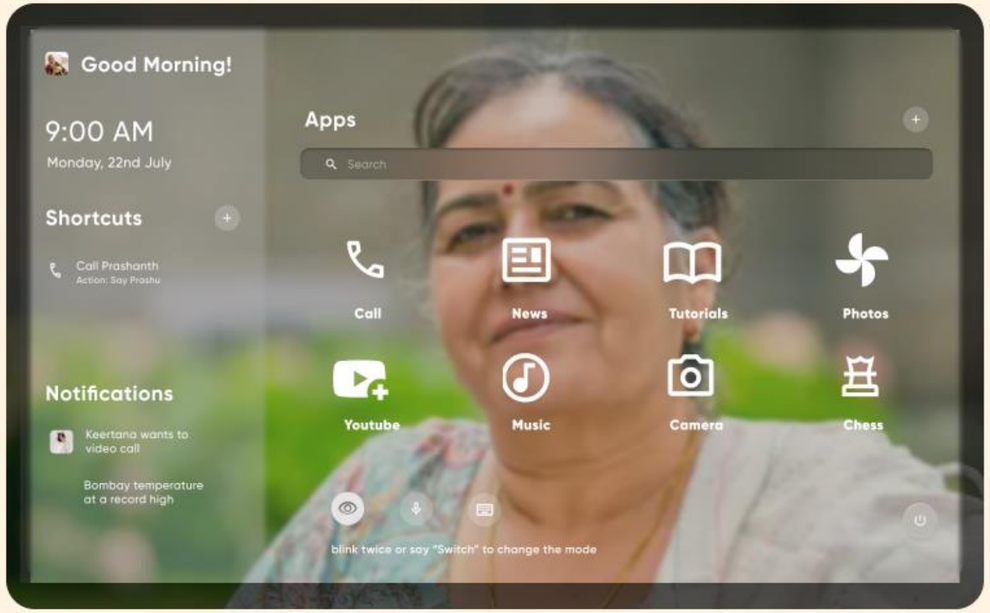


MiraALS

Empowering Reflecting On The ALS Jouney

Domain	Duration	Mentor	Tools
Accessibility	2 Months	Dr. Anirban Chaudhary	

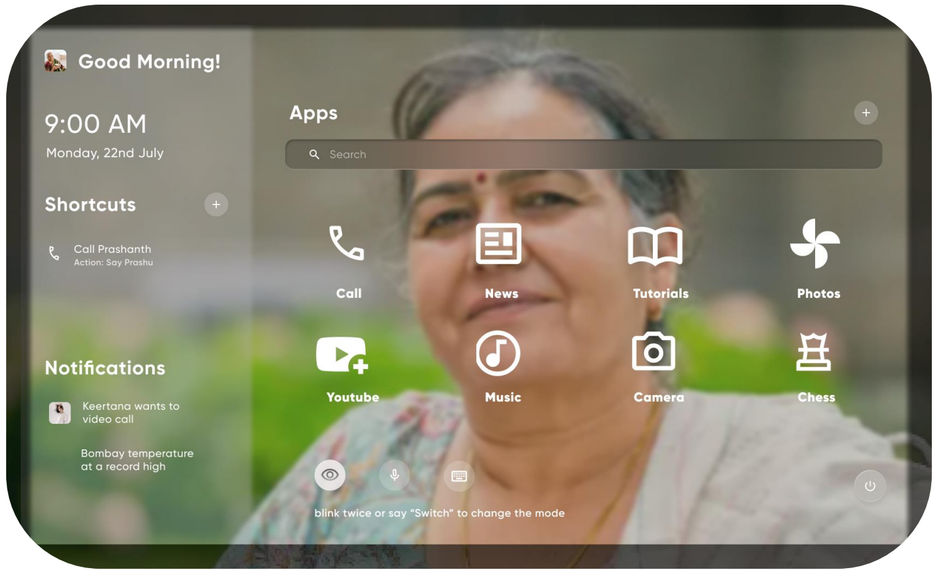
Project Overview

A research project aimed at finding the challenges faced by ALS patients and their caretakers and proposing an interface that is practical and solves the problem at its core.

Problem Overview

Caretakers of ALS patients find it hard to understand the needs of ALS patients and keep them engaged as the patients lose their motor and speech functionality with progression of ALS.

Proposed Product



An AI-powered smart mirror designed for ALS patients and caregivers. It addresses challenges throughout the disease's progression. For early stages, it offers voice banking and amplification to aid communication. As ALS advances, eye tracking and an AI voice assistant allow non-verbal communication. The mirror also provides entertainment like games and news. Caregivers benefit from real-time health monitoring, emergency alerts via an app, and a mood tracker. MiraALS blends technology and empathy, empowering patients, easing caregivers' tasks, and redefining the ALS journey.

About ALS

What is it?

Amyotrophic Lateral Sclerosis (ALS), is a motor neuron disease (MND) that causes loss in physical function due to neurodegeneration.

What are the effects?

Some of the symptoms include muscle weakness and atrophy, difficulty speaking and swallowing, and eventually, respiratory failure.

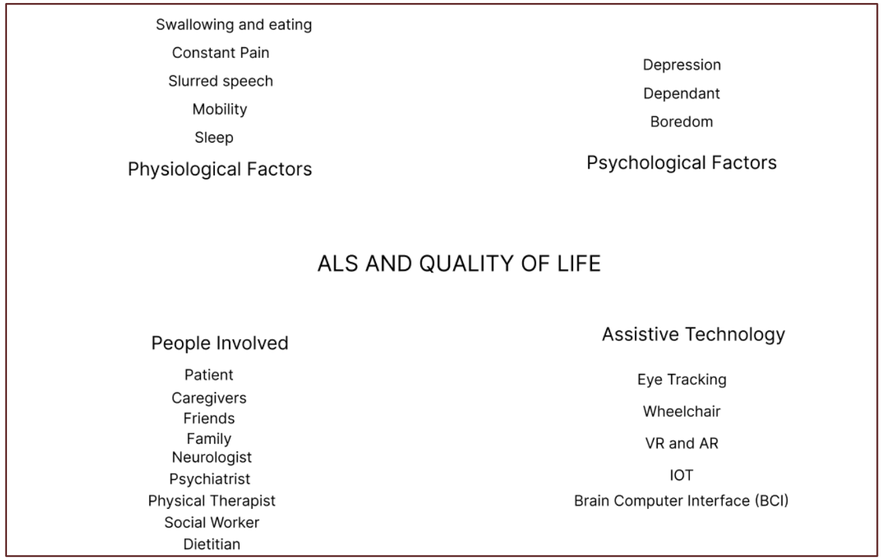
Who does it effect?

ALS is prevalent mostly in older males among the age group 60-70, there are some cases of early onsets from 40 years of age.

Treatment Options?

There is no known cure for ALS, the life expectancy among patients vary from 2-5 years, treatment is mainly focused on improving Quality of Life.

Secondary Research



Since there is no known cure for ALS, the life expectancy among patients vary from 2-5 years, treatment is mainly focused on improving Quality of Life

three to five in one lakh population above 50 years of age each year in India and causing around 1.5 lakh deaths annually as per estimates.

Literature Review

1. Impact on Quality of Life: ALS has a significant negative impact on the quality of life of individuals affected by the disease. Physical limitations, loss of independence, communication difficulties, and emotional distress are common factors that contribute to a reduced quality of life.

2. Physical Functioning: ALS progression leads to a decline in physical functioning, including muscle weakness, impaired mobility, and difficulty performing activities of daily living. These limitations can negatively affect an individual's quality of life by hindering their ability to engage in social interactions and enjoy meaningful activities.

3. Communication Challenges: ALS often results in speech difficulties and, eventually, the loss of verbal communication. Augmentative and alternative communication (AAC) devices, such as speech-generating devices and eye-tracking technology, play a crucial role in enhancing communication and positively impacting quality of life for individuals with ALS.

4. Psychological Impact: The emotional and psychological well-being of ALS patients significantly influences their quality of life. Feelings of depression, anxiety, grief, and social isolation are prevalent. Psychosocial interventions, support groups, and counseling can help individuals cope with these challenges and improve their overall quality of life.

5. Caregiver Burden: ALS not only affects the patients but also places a substantial burden on caregivers. The responsibilities of caregiving, witnessing the decline of a loved one, and managing the emotional and physical needs of both the patient and themselves can lead to caregiver stress and negatively impact their quality of life.

Secondary Research Analysis

Secondary research has gaps regarding accessibility tools and needs in the Indian context

01 Awareness regarding disorder and caretaking.

02 Depression among caregivers and patients, support groups and ways to combat it.

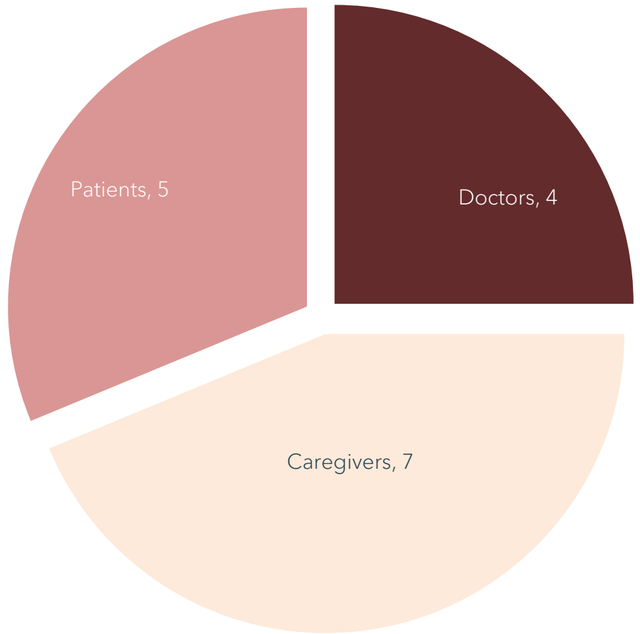
03 Technology and devices used currently
Openness to involvement of Robots , AI in assistance

Primary Research

This study aims at exploring problems related to accessibility and Quality of Life that are currently faced by ALS patients and their caretakers by in-person and remote interviews and the different ways and possibilities of overcoming them.

Demographic

Total number of participants - 16



Insights

physical:

85%

face a communication gap on a daily basis

69%

found eyetracking devices easy to use

psychology:

100%

face anxiety relating to finances and patient care

78%

found need for stimulus to keep patient engaged

social :

55%

compromise on social life

74%

awareness and support is unavailable

Affinity Mapping

Main and sub categories were created based on the questions and insights.

1. Help & Support
   - Awareness
   - Social
   - Financial

2. Psychological
   - Stimulus
   - Depression, Anxiety

3. Physiological
   - Sleep
   - Mobility
   - Speech

Conclusion

1. Primary research shows that
   - Depression is prevalent along with anxiety as shown in secondary research
   - Teletherapy is not a practical solution
   - Apprehension regarding robotic assistance

2. Assistive technology used currently is expensive, not made for Indian users and not easily accessible by older patients.

3. Urgent need for communication among patients with lost motor functionality.

4. Knowledge about primary caregiving assistance is missing.

5. Community sense, social interaction and stimuli among patients and caregivers.

Problems Identified

01	Assistive technology is too high tech and not being used by older patients.
02	Depression and anxiety among caregivers and patients that is responsible for faster progression of ALS.
03	Urgent need for communication among patients with lost motor functionality.
04	Knowledge about primary caregiving assistance is missing and caregivers do not know how to handle emergency situations.
05	Emotional and physical needs of both patient and caregiver can lead to caregiver stress and negatively impact their quality of life.
06	Boredom: Lack of community sense, social interactions and stimuli among patients.

Problem Statement

There is a lack of user-friendly and affordable assistive technology that can help ALS patients and their caregivers effectively communicate, maintain independence, and engage in daily activities to enhance their Quality of Life at different stages of ALS.

Project Proposal

The objective is to design a practical interface to help ALS patients and their caregivers of all age groups with the slight/no motor and speech function to improve their Quality of Life.

User Personas

Arun Bhatia

Engineer

Bio

Age: 40 Education: B.Tech

Status: Married Location: Bangalore, India

About

Arun is a devoted father and former engineer from India, who made the difficult decision to quit his job and become the primary caregiver for his mother with ALS. He faces financial struggles due to the high cost of ALS assistive technology and medical equipment in the country. Despite these challenges, Arun remains determined to improve his mother's quality of life by seeking affordable and practical solutions that can enhance her independence, communication, and overall well-being. His unwavering dedication and resourcefulness drive him to find ways to support his mother and provide her with the best care possible, while balancing the needs of his own family.

Goals

1. Provide the best care for his mother: Arun's primary goal is to ensure that his mother receives the best care possible while managing her symptoms and maintaining her quality of life.
2. Financial stability: Arun aims to find affordable solutions for ALS assistive technology and medical equipment to alleviate the financial burden on his family.
3. Emotional support: Arun seeks emotional support and guidance to help him cope with the challenges of caregiving and the emotional toll it takes on him.

Painpoints

1. Balancing caregiving responsibilities: Arun had to quit his full-time job to take care of his mother with ALS. He faces the challenge of balancing his caregiving responsibilities with his role as a father and husband.
2. Financial constraints: The cost of ALS assistive technology and other medical equipment is expensive in India. Arun is struggling with the financial burden of providing the necessary support and equipment for his mother's care.
3. Emotional stress: Arun is experiencing emotional stress due to witnessing his mother's deterioration from ALS and the challenges of caregiving. He may feel overwhelmed, worried, and saddened by the situation.
4. Limited support network: Arun may face limited access to support networks and resources specifically tailored to ALS caregiving in his local community.

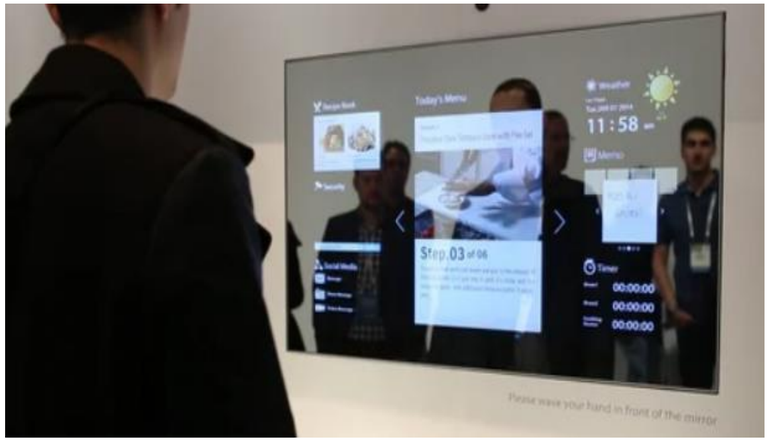
Concept Explorations

Simulator for patient care

Learn everything from the devices needed to handling situations and bedside assistance to reduce anxiety and increase confidence. Emotional support, personalizes care according to situation.

Mood and vital tracker

Caretakers can track and see in real-time and suggest activities for the patient. Community for the caretaker to connect with and buy/sell equipment. For the patient, physiotherapy and gaming according to mood and functionality.



A smart mirror

When speech is slurred, it detects the words and amplifies the voice. Suggests voice banking and uses AI to generate voice.
When speech is lost, interface teaches eye language, detects the eye motion, speak out in patients voice, and activate voice assistant.

Final Concept

Smart Mirror with the following features:

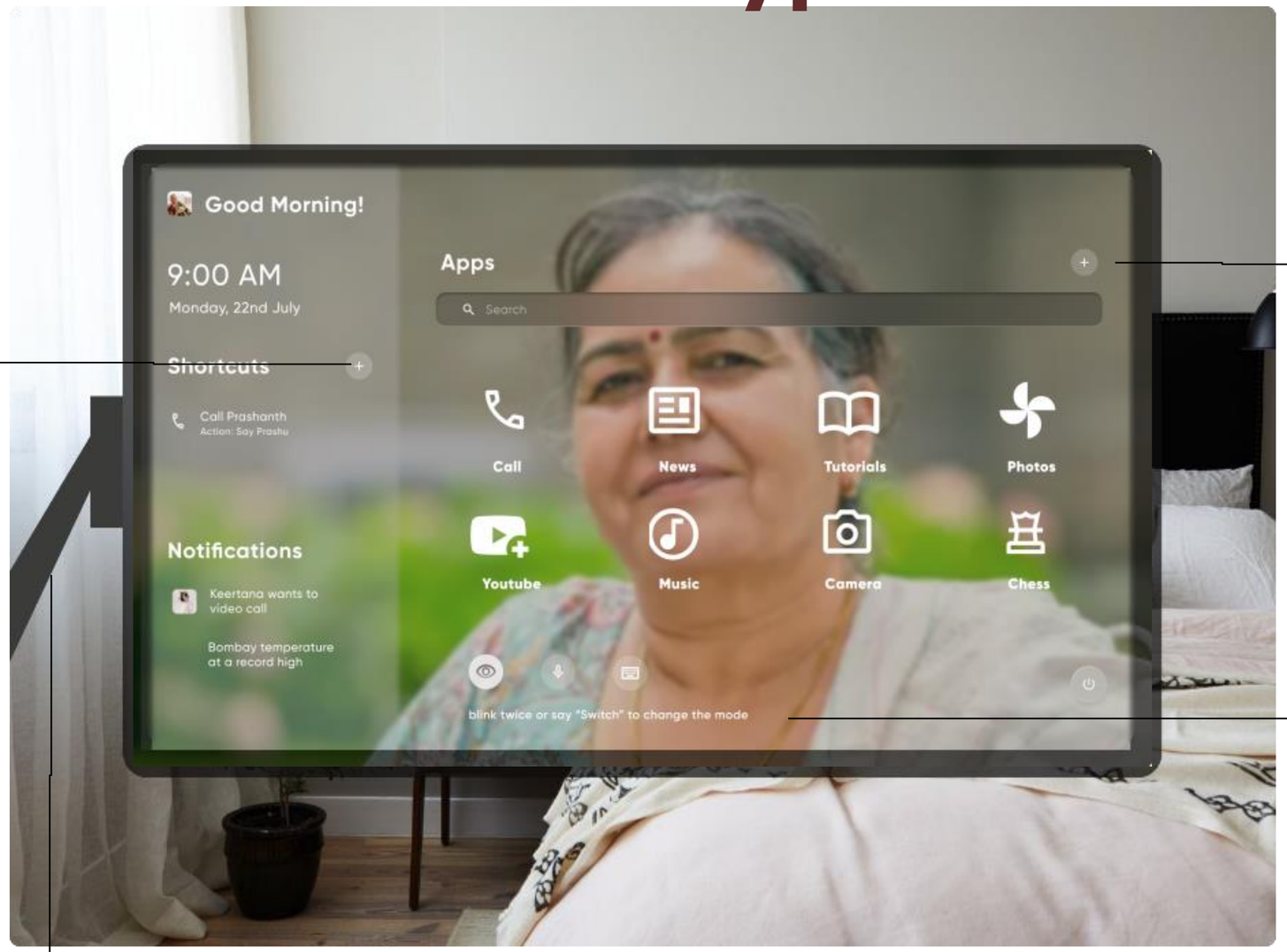
1. Empathetic Speech Response: MiraALS responds to slurred speech through voice banking and amplification, ensuring clear and effective communication for patients.
2. Eye Language Training: For patients who have lost speech, eye tracking enables non-verbal communication, granting them a means to express emotions and needs.
3. Personalized Activities: MiraALS offers a selection of personalized activities, physiotherapy exercises, and interactive games based on each patient's mood and capabilities.
4. Voice Assistant: With voice commands, MiraALS grants ALS patients independent control over various tasks and devices, fostering a sense of autonomy.
5. Engaging Stimuli: Patients can engage in music, watch videos, and make calls seamlessly using the mirror interface, enriching their daily lives.

Final Concept

Features for the caregiver

1. Real-time Alerts: MiraALS's integrated phone application delivers real-time alerts to caregivers, keeping them informed of any changes in the patient's well-being.
2. Vital Signs Tracking: Caregivers can track the patient's mood and vital signs through the mirror's app, allowing them to monitor their health effectively.
3. Hands-on Simulation: MiraALS provides caregivers with real-life simulations, offering practical experience and training to handle different stages of ALS progression confidently.
4. Stress Reduction: With caregiver support and insights, MiraALS aims to reduce stress burdens and improve the mental health of caregivers.

Prototype



Customize and Change most frequently performed actions

Apps added conveniently

MiraALS can be mounted on a wheelchair or attached to the bed.

Changing the mode at every stage with whatever is convenient

thank you.