PALS: <u>P</u>atching <u>ALS</u> through Crowdsourced Advice, Social Links & Public Awareness

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ABSTRACT

Amyotrophic Lateral Sclerosis (ALS) is a serious and poorly understood disease, impacting 50,000 people a year globally. Our research found that people with ALS express a lack of connection with other people with the disease, and that the general public lacks awareness about ALS. We also identified an engagement problem with the currently available resources to connect and support people with ALS. To address these issues, we introduce 'PALS' (Fig. 1) - an accessible crowdsourcing and connection quilt, first hung like a tapestry in the ALS clinic, then later used as an interactive public display. The quilt offers the opportunity to access crowdsourced information concerning individual experiences of ALS. Our work offers three primary contributions: 1) adding to limited HCI research concerning the ALS community by establishing the needs, 2) applying the 'PALS' quilt design solution to these needs, and 3) combining three modalities: crowdsourcing, tangible tapestry displays, and interactive waiting education in a unique way.
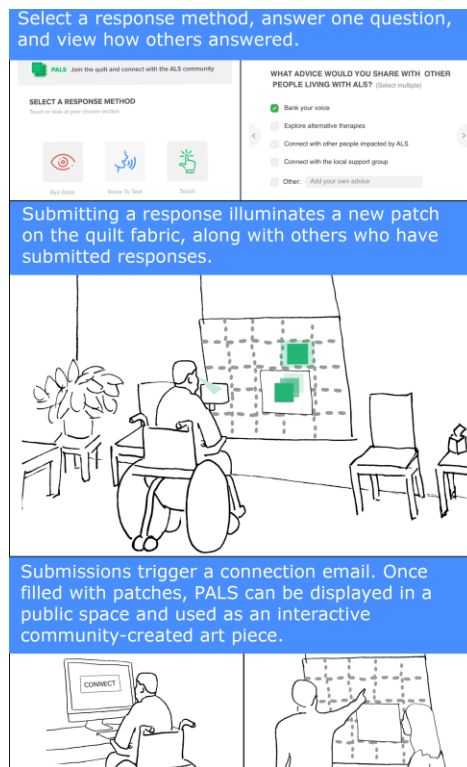
Figure 1: PALS in ALS clinic waiting room and interaction process overview.
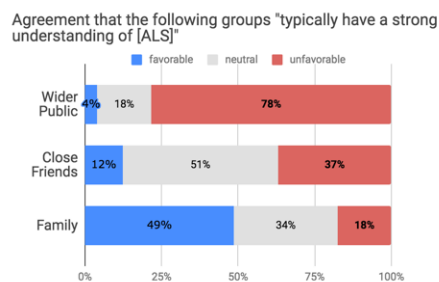

Figure 2: Speech Therapist survey results.

1 INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) - also known as Motor Neurone disease - is a neurodegenerative disease that impacts nerves in the brain and spinal cord, causing weakness, loss of movement, and eventually respiratory failure [10]. The disease impacts 50,000 people a year globally, with more than 50% of those diagnosed dying within two years of the diagnosis [12]. Rapid changes in condition and lifestyle often negatively impact the social connections of those experiencing ALS, and visits to the doctor or clinic have been reported as the most stable form of social interaction [4, 11]. Currently ALS is without a cure and enough funding so it is important to improve awareness and support for those experiencing the disease [10].

Since the media attention around the ALS diagnoses of Lou Gehrig in the 1940s and Stephen Hawking in the 1960s, there has been greater awareness of ALS [10]. Still, researchers more recently investigating public understanding of ALS found awareness to be limited [6], and our findings support this claim in greater London (Fig. 2).

Our initial interests followed current trends in Human-Computer Interaction and ALS, and focused on how assistive technologies are used to support communication [2]. Popular augmentative and alternative communication (AAC) devices such as text-to-speech systems generate a human or synthetic voice based on text input [3]. For those who have lost mobility, eye gaze or voice to text technologies are popular, allowing the user to control the cursor with their eyes or voice.

1.1 Related Work

1.1.1 Active Waiting Education The heterogeneity of ALS can create challenges with medical interpretation and planning, so providing solidarity and alternative insights could improve the experience in the ALS clinic [7]. Visits to the ALS clinic are medical necessity for ALS patients so waiting rooms are frequented by people with ALS and their carers. Current HCI literature has experimented with transforming clinic waiting rooms into informal learning environments [8]. When learning resources were provided in waiting rooms, it elicited collaboration and engagement in an active waiting education (AWE) [8]. We build on this research and attempt to reimagine the waiting room specifically for the ALS community.

1.1.2 Crowdsourcing Crowdsourcing has been identified as a helpful method to collect and assess solutions to problems between communities [4]. For ALS patients, using social comparison and creating understanding between those experiencing the same condition can offer valuable practical and social support [9].

1.1.3 Tangible Displays for Learning and Community Building Placing interactive displays in public areas has in the past been used to improve awareness of illnesses, and the use of a quilt has been used to symbolise community and create a sense of remembrance for the terminally ill (http://www.aidsquiltuk.org/). Previous HCI work has also used interactive displays to connect learning experiences for young people across various settings [1]. Public displays can serve as educational resources, collaborative methods of social documentation, and pieces of art [8].

Comments from User Research

Need to connect people with ALS to each other:

"It's very hard to reach the community of people who have [ALS]. I need to get linked to those people. Don't know how to do that." - interviewee with ALS

"We contacted the MNDA [local UK ALS association] but not linked to anyone." -focus group participant

"Meeting another person who lives with ALS who is at a different stage…may be a good source of support." - survey respondent

Lack of public awareness:

"[ALS] is not commonly understood until it affects someone in your network" - survey respondent

"The wider …only know about [ALS] if they have known someone close who has had it and then they think it is tragic." - survey respondent

Engagement with resources:

"Acceptance and agreement with the diagnosis is often a problem that impacts …accessing of services for support. In my experience people with [ALS] don't ask for as much support because they can only imagine [specific assistive technologies]" - survey respondent
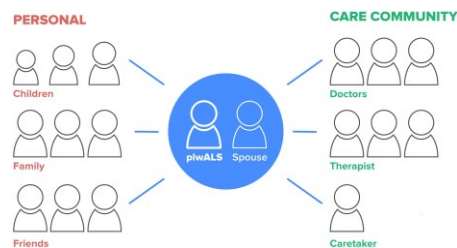
Figure 3: User research results

Figure 4: Relationship map shows strong personal and care community for person with ALS

Studies have shown that the use of textiles, in both virtual and real worlds, can improve psychological and physical well-being [5]. Artists have also used social media to encourage public participation and collaborative 'weaving' of a contemporary tapestry comprised of interactive fibre-optic technologies to display colour, light, and pattern (http://ligoranoreese.net/fiber-optic-tapestry/).

Drawing upon this previous work, our design combines crowdsourcing, tangible interactive displays, textiles, and active waiting education in a new and accessible way to suit the needs of our target community.

2 RESEARCH AND ESTABLISHING REQUIREMENTS

There is little existing HCI work related to the ALS community, so we focused our initial work on conducting user research to learn about the motivations and experience of people with ALS. All research was reviewed and given ethical approval by University College London.

2.1 Research Approach

A mixed methods research design was used to probe about social life and connectedness, being understood, and the care communities of people living with ALS in greater London.

We conducted five semi-structured interviews with participants with ALS (all male, mean age of 60 years, average 10 months since diagnosis), two of these interviews included their spouses. We ran one focus group, comprised of one ALS patient, their spouse, and a Speech and Language Therapist. We also conducted an online survey for which we received 74 responses from Speech Therapy professionals, 96% of whom indicated working with patients with ALS monthly or more frequently, and a mean tenure working with ALS patients of 14.5 years.

2.2 Results

Our triangulated results provided direction to the specific problem space we could tackle and indicated the user requirements for our design. We created an affinity diagram that resulted in three primary insights across the data collection methods we used (Fig. 3):

[1]   Although people with ALS feel well connected to and supported by their partners, family, friends, and care communities (Fig. 4), they often lack connection with other people living with ALS and would like to learn from the experiences of others. The most frequently cited suggestions from Speech Therapists for strengthening social ties for people with ALS related to strengthening an online community between people impacted by ALS (N=11), and connecting people living with ALS to each other (N=8).

[2]   ALS is not well understood by the public. 78% of our Speech Therapist survey respondents disagreed or strongly disagreed that the public has a strong understanding of ALS (Fig. 2).

[3]   Accepting an ALS diagnosis is difficult, and results in an engagement problem with the currently available resources. In London, although an online community forum exists (http://forum.mndassociation.org/forum.php), some of our participants are hesitant to use it and find the experience overwhelming and impersonal. Similarly, there is hesitation in exploring assistive technologies as it's difficult to imagine needing to use those technologies.
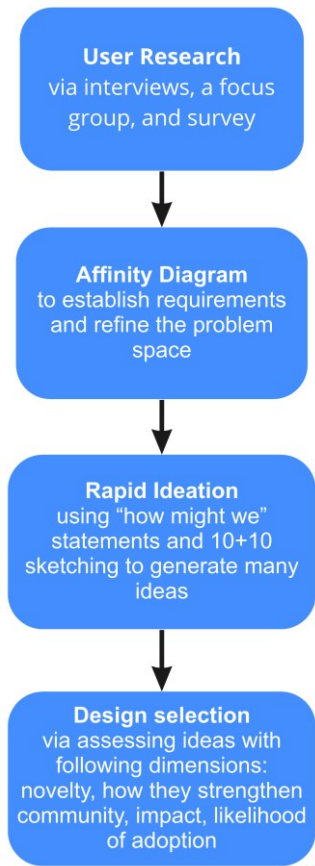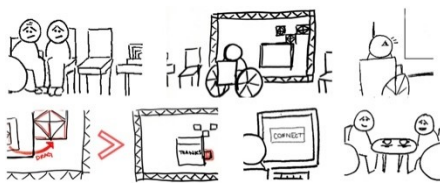
Figure 5: design process flow chart

Figure 6: Early PALS storyboard

2.3 Requirements (Req.)

Based on what we learned, we diagrammed common relationships between the relevant stakeholders and created personas for each: a person living with ALS, their spouse, and a Speech Therapist who works with ALS patients. From these personas, we decided that our intervention must meet the following requirements:

[1] Must accommodate changing physical capabilities including loss of voice and mobility

[2] Needs to promote hope, as purpose and staying positive is important for people impacted

[3] Useful for both people living with ALS and spouses as they approach problems as a unit

[4] Interaction should cater to a non-tech-savvy population

3 DESIGN PROCESS

After establishing the problem space and requirements for our design, we conducted rapid sketching ideation sessions for addressing the two primary insights from our research. We reframed each insight into a "how might we…" statement and brainstormed solutions for each issue. Our design process took a convergence > divergence > convergence trajectory (see Fig. 5 for a process overview). We plotted initial ideas on a 2x2 matrix assessing novelty and extent to which they strengthen community (chosen to ensure our work meets the design brief specification), then narrowed our ideas to those we scored highly for both dimensions. Our rapid ideation sessions had generated some similar ideas, so we grouped them into categories that included crowd-sourcing ALS information, new virtual connections for the ALS community, and location-based 1:1 links for those impacted by ALS. We plotted these ideas on two additional dimensions: impact on our target community, and likelihood of adoption based on user motivations (chosen to ensure our design meets our user requirements). This led us to combine some of the initial idea categories, narrowing the focus of our designs to connecting people impacted by ALS with each other to enable better community support and information sharing.

4 PALS ('Patching ALS')

After storyboarding how we might use technology to reach this goal, we decided to pursue one design that we felt best addressed our findings (Fig. 6). PALS ('Patching ALS') is an interactive crowdsourcing and connection quilt which facilitates connections and information sharing between people directly impacted by ALS, and improves awareness about the disease (Fig. 1).

The PALS quilt is hung like a tapestry in the ALS clinic waiting room and is comprised of an accessible interactive screen embedded within responsive, light-up fabric.

While waiting for their appointment, people with ALS and their spouses can interact with the quilt via eye gaze (in this case utilizing an additional eye-gaze device), voice, or touch. They answer one question about the advice they would give to someone impacted by ALS, can see what others said, then decide if they'd like to connect with someone else who responded similarly.

The interaction creates a custom patch which illuminates on the quilt upon answer submission. If the respondent chooses to connect with someone, this triggers an email introducing them to someone else who also opted in.
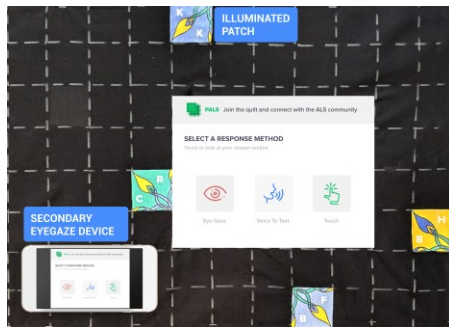
Figure 7: Prototype. Patch could use conductive thread and the Arduino Lilypad kit to create touch-responsive. Illuminating fabric.

Comments from Design Evalution

Confirmatory:

"I looked at the...forum, but I found it difficult to use... I gave up on it. This is...something I'd definitely use... I would love to engage by email or even meet up with people to discuss problems and thoughts. I'm sure we can exchange some really valuable assistance." - interviewee with ALS

"It would be useful for people to be able to...make suggestions. If the outcome is that you link up to people with similar ...aspirations...that would be great." - spouse of interviewee with ALS

"I can see it working really well and people loving it. It's good that...[users could] be matched with different people based on their answers." - principle Speech Therapist

Constructive:

"In a customized chair, they'll need at least 3 feet [and a] secondary remote, something that would connect wirelessly to that screen to allow you to [use it]." -Focus Group participant, assistive technology specialist

Figure 8: Stakeholder and User Feedback

Once the quilt is filled with patches, it can be displayed in a public space as a community-created art piece that helps build ALS awareness. The illuminated patches are interactive – if a patch is pressed, the screen shows an explanation of the ALS advice shared by its owner.

5 EARLY DESIGN EVALUATION AND ITERATION

We gathered initial feedback on our design concept from Speech and Language Therapists working with people with ALS by sharing a description and early illustration of the interaction (similar to Fig. 1) on the @VoiceBankingMND Twitter feed. The response to the concept was largely positive, receiving 14 likes and three confirmatory comments in particular around utilizing the active waiting education with the ALS population. One Speech Therapist commented, "I love this idea! An interactive waiting room." One Therapist expressed hesitation about engagement saying, "Feedback often from people living with ALS is [they] don't want to meet anyone worse and see what's to come." To pressure-test whether there would be interest in engaging with PALS from our target user group, we circled back with one of our participants with ALS, who was enthusiastic about the concept and initial design, describing PALS as "something I'd definitely use." (Fig. 8).

We then created a semi-working prototype using fabric on foam core and an iPad for which we created two click-through prototype applications in Adobe XD (Fig. 7). We conducted two usability sessions utilising the "think-aloud" protocol, one with a person with ALS and their spouse, and another with an assistive technology specialist. Based on findings from those sessions, we updated and combined the user flow for the click-through application prototype (interface screens in Fig. 9).

We brought our prototype to a stakeholder focus group at the Royal Hospital for Neuro-disability in London, comprised of three Speech Therapists, an Occupational Therapist, and two assistive technology professionals, who provided feedback on the design and concept. Overall focus group participants were favourable about the concept, but had concerns about the accessibility of the initial design for eye-gaze, low-mobility, and wheelchair users. They suggested incorporating a separate device that mirrors the PALS screen for these users. Incorporating this feedback, we addressed the accessibility issues identified by adding a secondary device that mirrors the display on the main screen for eye-gaze or low mobility wheelchair users.

Finally, we expanded the design to also address the public awareness problem by designing a simple patch interaction that allows the quilt to also be used as an educational public art piece once it is filled with patches.

6 DISCUSSION

Initial user feedback and reflection on PALS suggests the design addresses the requirements we defined for the group and provides a useful new solution to the problem space. The accessibility of the system via eye-gaze, voice, or touch as well as the secondary screen provide flexibility for varying physical capabilities, allowing user to interact with it regardless the progression of their condition (Req. 1).
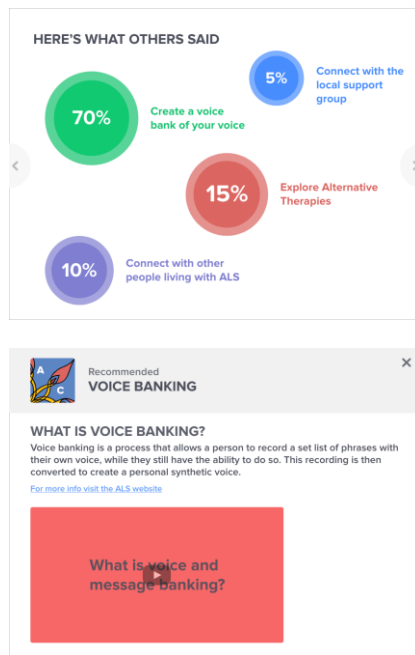
Figure 9: Selected interface screens

Further, it encourages engagement with and awareness of some of the available alternative communication technologies for people with ALS, addressing the engagement problem we identified. The design is useful for both the ALS patient as well as their spouse (Req. 2), as we learned that people attend appointments with their partners, and both can benefit from advice and connection. The positive framing of the advice question helps promote hope, as it provides a chance to learn something that may improve someone's individual experience (Req. 3). Finally, the simplicity of the interaction with the quilt, paired with a follow up email caters to users who may not be very tech savvy, as we found that our ALS participants communicate via email, accessing it with their relevant assistive devices if needed (Req. 4).

Although PALS is designed for people impacted by ALS, the concept of crowdsourcing advice and co-creating a visual of people that are part of a specific community may be useful beyond ALS. For this reason, applications of PALS to other populations where social connection within the community is needed could be explored.

ACKNOWLEDGMENTS

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