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USER CENTERED APPROACH TO THE SUPRA-FUNCTIONAL NEEDS OF PEOPLE LIVING WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS)

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ABSTRACT

User-centered design relies upon the appreciation that assistive technology device solutions need to include the functional and supra-functional (e.g., emotional, social, cultural) needs of users. Developing solutions without basing decision-making on both quantitative (functional) and qualitative (supra-functional) needs can lead to imbalanced devices, services, and/or environments. Satisfying both functional and supra-functional needs is the foundation of user-centered design, which in itself relies upon empathic understanding of the person that one is aiming to serve.

This paper presents a study of the lived experiences of people living with Amyotrophic Lateral Sclerosis, their caregivers, and members of the healthcare management team from a human-centered perspective in the pursuit of pain points, deeper understanding of the emotional needs, and revelation of opportunities for improving quality of life and human experience through more user-centered design. We focus on user-centered design-thinking research tools (e.g., mood boards, journey maps, personas) to (a) understand the authentic experience of the individual in their vernacular and their terminology, and (b) to support a data rich conversation that focuses upon both functional and supra-functional needs to highlight opportunities for design interventions).

Keywords: ALS, empathy, emotional needs

1. INTRODUCTION

Amyotrophic Lateral Sclerosis (ALS) is an idiopathic, fatal neurodegenerative disease that affects nerve cells in the brain and the spinal cord [1]. The progressive nature of ALS leads from mild muscle weakness to complete loss of voluntary movement and mobility. As a consequence, ALS patients depend on increasing assistance from caregivers (familial or paid) and their healthcare management team (e.g., medical providers). To cope with declining motor function, ALS patients utilize a variety of assistive technology devices and services that often must change as the patient's health and functional abilities decline. Many times (often expensive) assistive technology devices are purchased for these patients, but are then frequently abandoned, underused or misused because the design might not have been specifically for ALS patients or ALS patients/caregivers did not have time to learn how to use the device due to the rapid progression of the disease.

ALS is the most common adult-onset motor neuron disease [2]. It usually affects people between the ages of 40 and 70. ALS is a difficult disease to diagnose, averaging 12 months from onset of symptoms to diagnosis. Once diagnosed, about half of ALS patients live for two to three years, 20% of patients live five years or more, and up to 10% will live more than 10 years [3]. Annual cost per patient in the United States has been reported to be $69,475 [2]. It is estimated there are at least 16,000 Americans who have the disease at any given time [1].

Worldwide, the incidence rate is 1.9 per 100,000, and the number of ALS cases has been projected to increase by 69% between 2015 to 2040 (from 222,801 to 376,674, respectively), predominantly due to the aging of the population [2].

Due to the low incidence rates of ALS, research related to this disease and patient quality of life is sparse and only recently have there been efforts to explore these topics [4], [5], [6]. Over the past decade, there has been an increase in studies exploring the care needs and services provided to ALS patients and caregivers (e.g., [7], [8], [9], [10]). Few studies have been published that specifically explore assistive technology devices that have been prescribed or developed for patients with ALS ([11], [12], and [13]). These studies have focused on existing assistive technology devices ([11], [12]) or devices that have been prescribed as standards of care and identifying provision process challenges [13]. No work has yet focused on understanding the appropriateness and emotional impact of current assistive technology devices and the patient's and support network's desired emotional needs.

This paper presents preliminary results of a pilot study to explore the assistive technology device needs of ALS patients, their caregivers, and healthcare management team. This exploration was conducted using interrogative methodologies and visualization tools common in the user-centered design and design research community.

2. MATERIALS AND METHODS

This pilot study involved a comprehensive investigation into the authentic needs of ALS patients, their caregivers, and healthcare management team (via one-to-one interviews and visual design audits of the living environments). The approach was based on the lived experiences (e.g., phenomenology and grounded theory), observing nuanced interaction with their material landscape (e.g., their environment, products they surround themselves with), and the support system (e.g., caregivers, clinicians). Specifically, the aims of the study were to: (1) Conduct videoconference interviews with patients, caregivers, and healthcare management team members to elicit a more holistic perspective of living with ALS and caring for ALS patients. (2) Process population-specific questionnaire data and pictures of patients' environment and assistive technology devices to establish a visual database on the material landscape of ALS patients. (3) Create a list of areas of opportunity to better serve the lives of individuals with ALS by providing a resource to ensure that the voice of the patient with ALS is heard, responded to, and served more effectively.

The study was approved by the Institutional Review Board of the University of Illinois at Urbana-Champaign. Study participants were recruited via email distribution, social media posts, and announcements at virtual meetings of the ALS Association Greater Chicago Chapter. All study participants provided informed consent. All interviews were conducted via videoconferencing.

The focus of the questionnaire was on the social, emotional, cultural, and aspirational needs. Each subgroup received a questionnaire that contained up to 38 questions. Table 1 presents the questionnaire given to ALS patient participants that addressed the topics of demographics (e.g., date of birth, gender identity, etc.), ALS overview (e.g., how would they describe ALS in their perspective), activities of daily living (e.g., how has ALS impacted their ability to feed themselves, prepare meals, utilize transportation, etc.), technology overview (e.g., what technologies and devices have been most valuable and useful for them, what were their resources for learning how to live with ALS, etc.), and challenges with ALS (e.g., what are the most significant challenges that they face while living with ALS, further comments and suggestions, etc.).

TABLE 1: ALS Patient Questionnaire Used in Pilot Study

Demographics
1. Date of birth
2. Gender identity/sex
3. When did your symptoms that could be related to ALS first occur?
4. When were you diagnosed with ALS?
ALS Overview
1. How have you been impacted by ALS?
2. How long have you lived with ALS?
3. How would you describe ALS? In your own words.
4. What keywords would describe ALS from your perspective?
Activities of Daily Living
From your experience, how does ALS impact your ability to:
1. ambulate/change position/walk independently.
2. feed yourself.
3. dress yourself.
4. manage toileting (mental/physical ability).
5. manage your personal hygiene.
6. Continue your employment/career/profession/volunteer work.
7. prepare meals.
8. shopping.
9. communicate (speech, handwriting, typing, using assistive devices)
10. perform housework.
11. manage finances.
12. manage medication.
13. utilize transportation (driving, cab, bus, train).
14. engage in extracurricular activities (hobbies, socializing).
Technology Overview
1. Can you please describe the technologies (assistive tools or devices) that have been most valuable and useful for you?
2. Can you please describe the technologies that have been the least valuable and useful for you?
3. What type of technology or technologies do you wish were available for someone living with ALS?
4. What type of device or devices do you wish were available for someone living with ALS?
5. What type of service or services do you wish were available for someone living with ALS?
6. What type of information do you wish you had been aware of when you were first diagnosed?
7. What were your resources for learning how to live with ALS?
8. Did/where/how you get a list or lists of information?
9. How did you make sense of all of this information?
10. Did you experience an information overload?
11. Is there a ranking of essential information to receive on proceeding through this process? Could you suggest such a ranking?
12. Is there an information gap? Suggestions on how to bridge the gap?
Challenges with ALS
1. What are your most significant challenges while living with ALS?
2. Now that we are toward the conclusion of the interview, what do you believe you do successfully?
3. Any further comments, observations or suggestions?
4. What is one personal moment of "joy" throughout this journey?

The inclusion criteria included all participants to be 18 years or older, have access to an online device (computer, tablet, smartphone), and have access to a videoconferencing software or app (e.g., Zoom, Google Hangouts). For the ALS patient test group, the participant had to be an ALS patient at any stage of disease progression. The ALS patient had to have the ability to comprehend interview questions and/or provide coherent answers, or have another person present to help articulate the answer to an interview question should their ability to speak aloud be diminished or absent due to ALS or other non-cognitive reasons. For the caregiver test group, the participant had to be a caregiver for an ALS patient with at least 320 hour of interaction (e.g., 2 months for 8 hours/day, 5 days/week). For healthcare management team test group, the participant had to be a care management team member with expertise in ALS (e.g., physician, nurse, physical therapist, social worker). To date, we have interviewed five ALS patients at varying disease states, three caregivers (2 familial, 1 paid), and five healthcare management team members (2 nurses, 2 doctors, 1 social worker). The intended sample size goal of this pilot study was five participants from each category. In addition, we interviewed a patient with spinal muscular atrophy, a motor neuron disease that involves lower motor neuron degeneration, due to the amount of interest by the patient. Their results provided additional perspective of lived experiences in adapting to severe immobility in a longer period of time compared to that of an ALS patient.

3. RESULTS

Through the blended qualitative research methods approach, the questionnaire data and photographs were evaluated and translated into design rich information. This process included creating visualizations of the findings into information graphics (e.g., personas, mood boards, journey maps). Based in phenomenology, these tools reveal the vernacular of the person and highlight their visceral needs (e.g., emotions, aspirations, fears, values). Enabling ALS patients, caregivers, and healthcare team members to communicate utilizing such a design tool will add richness to the qualitative data that had not been previously possible. While these visuals support conversation, for the design researcher, they can further fully support the exploratory nature of this study beyond focusing on the significant tangible/functional needs of people.

3.1 Personas

With the research from the patient questionnaire employed within the initial pilot study, we developed a persona for every participant in each subgroup (e.g., patient, caregiver and healthcare management team member). Personas enable the design researcher to appreciate the individual more holistically.

From the patient personas, we were able to demonstrate an understanding of each participant's background (e.g., age, date of diagnosis), obstacles (e.g., difficulties eating due to struggles of swallowing), and examples of helpful and frustrating assistive products they have used (e.g., wheelchairs help transport patient to desired destination safely). These personas helped us summarize the takeaways from their interviews.

ALS Patient
Age: 68
Gender: Male
Symptoms First Occur: Aug 2019
Diagnosis: Feb 2020

Obstacles

Only One activity a Day
- Has to choose between brushing teeth, combing hair or shaving; lifting his head is too exhausting

Bathroom Struggles
- Has difficulties getting up from toilet, has to have sister to shower him, uses laxatives daily

Eating
- Chokes every time he eats, is in need of cough support / suction machines

Dying Dreams
- Future ambitions to open up his clinic was put to a stop

Physician communication
- Getting a hold of specialists is difficult, slow and frustrating

Products Used

Wheelchair – Helpful
- Portable and collapsible enough to bring him to his daughter's dance performances across country

AI (e.g. Amazon Alexa) – Helpful
- Can scream to alert Alexa when he falls or needs urgent attention

Railing – Hindrance
- The railing for him to hold on to in the bathroom was set up on the wrong side for his dominant arm

Bed Slip – Hindrance
- Plastic bed slip slides him down to where his feet hangs off the edge

FIGURE 1: Sample of persona of a study participant (ALS patient)

3.2 Mood boards

The insights of each persona were then used to create a mood board. The mood board is a visual tool that enables users to discuss their personal experiences (in this case living with ALS, caregiving or medically supporting a patient with ALS) [14]. These boards are comprised of non-literal visual elements that support conversation and enable the design researcher to develop a deeper level of understanding and insight into a person's lived experiences and were based on words provided during the participant's interview.

These developed mood boards highlighted the similarities and differences on how each participant and subgroup felt and the personal issues that they faced living with ALS. When mood boards were juxtaposed, these similarities and differences can be quickly and easily seen: patients were focused on the consequences ALS has on their body and lifestyle; caregivers focused on burnout and the changes within the relationship with their patient; healthcare management team members focused on the disconnect and lack of medical advice follow through given to patients; but all participants depicted ALS as a negative change and stressor physically, mentally, and emotionally for all involved.

FIGURE 2: Mood board material based on the interview and questionnaire of an ALS patient

FIGURE 3: Mood board material based on the interview and questionnaire of a caregiver

FIGURE 4: Mood board material based on the interview and questionnaire of a healthcare management team member

3.2 Photographs

A photographic documentation of a number of environments was sent in via email from each ALS patient participant. Photographs of a patient's living environment were collected from each patient and caregiver participant post interviews to support the research and observations of those participants and compliment the insights of the personas. These images included assistive technologies, equipment, tools or products that they use and find helpful or a hindrance. These photographs were used to highlight the assistive devices and environmental factors for those impacted by ALS. Each photograph was then categorized and compiled into a collage by their similarities and functions. Groups included bathroom equipment, house modifications, accessible transportation, body devices, and wheelchairs.

The photographs highlighted that living with ALS requires substantial home modifications for patients to maneuver around in their day-to-day lives. These changes, for example, can include the remodeling of a bathroom (e.g., the installation of handlebars on walls for a patient to hold onto for balance). Although these modifications are to help patients live more safely and independently, these photographs also indicated that these home changes are a daily reminder to patients of their condition and how much more of a financial stressor it is for living with ALS on top of other medical costs.

FIGURE 5: Photographs of participant spaces (provides visual cues)

3.3 Journey Maps

Through the research and insights of the questionnaire data, personas, mood boards and photographs, we generated journey maps for both ALS patient and caregiver. A journey map is a synthetic visualization of a person's process to accomplish a goal.

The journey maps depict what happens at each touch point and phase from their perspective (e.g., ALS patient pre-diagnosis experiences physical symptoms or an incident that requires medical attention). These journey maps visually communicate the individual's emotional state (e.g., graph of emotions, direct quotes from interviews, etc.), needs (e.g., the need to find the cause to the changes within the body), pain points (e.g., change in quality of life), actions they will take

(e.g., get diagnosed), and external role players at the point in time (e.g., doctors, specialists, family members, etc.). This visualization tool allowed us to identify key moments in patient and caregiver experiences for future opportunities in helping improve their quality of lives and the development of assistive products and services.

Figure 6 illustrates a smaller section of a much larger diagram that includes their emotional state, external role players and further touch points within their journey.

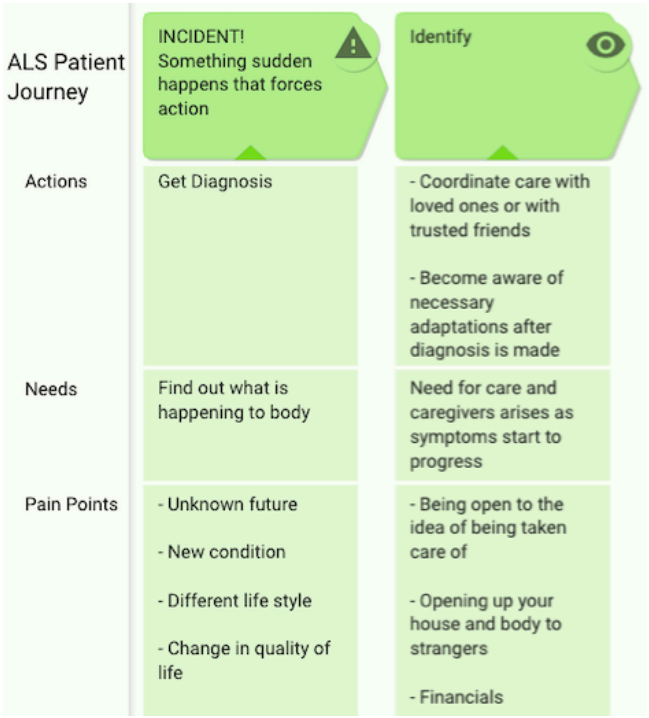

FIGURE 6: Sample of the Journey Map of an ALS Patient (e.g., two touch points, incident and identify, of the journey of an ALS Patient through the phases of pre-diagnosis and post-diagnosis)

4. DISCUSSION

The findings of our research support that after the symptoms of an ALS patient occur, both patients and caregivers encounter a downward turn in quality of life. Furthermore, all participants conveyed that the mental and emotional aspect of ALS is half the battle alongside their physical condition. ALS patients and caregivers can experience significant external and internal stressors that take a toll on them physically, mentally and emotionally. These stressors include financial burdens from house renovations and medical costs. There can be a high rate of anxiety and depression in relation to the patient's physical deterioration and early death. Increased responsibility 'overload' experienced by loved ones (caregivers) transforming into care givers can place significant pressure on familial relationships. The time intensive stressor of independent research on products and plan of action symptoms progress can cause caregiver burnout, and this neglect towards caregivers can be detrimental on both themselves and their patients. If a caregiver burns out from stress, they will not be able to function effectively and provide the necessary care to their patients. It has also been shown that a patient's emotional well-being can influence their physical condition, and thus attention given solely towards a patient's physical wellbeing is not enough when providing them with care [15]. With these in mind, managing the stress levels of both patient and caregiver is crucial in their day-to-day lives.

From the results of the questionnaire data, all participants expressed that assistive products and services contribute to raising their stress levels and frustrations in activities of daily living and quality of life. The research observations convey that timing is critical with ALS (e.g., the time window is short for researching what products to get and when, learning how to use, setting up). If a product arrives after a certain body part needed for the product is affected, the product can no longer be used (e.g., a walker will be unusable when receiving after the patient's legs are affected) and the high price of the assistive technology paid has gone to waste. Though the assistive products have been created to help patients with their daily tasks, if they fail to resonate with the patient or negatively impact the human experience design, the product is then rendered useless. For example, the more features that a bed mattress has, the more complex and crowded the remote control interface will be. This in turn created confusion and mental exhaustion to the patient and caregiver when trying to set up or understand how to operate the bed mattress controls. If the use of a remote control is not easily understood, the users will then find the features of the bed impractical and not utilize. Not only can better user-centered design make products usable and simplify the decision-making process of activities of living, but it can also increase their affordability (e.g., the more unnecessary features a bed mattress provides, the higher the cost it will be that a patient cannot afford). Refining the product design of a product or service to the essential needs of the users can lower cost, and expand its accessibility.

As stress builds and quality of life declines, ALS patient participants have voiced the need to hold onto their dignity, independence, and sense of normalcy in life. Insights have shown the patients want to improve their quality of life without the alienating reminder of their condition. Moreover, assistive devices have the ability to aid them in this process, but are currently adding to their frustrations. Assistive technologies and services should be helping to improve patient and caregiver lives, not worsen their already present issues. With a time critical and degenerative disease that ALS is, product designers and engineers need to carefully consider the specific needs and wants of its users in order for them to effectively and efficiently provide holistic assistance. Not only should these assistive products and services be designed with the ability to adapt to the ALS patient's individual body, but also to their environment, exclusive daily life activities and progression stages. The involvement of user-centered design during the development of assistive products and services can make these devices more acceptable to their users, decrease these existing stressors on patients and caregivers as they cope with their new normal, and help ease the progression of ALS.

5. CONCLUSION

This study highlights the personal side to living with and relying on assistive technology that often focuses on utilitarian functionality alone above supra-functional needs. Empathic user-centered design thinking is a crucial tool in improving the quality of lives for patients living with ALS and their caregivers. Without consideration of the human experience, solutions to their obstacles and problems will not be effective as needed by the users. The development for their products, services, and environments require the balance of both quantitative and qualitative research.

This study employed user-centered design research to complement the work of the wider research team that includes designers, design researchers, engineers, and clinicians providing neurological care. By working concurrently as technology was being developed by the rest of the team, we were able to ensure the 'voice' of the individual that is impacted by ALS was at the heart of the decision making. Integrating the hard sciences with the more visceral qualitative and emotional data based on the highly personalized human experience, values, expectations and often difficult to articulate needs, represents a holistic approach to assistive technology development. Meeting unmet needs of patients is ongoing for this team. Exploring the needs of patients concurrently with the development of assistive technology offers a more holistic approach to new product development resulting in more empathic design outcomes.

Going forward this research will identify areas of user needs, supported by visual data, user testimonies in their vernacular and initial parameters for assistive technology developers the form of a database.

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