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REED, Heath <http://orcid.org/0000-0003-2615-3315>, STANTON, Andrew, SOOD, Avika, JOSHI, Purba and RANE, Mandar

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CONTEXTUAL STUDIES TO UNDERSTAND THE PROBLEMS AND NEEDS OF PEOPLE LIVING WITH ALS/MND THROUGH STAKEHOLDER WORKSHOPS IN INDIA

Heath Reed[1], Andrew Stanton[1], Avika Sood[2], Purba Joshi[3] and Mandar Rane[3]

[1]Lab4Living, Sheffield Hallam University, UK
[2]Ativa, Industrial partner, IN
[3]School of Design, Indian Institute of Technology, IN

Abstract

ALS/MND (amyotrophic lateral sclerosis/motor neurone disease) are currently incurable, progressive neurodegenerative disorder of nerve cells in the brain and spinal cord.
Needs of people who have ALS/MND differ, in part as per their disease progression stage. To understand concerns of patients and allied stakeholders, Lab4Living(L4L), School of Design at IDC, IIT Bombay, and Neurogen, a clinic with dedicated Neurorehabilitation resources, collaborated with a focus on developing new assistive technology (AT) and inclusive designs for people living with ALS/MND in India.
The research comprised local contextual investigations through two participatory workshops with support of Asha Ek Hope Foundation, and involved people living with ALS/MND, their caregivers, Occupational Therapists and Design Researchers.
The paper describes methods used, insights built, and outcomes to date including concept designs for new AT and inclusive designs, impacting on the Design curriculum in India , informed by this study, that have since progressed to user evaluation stages of R&D processes.
Authors gained insights about why the design of products, and their facilitating services, for ALS/MND patients may differ from a standard product/service development process. We suggest products designed for ALS/MND should co-exist as a part of a designed ecosystem. This ecosystem could facilitate sharing of products amongst patient populations, while addressing concerns of manufacturing low volumes of batch production items at an affordable cost for all socio-economic groups. The design of this ecosystem and its interconnectedness may be a critical factor in making products feasible and sustainable.

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Keywords: human centred design, MND/ALS, participatory research, design approaches, rehabilitation

Introduction

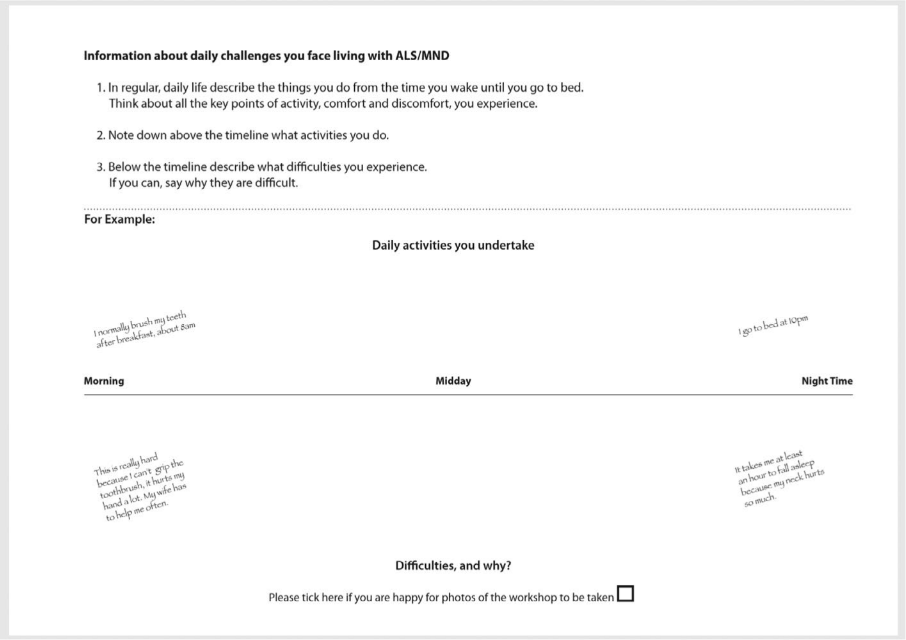
This project forms a part of a wider study seeking to investigate and provide responses to social, sustainability, health inequality or economic issues faced by countries on OECD (Organisation for Economic Co-operation and Development) forum's DAC (Development Assistance Committee) country list. Specifically, this branch of SHU GCRF activity is framed around uncovering challenges and barriers people living with MND/ALS experience in India, given 1. Size of population (compared with EU nations), 2. Relative lack, with respect to population size, of assistive technology (AT) infrastructure and 3. Given comparatively low levels of income in relation to AT provision. Design responses therefore are required to be 'frugal' in this context. The project was delivered by Design Researchers working with L4L, industry based Design partners in India, Ativa, and Design academics from Industrial Design Centre (IDC), School of Design, Indian Institute of Technology Bombay (IITB), crucially, people living with ALS/MND, patients of Health Care Practitioners based at NeuroGen, Centre for Stem Cell Therapy and Neurorehabilitation, Mumbai, and their carers.

Our interest and motivation in undertaking this work was driven by technical and quality of life understanding of this debilitating disease from a developed country perspective, gained through a previous L4L project named 'Head Up', and to apply creative strategies to explore challenges and potential solutions in 'frugal' ways, in the context of India. Whereas the Head Up project specifically considered head drop, a project that successfully delivered a new type of commercially available orthotic to improve quality of life for people across the world ('Revolutionary neck support collar now available on the NHS for people with motor neurone disease'), this study investigated some of the wider issues of daily living with ALS/MND, in India. It aimed to extend the range and reach of these kinds of products, and to maintain functional benefits at local cost effectiveness levels. Many product concepts were derived from these sessions. The following captures key methods and findings, and illustrates and describes some outcomes, but many are not disclosed for reasons of IP. Based on this initial study we plan to progress this work, subject to further funding.

Methods

With consent of NeuroGen, through which participants were recruited, the team produced materials in paper format to inform and raise awareness of this research, distributed approximately three weeks prior to the events. One document asked people interested in contributing on the day to think and record their daily challenges. This was presented as a daily timeline identifying what they did, when, and any challenges they encountered. People living with ALS/MND were asked to include their care givers in this insight capture. The daily timelines were reviewed and contributed to insights and understanding reported here, despite the fact the exercise was intended more to allow participants to think about/help in preparation for workshop discussions. Invitation and timeline documents were produced in English and translated into Hindi and Marathi, these three languages believed to cover a significant percentage of the anticipated group attending (Figures 1&2). Consent to take part information and participant rights were integrated within these two documents, alongside agreements for photographic/audio recording. From previous experience the team felt strongly that persons at different stages of disease progression would not attend at same times, to avoid possible stress of potential early stage patients observing late progression patients. Following the workshops, audio recording were transcribed, reviewed, and key considerations extracted.

The workshop comprised two main sessions. Firstly, approximately one hour involved the design research team and seven Occupational Therapists (OT). This session focused primarily on challenges of existing AT and its provision. A number of OT's from the team also reported as having been diagnosed with ALS themselves. Secondly, the group reconvened with seven ALS patients for approximately two hours. Some patients were accompanied by their family carer, who also contributed to loosely structured and conversational (by intent) discussions. Following an introduction and outline of aims, the group divided into 'one-on-one' sub-groups. The final one-half hour of session comprised whole group discussions. Insights were recorded in note form.



Information about daily challenges you face living with ALS/MND

1. In regular, daily life describe the things you do from the time you wake until you go to bed.
   Think about all the key points of activity, comfort and discomfort, you experience.
2. Note down above the timeline what activities you do.
3. Below the timeline describe what difficulties you experience.
   If you can, say why they are difficult.

For Example:

Daily activities you undertake

I normally brush my teeth after breakfast, about 8am

I go to bed at 10pm

Morning **Midday** **Night Time**

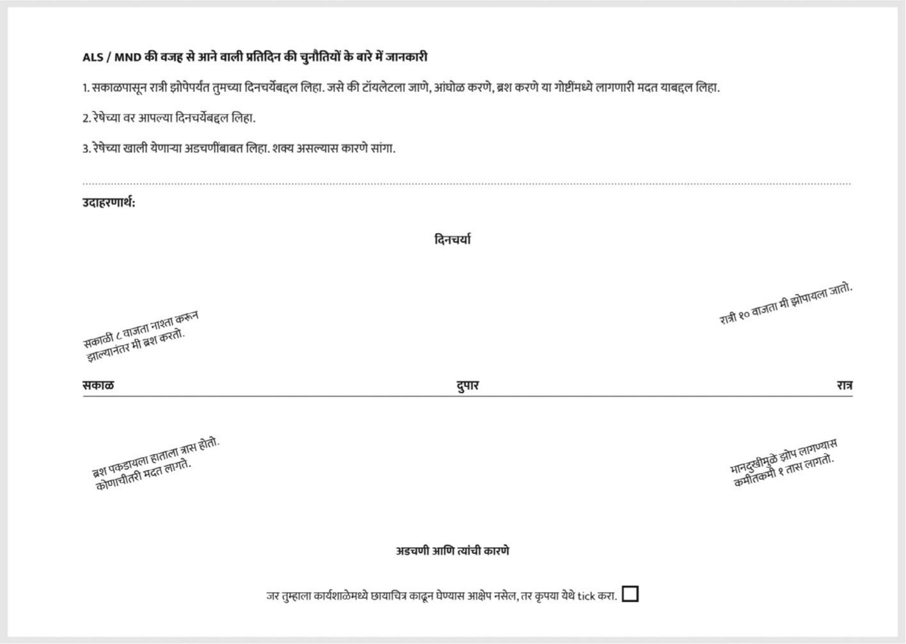
This is really hard because I can't grip the toothbrush, it hurts my hand a lot. My wife has to help me often.

It takes me at least an hour to fall asleep because my neck hurts so much.

Difficulties, and why?

Please tick here if you are happy for photos of the workshop to be taken ☐

Figure 1: English version of Timeline



ALS / MND की वजह से आने वाली प्रतिदिन की चुनौतियों के बारे में जानकारी

1. सकाळपासून रात्री झोपेपर्यंत तुमच्या दिनचर्येबद्दल लिहा. जसे की टॉयलेटला जाणे, आंघोळ करणे, ब्रश करणे या गोष्टींमध्ये लागणारी मदत याबद्दल लिहा.
2. रेषेच्या वर आपल्या दिनचर्येबद्दल लिहा.
3. रेषेच्या खाली येणाऱ्या अडचणींबाबत लिहा. शक्य असल्यास कारणे सांगा.

उदाहरणार्थ:

दिनचर्या

सकाळी ८ वाजता नाश्ता करून झाल्यानंतर मी ब्रश करतो.

रात्री १० वाजता मी झोपायला जातो.

सकाळ **दुपार** **रात्र**

ब्रश पकडायला हाताला त्रास होतो. कोणाचीतरी मदत लागते.

मानदुखीमुळे झोप लागण्यास कमीतकमी १ तास लागतो.

अडचणी आणि त्यांची कारणे

जर तुम्हाला कार्यशाळेमध्ये छायाचित्र काढून घेण्यास आक्षेप नसेल, तर कृपया येथे tick करा. ☐

Figure 2: Marathi version of timeline

OT viewpoint summary

The session format was ‘roundtable’, with the design research team and OTs exchanging insights based on what existing AT is available, and its limitations. Conversation then led into challenges for carers, and provision in India. During the task it was felt that the first priority was eating and addressing poor hand function, often a result of the disease.

One existing product, the ‘universal cuff’, a Velcro hand ‘wrap’ for holding implements (spoons, forks, hairbrushes) was demonstrated by OTs. A shortcoming highlighted was the limited number of tools it could accept and the design of the cuff’s, tool accepting pocket. It was felt to be in the wrong position for many people resulting in the wrong angle of implement hold for different tasks. It was further highlighted that eating with a spoon was not a ‘traditional’ method in India. It was noted that, depending on body region affected, hand-based aids could be less useful if function is impaired simultaneously with limitations higher up the arm/shoulder. It was regularly highlighted that the disease affected individual patients differently, and it could affect different parts of the body at varying rates, either rapidly or more slowly. There was some debate between OT’s as to where the disease manifests first, either in the shoulder or in the hand. It was agreed however that even though many people can have different manifestations, the effects eventually and generally are common as it progresses.

There was debate about how stigmatizing AT was, with some reporting that patients did not ‘want to wear it and use it in the community’. A general consensus amongst ATs was as long as it worked easily, and well enough to provide greater independence, then look (appearance?) and associations with AT become secondary. However, devices that were both visibly and functionally ‘lightweight’ are preferable.

Issues around the complexity of body movements during tasks, and if designs should focus on supporting either specific or more complex movements (wrist and whole arm for example) were discussed in terms of where new designs should concentrate. As a complex problem (individual’s condition, stage and regions affected) it was agreed as many options as possible should be integrated. This suggested consideration of a modular, lightweight, literal ‘suite’ of interchangeable device options. Importantly, for the design research team, realisation that motion is affected most where the person needs to ‘fight’ against gravity was established. The team began to consider how gravity may be used to support rather than hinder specific actions. It was proposed a next step of this research could start with an analysis of common task related body movements, from which means of utilising gravity or ‘movement boosters’, to aid those tasks, may be derived. This was seen as important to conserving energy where physical fatigue can be a major factor. Principles of clothing that helped blood flow were also raised in relation to the ‘suite’ of interchangeable device options.

All AT available, with few exceptions, was deemed to be prohibitively expensive in India, and as such unlikely to be taken up. For example, larger installed body moving hoists were deemed not to be in widespread use because of limitations of cost and fit in/at home. In terms of ‘manual handling’ comments were made about India’s large population and possibilities that more carers may be available, subject to training. Conversation moved to manual handling of people to and from bed. This is not only physically challenging but psychologically also, as, where people need turning at night, it is a carer who is required to help, who ‘often lift them’, to move or transfer. Specialist equipment to aid this process is available, but again its availability is limited due to cost and space in the domestic situation. Devices to aid turning in bed, to avoid discomfort, and eventual pressure sore onset, and getting up from bed were discussed, and were also described as problematic.

The OT group felt a significant barrier to physical fitness was exercise, explaining it was very difficult to simply get people to walk. Ideas and examples of ‘passive movement machines’ were discussed but that current provision was limited in what kinds of exercise they offered. In many cases needs change often, so every product investment could become redundant very quickly. One OT commented, ‘that is the biggest challenge. As the disease progresses the number of devices required goes on increasing and you have a pile of devices which are useless’. However, regarding beds it was agreed investment here may be longer lasting. Questions of access to AT were discussed and ideas about sharing certain types of AT between patients tabled. Hospital representatives confirmed they do pass redundant equipment to others in need, but there was no ‘system’ in place to manage that.

A specific condition was highlighted as very painful, distressing and functionally debilitating, known as subluxation, whereby upper arm dislocates from shoulder. Design Researchers were advised that there are products that attempt to address this but that they ‘work in the wrong way’, and they don’t work at all when both shoulders are affected/bilaterally (more about this in patient group discussion). The session also covered aspects of communication, although this was limited, and around a lack of equipment for aqua therapy.

Figure 3: OT lively roundtable discussion at NeuroGen

Summary of Patient and carer workshop

Of particular interest in this session were notions of who we were designing for. Of course, ultimately, we are concerned with provision of solutions that meet often complex needs of the patient, to ensure they can live full, happy and as independently as possible. But the design briefs (design requirements) we develop can equally have drivers powered by other foci, on the specific needs of the carer, for example.

When demonstrating how a physically smaller primary carer for a physically heavier ALS patient undertook his transfer from chair to bed, she expressed concern that she didn't have strength to hold his weight high enough such that no load was placed on his feet, that she may slip, lose grip, or otherwise injure her husband during process. Breaking the ankle was of particular concern to her. This physical strength issue is compounded where the patient lacks physical control and is unable to assist maneuvering. An example demonstrated by the couple was of 'foot drop', and peripheral neuropathy. These conditions result in a lack of self-control of the position of the foot/where the ankle will not support the foot parallel to the floor, and a lack of sensation informing what the foot is coming into contact with (floor, objects etc.).

The carer demonstrated how when handling their partner's mass, stood face to face, she would stand on one leg, using her free foot one to 'kick' the patients foot into an appropriate position as not to cause injury when load bearing. This combination of control and feedback problems may be able to be addressed through AT provision focused on the needs of the carer, rather than patient. For example, an ankle orthotic that is designed to help patients' feet stay parallel with the floor would certainly help the carer, but may be further augmented with features enabling the carer to more easily reposition feet such that it reduced potential for injury during transfer, and importantly reduce carer anxiety about causing damage through accidental falls.

Whether an ALS/MND patient maneuvers themself out of bed alone or has assistance, it was highlighted that this act is a particular challenge. People described varying amounts of body pain following longer sleeps, some very severe. Mainly, it was speculated this was a result of not being able to move or reposition frequently during sleep. If laying supine (face upwards) persons described firstly 'flinging' an arm, from the shoulder, over their body so they could role onto one side. Secondly, legs would be controlled over bed edge until above or on floor. If an over bed handle was available, it could then be grasped to pull body upright. If not, they may bend the torso forward until stomach muscles could be used to become upright, as well as employing various other coping strategies. From this sitting on bed edge position, the person could, depending on severity of their condition, move forward to a standing and/or ambulant situation. Points of intervention discussed around these scenarios included how we might decrease discomfort through design of sleeping surfaces, how to facilitate more accessible over bed grab handles and how might we provide systems that assist transitions from supine to standing/walking. The design team recognized it is not possible to procure and install 'developed' country type AT (hospital beds and the like) into, what are often very low-income situations, and considered 'frugal' adaptations to existing furniture.

A further area of what we have come to call 'arm drop', (aforementioned subluxation), was discussed. This manifests, as described by patients, as the top of the arm (humeral head; the 'ball' of the ball and 'socket' joint within the shoulder) dislocating as, it is thought, a result of gravity and a loss of muscle mass holding the shoulder joint in place (a union of scapula features (acromion and coracoid process), and clavicle, holding the humeral head in place). The condition effectively renders the patients' arms useless/with very limited function. There was a high proportion of Indian patients in the group with the condition, the reason for which was not established. Figure 4. shows one of the patients attending the session posture (center image, gentleman in pink shirt). It can be seen that his arms are 'dangling' by his side and appear over long. Existing aids to help keep the shoulder joint intact were discussed as largely, mechanically inadequate.

Figure 4: Examples of subluxation in the patient group

Summary of findings

A finding of both workshops was AT items should be cost effective such that they can be available to the majority of those that would benefit from them. This is a multifaceted problem, one involving many aspects of products being 'fit for purpose', including device functional specifications, materials selection and processing/fabrication, product life cycle, repair, manufacturer, marketer and distributor mark ups, not to mention research and design development costs. In discussion with the groups the design team connected many of these issues into a potential, single 'simplification' of said complexities. Requiring further investigation, and subject to regulatory and other compliance criteria, the idea revolves around the notion that it could be the hospital (or clinic) that would procure, own, develop and distribute AT items. The clinic may then offer continuous and bespoke support to its patients, issue, collect, service, and re-issue devices to new patients. This sharing of equipment concept would be seen as an essential component of a product-service ecosystem, and design of these devices would need to take new product use life cycles into account. The approach could allow for continuous, iterative product improvements, and for new AT opportunities to be identified. Many barriers to this approach would need to be overcome to enable facilitation, in particular those concerning economy and operationalization, but if those could be overcome the benefits may be significant.

- Needs are highly complex with at least four primary multipliers, summarised as 1. personal situation (social/economic), 2. personal routines/tasks undertaken 3. Nature/locality of affliction, 4. stage of disease progression.
- Consideration must be made towards cost and new methods of distribution and ownership explored.
- There are many, many new product opportunities. Lack of investment in these areas is key to current overprice and undersupply.
- General themes for development of new AT products include
    - Moving (oneself around an environment) and handling/ transfers (by others)
    - Supporting body movements (against gravity) and integrating physiotherapy
    - Dexterity/specific hand aids
    - Product service/supply
- Designs need to be adaptable to accommodate disease progression.

In respect to the context of India, the research revealed important and valuable factors to inform potential solutions but highlighted the need for a more extensive national study. However, the work did open some avenues for further investigation, for example, that eating cultures needed addressing with designs reflecting local practices. Generally, economies of scale need addressing through AT designs in line with peoples means. It would be beneficial for people around the world to have more affordable products, this is particularly true of economically 'poorer' societies. It is recognised that India has a very large population and as such may be able to provide a larger number of carers, subject to adequate higher volume training programmes.

Outcomes

Figure 5 and 6: Universal Cuff prototype(left) by Nikhil Dhamnaskar and Gaurav Nandan’s Foot Orthotic prototype(right)

While many of the potential interventions this study presents remain simply ‘ideas’ and concepts, the research helped the design team grasp what the real, on the ground issues are, and opened avenues for future investigation, subject to funding. However, two areas of the debate have evolved into new product developments. Use issues with the ‘universal cuff’ and those associated with ‘foot drop’ were translated to student design briefs by the IDC team. Two students, Nikhil Dhamnaskar–Universal Cuff prototype and Gaurav Nandan–Foot Orthotic prototype (figures 5&6.) undertook these briefs as part of their IDC Masters in Design, 2019. Embedding and supporting projects such as this within the Design curriculum in India has potentially long-term benefits in further raising and in developing the next generation of designers working within the field of design for health, and in improving the practice and manufacture of AT in India.

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