

Digitally fabricated design interventions for als/mnd

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1 Abstract

Amyotrophic Lateral Sclerosis (ALS), or motor neuron disease (MND), is a progressive neurodegenerative disorder that results in the loss of muscle control and function (Kiernan et al., 2011). To manage the daily activities of people with ALS, Assistive Technologies (ATs) are essential (K. A. Connors et al., 2019). However, many current ATs available in the market do not cater to the individualised and rapidly changing needs of people with ALS (K. Connors et al., 2019). Frequent procurement can take a financial toll on the family (Bromberg et al., 2010). This practice-based PhD (Winter et al., 2000) project is developing custom-made ATs to maximise independence and enhance the quality of life of people with ALS.

This research is part of a joint PhD between IIT-Bombay, India and Monash University, Australia. It provides a platform to understand the users in different cultural and economic contexts. Allowing for a broader analysis of the needs of people with ALS and their caregivers, leading to more effective and impactful solutions. This project began with a comprehensive user study of Indian participants which helped define the scope of the PhD. The findings indicate that people with ALS use an AT device briefly, which becomes irrelevant due to the disease's progressive nature (K. A. Connors et al., 2019). Hence, devices must be 'purpose-built', 'relatively affordable,' and 'readily available' for people with ALS (Eicher et al., 2019). We are conducting a similar study in Australia, and we aim to compare and contrast our understanding to perform a broader analysis of people with ALS and their caregivers.

During our Interviews with clinicians in Australia, we discovered that the clinicians had created custom ATs for their patients independently. This discovery sparked conversations about clinicians' approaches to making ATs themselves and comparing their methods with those of Makers (including but not limited to designers, engineers, and skilled craftsmen). From our study on DIY Assistive Technologies (DIY-AT) (Bohre et al., 2023) and interviews with clinicians and makers, we hypothesised that clinicians' DIY approach was primarily focused on caring for the patient, involving modifications to readily available market items (Hofmann et al., 2016; McDonald et al., 2016) and is limited by the skills and resources they have. On the other hand, makers aimed to refine and utilise their crafting



skills, limited by the need for clinical input and patient-care-centric motivation (Buehler et al., 2015; Tanenbaum et al., 2013). We aim to study how these approaches can be effectively bridged by user-centric and participatory design approaches to facilitate collaboration and the creation of more meaningful solutions for people with ALS. We also aim to study how 'By leveraging digital fabrication techniques, faster turnaround times and bespoke designs can be created tailored to the specific needs and limitations of People with ALS' (Hofmann et al., 2016).

In the process, we will identify and report the barriers and facilitators of using digital fabrication over conventional mass manufacturing for making ATs for people with individualised and varying needs. The knowledge gained from this project will inform a design framework and empower clinicians to develop bespoke DIY-AT devices for a broader range of people with individualised and varying needs, improving the timely delivery of appropriate AT devices for ALS and enhancing their quality of life and independence.

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