to provide easier access to predefined or saved text [27]; however, this typically requires users to create their own saved texts or choose from a limited selection of premade text phrases, and still requires slow and error-prone gaze techniques to search for or navigate among these pre-composed messages. Some systems have explored using natural language generation to support AAC users in storytelling [34] and even telling jokes [42], but these approaches have not been widely adopted.

A second major area of innovation is in improving the quality of text-to-speech output from AAC devices. Poor quality speech is seen as a significant negative factor in AAC use [31]. Recent research has explored creating personalized voices that can match the user's previous speaking voice [40,46]. These approaches require individuals to perform *voice banking* by recording a set of spoken phrases. Voice banking is currently time consuming and can be impossible if the patient loses their speech capabilities rapidly, although recent research has reduced the number of phrases that need to be recorded.

Communication Needs and Preferences of AAC Users
Several studies have explored the impact of AAC technology on people with ALS. Beukelman et al. note that AAC technologies are adopted at a high rate by people with ALS [4]. Caligari et al. found that AAC improved communication and quality of life for people with ALS, and that computer-based AAC provided benefits beyond non-electronic communication boards ("e-tran boards") [7]. A study of caregivers of people with ALS revealed PALS primarily used their AAC devices for expressing needs, conveying information, and maintaining social closeness [10]. Murphy interviewed 15 people with early-stage ALS and their communication partners, and found that many had difficulty interacting with their AAC devices [31].

While not focusing specifically on ALS, several studies have explored the unmet needs and challenges of AAC users. Wickenden conducted ethnographic research with a group of teenage AAC users, and found that they often felt like they stood out due to their use of an artificial voice, and sometimes struggled to communicate with strangers, but were able to communicate comfortably with experienced conversation partners such as close friends and family [44]. Baxter et al. [3] conducted a systematic review of negative attitudes toward AAC devices, and found that AAC users were concerned with device reliability, time required to generate a message, problems with speech pronunciation and volume, and mismatches between the synthesized speech and the user's natural voice. Portnuff [33] presented a hierarchy of speech synthesis requirements based on his

	Gender	Age	Years w/ ALS	Modes of Communication	Interview Partner
A1	M	49	3	Speech when fatigue is low; EZSpeech on Apple iPad tablet; owns an eye gaze system but has not used it	None
A2	M	48	5	Tobii Dynavox; e-tran board	Wife (P2), Friend (P2b)
A3	M	48	3	Tobii Dynavox; e-tran board	Domestic Partner (P3)
A4	M	53	3	Microsoft Surface tablet with eye tracker; Tobii Dynavox; Apple iPad tablet; hand signals	Wife (P4)
A5	M	51	4	Speech when fatigue is low; Microsoft Surface tablet with eye tracker; Tobii Dynavox; Apple iPhone	Wife (P5), Mother (P5b)
A6	M	39	5	Microsoft Surface tablet with eye tracker; e-tran board	Caregivers (P6, P6b)
A7	F	54	4	Tobii Dynavox; e-tran board; limited vocalizations	Husband (P7)

Table 1. Study participants, modes of communication used, and their chosen conversation partners. Many participants used Tobii Dynavox, a popular eye gaze-enabled AAC device. E-tran (eye transfer) boards are a low-tech AAC device comprising a printed board with letters of the alphabet; PALS indicate letters to their communication partner by blinking or performing eye gestures.

own experiences (echoing Maslow's hierarchy [29]), which includes intelligibility, being "socially interactive", expressiveness, talking to animals, and being able to sing.

While the challenges of using AAC and related technologies by people with ALS has been extensively studied (e.g., [3]), and continues to be studied, this work contributes to this growing body of literature by focusing on breakdowns and workarounds related to expressing one's personality through an AAC device (rather than on performing basic, transactional communications), and in introducing new metrics and design approaches to address these breakdowns through improved human-computer interaction.

HCI and CSCW Issues in Chronic Illness

The HCI and CSCW research communities have previously explored the effects of chronic illness on patients and their families. Unruh and Pratt [39] note that managing illnesses such as cancer can require patients to perform significant work in balancing treatment with ongoing life. Prior work has shown that individuals with chronic illnesses often struggle to maintain relationships as their health status changes [23,24]. Patients with chronic illnesses may reassert their identity and support social relationships through sharing stories [28] and connecting with peers [18,23]. The present work investigates a population that has not been extensively studied within these communities. ALS presents complementary challenges to those researched previously, as PALS are often quickly and severely impaired in their ability to communicate with others, so that any work related to identity construction and relationship management is both impaired by the individual's disease and by the limitations of AAC devices.

INTERVIEW STUDY

To explore how PALS navigate changes around their communication ability, and the extent to which AAC use impacts their self-expression, we conducted an interview study with PALS and their conversation partners.

Participants

We interviewed seven people with ALS (one female). Our interview participants were members of an existing community group that skewed male, although this gender distribution is also influenced by the fact that ALS is more common in men [30]. Participants varied in their communication ability from speaking with moderate difficulty to being entirely dependent on their AAC device. To gain a more robust understanding of our participants, and to provide the participant time to compose responses, PALS were encouraged to invite a close companion (e.g., spouse or close friend) to join in the interview. Table 1 describes our participants and their companions.

While in-depth qualitative research such as interview studies often have relatively small numbers of participants, we acknowledge there are possible limitations of generalizing from a small sample size. For example, it is possible that participants with the motivation, stamina, or communicative ability to participate in our study may have fundamentally different AAC experiences and needs than other ALS patients. However, small samples are an unfortunate reality of conducting research with a small base population of potential participants (the incidence rate of ALS is about one person per 50,000 [1]); further, conducting interviews with AAC-reliant ALS patients is logistically complicated by practical issues including participants' low communication bandwidth, as well as the fatiguing effects of extended communication.

Procedure

We conducted semi-structured interviews in person with each of the participants, at their home or care facility or at our research lab. Each interview session lasted between one and two hours. Our interview protocol addressed the following topics: technologies participants had used or tried to support communication, how the participant expressed his or her personality before ALS through conversation and writing, how the participant has adapted to their changing communication ability, and how technology could improve their ability to communicate and express themselves.

We designed our interview to enable the person with ALS to share their experiences while accommodating the slow output of AAC and the participant's potential fatigue. We emailed each participant a copy of the interview questions several days before our meeting so that they could prepare full or partial answers ahead of time if they wished. We also encouraged participants to send follow-up comments by email if they wished to share anything after the interview. We dynamically adapted the length and detail level of the interview to the communication ability and fatigue level of each participant; for example, when one participant's eye tracker began to experience technical difficulties part way through the interview, we adapted subsequent questions to allow yes/no responses to be conveyed via eye blinks.

To reduce some of the demands of participating in a lengthy interview, and to provide another perspective on the participant's experience, we invited each participant to bring a family member or caregiver to the interview. Six of our seven participants brought one or more conversation partners to the interview. When referring to participants, we use the shorthand A1-A7 to refer to PALS, and P1-7 to refer to the corresponding partner. In three cases, a second partner joined the interview (P2b, P5b, P6b).

Introducing a communication partner to the interview creates a risk that the person with ALS might be less able to contribute to the discussion, for example if the communication partner felt compelled to fill in conversational gaps or talk over the participant. As our research focused on the person with ALS's experiences, we accounted for this concern in several ways. First, we asked participants to choose a communication partner with whom they interacted often. Because the partners knew the person with ALS well, partners typically deferred to the person with ALS, sometimes expanding upon or clarifying their responses, or adding their own complementary perspective. Second, we made it clear before the interview and during the interview that the focus was on the person with ALS, and that the communication partner was there to support the person with ALS as he or she preferred. Finally, as prior research has addressed issues experienced by caregivers of people with ALS (e.g., [8,12]), our questions focused on the experience of the person with ALS only.

We audio recorded each interview and took field notes. Each interview was conducted with at least two of the authors present: one researcher primarily asked questions and led the interview, while the other took notes and asked follow-up questions. The first and second author analyzed the interview discussions and notes, and iteratively grouped them into broader themes using open coding [9].

FINDINGS
Our interviews illuminated three primary themes in participants' AAC-mediated communications: (1) the challenges of participating in real-time conversations; (2) the limitations of AAC technology for expression of core personality attributes; and (3) desires and obstacles relating to interactions with broader audiences beyond immediate caregivers. We discuss the challenges participants experienced in these areas, as well as workarounds that they developed to achieve their communication goals.

Participating in Conversations
The ability for a person with ALS to be an active participant in synchronous conversations while using AAC technology was extremely important both to the people with ALS and to their partners, and impacted self-expression abilities. Several properties of AAC use negatively impacted AAC-mediated conversations, particularly *pacing*, *volume*, and *pronunciation*; participants also commented on the impact of AAC use on changing the nature of their *role* in synchronous conversations.

Pacing
Pacing of communications was the most common source of challenge mentioned by our participants. This included both *conversation-level pacing* of successive bursts of speech, impacting conversational flow and turn-taking, and *utterance-level pacing* of individual components of a block of speech, impacting emphasis and delivery.

Conversation-level pacing was impacted by the low throughput rates of the AAC devices, which resulted in unnaturally long pauses between successive conversational turns, or often in non-sequitur interactions wherein the conversational topic had changed before the AAC user could respond to the prior topic. A4 noted that "group [conversation is] most affected" by these pacing problems, because when he speaks with multiple conversation partners, they tend to fill in the silence while he is composing responses by advancing the conversation to new topics, rather than awaiting his response. However, A2 felt that group conversation had the advantage of giving him extra time to compose his responses while others were chatting amongst themselves. A3 noted that, when using his eye-gaze AAC device, he is "always [a] step behind in conversation." A7 said that these factors made it "difficult, if not impossible, to keep up with the pace of natural conversation." A5 observed, "conversations move quickly, and I don't speak quickly anymore… the correct accuracy never gets out there [since everyone else has moved on] … timing is everything."

Conversation-level pacing was also impacted by lack of feedthrough [2]. Conversational partners often had low awareness of whether the AAC user was composing a response, and thus were unsure whether to wait for a response or continue the conversation. Lack of information about device state meant that conversation partners could be surprised when the AAC user responded. P2 described how her husband has to "burst in" to conversations, and that when her husband "engages the Tobii, it has that interruptive kind of spin to it," though she is familiar enough with this communication style now to understand not to interpret such "interruptions" as rudeness. P2 noted that the slow pacing of conversations with her husband

prompted some conversational partners to become disengaged, describing how "others are a little unnerved, break out the phone [mimics texting] because… of downtime while he's formulating a response…" A6 developed a method for indicating when he wished his conversation partners to wait: he would quickly speak a word that is easy to type, such as "but" or "also," to indicate that he was preparing to say more.

Difficulties with conversation-level pacing also impaired communication when back-and-forth conversation was needed. A3 noted, "[in] arguments, for example, it is really hard to compete [when using AAC]." A7 agreed, stating that "My husband wins every argument now that I'm reliant upon AAC." A4 noted that he could not properly convey sarcasm via AAC because "timing is key [for humor]," though his wife, P4, noted that his jokes seem to still land well "in clinic… but I think that's a context where they [doctors] know to allow time for response."

Lack of control over utterance-level pacing was also an obstacle to effective communication for our interviewees. Typically, the AAC device will read all of the user's composed text at once, providing little or no control over the rate of speech or length of pauses. A4 indicated that a critical feature he would like in his AAC device is the "ability to add delay and emphasis" to rendered speech and the "ability to change speed of delivered [speech]." A1 also expressed a desire for this type of pace control, stating, "I want to be able to control spacing and speed and tone, like pitch… if you could have a dial to control the speed as it's playing or just pause it so someone can talk back and you can have a more natural conversation."

A1 summarized the challenges associated with the lack of utterance-level pacing control when describing a time he had prepared text in his AAC, but was dissatisfied with the outcome: "when I hit speak, there is no pause between my sentences [where I put a hyphen], and that would piss me off because it becomes a run-on… that forces me to type a sentence, hit speak, delete it, and retype a new one… why put a period if it's not going to pause [between sentences]?" Adding punctuation to the text had very little or even no discernable impact on pacing or emphasis in the rendering of speech, which frustrated our participants. A1 also noted, "when I use an exclamation point, it doesn't recognize [to generate that speech more emphatically]."

Some participants noted that humor was particularly difficult to convey without the ability to control inflection and timing of utterance delivery. For example, A7 said, "Each day presents countless frustrations as humor and incisive comments require timing and inflection." A3 notes that with his AAC device he is able to convey "no sense of humor… it [humor] just doesn't come across in the same way… it [the speech rendering] doesn't pause where you would pause, that's a really big one."

Volume

Participants expressed concerns about producing sufficient volume when speaking, and being able to control volume. Increasing the volume of speech was considered crucial for conversations with larger groups of people. A5 expressed that he was often not heard in group conversations. A1 noted that he had simply decreased his participation in group conversations due to their difficulty: "more than two people is rare, if ever."

Four participants indicated that they paired their AAC device (typically a tablet with built-in speakers) with a higher-quality, external speaker to increase the volume and clarity of rendered speech. However, some participants did not use additional speakers for reasons such as lack of technical knowledge, cost, or compatibility issues; even those who did use external speakers often could not use them in certain situations (e.g., due to portability issues, technical malfunctions, etc.). For instance, A1 noted, "An example of one of the limiting agents is that I can't go to a restaurant or somewhere with traffic because I can't project my voice [over the ambient noise]. I have a speaker, an amplifier, but it's cumbersome and I never have it when I really need it, so I avoid all restaurants…"

In addition to audibility, the inability to modulate speech volume also impacted AAC users' social roles. For instance, A5, a parent of young children, noted that he could now only "yell" quietly at his children when disciplining them.

Pronunciation

When using text-to-speech (TTS), mispronunciations were common, including mispronunciations of commonplace words, of proper nouns, of words in foreign languages, and of non-dictionary terms. For example, A3 (who, like all of our participants, was a native English speaker), attempted to add some levity to a greeting by using a Spanish slang phrase "qué onda? [what's happening?]", the pronunciation of which was unintelligible when rendered by his AAC system, whose TTS engine presumably expected input in English only. A3 also attempted to make a celebratory whooping noise by typing "wooooooooooooooooo," but his device ignored the extra vowels in this out-of-dictionary word and rendered a brief "wo."

Both A2 and A3 noted that their systems pronounced their partners' names (which were relatively uncommon names) in very unusual ways. A2 noted that he had to intentionally misspell his wife's name by adding an extra letter "t" in order to force the speech engine to render it more accurately. Several participants described intentionally misspelling common words in order to achieve their preferred pronunciation. For example, A6 would write "werk" instead of "work" to get a more natural-sounding rendering. The need to intentionally misspell words to support better pronunciation impacted AAC users' ability to take advantage of some rate enhancement technologies (word prediction, spelling auto-correction), and ran counter

to the personal tastes and styles of some users, raising concerns about appearing less intelligent or detail-oriented.

Other types of proper nouns, including acronyms, were also problematic for some text-to-speech engines. Ironically, the acronym for "ALS" (a frequent topic of conversation among this demographic) was rendered to sound like the word "alls" by the software used by most participants, unless they doubled their typing effort and halved their communication speed to add spaces or periods after each letter of the acronym ("A.L.S."). While many AAC devices offer the ability to specify custom pronunciations, our participants did not use this feature frequently.

Roles
Our participants described how the shift from natural communication to AAC-mediated interactions had fundamentally altered the role they played in conversations. Particularly for those who had extroverted personalities and had formerly been drivers of conversation, the shift to AAC use relegated them to a more passive role, primarily because they were no longer able to speak quickly or for extended periods of time. Describing his personality before ALS, A6 said, "I think I was a good public speaker. I think I told good stories. I was often the center of conversation. I guess I feel I helped guide conversation, for better or worse, for other participants." Describing her now mostly passive role in conversation, A7 said that she and her husband use FaceTime video chat to communicate with her daughter, but that "[P7] carries the conversation with me nodding, smiling, and punctuating with a word here and there."

This more passive conversational role was challenging not only for PALS to adapt to, but was also difficult for their communication partners. A2 noted, "it is harder for others to adapt to my new communication style." P2 agreed, saying, "I think his family as a whole… they're animated people, so I would say the whole sibling engagement was very spontaneous and there was a lot of banter… and I can definitely say that some have not made the adjustment to silence-engagement-silence-engagement … I think it's uncomfortable [for them]." A1, who described himself as having been very outgoing prior to his illness, recounted an anecdote where two friends came over for dinner, and he was too fatigued to carry the conversation; he noted, "I could tell they were having a really hard time [with my not dominating the conversation as I used to] … the part I've become acutely aware [of] is, we all have a role… there are people who have dinner parties and people who go to them… and I was the one who had them…"

Several participants mentioned that their changes in communication ability have made it more difficult to talk to certain people, and thus do not interact with them as much. Typically, our participants found that these conversation partners could not adapt to the changes in the PALS' communication. A7 wrote, "communication with my family and close friends has diminished or dried up altogether; They are impatient and cannot sit still on a single subject so I may respond or contribute. My mother and many caregivers, assume that my lack of eye contact [because I am looking at the eye tracker], signal [sic] disinterest." A1 commented, "I see with certain friends there's going to be radio silence if I don't provoke them somehow [by driving the conversation]." A3's partner stated, "if somebody's coming over, he'll write an agenda of questions for them… because otherwise it's really awkward…especially for somebody who doesn't come over very often and is not very comfortable with the pauses."

Personality Expression
Participants described a number of situations in which conveying their personality had been impaired by changes in their pacing, volume, and clarity while speaking. Even non-communication aspects of participants' self-expression were impacted by AAC use. A7 lamented that her ability to express herself through fashion was restricted by her gaze-based AAC device: "AAC use influences my make up [sic] and wardrobe choices; it took months to find that my pink Shimmering Diamonds eyeshadow was interfering with my ability to get a good [eye tracker] calibration." Using AAC also had an effect on participants' ability to discuss their interests, express humor, tell stories, and present themselves as competent individuals.

Discussing and Sharing Interests
Topics that participants wanted to talk about went far beyond basic wants and needs, and extended to a diverse set of interests. Some of the topics PALS wished to talk about include gardening, travel, dogs, the environment, philosophy, *Star Wars*, music, and ALS awareness. A7 described a range of topics she liked to discuss: "I'm a passionate person; the environment, social justice, and ableism number among the topics that get me going." Family experiences were another desired topic of conversation. During his interview, A2 shared a long and poignant story he had composed about a family vacation. A6 expressed the desire to discuss his young son's day with him, and to record advice for his son to reflect on in the future. Two participants still used AAC to compose communications related to their careers and to ongoing professional obligations.

Voice Expression and Tone
Most participants expressed dissatisfaction with the options available for synthesized speech. This dissatisfaction concerned both the availability of text-to-speech voices and the expressive qualities of those voices.

As people with ALS lose their ability to speak, they may record specific phrases to play back later, or may voice bank several hundred phrases to create a custom voice font. Three participants (A3, A5, A6) described recording some phrases for posterity, while only one participant (A6) had banked enough speech to create a custom voice font. A6 strongly valued the preservation of his voice, stating, "I absolutely love that I don't have a generic voice."

Our other participants used one of the default voices provided by their AAC system. According to P5, "[A5] missed the window on voice banking." P5 strongly encouraged others with ALS to voice bank early, because the value for loved ones to hear the PALS' voice is "enormous." While it is possible on most AAC systems to switch between predefined voices and to change the default rate or volume of speaking, PALS sometimes did not know how to use this capability. P7 stated, "[A7] doesn't know how to change the voice, this is something that was set for her when she first started using it."

Those who did record voice samples after diagnosis were not always able to use them effectively. One problem occurred when PALS recorded phrases that they no longer needed. P3 described how A3 had banked some phrases that had been appropriate to use only during earlier stages of disease progression, such as phrases related to food that were no longer relevant since he now received nutrition through a feeding tube. Another limitation was that current AAC devices make it difficult to intermingle previously recorded speech and text typed by the AAC user, requiring the user to awkwardly switch between the keyboard application and the stored voice sample application.

Several participants noted that they were dissatisfied with the monotone of their synthesized speech. This especially became a problem when conveying emotion. Participants noted times in which they were unable to convey a specific emotion through their speech. A3 noted that his AAC's delivery "is monotone every time"; A7 stated "emotions don't come through." P2 noted that emotion "is a layer that's missing" from her husband's AAC communications. In addition to rendered speech not conveying the nuance of emotion, the experience of intense emotions could actually impair the effectiveness of eye tracking systems: A7 observed, "Strong emotion hinders Tobii usage, tears confuse eyegaze technology and anger prevents focus."

Participants also noted times their communication falsely suggested emotions that they were not actually feeling. PALS often used terse sentences to communicate quickly and with minimal fatigue, and such brevity was sometimes misconstrued as rudeness by others. A1 commented, "there are only so many please and thank yous you can write." Our participants described how they had learned to be more explicit when communicating emotions. For example, A4 described his strategy: "I just say emotions in the first sentence" [e.g., stating "I am angry"], and A6 stated, "I have to write the words 'I'm disappointed', or 'I'm getting frustrated.'" A4 stated that he feels he is considered "condescending" because of the sound of his AAC device, and that he inadvertently conveys "anger, sadness, [and] misery." A6 noted, "I think I'm heard by others as less compassionate with my voice so non-expressive." A1 described his difficulties conveying emotion to his conversation partners as being similar to communicating with a stranger over text, "that mood or that flavor … when

you read a text from someone you don't know well… that now is how I'm starting to feel with everyone." P6 described how A6's custom voice presented some words with a negative emotional tone, "I always joke with him because the way it reads his voice to say 'not' is very harsh … like if he says 'it's not OK' it says 'it is *not* OK' [very harshly] ... and I'm like 'you're such a dick, dude' ... but it's such a natural communication for us at this point, so I don't even think 'oh, this is how it's programmed to say it.'"

Humor
Several of our participants noted that their ability to share their sense of humor had been negatively affected as their communication abilities changed. As noted earlier in the "Pacing" section, the inability to compose responses quickly or to control the pacing or emphasis of speech playback were key inhibitors of expressing humor. As humor can be expressed in different ways, our participants also found their sense of humor impacted in different ways.

Being able to respond with a quick comeback was described by several participants as being a key aspect of their personality, and this was negatively affected by the slow output of their AAC device. P6 said that before ALS, A6 always had quick jokes, but now he misses the timing and will keep the jokes to himself. A5 states, since his diagnosis, "I'm really a funny guy, but this whole speech impediment thing is wreaking havoc with my [delivery]. I have a dry sense of humor, so... I think I have dumbed down my humor for the masses." A4 said that being humorous had become difficult because of "inflection, word pronunciation, [and the] strange computer voice."

Communicating humor was also impaired by the AAC user's inability to control tone and communicate sarcasm. This lost ability to be sarcastic was significant to our participants. When asked how his AAC technology could be improved overall, A6 stated, "I think speed is the number one factor. And the ability to express sarcasm is number two."

Despite the challenges of being funny while using AAC, some of our participants found that they adapted to use the AAC device itself as a vehicle for humor. Participants noted that certain things sounded humorous simply because they came from the AAC device. When asked to describe his personality in his own words, A3 said that he was "At times avuncular and cantankerous, with the reflexes of a mongoose and a brain like a sieve. A true Renaissance Man, I once grew 17 varieties of green beans."

Using AAC to curse and speak in accents was also popular. A3 saved a few phrases full of curse words. P3 said, "He [A3] wasn't a big swearer before but partly it's because it's just funny to hear it coming out of Tobii." A3 set his device to a default voice that had a thick southern accent because he found the accent humorous. A4 and A6 also sometimes switched their voice settings for humorous effect; A4 switched to a voice with a heavy accent for some jokes,

while A6 sometimes switched his voice to a female voice, and changed his voice settings to impersonate Darth Vader.

Participants also played music back through their AAC devices, sometimes to humorous effect. P6 had saved hip hop songs related to cruising around town on her AAC device, and played them back while moving through hospice in her wheelchair. A2, who used to sing often around the house, now plays music instead. He noted that he also plays music from his children's childhood in order to tease or embarrass them.

Telling Stories

Several participants described themselves as storytellers, and discussed how their changing communication abilities made it difficult or impossible to share stories like they used to. Participants experienced several challenges to telling stories: effort in preparing and delivering the story, their limited ability to control pacing and delivery, and their inability to use expressive voices in storytelling.

While writing long texts required considerable effort, our participants sometimes took the effort to write out detailed stories. A2, A3, A6 and A7 described instances in which they wrote longer conversational pieces that they played back later at an event or gathering. A2 noted he had created and saved over 500 text files composed with his AAC device, many of which contained long and elaborate personal stories. However, managing the saved text files was sometimes difficult. On several occasions, A3 had written long texts to share in a social setting, but accidentally deleted those texts because the AAC device's Delete key was adjacent to the Save key.

The ability to tell a story effectively was also impaired by participants' difficulty in imitating voices and accents. A1 said, "I told long, elaborate stories, and I mimicked my family and friends, and that has been lost, not just to me, but, my friends have pointed that out, that they miss me imitating my grandmother or whatever." A5, who still can speak but is losing control over his voice, said that he loves to impersonate others in stories, but "no one knows… all my voices sound the same."

In addition to telling stories, some participants enjoyed sharing favorite quotations, and stored favorite quotations on their AAC device. A2 and A3 both stored inspirational quotes from historical figures, A3 had stored favorite movie quotes, and A7 stored humorous quotes from cartoons. A7 wrote, "I was under the impression that I could prerecord a particular phrase in a particular voice and looked forward to fun moments where I'd pull up Marvin the Martian saying, *I'm going to dis-in-tuh-grade-you!* … Unfortunately, this is not possible at this point." A7 recorded many of these humorous phrases with the help of her adult daughter, and considered this a bonding experience. A4 saved curse words, which were sometimes removed by his keyboard's auto-correction, and humorous quotes, such as "Hey good lookin' want a ride in my Maserati?".

When writing became difficult, participants sometimes shared other media, such as photos and video, to convey experiences. A7's hospice room was extensively decorated with photographs she had taken, and she and her husband referred to these photos and the stories behind them during their interview. P6 described how A6 sometimes shared videos on his device screen rather than writing out a story he wished to share: "[A6] shows off a lot of pictures and videos... that's an easy way for him to show something without having to describe it or talk about it. He's just like, 'look at this.'"

Expressing Correctness and Precision

Another aspect of personality that was affected by use of the AAC device was the ability to present oneself as competent through proper spelling, grammar, and pronunciation. Extra effort was required to correctly input text into the AAC, and some participants considered this to be very important. A7's husband (P7) stated, "She's still a stickler for spelling things right… she spells something wrong, she backs out and makes sure it's exact, it's gotta be spelled right… it would save her a lot of frustration if she just slanged it and got her point across."

However, some participants struggled to maintain the polish of their communication as writing and speaking became more difficult. A1, who increasingly found speaking and typing to be more difficult, stated "Even in my texting I used to use punctuation and capital letters, I'm that guy, so I've had to let go when I write to anyone and just say 'fuck it' and overlook typos and whatever." A1 also noted that his fatigue was affecting his choice of words when speaking, and stated "I was a wordsmith… I'd say about two years ago I, because my spasticity has forced me to swap out words and I know the word I'm saying at the doctor's is not the one I want, but it's the one I can say smoothly, and it's a problem because than people get the wrong idea ... I mean the whole point is to be understood accurately, and so I don't think I'm accurately able to convey what I wish to anymore, and that is a real, I've grieved that already."

Communicating Concisely

Participants noted a major change in their communication: they now communicated more directly and concisely than they previously did. P2 noted that A2 was able to be more direct than most people because others were aware that communication was costlier, "the bluntness is kind of cool, too, because he doesn't have time to beat around the bush," and, "It might be rude if you and I say it, but for him to say it, it's much more … socially acceptable to say." A5 said, "Somewhere along the line I think I just stopped thinking about it too much, stopped caring about it too much, just worried about getting the point across."

In other cases, the difficulty of communicating made our participants more deliberate about what they chose to say. A5 noted that he sometimes asked himself, "Is what I have to say worth that much effort? … Usually it's not." A1 considers his fatigue when deciding what to say, "I have to

make sure it's worth the effort." When describing his current communication ability, A2 said he is "slower so I always want to say something but just keep it to myself… [I feel] frustration." A3 said, "Tobii is tiring… I'm good for maybe 2 hours." When asked how his communication has changed since his diagnosis, A3 simply said "Economical."

In some cases, the motivation to be clearer and more direct may have actually improved communication ability for our participants. A7 stated, "I think one arena that's improved as a result of AAC use, is my ability to express myself succinctly, when I must."

Interactions with the Wider World

As in prior work studying AAC [44], our participants were often more effective communicating with close companions and in familiar settings, than they were communicating with strangers or in unfamiliar settings. Interacting in public settings or with strangers, interacting with non-adults (including non-humans), and interacting with people on the internet were all difficult.

Communicating in Public

Beyond ambient noise, communication issues such as pacing were particularly problematic when speaking with strangers; for instance, A1 described how clerks in stores did not anticipate the slow pace of AAC communication, and would often be rude or impatient with him as he attempted to complete transactional conversations. A7 described challenges in communicating with nurses in her hospice facility, as there was a high turnover of nursing staff, and because many of the staff were non-native English speakers and seemed to have greater difficulty understanding her computerized speech.

Communicating privately with someone while in a public setting was often difficult, as it is not easy to precisely control the volume of an AAC device to "whisper" to a nearby companion. A6 uses instant messaging on his AAC device to send private messages to his caregivers. When in group settings, A6 also uses a series of rapid blinks to covertly indicate to his caregiver that he wishes to exit a group conversation.

Beyond Adults: Pets, Agents, and Children

Interacting with family pets through AAC also proved challenging. One of our participants, A4, now experiences difficulties interacting with his 15-year-old cat. P4 noted that now that A4 relies on AAC, he "can no longer call the cat" because the cat does not recognize the computer-generated speech as a human voice. The loss of the ability to interact with a beloved family pet may further detract from PALS' quality of life.

Several PALS wanted to interact with conversational agents such as Apple's Siri or Amazon's Echo. While A5 described Siri as "dumb" for not being able to recognize his dysarthric speech, he was able to successfully get Siri to understand computer-generated speech. To send messages using his phone, A5 would type commands with his eye-gaze AAC device, have them spoken aloud, and Siri would listen to and act upon the spoken commands. A6 successfully used computer-generated speech to trigger voice interactions with Echo in a similar manner.

Interacting with young children posed a challenge to the AAC users we interviewed; three of our participants had young children. A5 mentioned that disciplining his children via AAC is difficult because of his inability to modulate volume. A5 also described trying to read bedtime stories to his children via AAC – he eye-types sentences from the book into his speech device, and then has the device play the sentences aloud; the children fill the downtime by looking at the accompanying illustrations while he types. He noted that this interaction worked reasonably well for his children at the moment, since they are preschoolers and read books with relatively small amounts of text and many pictures, but that it might not adapt well as they age into denser books. A5 also noted that his AAC device does not support some types of interactions he used to have with his children, such as singing them to sleep.

A6 described challenges communicating with his pre-school aged son. As his son is not old enough to read, he can only communicate with him using synthesized speech, and his inability to modulate the volume of the synthesized speech means that anything he says to his son is "public" for any other people nearby to hear. A6 also found it difficult to communicate a sense of urgency to his son: "It's almost impossible to express frustration when I'm trying to get [my son] to hustle up and get ready… So I have to use words like '[son], you need to hurry.'" A2 noted that he has replaced singing with his children with playing music from his AAC device. For example, he sometimes plays the theme music aloud from a popular cartoon program when interacting with his children.

Online Interactions

For some participants, online interactions had already been a core part of their lifestyle and identity. For others, online interactions took on an increasingly important role in their post-diagnosis life, in large part because the asynchronous communication pace of online postings was better suited to the capabilities of AAC devices than synchronous conversation. A2 noted, "[I] never wrote before. Now I write like I used to talk." A6 noted that a big change in his communication is that he now writes journals, primarily to record his thoughts for his young son. A7 took up blogging as a way to communicate her thoughts with a large and wide audience. A7, an avid reader before her illness, now enjoyed reading by listening to audio books, and used her AAC device to write reviews of those books to share on the social media site goodreads.com. Some participants also wanted to be able to participate in health-related forums, such as wheelchairjunkie.com or patientslikeme.com. P6 noted that interacting with A6 via social media felt more "normal" and akin to her communications with non-AAC using friends where delays between messages are expected.

Despite the benefits of going online, writing blog or social media posts was still quite difficult due to the low speed and high error rate of AAC communication. Several participants described occasions where they accidentally deleted large blocks of text they had composed before posting/speaking/saving them, a class of error that should be avoidable with better UI design by AAC device makers; the consequences of these deletion errors caused great anguish considering the effort involved in composing these messages. A5, an avid motorcyclist and traveler before his illness, still enjoyed his hobby vicariously by reading and posting to forums like adventurerider.com – however, he expressed concern that as he became increasingly reliant on his AAC device, his ability to effectively participate would be hampered by the device's poor usability: "theoretically I would think I'm going to spend more time [online, as my condition progresses]… but the [AAC device] is a P.O.S. [piece of shit] so I don't use it… [composing a post is] more trouble than it's worth."

Some types of online media were completely inaccessible to AAC users due to compatibility issues. For example, A7 noted that photography used to be a serious hobby of hers before she became ill, but she could no longer operate a camera or photography-related software: "Prior to ALS taking away the use of my limbs, I spent hours on photography and photography-related applications; Photoshop Elements, Phoster, Shutterfly, Instagram, and Photoblog. Now, I'm unable to access any of it."

DISCUSSION

Our research sits at the intersection of two active and complementary research areas. On one side, use of AAC devices by people with ALS has been studied extensively within the rehabilitation and speech language pathology research communities (e.g., [3]). However, while this research has raised awareness of technical issues with current systems, these problems have persisted for many years despite this awareness. On the other side, fundamental improvements in technologies such as speech synthesis (e.g., [40]) and brain-computer interfaces (e.g., [6]) may lead to more fundamental changes in how people with ALS and related conditions may communicate via technology. Progress in these research areas is proceeding, but is not yet here, and we must consider what solutions are possible given current and upcoming technologies.

Our study considers breakdowns and workarounds in the use of AAC by people with ALS and their conversation partners. As HCI researchers, we identify breakdowns in the use of current technologies as opportunities to improve design [45], and consider the effects of environmental and social context on the usability of these technologies [35].

Many of the issues raised by our participants may be addressed using current technology. Our findings suggest that we must consider AAC in a broader sociotechnical context, considering both the varying social and environmental contexts of use, as well as the variety of

intended and unintended uses of these technologies. In the following section, we suggest a series of metrics for measuring AAC device effectiveness that consider the broader use contexts of AAC, and consider the range of needs served by AAC devices. We then discuss guidelines and potential design directions for improved AAC devices, using currently available technology, that may begin to address the challenges in expressing oneself using AAC.

Considering AAC Metrics Beyond Performance

An AAC system can be evaluated in many ways. An HCI perspective may emphasize performance metrics such as speed and accuracy. Research from the speech-language pathology and disability studies community may emphasize how an AAC device supports its user in achieving everyday goals. For example, Light uses the term *communicative competence* to describe effective communication for AAC users that considers the AAC user's ability to use the AAC technology, to participate in social etiquette routines, and to develop compensatory communication strategies [22]. Portnuff [33] considers a hierarchy of communication needs that includes forms of expression such as talking to pets and singing. Our participants frequently emphasized the importance of the social and expressive aspects of their AAC use, providing further support for foregrounding these factors in the design of AAC systems.

In this study, we specifically examined the needs and desires of adults with acquired motor disabilities. People with ALS maintain their regular cognitive abilities, and their ability to process language, but must adapt to drastically different means of expressing themselves. Our participants discussed how their ALS diagnosis affected their ability to present themselves to the world, and discussed what they had lost: close ties with friends, favorite jokes and stories, the perception of being compassionate, humorous, or articulate. Here we consider other ways that researchers and AAC system designers may wish to evaluate AAC technologies, especially in situations where the user has transitioned from one level of communication capability to a more constrained level without accompanying cognitive losses.

Authenticity: A significant theme that emerged in our interviews was how progression of ALS, and adoption of AAC, could change an individual's ability to "sound like themselves." Challenges to expressing one's self may face any AAC user, but may be especially salient for people with ALS and related conditions, as they typically experience a rapid decline in their ability to communicate through traditional means such as speaking, writing, and nonverbal body language, with little or no change in their cognitive abilities. Our participants seemed to share one metric for success with their AAC: whether it enabled them to communicate their ideas, thoughts, and personality as they were previously able to. When participants were unable to interact the way they used to, they often expressed frustration or disappointment, and sometimes

worried that their personality would be misinterpreted or overlooked. Control over communication is key to one's sense of self [15]; being unable to fit in may subject a person to stigma and associated undesirable treatment [14,36].

We use the term *authenticity* to refer to how an AAC user's communication effectively expresses his or her personality, communication style, and sense of humor. Authenticity is related to traditional goals of improving AAC: it may benefit from speeding up the text input rate or increasing the quality of the speech synthesizer. However, authenticity may not always overlap with traditional metrics. For example, higher-quality synthesized speech may be avoided if it does not match the user's perception of their own voice, as demonstrated by Stephen Hawking's continued use of an obsolete speech engine [21]. Authenticity also cuts across technical requirements. Being able to represent oneself as humorous, sarcastic, and quick-witted requires fast text input, an expressive voice, and control over inflection.

Achieving authenticity is a high-level goal for AAC devices, but it is a goal that was shared by the majority of our participants. For people with ALS, authentic communication may be measured in comparison to the individual's personality and communication style before their ALS diagnosis. Our ultimate goal might be to consider an "AAC Turing Test," in which the user's output using AAC is compared to his or her output before using AAC, with success defined as when a judge could not determine which utterances were made using AAC.

Situational Correctness: We should not only consider correctness as whether the user is able to type the characters they intended, and whether the text is grammatically correct, but whether the text correctly matches the user's current context. Correct punctuation may be important when writing so that the writer appears competent, but requiring punctuation for spoken text may simply slow down the user. Our notion of correctness should include the flexibility to communicate non-dictionary terms such as bilingualism, slang, curse words, and wordplay. Ease of changing pronunciation and correcting grammar should be evaluation criteria for AAC devices.

Expressing and Accommodating Emotion: We should consider how AAC output allows the user to express themselves using their own typical vocabulary, tone, and pacing, and to support changes between different levels of expression and emotion, enabling the user to dynamically take on different levels of emotion or seriousness during conversation. A second concern arises when the user's own affective state impairs their ability to communicate, as with A7, who was unable to use her eye-tracking device while crying. Multiple participants commented that they experienced rising frustration (and waning patience) when using their devices, creating a negative feedback loop between user and device. We should ensure that an AAC device functions regardless of its user's emotional state.

Goal-oriented speech: We may wish to consider how a user can achieve a greater variety of goals via their AAC, beyond basic needs such as eating or safety. For example, A4 used his AAC device to help purchase a car by pre-composing phrases he anticipated would be relevant. For very capable AAC users, we may wish to consider new testing scenarios wherein a user must complete a complex task, such as negotiating a purchase or running a meeting.

Conversational metrics: An effective AAC device should maximize the AAC user's ability to participate equally, to take turns with conversation partners, and to direct the conversation when they wish to. Devices could also be measured on their intelligibility to a varied demographic of conversational partners (adults, non-native speakers of the user's language, young children, domesticated animals, computerized agents, etc.).

Improving Authenticity and Expressiveness in AAC

A major area of improvement for AAC would to better support pacing and turn-taking during conversations. Many participants noted that the slow pace of their speech caused confusion during conversation, as their partner did not always know when they were typing, and thus when to wait for them. Future AAC devices could more clearly indicate when the user is typing, or could indicate when the AAC user wishes the conversation partner to wait for them. A1 suggested that AAC devices could also convey the user's mood, such as angry or tired, to help conversational partners communicate better with the AAC user.

We have begun to explore this problem through designing external status indicators that can be attached to the back of an AAC device and provide conversation partners with information about the current status of the AAC user. This design has been based in part on the ellipsis characters that appear when a user is typing a response on many instant messaging platforms. Our prototype AAC status indicator changes color based on whether the user is listening or whether they are typing a response, and can signal when the user is about to speak (Figure 1).
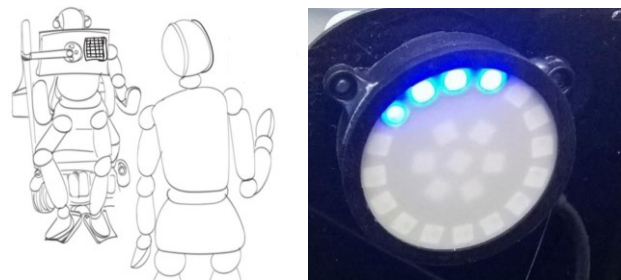

Figure 1. Prototype status indicator to provide conversation partners with information about when an AAC user is typing a response. Left: A system sketch shows indicator attached to AAC device. Right: Our prototype, attached to an AAC device, displays a blue circle pattern while the user is typing.

Another key improvement would be to increase the expressiveness of AAC tools. There may be multiple ways

to achieve this goal. For example, AAC tools could allow users the option of "performing" an utterance as it is synthesized, perhaps by using on-screen buttons or gestures to dynamically control playback rate or volume of individual words or phrases within a larger block of text. Alternately, the user could add clues to their intent through emoji or other special characters, which could be read aloud or displayed on an externally-facing display.

Facilitating smoother transitions between prepared and "live" content would also improve users' AAC experience. Our participants often prepared pre-composed stories or phrases, but sometimes couldn't easily access phrases stored in different apps or on different devices. Some participants played music or showed photos or videos as an alternative to explaining something or telling a story. Future AAC devices could enable users to integrate prepared statements with live comments, and to integrate sounds, photos, and videos into the stream of communication; such multimedia communication could be facilitated by technology designs such as dual-display devices (e.g., a user-facing input display coupled with a partner-facing output display) or through dynamic pairing with the personal mobile devices of conversation partners.

The Need for AAC Corpora and Data Sets

There is a lack of data on the communication habits and patterns of AAC users, particular users such as people with ALS who retain cognitive function and rely on AAC devices to overcome physical limitations in speech production. Other populations who use AAC, such as people with aphasia or cognitive disabilities, may exhibit very different communication patterns and needs.

There are currently no corpora of communications gathered form this audience. Vertanen and Kristensson [41] created a simulated corpus by asking workers on Amazon's Mechanical Turk platform to "imagine they were the user of an AAC device… and invent things they might want to say." The corpus produced through this method envisions AAC users primarily making transactional statements (e.g., "Can I have some water please?" or "Who will drive me to the doctor's office tomorrow?").

While such transactional communications are indeed important to AAC users, and supporting these interactions is clearly necessary for basic health and safety, our interview findings suggest that such simulations may not adequately capture the richness and variety of communications currently expressed via AAC. Our participants used AAC to discuss politics, tell long stories, share jokes, and express their personalities and thoughts in complex ways that a simulated corpus may not capture. Creating datasets of AAC utterances and saved texts would help support development of improved communication technologies by facilitating improved word prediction algorithms, as well as deepening our understanding of the communication needs and goals of this user base.

CONCLUSION

ALS and related conditions can impact the lives of individuals and their families in many ways. Our study explored ways in which the changes brought about by ALS affect a person's ability to stay connected to friends and family, and to interact authentically as themselves in these situations. Our findings highlight several opportunities for improving the usability and functionality of AAC technologies, a need for creating and sharing corpora of AAC speech, and the potential of new evaluation metrics to capture important aspects of AAC use, such as the authenticity of AAC communication to the user's personality and preferred communication style.

While AAC technology can be further improved in supporting even basic communication, there are additional opportunities to better support individuals in how they communicate and authentically express themselves. Our findings suggest that deeper support for preserving users' personality attributes in AAC-mediated communication has the potential to enhance quality of life for AAC users and their communication partners.

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