

Humanizing information about meaningful activities for people with dementia

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Abstract. Stigma and discrimination regarding dementia are still very impactful on the experience of having dementia and of being a carer. To tackle this issue and uplift the quality of life of people with dementia and their carers, efforts are being made to push forward a change in the societal perception of dementia. These include raising awareness and promoting inclusive initiatives that jointly involve people with dementia and their carers, such as engaging in meaningful activities. Meaningful activities have a crucial role in enhancing the well-being of people with dementia, as a means for participation, connection with others, self-expression, and control.

This position paper calls attention to the need for improving the design of information so that it is tailored to people with dementia and supports their self-determination, individuality and autonomy, and the feeling of living a meaningful life. Although there is plenty of information about dementia, often this is not targeted to people with dementia, nor designed in a way that facilitates their access and understanding. This is an opportunity for design practice and research to contribute. This position is driven by person-centred, rights-based and participatory design approaches and is anchored in the authors' previous research on co-designing with people with dementia and their families to support their engagement in meaningful activities.

Keywords: communication design, participatory design, dementia, information, meaningful activities.

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1 Introduction

As dementia evolves, people diagnosed and those who care for them face several challenges related to the gradual worsening of symptoms and the subsequent need for more support. The experience of having a diagnosis of dementia and of being a carer can be very demanding, not only due to the disease's symptoms and progression but also due to the stigma and discrimination surrounding dementia. Both aspects notably contribute to making dementia a highly feared condition [1].

This position paper advocates for design practice and research to have a prominent role in the development of information for and with people with dementia and informal carers, which is particularly relevant when the information focuses on strategies to make their lives more meaningful. This position paper is grounded in person-centred values [2, 3], as well as rights-based [4] and participatory design [5] approaches. In addition, it emerged from previous research [6] by the authors, where family carers of persons with dementia have shown a need for information on how to communicate and support the person with dementia to take part in activities. The aforementioned designed study, conducted in Portugal, aimed to contribute to the maintenance of social relationships and the preservation of personhood. This was explored through designing opportunities for communication and meaningful engagement, by involving people with dementia and family members in co-designing artefacts according to their preferences, interests, and abilities [6]. Nonetheless, even when using the artefacts that were personalised for the person with dementia, family carers mentioned that engaging their relatives in activities was demanding, due to a perceived lack of knowledge and information resources [7]. Subsequently, these conclusions led to a recently started ongoing research project that aims to fill the above-mentioned gaps by exploring and improving information regarding strategies to engage people with dementia in activities, targeting both family carers and people with dementia.

To substantiate the conviction that the design of information directed to people with dementia should be improved to support their independence and pursuit of a meaningful life, the paper is structured as follows. First, it presents a brief account of the theoretical framework that underlies this position, including (a) the importance of dementia awareness and literacy as a means to encourage a dementia-friendly society, and (b) the relevance of providing information on keeping active to people with dementia, as a means to support their self-determination and engagement in meaningful activities. Second, the paper introduces a preliminary web search about available information resources on meaningful activities in the Portuguese language and its findings. Third, the paper closes with considerations for future developments in designing information for persons with dementia.

2 Theoretical framework

2.1 Importance of dementia awareness and literacy

Raising public awareness and dementia literacy is fundamental to reducing stigma and contributing to a more inclusive society [1]. This is stated in the World Health Organization's (WHO) *Global Action Plan on the Public Response to Dementia 2017-2025* [8] and throughout the national dementia plans of several European countries [9]. Concurrently with other work fronts related to care services for people with dementia and their carers, these political documents and guidelines have prioritised the need for increasing public cognizance and friendliness of dementia, based on person-centred and rights-based approaches [8, 9]. The recently published *WHO Toolkit for Dementia-friendly Initiatives* [10] is an example of the efforts that are being made to encourage a shift of attitudes towards dementia and to empower people with dementia to live according to their preferences and values. van Corven and colleagues [11] point out four domains that are crucial for the empowerment of people with dementia: "having a sense of personal identity, having a sense of choice and control, having a sense of usefulness and being needed, and retaining a sense of worth" (p.2). As part of this change of attitudes towards dementia, people must be understood beyond their diagnosis and the dysfunctions associated with it. Sabat [12] explains how fundamental aspects of humanity are maintained, despite the diagnosis. The same author advocates the importance of supporting the relevant remaining cognitive capacities and strengths in order to maintain independence and meaning in life, through raising public awareness, education and psychosocial approaches.

Kimzey and colleagues [13] call for the promotion of health literacy through health education and information suited to the needs of people with dementia and their carers, since the diagnosis. Health literacy is understood as "the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health" [14, p. 6]. Furthermore, health literacy interventions contribute to a person- and community-centred process of empowerment that enables people to make informed choices to improve their health [14]. Prior studies [15–17] indicate that although there is a considerable amount of information about dementia, particularly web-based, people with dementia and informal carers reported that they often felt overwhelmed and unable to find the specific information they needed. This difficulty is mainly associated with a lack of adequacy of information and, in some cases, with how information is presented, in a way that makes it hard to navigate and understand [16].

This constitutes an opportunity for design to intervene, due to its ability to mediate and adapt information to different audiences, and to contribute to the well-being of people with dementia [18]. Aligned with the movement to encourage friendliness, inclusiveness, and the empowerment of people with dementia [8, 10], this paper calls for attention to designing information that is (more) accessible, adequate, and tailored to encourage the self-determination of people with dementia. In particular, and as a starting point, this research focuses on information that supports people with dementia to keep active in ways that are meaningful for them.

2.2 Importance of information regarding meaningful activities for people with dementia

In a recent review that included the perspectives of both people with dementia, informal and formal carers, Strick and colleagues [19, p. 5] found that “the fundamental purpose of occupation is to support the person living with dementia to feel they were living a meaningful and fulfilling life”. Prior studies that looked for the perspectives of people with dementia regarding their engagement in activities, identified that activities are meaningful when they constitute opportunities for pleasurable and enjoyable moments that reflect individual interests, values, and motivations, as well as when they nurture a sense of belonging and connection to the self, to others and the environment [20, 21]. The value and meaningfulness of occupation should be perceived by the person with dementia, which is affected by their worldview and that of their carers, and the social and physical environment where the activities occur [19].

Meaningful activities are considered crucial for the well-being of people with dementia to address their psychological needs [2]. Their paucity has been associated with more social isolation, challenging behaviour, and decreased quality of life [22]. Engagement in meaningful activities and leisure has been linked with several interrelated benefits: as a way to maintain a positive attitude, a sense of hope, and to feel they are fighting against and coping with symptoms through being proactive, hence in control [23, 24]; as a source of enjoyment, stimulation, self-expression and choice [24, 25]; as a chance for participation and communication with others, contributing to the maintenance of social relationships [25, 26]. Meaningful activities were also found to be pertinent for the informal carers of people with dementia as a means to engage in social interaction with their loved one, and as opportunities for respite [25].

In a study on the perspectives of people with dementia about activities, Han and colleagues [21] concluded that people with dementia “want to engage in personally meaningful activities to be connected with self, with others, and with the environment” (p. 121). Nevertheless, often people with dementia do not have opportunities to engage in activities on their own terms, reported as one of their most frequent unmet needs [24]. For occupations to be meaningful, a supportive environment is required, where the person with dementia feels valued and finds security and freedom [19]. However, despite being mostly emphasized as beneficial, family carers also associated activities with difficulty, resistance, uninterest and frustration, particularly due to the progression of dementia symptoms, difficulties in planning and finding activities that their relatives with dementia value, and lack of resources and support [21, 25]. This might explain why learning skills and strategies to communicate effectively and support capacities, as well as to stimulate and provide activities for the person with dementia are among the training and information needs, conveyed by informal caregivers of people with dementia [27–29].

The awareness and perception of carers and persons with dementia about the importance of keeping active, influences its meaning and conditions the accessibility of people with dementia to occupational opportunities [19]. Information and support should be provided to people with dementia, and their informal carers, to recognise

motivations, desires and needs for engagement in activities, which is crucial to suit and adjust such activities to each individual and ensure satisfaction [21].

3 Preliminary search

A preliminary web search was undertaken to understand what information on promoting independence and meaningful activities is readily available for people with dementia and their carers in Portugal, the context of research. The country has a percentage of older people above the European average and ranks fourth among OECD countries on the prevalence of dementia [30, 31].

In a systematic review, Soong and colleagues [16] refer the Internet as the primary source of information for people with dementia and informal carers, as well as the most preferred one. In a study undertaken with family carers, Allen and colleagues [15] found that the most valued characteristics of information sources were trustworthiness, accessibility, and the ability to answer specific questions. Although participants in that research revealed a preference for obtaining information from a relational source, such as a well-informed healthcare professional, the Internet was favoured and predominantly used due to its accessibility [15]. Likewise, informal carers in Portugal also value web resources for their convenience (the possibility to access at any time and from any location), despite some discomfort or lack of experience when using the Internet [32].

A preliminary web search was performed on Google, deliberately as if a person with dementia or an informal carer located in Portugal would search for information on activities for people with dementia. The search was done in Portuguese, using the keywords: people with dementia/dementia and activities, occupation or stimulation. The 10 most frequent websites from the emerging results were analysed. All pages with contents in Portuguese were eligible for analysis, irrespective of the nationality of the organisation producing the contents (e.g., the pages could either be in European or Brazilian Portuguese). Although there might be cultural differences in the contents, for instance, from Brazil vs. Portugal, the search was aimed at mimicking a natural search from a user, who most likely does not filter the results by country. Since the research targeted information resources directed at persons with dementia and informal carers, academic papers, thesis and dissertations were excluded. Social media results (facebook and pinterest) were also excluded due to their volatility. In total, eight websites and two PDF publications from Portugal and Brazil, were analysed. Table 1 (websites) and Table 2 (PDF publications) show the findings.

Despite the high prevalence of dementia in Portugal, the information available on the web to support the engagement of people with dementia in activities is sparse. Among the ten most frequent results, three of them were not produced by Portuguese organisations. Available information is mostly provided by private healthcare clinics, generalist or specific to neurological conditions and occupational therapy (3 in 8 websites); health information websites, generalist or specific to dementia and occupational therapy (3); and by not-for-profit associations (2), including the Portuguese dementia association, Alzheimer Portugal, and an association for people

with disabilities. The two PDF publications were available through a mental health information website and the website of a not-for-profit care organisation. Worth mentioning that none of the ten most frequent websites displayed through the google search was a governmental website, which are frequently regarded as reliable and trustworthy sources of information [15]. Within the analysed websites, the content related to activities for people with dementia consisted of: informative articles (in 7 websites, out of 8), some broadly referring to the importance and approaches of different therapeutic interventions related to keeping active, mostly occupation therapy and cognitive stimulation (4), and others with more practical tips and suggestions on what to do and how to conduct the activities (5); about or related to the services offered by the clinics, organisations or training websites (5); training events on the subject (2) and activities-related resources or products (1).

Table 1. Most frequent websites with information on activities for people with dementia¹

	Website organisation	URL	Country	Activities-related content	Target
1	NeuroSer Private healthcare clinic (neurological conditions)	Neuroser.pt	Portugal	Information articles with tips and suggestions. Information about the clinic's services.	Informal carers
2	Alzheimer Portugal Not-for-profit dementia association	Alzheimerportugal.org	Portugal	Information on past training events. Information articles with tips and suggestions. Information about activity products and resources.	Formal and informal carers People with dementia General public
3	Projecto Eu Consigo Private healthcare clinic (occupational therapy)	www.projectoeuconsigo.pt	Portugal	Information on past and current training offers. Information articles on the importance of occupation and strategies to support it. Information about the clinic's services.	Mostly formal carers (OT) Informal carers
4	Joaquim Chaves Saúde Private healthcare clinic (miscellaneous of specialities and clinical analysis lab)	www.jcs.pt	Portugal	Information articles on the importance of occupation and cognitive stimulation.	Informal carers
5	Fundação AFID Not-for-profit association on disabilities	www.afid.pt afidsenior.pt	Portugal	Information and news about their services within their facilities, in particular, a Neurostimulation Unit.	General public
7	Alzheimer 360	alzheimer360.com	Brazil	Information articles with tips and suggestions.	Formal and informal carers

¹ The 6th most frequent website was the Federación Iberoamericana de Asociaciones de Personas Adultas Mayores (FIAPAM), due to an article on Cognitive Stimulation Activities in the routine of a person with Alzheimer's (Available at: <https://fiapam.org/atividades-de-estimulacao-cognitiva-na-rotina-da-pessoa-com-alzheimer-aspectos-praticos/>). However, with the exception of this article which was translated to Portuguese, most website's contents are in Spanish. Therefore, this website was excluded from the analysis.

	Information and training platform (including both free and paid content)				
9	Saudebemestar.pt Information website on health (miscellaneous issues)	www.saudebemestar.pt	Portugal	Information article on approaches to cognitive interventions for people with dementia.	General public
10	Reab Information and training website (occupational therapy)	www.reab.me	Brazil	Information articles with practical tips for specific activities.	Formal and informal carers

Table 2. Frequent PDF publications with information on activities for people with dementia

Publication title ²	Coordination	Publication date and country	Description and activities-related content	Target	URL
6 Care Manual for caregivers of people with dementia (2nd edition)	Alzheimer Portugal (translation and adaptation to Portuguese) and Alzheimer Europe (original version)	2006 Portugal	Comprehensive guide on how to care for someone with dementia. Sub-section dedicated to “Leisure, activities and exercise”.	Formal and informal carers	https://www.saudemental.pt/backoffice/pdfs/636cda5370.pdf
8 Dementia: good practices handbook	União das Misericórdias Portuguesas (not-for-profit organization)	n.d. Portugal	Manual on what dementia is, and how it affects people; on different intervention approaches; and on supportive architecture and environments. Sub-section on “Neurostimulation: cognitive, behavioural and functional intervention”.	Formal (and informal) carers	https://cdn.ump.pt/files/files/Manual_Boas_Praticas_Dementia.pdf

From a person-centred and rights-based perspective, a striking aspect was that most of the information was exclusively directed to (formal or informal) carers of people with dementia. Only the Alzheimer Portugal’s website had some articles targeted to people with dementia, including one about activities found through navigating on the website (and not displayed in the google search results). The lack of information in Portuguese specifically targeting people with dementia was confirmed by the authors in consultation with Alzheimer Portugal.

When analysing the 8 websites and 2 PDF publications from a visual communication design perspective, several issues were identified in the way information is presented and organised. Such concerns might make it harder for someone with dementia to navigate, read and comprehend. The analysis of the websites from a design perspective

² The titles were freely translated from the Portuguese, by the author.

took into account the design requirements and recommendations identified in previous international research [33–35]: 4 out of 8 websites had poor colour contrast between the text and the background, or in specific elements (e.g. headings, highlights, links); 6 out of 8 websites had inconsistent, inadequate or very subtle text hierarchy; 7 out of 8 websites had issues with spacing – 4 had inadequate line spacing (too wide or too tight), 3 had inconsistent or inadequate spacing between paragraphs, 1 had inconsistent spacing between words and another 1 had inadequate spacing between website elements (e.g. main content and sidebar); all 8 websites do not make the best use of images: the choice of images is often irrelevant, redundant or inadequate (culturally, or because it presented the person with dementia as withdrawn) and, in some websites, they are too small (3), stretched (1) or with low resolution (1); in all 8 websites, it was hard to find specific information, due to the lack of organisation of information articles in a way that facilitates finding them (e.g. no apparent organisation; organised by date rather than by content, or due to being more generic health-related websites); in 3 websites the text size was too small, and in 2, the text column was too wide; 2 websites were found to use inadequate typefaces (too ornamental, or not adequate for reading long texts on screen); 4 out of 8 websites were found to have a dense overall appearance (too many elements, lack of white space), and 2 were found to use elements that might be confusing (such as sliders or dense sidebars). Regarding the 2 PDFs, both were very lengthy, dense and text-heavy publications and one of them had issues with the typeface choice (inadequate for long text reading), tight line spacing, and inadequate choice of images (infantilising, naive, poor-quality illustrations).

4 An opportunity for design

The UN Convention on the Rights of Persons with Disabilities [36] recognises the importance and need to ensure that persons with disabilities, such as persons with dementia, have better and equal access to information, namely about available resources to support them. Moreover, the Convention highlights the pressing need of designing inclusively, for everyone to use (inclusive design)[36]. There are international examples of web resources targeting information on dementia and for people with dementia designed in a dementia-friendly way. For instance, the Alzheimer’s Society UK provides information on how they improved their website’s accessibility and usability for people with dementia [37] and compiled guidelines to design dementia-friendly websites [35]. Even though good examples exist, only a few studies address the information needs and preferences of people with dementia [16]. In addition, dementia-friendly information is still not a generalised practice. This assumption is supported by the preliminary search presented in this manuscript, which demonstrated that, from a dementia-friendly (design) perspective, there are significant gaps for web resources available in Portuguese. Just one of the 10 analysed websites and publications had information directed to people with dementia, but only to their carers. All these resources had design issues that might make it harder for people with dementia (and even their carers) to find, read and understand the information provided, regarding the choice of colours, the use of images, the website layout and text formatting, and navigation. Another concern is the observed

need for improving the visibility of relevant information and websites on the web. The content of many of the web search results did not specifically provide information about keeping active and meaningful activities (but rather on related training events and available health and therapy services). However, in some cases, more relevant content was found on the same websites when further exploring them. Most of the results come from private healthcare clinics and informational websites, which are sources that do not match what people with dementia and informal carers perceive as trustworthy [15], which also correspond to their information source preferences [16]. Moreover, many of the information articles addressed the topic of activities for people with dementia broadly and generically, which might make it more difficult to relate to individual needs and situations.

The differences between the international dementia-friendly examples and those found in the preliminary search might also relate to how different cultures view and represent dementia. Comparative studies that analyse the relationship between cultural portrayals of dementia and how information is presented is an interesting and necessary topic for future research.

The existing knowledge and guidelines can still be further investigated from a design perspective. Design — as a research approach, practice and way of thinking — deals with mediation between i) artefacts and the characteristics, needs and desires of future users; as well as ii) utility, usability, symbolic construction and aesthetics [38, 39]. Moreover, through the designed artefacts, design can play a role in mediating, encouraging and supporting happiness-enhancing activities [40] and social interaction [41, 42]. Visual communication aspects can be explored to make information resources more dementia-friendly, i.e., more accessible, adequate, usable and appealing. Furthermore, prior research has suggested that information resources should match individual needs, and that ways to make them relational should be sought [16]. In addition, drawing on the idea that artefacts can support the promotion of positive experiences for people with dementia [43], it might be possible to design information resources in a more humanized way. Thus, design might deliberately contribute to encouraging the self-determination of persons with dementia, as well as their autonomy and individuality. In this sense, and regarding information content, the focus on meaningful activities is instrumental. Especially in the early stages of dementia, and for as long as possible, people should be supported and incentivised to have control and find ways to make their lives more meaningful [39]. Strick and colleagues [19] affirm that a catalytic environment is required for meaningful occupation. This paper aims to put forward the hypothesis that if information on meaningful activities is carefully designed and tailored to people with dementia and their carers, it might promote this supportive environment and augment their occupational opportunities.

Aligned with a rights-based perspective that people should have a say about what might impact their lives, information resources must be designed in participatory processes, collaborating with people with dementia and informal carers as experts by experience, to share control and inspire change [44]. The guidelines and other initiatives advocating for making information and websites more accessible, such as The UK Network of Dementia Voices, also claim the importance of involving people with dementia in producing websites and information resources [34, 35, 45]. In a study on promoting

health literacy in people with dementia and informal carers, Kimzey and colleagues [13] also emphasize the need for their inclusion in the development of information materials, which would additionally contribute to the literature in this field. An interesting example of information co-created with people with dementia is the self-help guide *My Life, My Goals* [46].

Even though guidelines on dementia-friendly websites and information are available [33–35], the preliminary search work presented in this manuscript identifies several gaps in information websites concerning how dementia-friendly their design is. However, this preliminary search was exploratory. More in-depth, systematic and comprehensive research will be conducted by the authors, who will not lose sight of the importance of disseminating the findings to people with dementia, their relatives, and those who design contents targeted at them. The importance of public dissemination and communication of research results has been increasingly recognised and reinforced. Effective strategies should be sought to raise awareness about the knowledge of how to produce and design dementia-friendly information, and its implementation should be supported and pushed forward. This knowledge would be particularly relevant to dementia and healthcare information providers, to ensure that dementia information materials and resources are dementia-friendly. It would also be essential for design practitioners so that these dementia-friendly concerns can be taken into consideration in all kinds of information and web resources, as part of the desired shift toward a dementia-inclusive society proposed by WHO [8, 10].

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