Recommendations for Designing Information for People with Dementia: Protocol for a Scoping Review

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Abstract:

Background: Aligned with the societal efforts for the inclusion and empowerment of people with dementia, there is a need for targeted information for them. Despite abundant dementia-related information, it often fails to cater directly to individuals with dementia and lacks tailoring to their needs and capabilities, frequently due to inadequate design. Objectives: This paper presents the protocol of a study aiming to provide an overview of recommendations for designing information for people with dementia. Method: A scoping review will be conducted. Scientific databases and grey literature will be searched using inclusion criteria focused on recommendations on information design and related design domains for people with dementia. Two reviewers will perform title, abstract and full-text screening. Data collection will include citation details, source characteristics, and key findings related to the review objective. Conclusions: The scoping review is anticipated to deliver a thorough understanding of how to design information resources for individuals with dementia. The synthesized recommendations are expected to be valuable resources for design practitioners, dementia care providers, researchers, and organizations involved in interventions for people with dementia. These contributions are expected to foster equal opportunities for individuals with dementia to access information, ultimately enhancing their social participation and dignity.

1 INTRODUCTION

Dementia is an umbrella term for multiple and progressive diseases affecting cognitive abilities and behaviour (World Health Organization, 2017), with Alzheimer's Disease being the most prevalent one. Dementia affects about 10 million people in Europe,

and it is estimated that these numbers will almost double by 2050 (Alzheimer Europe, 2019). It is considered a public health priority due to its epidemic scale, its impact on the person with dementia, families, and health economies. Dementia is a main cause of dependency among older people (World Health Organization, 2017).

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The World Health Organization calls for a broadscale shift in how society views dementia, encouraging initiatives that actively involve and empower individuals with dementia and their caregivers (World Health Organization, 2017, 2021). To contribute to their sense of choice, control and worth, tailored education and information on dementia must be provided to those who are living with the condition (Kimzey et al., 2021). Despite the abundance of information on dementia, particularly web-based, people with dementia and their informal caregivers often report feeling overwhelmed and unable to identify the most suitable and reliable sources (Allen et al., 2020; Soong et al., 2020; Teles et al., 2021). Moreover, the inadequacy of content, and its complex appearance, make navigating and understanding the information difficult (Soong et al., 2020). These challenges present a chance for design to contribute, given its capacity to mediate and tailor information for diverse audiences. Although there are guidelines on how to design websites and information for people with dementia produced by dementia advocacy groups and associations (The UK Network of Dementia Voices, 2013b, 2013a; Williams, 2017), the specific field of designing information for people with dementia remains scarcely investigated.

This paper presents the protocol for a scoping review to survey and synthesize recommendations for tailored information design for people with dementia. The scoping review method was selected for this study to provide a comprehensive overview of a potentially diverse body of literature on this topic. Protocol publication increases transparency on the review process, informs the scientific community on ongoing research and minimizes duplication and allows to solicit early feedback from a broader scientific community.

No current or ongoing reviews on the topic were found on preliminary searches. This scoping study is part of the ongoing research project "DECOHDE: Design for a humanised communication of dementia" to inform the design and development of an information platform dedicated to people with dementia.

2 METHOD

This scoping review will follow the Arksey and O'Malley (Arksey & O'Malley, 2005) framework as well as the guidelines from the Manual for Evidence Synthesis of the Joanna Briggs Institute (JBI) (Peters et al., 2020). Findings will be presented in accordance to the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses for Scoping Reviews Checklist (PRISMA-ScR) (Tricco et al., 2018).

The method for conducting this scoping review is described in the following sub-sections, and comprises the steps outlined in Table 1. The protocol was registered on the Open Science Framework Registries platform (Branco et al., 2024).

Table 1: Scoping review steps.

Step 1	identify the research question
Step 2	identify relevant studies – definition of search strategy and search terms
Step 3	study selection – definition of eligibility criteria and screening procedure
Step 4	data charting – definition of extracting entities
Step 5	collating, summarizing, and reporting results

2.1 Identify the Research Question

The main research question is: "What are the recommendations for designing information for people with dementia?"

Adapted from the PCC (population, concept, context) framework, the following key elements were defined as the focus of this study. First, it will be specific to people with dementia, excluding studies that refer to the design of information solely for carers (formal and/or informal). Second, the concept of recommendation is broadly used to refer to any kind of guidelines, principles, best practices on how information is designed to people with dementia. Third, the practice of designing of information is tied with the field of information design, concerning "(...) the process of translating complex, disorganized, or unstructured data into accessible, comprehensible information" (Erlhoff & Marshall, 2008, p. 213), which may require the use of research methodologies from the social sciences in the analysis and planning phases, as well as practical design skills. These include skills from several design domains, such as communication design/graphic design (related to the configuration of text and images to communicate messages), digital/interface design (referring to the mediation and creation of "access points to digital information" (Erlhoff & Marshall, 2008, p. 225), and interaction design (concerning the use and relation between people and any type of products) (Erlhoff & Marshall, 2008).

Due to difficulty of finding specific studies on information design, an additional research question encompassing the related design domains is: "What recommendations should design practitioners consider when designing graphic resources or digital products for

people with dementia?" To understand whether any encountered recommendations during the review were validated by people with dementia, i.e., whether participative processes were in place, a sub-question was also raised: "How were people with dementia involved in the formulation of design recommendations?"

2.2 Identify Relevant Studies – Search Strategy

The search strategy targets both scientific databases and grey literature, particularly documents by dementia associations (e.g., Alzheimer's Society), advocacy groups (e.g., DEEP) and international agencies (e.g., World Health Organization). This decision arises from exploratory searches revealing that grey literature provides substantial and relevant information on this topic, coupled with the observation that academic studies on this matter are limited.

Searches will be performed on the following academic databases: Scopus, Web of Science Core Collection, Academic Search Complete, Web of Science Scielo Citation Index and PubMed. Since this study's main field of knowledge is design, but also deals with dementia care, information and communication technologies and human-computer interaction, Scopus, Web of Science Core Collection and Academic Search Complete were chosen for its broad reach and interdisciplinary scope. Being also interdisciplinary, with a focus on regional journals from Latin and Central America, Iberia and South Africa, the Web of Science Scielo Citation Index was included to diversify the geographic scope of the studies. PubMed was selected to increase the chances of identifying relevant studies within the healthcare sector. The search functions of the selected databases are similar, facilitating the adaptation of search strategies from one to another. A complementary search, based on the same search query (see 2.2.1), will be conducted on key journals and conference proceedings, that are not indexed in the databases: Design for Health Journal, Visible Language Journal; Design4Health Conference, and Dementia Lab Conference.

Grey literature search will consider PhD Thesis and be performed through Web of Science ProQuest. Only PhD thesis will be included in the search due to their in-depth contributions (when compared to Master thesis), and due to the feasibility of the review. In addition, the web search engine Google (using incognito window) will be searched using simplified strings to potentially identify recommendations by international agencies and dementia associations or advocacy groups.

2.2.1 Search Terms

To define the search terms, exploratory searches were performed on Scopus and keywords were identified from relevant studies. A search query was then created for all the selected databases; and adapted to search strings to apply on Google searches.

Given the limited number of results obtained from the exploratory searches, there was the need of broadening the design domains (e.g., service design, user experience, user interface, e-health, m-health, usability, internet interventions, web-based interventions), and of adding the mediums where the information is provided (e.g., website, *app*, mobile, touchscreen, brochure, pamphlet, book, information platform). Interior and environmental design, architecture and robotics were domains excluded from the scope of this review. Search terms were grouped into three key elements of the research question: people with dementia, recommendations and (information-related) design (Table 2). Query strings for all databases and Google search are presented in Appendix 1.

Table 2: Search terms.

Key elements Search terms

People with dementia	dement*, Alzheimer, "ne disorder"	urocognitive
Recommend-dations	recommendation*, guidel requirement*, principle*,	
Information + design	"information design", "communication design", "graphic design", "visual communication", "digital design", "web design", "interaction	resource", "information platform", website, app, mobile, touchscreen; brochure,

2.3 Study Selection

2.3.1 Eligibility Criteria

Inclusion and exclusion criteria were defined considering the key elements from the research question (Table 3). All study designs will be considered for search, except if they only consist of a design process description with no conclusions

regarding recommendations or guidelines. Opinion articles, commentaries, journal or conference editorials, and master thesis will be excluded.

The database search will encompass studies and documents published in English, Portuguese, and Spanish, whereas the Google search will only be conducted in English, due to the feasibility of the review. There will be no constraints regarding the publication date (inception to search date).

2.3.2 Screening Procedure

Two reviewers will independently screen the search results, according to the inclusion and exclusion criteria, over two rounds: title and abstract screening followed by a full-text screening of the selected studies. The software Rayyan (Ouzzani et al., 2016) will be used to support the screening process in tracking the decision-making process.

In the Google search, for each search string the first page of results (around 60 results) will be subject to screening following the same screening procedure as for the database searches.

All search results will be imported into Rayyan. Duplicates will be removed. A pilot screening of 25 sources will be undertaken to test the screening process, the eligibility criteria and make refinements if necessary. Titles and abstracts of all search results will be screened based on inclusion criteria. Motives for the exclusion of studies will be documented. The full text of all studies/sources selected at this stage will be retrieved, and then assessed based on eligibility criteria. Motives for the exclusion of sources will be recorded. Any divergences occurring

during the screening process will be solved through consensus or a third reviewer. Studies authored by some of the researchers in the team might be included in the review. In those cases, other researchers in the team will be asked to act as reviewers. Corresponding authors of non-available articles will be contacted during the full-text review process. The selection process will be fully reported using the PRISMA-ScR flow diagram (Tricco et al., 2018).

2.4 Data Charting

After selecting the documents to include in the review, two reviewers will extract the data using a charting table developed by the research team. Extraction will be performed independently by one researcher and verified by another.

The extraction entities for the data charting table include basic citation details and source characteristics, and key findings related to the research questions, including details on the recommendations, information to help contextualizing the recommendations, and information on whether people with dementia were involved in processes that led to those recommendations (Table 4). The charting table will be subject to a pilot testing, with three selected sources and refined if necessary. Divergences in the extraction phase will be solved through meetings to achieve consensus or by a third reviewer. Corresponding authors of the included studies may be contacted to provide information on potentially missing data.

Table 3: Inclusion and exclusion criteria.

on information and concept Studies and docume recommendations or best practices for design domains Studies and documendations or best practices for and adjacent design in the search terms types of sources Types of collisions or prepared types of sources reports, toolkits, go related organisations.	nents focusing specifically d/or design for people with dementia nents which include , guidelines, principles, requirements or designing for people with dementi-	, a
recommendations or best practices for best practices for best practices for design and adjacent design in the search terms types of prepared organisation or best practices for best practices or best practices for best practices or best practices for best practices	, guidelines, principles, requirements or designing for people with dementi	a
domains and adjacent design the search terms types of Original research reports, toolkits, go related organisation		0, 1, 1, 1, 1, 1, 1, 1, 1, 1, 1, 1, 1, 1,
reports, toolkits, g	nents on information design gn domains, as identified s	Studies and documents on interior design, environments/ environmental design, architecture, and robotics
language English, Portugue	(peer-reviewed or not); PhD thesis; guidelines, resources from dementiatons	Opinion articles, journal or conference editorials, commentaries, Master thesis
search English only for C	se, and Spanish for the database Google search	
date No time span limi		*

Table 4: Extraction entities.

Citation details	title, author(s), publication date, outlet
Source characteristics	country, type of document, aims /purpose
Context	methods, design (-related) domain, outputs
Recommend- dations	main topics, details of recommendations
Validation with people with dementia	involvement of people with dementia (Y/N), sample size, design process stage

2.5 Collating, Summarizing and Reporting the Results

Results regarding the geographic area, date and field of knowledge distribution and methods used in the selected sources will be synthesized. Charts or/and tables may be used to improve the visualization of results. Regardless of the type of study or document, the key findings related to the research questions will be coded, thematically organized, and synthesized. These will be presented in a summarised list of recommendations for designing information for people with dementia. Additionally, conclusions on the involvement of people with dementia in recommendations will be presented.

3 DISCUSSION

Design can play a crucial role in enhancing the wellbeing of individuals with dementia, as advocated in the World Alzheimer Report 2020 (Fleming et al., 2020). There has recent growth of research on dementiarelated design (Brankaert & Kenning, 2020; Halsall et al., 2023; Niedderer et al., 2024; Rodgers, 2022; Tsekleves & Keady, 2021). Some reviews were found on design considerations for individuals with dementia, covering different aspects. While some aimed at identifying general principles for product design (Wesselink et al., 2022), and usability and acceptability of technologies (Holthe et al., 2018), others focused on barriers, design suggestions and functionalities of mHealth applications (Engelsma et al., 2021; Gosak et al., 2023). However, no review was found specifically focusing on designing information tailored for people with dementia.

The exploratory searches undertaken to support the decision-making process in the search query unveiled the scarcity of studies on information design for people with dementia, which further supports the contribution of this review to the field. This review will identify and focus on studies that have generated recommendations through their practical experiences in designing for individuals with dementia within distinct design research projects. Therefore, it aims to consolidate and organize dispersed knowledge relevant to information design for people with dementia. This gap presents an opportunity for researchers and designers to significantly contribute to improving the lives of people with dementia by creating accessible, user-friendly, and relevant information resources.

Aligned with a participatory design approach (Branco et al., 2017) and with the societal effort of supporting inclusion and empowerment of people with dementia, we also seek to understand if recommendations were produced based in projects and research that involved people with dementia and the level of their participation, although this will not be an inclusion criterion.

4 CONCLUSIONS

This scoping review is expected to result in a synthesis of knowledge on recommendations for designing information resources for people with dementia, specially focusing on digital means. By highlighting the importance of participatory design, we hope to encourage the involvement of people with dementia in design processes, ensuring that end results meet their needs and preferences.

In the short term, the findings from this review will be utilized to inform our research project to create an information platform specifically tailored for people with dementia. In the long term, it is anticipated that this platform will play a role in fostering equal opportunities for individuals with dementia to access information, ultimately enhancing their social participation and dignity.

Along with the academic dissemination of the finalised scoping review through the publication of an article, the research team will adapt the search results for public dissemination, particularly information providers and designers, to ensure that the considerations for dementia-friendly practices are incorporated across various information and web resources, aligning with the World Health Organization's vision for a dementia-inclusive society (2017, 2021).

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APPENDIX

Search strategy and query strings, for both published and grey literature. Searches performed on 19 January 2024.

Published Literature

		#
database	query	results
Scopus	(TITLE-ABS-KEY (dement* OR alzheimer OR "neurocognitive disorder*") AND TITLE-ABS-KEY (recommendation* OR guideline* OR requirement* OR principle* OR "best practice*") AND TITLE-ABS-KEY ("information design" OR "visual communication" OR "communication design" OR "graphic design" OR "digital design" OR "web design" OR "interaction design" OR "service design") OR TITLE-ABS-KEY (ehealth OR mhealth OR "internet intervention*" OR "web-based intervention*") OR TITLE-ABS-KEY ("user interface" OR "user experience") OR TITLE-ABS-KEY (usability) OR TITLE-ABS-KEY (website OR mobile OR app OR "information resource" OR "information platform" OR touchscreen) OR TITLE-ABS-KEY (booklet OR pamphlet OR brochure) AND NOT TITLE-ABS-KEY (robot* OR environment* OR architectur* OR "interior design")) AND (LIMIT-TO (LANGUAGE, "English") OR LIMIT-TO (LANGUAGE, "Portuguese"))	682
Web of Science Core Collection	(TS=(dement* OR Alzheimer OR "neurocognitive disorder") AND TS=(recommendation* OR guideline* OR requirement* OR principle* OR "best practice*") AND TS=("information design" OR "visual communication" OR "communication design" OR "graphic design" OR "digital design" OR "web design" OR "interaction design" OR "service design" OR "user interface" OR "user experience" OR usability OR ehealth OR mhealth OR "internet intervention*" OR "web-based intervention*" OR "information resource" OR "information platform" OR website OR app OR mobile OR touchscreen OR brochure OR pamphlet OR book) NOT TS=(robot* OR environment* OR architectur* OR "interior design")) AND (LA=("ENGLISH" OR "PORTUGUESE") AND LA=("ENGLISH" OR "PORTUGUESE"))	611
Academic Search Complete	AB (dement* OR Alzheimer OR "neurocognitive disorder") AND AB (recommendation* OR guideline* OR requirement* OR principle* OR "best practice*") AND AB ("information design" OR "visual communication" OR "communication design" OR "graphic design" OR "digital design" OR "web design" OR "interaction design" OR "service design" OR "user interface" OR "user experience" OR usability OR ehealth OR mhealth OR "internet intervention*" OR "web-based intervention*" OR "information resource" OR "information platform" OR website OR app OR mobile OR touchscreen OR brochure OR pamphlet OR book)	212
Web of Science Scielo Citation Index ¹	TS=(dement* OR Alzheimer OR "neurocognitive disorder") AND TS=("information design" OR "visual communication" OR "communication design" OR "graphic design" OR "digital design" OR "web design" OR "interaction design" OR "service design" OR "user interface" OR "user experience" OR usability OR ehealth OR mhealth OR "internet intervention*" OR "web-based intervention*" OR "information resource" OR "information platform" OR website OR mobile OR touchscreen OR brochure OR pamphlet OR book)	27

¹ For the Web of Science Scielo Citation Index there was the need to make adaptations to the query string, since the exact query used in Web of Science Core Collection only yielded 3 results. First, the recommendation-related search terms resulted were excluded. Second, by

analysing the search results, the search term "app" yielded results on the unrelated theme of "primary progressive aphasia", therefore this term was also removed for the search on this database.

("dement*"[Title/Abstract] OR "Alzheimer"[Title/Abstract] OR "neurocognitive disorder"[Title/Abstract] AND ("recommendation*"[Title/Abstract] OR "guideline*"[Title/Abstract] OR "requirement*"[Title/Abstract] OR "principle*"[Title/Abstract] OR "best practice*"[Title/Abstract] AND ("information design"[Title/Abstract] OR "visual communication"[Title/Abstract] OR "communication design"[Title/Abstract] OR "graphic design"[Title/Abstract] OR "digital design"[Title/Abstract] OR "web design"[Title/Abstract] OR "interaction design"[Title/Abstract] OR "service design"[Title/Abstract] OR "user interface"[Title/Abstract] OR "user experience"[Title/Abstract] OR "usability"[Title/Abstract] OR "ehealth"[Title/Abstract] OR "mhealth"[Title/Abstract] OR "information platform"[Title/Abstract] OR "information resource"[Title/Abstract] OR "information platform"[Title/Abstract] OR "website"[Title/Abstract] OR "app"[Title/Abstract] OR "mobile"[Title/Abstract] OR "book"[Title/Abstract] OR "book"[Title/Abstract] OR "book"[Title/Abstract] OR "book"[Title/Abstract] OR "book"[Title/Abstract] OR "book"[Title/Abstract]]

Grey Literature

database	query	results
Web of	(TS=(dement* OR Alzheimer OR "neurocognitive disorder") AND TS=(recommendation* OR	61
Science	guideline* OR requirement* OR principle* OR "best practice*") AND TS=("information design"	
ProQuest	OR "visual communication" OR "communication design" OR "graphic design" OR "digital design"	
	OR "web design" OR "interaction design" OR "service design" OR "user interface" OR "user	
	experience" OR usability OR ehealth OR mhealth OR "internet intervention*" OR "web-based	
	intervention*" OR "information resource" OR "information platform" OR website OR app OR	
	mobile OR touchscreen OR brochure OR pamphlet OR book)) AND (DG==("DOCTORAL"))	
	and Doctoral (Degree Type) and English or Portuguese (Languages) and English or	
	Portuguese (Languages)	

Google search strings dementia guidelines "information design"; dementia guidelines "visual communication"; dementia guidelines "communication design"; dementia guidelines "graphic design"; dementia guidelines "digital design"; dementia guidelines "web design"; dementia guidelines "interaction design"; dementia guidelines "service design"; dementia guidelines "user interface"; dementia guidelines "user experience"; dementia guidelines usability; dementia guidelines ehealth; dementia guidelines mhealth; dementia principles "information design"; dementia principles "visual communication"; dementia principles "communication design"; dementia principles "graphic design"; dementia principles "design"; dementia principles "web design"; dementia principles "interaction design"; dementia principles "service design"; dementia principles "user interface"; dementia principles "user experience"; dementia principles usability; dementia principles ehealth; dementia principles mhealth.