

Research Plan

Title: Who's Care.

Team:

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Project Background

Problem Context

Alzheimer's disease represents a growing challenge in our Arab communities, where studies indicate that the prevalence of dementia is increasing among populations over 50 years old. In Egypt specifically, the rate has reached 2.9% among the population over 50 years old. These are not just statistics, but human stories that deserve our attention and support.

Current Challenges

We face specific challenges in our Egyptian and Arab society including Heavy reliance on traditional families, Care Lack of knowledge about the nature of the disease, Psychological and financial pressures on caregivers Shortage of specialized support and resources.

Available Opportunity

The strength of family bonds in our Arab society can be a starting point for developing innovative care models that combine authenticity with modernity, taking advantage of modern technologies to provide appropriate support.

Research Objective

Primary Goal:

To develop innovative digital solutions that are culturally appropriate for supporting Alzheimer's patients (early to moderate stages) and their non-professional caregivers in Egypt, using human-centered design methodology to ensure effectiveness and sustainability.

Secondary Objectives:

1. Understand the real needs of users in the Egyptian and Arab context
2. Develop a digital solution prototype that meets these needs
3. Test and improve the solution based on user experiences
4. Establish guidelines for developing similar solutions in the Arab region

Core Research Questions

Primary Questions:

1. What are the most urgent daily challenges faced by Alzheimer's patients and their caregivers in the Egyptian context?
2. How does the Egyptian cultural and social context influence the care experience and its requirements?
3. What are the currently available technological solutions and how suitable are they for the local context?
4. How can we design a digital solution that is easy to use and culturally acceptable for elderly patients and their families?

Detailed Questions About :

Patients:

1. What daily activities do they find most difficult?
2. How do they prefer to receive help and support?
3. What are their basic fears and concerns about using technology?

Caregivers:

1. What are the biggest sources of stress and anxiety in their journey?
2. What type of support and information do they need most?
3. How can technology help them without complicating their lives?

Cultural Context:

1. How do religious and family values affect the care experience?
2. What are the specific challenges for women as primary caregivers?
3. How can we design solutions that respect privacy and dignity?

Research Methodologies

1- Interviews

- Personal interviews with patients and caregivers.

- Duration 30 minutes per interview.
- Focus on daily challenges and personal experiences.

2- Survey Research

- Structured questionnaires.
- Collect quantitative data about needs and preferences.
- Measure satisfaction levels with current services.
- Identify development priorities.

Participant Characteristics

- Primary Group “Alzheimer's Patients”

Basic Criteria:

- Age: 60+ years.
- Diagnosis: Early to moderate stage Alzheimer's.
- Ability to communicate and participate in research.
- Personal consent or from a guardian.

Desired Characteristics:

- Diversity in educational level (illiterate, basic, intermediate, higher education).
- Diversity in economic level.
- Gender representation (male and female).
- Geographic representation (Cairo, Port Said, Minia).

Target Number: 5-10 patients.

- Secondary Group “Caregivers”

Basic Criteria:

- Provide daily care for Alzheimer's patients.
- Non-professionals (family members or friends).
- Speak Arabic fluently.

Desired Characteristics:

- Age: 25-70 years
- Relationship to patient: spouse, son/daughter, sibling.
- Care duration: 6 months to several years.
- Different levels of technical experience.

Target Number: 10-20 caregivers.

- Support Group “Specialists and Experts”

Criteria:

- Neurologists or psychiatrists specializing in Alzheimer's.
- Social workers.
- Assistive technology experts.
- Representatives from Alzheimer's associations.

Target Number: 3-10 experts.

Recruitment and Access Strategies

1. Medical and Institutional Partnerships

Hospitals and Clinics:

- Ain Shams Specialized Hospital - Neurology Department.
- Elderly health centers.
- Specialized psychiatric clinics.

Organizations and Associations:

- Egyptian Alzheimer's Association.
- Elderly care associations.
- Elderly care centers.

2. Community Outreach

Social Centers:

- Social clubs and youth centers.
- Mosques and churches.
- Government social service centers.

Personal Networks:

- Utilize the team's personal relationship network.
- Get referrals from previous participants (Snowball Sampling).

3. Digital Recruitment

Social Media:

- Create specialized pages on Facebook.
- Use LinkedIn to reach specialists.
- Connect with local communities via WhatsApp.

Electronic Websites:

- Publish participation invitations on medical websites.
- Connect with bloggers and influencers in the health field.

Implementation Timeline

Phase 1: Planning and Preparation (2 days)

Day 1:

- Obtain legal and ethical approvals.
- Prepare research tools (questionnaires, interview questions).
- Develop project introductory materials.

Day 2:

- Begin communication with partners and institutions.
- Launch recruitment campaigns.
- Schedule initial appointments with participants.

Phase 2: Primary Data Collection (3 days)

Day 3:

- Conduct in-depth interviews with patients and caregivers.
- Ethnographic research and home visits.
- Distribute and collect questionnaires.

Day 4:

- Organize focus groups.
- Interview specialists and experts.

Day 5:

- Preliminary analysis of collected data.
- Complete remaining data collection activities.

Phase 3: Analysis and Design (2 days)

Day 6:

- Comprehensive analysis of qualitative and quantitative data.
- Identify basic needs and priorities.
- Develop User Personas.

Day 7:

- Design initial solutions.
- Develop testable prototypes.
- Prepare a testing plan.

Phase 4: Testing and Improvement (2 days)

Day 8:

- Test prototypes with users.
- Collect observations and suggested improvements.

- Modify designs based on experiences.

Day 9:

- Test improved version.
- Verify solution effectiveness.
- Prepare final recommendations.

Phase 5: Documentation and Presentation (1 day)

Day 10:

- Write final report.
- Prepare a presentation.
- Organize results presentation sessions for participants and interested parties.

Legal and Ethical Considerations

Participant Protection

- Obtain informed consent from all participants.
- Ensure confidentiality of personal and medical data.
- Respect participants' right to withdraw at any time.
- Take special precautions when dealing with dementia patients.

Data Management

- Encrypt all sensitive data.
- Store data in secure locations.
- Not share participant information with external parties.
- Delete personal data upon research completion.

Expected Outcomes

Research Results

1. Deep understanding of needs of Alzheimer's patients and caregivers in Egypt.
2. Identify gaps in current solutions and services.
3. Design innovative and culturally appropriate digital solutions.
4. Establish guidelines for developing similar solutions in the Arab region.