

OPTIALZ: user-centred optimization of a digital platform and an AI Assistant supporting people with mild Alzheimer's disease, their caregivers and care professionals

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Background

- Alzheimer's disease (AD) is the leading cause of dementia, accounting for 60–70% of cases. Around 800,000 people live with AD in Spain, and roughly 80% remain at home, depending on the intensive daily support of family caregivers.
- Family caregivers (≈70% women) and care professionals face high burden and limited access to reliable information and adequate digital tools; sustained stress is linked to a high prevalence of physical and psychological health problems (the "caregiver syndrome").
- Older caregivers and people with AD are affected by a well-documented digital divide: only ~27% of people aged 65–74 report basic digital skills, limiting their access to accessible, autonomy-promoting technology.

Aim

To evaluate and optimize the efficacy of the user-centred digital platform AreaAlzheimer and an accessible AI assistant through a co-creation process with people with mild Alzheimer's disease and their caregivers.

Methods

Study design

Observational, non-interventional study using a mixed-methods design (quantitative + qualitative) framed as an iterative co-creation process with end users.

Participants

70 participants recruited by purposive sampling from the Fundació Pasqual Maragall database: family + professional caregivers (n=55) and people with a mild AD diagnosis (n=15; mild cognitive impairment or early dementia, GDS-3, with disease awareness). Sessions held in person (Barcelona) or online.

Procedure – three phases

Phase 1 – Needs & technology use: surveys, semi-structured interviews and focus groups to map care needs, digital competence and AD knowledge.

Phase 2 – Prototype design & initial evaluation: an interactive prototype is built from Phase 1 insights and tested for usability, accessibility and usefulness; participatory workshops co-create content.

Phase 3 – Validation & optimization: user-driven adjustments are integrated and the optimized platform is validated through UX metrics.

Measures (efficacy)

- Accessibility — Single Ease Question (SEQ)
- Usability — System Usability Scale (SUS)
- Usefulness — Perceived Usefulness Scale (PUS)
- Behavioral intention — Behavioral Intention Scale (BIS)
- AD knowledge is measured with the Spanish Dementia Knowledge Assessment Scale (DKAS-S).

Data analysis

Quantitative data: descriptive and bivariate statistics in SPSS v29 (χ^2 /Fisher's exact test; normality via Kolmogorov–Smirnov).

Qualitative data: thematic/content analysis with code co-occurrence mapping in Atlas.ti v25.

Ethics and AI

Conversational AI offers real opportunities in dementia care—quick access to reliable information, caregiver relief, support in organizing care—but raises ethical dilemmas that go beyond usability and efficacy. A care-ethics, person-centred lens (Albuquerque, 2023) warns that assistive technologies can promote autonomy or instead deepen vulnerability when they replace human care or foster dependence, demanding attention to power asymmetries and to the preferences of people with mild dementia, whose autonomy persists yet is threatened by algorithmic bias. Hermeneutic and epistemic-justice approaches further require that the assistant capture users' emotional and behavioural cues without pathologizing or infantilizing them.

The SHERPA assistant translates these principles into concrete safeguards: answers anchored to a validated knowledge base (RAG architecture) to limit hallucinations, explicit exclusion of medical diagnoses, no persistent memory or access to health records, pseudonymized conversations, and periodic human quality review. This work contributes to a growing body of published literature on the impact of assistive AI on the quality of life and dignity of people with dementia (e.g., Schneider et al., 2024; Su et al., 2022).

Expected Results

- A detailed needs assessment for each user group, plus identification of barriers and facilitators to digital-technology access.
- Content and design improvements informing a functional, user-validated prototype of AreaAlzheimer.
- Efficacy evidence (SEQ, SUS, PUS, BIS) comparing the initial and optimized versions of the platform.
- Ethical guidelines regarding vulnerable public and AI (white paper)



Conclusions

- OPTIALZ applies a user-centred, co-creation approach to ground a digital care platform in the real needs of people with AD and their caregivers.
- The expected validated prototype of AreaAlzheimer and AI assistant should improve the platform's accessibility, usability and relevance.
- By reducing caregiver burden, fostering autonomy in people with AD and supporting professional practice, the study aims to inform the development of effective, inclusive digital care tools.
- Implementing new guidelines of AI applications regarding vulnerable public, specifically people with dementia

→ References

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