Co-Care: Co-created ICT solutions for Alzheimer's Informal Caregiving

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D4	**Toolkit**	**Creation and development of the Toolkit**

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Table of contents

List of terms and abbreviations

The World Health Organization	WHO
Person living With Dementia	PWD
Information and Communications Technology	ICT
Work Package	WP
Information Technology	IT
mobile Health	mHealth
Activities of Daily Living	ADLs
Instrumental Activities of Daily Living	IADLs
Fundació Pasqual Maragall	FPM
Alzheimer Portugal	AP
Alzheimer Society	AS
United Kingdom	UK
Contact Help Advice and Information Network	CHAIN
Global Positioning System	GPS
Save Our Ship	SOS
General Practitioner	GP

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Executive Summary

This document describes the process of creating and developing the Toolkit. The elaboration of this technological tool is established in 3 phases: the assessment of needs, the co-creation of the resource, and the testing of the tool developed. This process has been carried out throughout its journey hand in hand with those people who care for or assist or assisting people with Alzheimer's, such as informal caregivers and professionals who are experts in the scope, specifically: the assessment of needs, the co-creation of the resource, and the testing of the tool developed. This process has been carried out throughout its journey hand in hand with those people who daily are caring for or assisting people with Alzheimer's, such as informal caregivers and professionals who are experts in the scope. In the hands of the technology company, a technological tool has been developed focused on co-creation, health, and the caregivers with resources and contents of utility, interest, and profit for those informal carers, professional experts, and people with Alzheimer's. The conclusions of the document provide an evaluation and perspective of the work carried out to assess whether the Toolkit is feasible to continue to be developed and implemented.

Toolkit

1. INTRODUCTION

The prevalence of dementia is increasing as the global population ages. The World Health Organization (WHO) (2021) estimated that 50 million people currently live with dementia around the world and that this number will triple by the year 2050. Currently, most individuals living with dementia are cared for by families and friends (WHO, 2017), who are essential to the care recipient's quality of life (Farina et al., 2017).

Family and friend caregivers incur physical, psychological, social, and financial costs as part of their role and often experience stigmatization due in part to the lack of understanding surrounding dementia in the majority of countries (WHO, 2018). Caring for a loved one with dementia can be burdensome, and many caregivers suffer from reduced quality of life (Takai et al., 2011; Tomomitsu et al., 2014), limiting social engagement and support (Waligora, Bahouth & Han, 2018), stress-related cognitive dysfunction (Oken et al., 2011), and depression and anxiety (Sörensen and Conwell, 2011; Laks et al., 2016). Evidence suggests that caring for a Person living With Dementia (PWD) is more burdensome than caring for persons living with other illnesses (Alzheimer's Association, 2012; Pinto and Barham, 2014). Research suggests that the prevalence of anxiety disorders is higher for caregivers of PWD than for other caregivers (Cooper et al., 2007) and that the likelihood of self-reported depression is higher for caregivers of persons with dementia than non-caregivers (Posner et al., 2015; Tomomitsu et al., 2014). When comparing caregivers of PWD to other caregivers, caregivers of PWD were found to have significantly worse subjective well-being and physical health (Brodaty and Donkin, 2009; Pinto and Barham, 2014).

The ubiquity of mobile technology and its applications has the potential to contribute to manage those needs. In general, mobile apps are reasonably priced and user friendly and offer an information repository collected from various sources (Frisbee et al., 2016; Ports et al., 2020; Dayer et al., 2013). Caregiving-related apps are specifically designed to provide users with a platform to gain appropriate and trusted information, manage medication taking, improve communication with care providers and support groups, connect with counterparts, reserve transportation, and manage the health condition of care receivers in an organized manner (Saltzman, 2021).

Although there are hardly any studies in the literature that investigate the role of caregiving related apps in reducing caregiving-related burden (Wittenberg et al., 2019), it is very likely that such apps significantly lessen the stress caregivers face by providing a convenient platform to receive informational and emotional support (Grossman et al., 2018). Despite the considerable role of caregiving apps in reducing stress and improving the overall quality of life among caregivers and although more than 57% of American caregivers have a smartphone, only 40% of them use a caregiving-related app (Wang et al., 2016). This raises the concern of finding solutions to increase caregivers' access to and effective use of such beneficial resources.

Some studies highlight the roles of caregivers' digital literacy and sociodemographic factors on their natural propensity to use various internet-based tools and services for caregiving purposes in general (Chiu et al., 2011; Shaffer et al., 2018). However, the current understanding of caregivers' intentions to use related mobile apps for their responsibilities is limited, and we could not find any published studies that directly investigated the influential factors.

Our research[1] team conducted a review with two research questions that guided this piece of work:

Are the digital solutions available (1) designed to improve the life of informal Alzheimer's caregivers? And (2) designed to meet the needs of caregivers? Our results suggest that in the last 5 years there has been an investment from associations, companies and universities to address the constraints and difficulties felt by informal caregivers in their daily life. However, there is still room for further development. Our literature review showed that there are technological tools that can improve the practical life and well-being of caregivers, namely: educational resources and development of competences, psychological health and social engagement. There are also digital solutions which focus on specific needs of caregivers such planning, personal health and caregiving tasks. Despite this, there is still a lack of digital resources in many other important domains, such as the physical health of the carer, the management of responsibilities or crisis planning to mention a few.

When looking into the design process, we found that the available Information and Communications Technology (ICT) solutions are still at an early stage of development and at the level of exploration and initial implementation. More worryingly, caregivers had not played an active or influential part in the design of these tools. In fact, in 85% of the literature found, references to co-design processes were absent. Our research shows that, when caregivers were included, they were mainly requested to contribute at the end of the process with potential improvements. Meaningful participation during the design phase, where it is needed most, is still scarce.

For this reason, we aim to improve the autonomy and quality of life of family caregivers of people with Alzheimer's by using the e-health toolkit designed from their point of view and in order to cover their needs. And the specific aims include:

- To give family caregivers tools to choose ICT-based solutions to facilitate their daily work/life as caregivers.
- To develop and improve their skills to better use ICT-based solutions in terms of navigation but also critical thinking and contrasting use and benefits of tools.
- To be able to connect with peers in the same situation to share and exchange impressions regarding solutions but also their role as family caregivers.
- To give them ICT-based tools to facilitate their daily work/life, improving their skills and to connect with peers to help them maintain wellbeing.

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[1] Soares, Célia; Macedo, Patrícia; Madeira, Rui; Colaço, Gabriela; (2020) State of Play report on co-created ICT-based Alzheimer care solutions. Deliverable 1 of the Co-Care project funded by Erasmus+ Program of the European Union GA No: 612532. Available at: https://co-care.eu/en/reports.

2. METHODOLOGIC DESIGN

2.1. Design

The design of the Toolkit was set out as can be seen in Figure I. However, some changes and modifications have been made during the development of the project, which are detailed below.
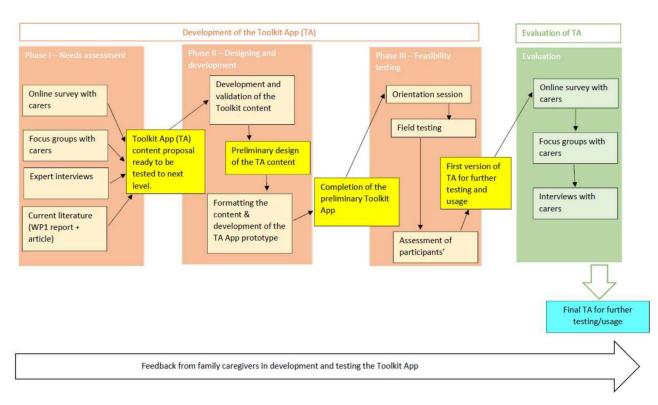

Figure 1. Toolkit design planned implementation process

In phase I, called needs assessment, the aim was to identify the needs of family caregivers and contrast them with reality. To do so different data collection procedures were done in order to have a proposal of format and content for the Toolkit after finishing this phase.

- Report done in Work Package 1 (WP1) with identified needs for family caregivers as well as existing technologies crossed with which technologies would cover what needs as well as facilitators and barriers to consider.
- Focus groups with family caregivers to (a) gain an in-depth understanding of family caregivers' perceptions toward the needs, barriers, and challenges faced when managing their care recipients; and (b) identify the experiences of and opinions for using mobile Health (mHealth) applications in health information seeking.
- Experts' consultation to identify healthcare and Information Technology (IT) experts' opinions on the provision of care of people with dementia and the development of an mHealth

application for caregivers (starting point: summary report, based on the results of the online survey and focus groups, prior to the interviews).

- Online survey to family caregivers to examine the general understanding of the current needs of caregivers and their use of mHealth applications in health information seeking.

Phase II, called development of the Toolkit, aimed to design and develop a user-centric preliminary mHealth application (Toolkit) with an iterative codesign process (including content and prototype development). In order to do this, it took several steps to have at the end a draft version of detailed content overview of the Toolkit and App Toolkit proposal ready to be tested at a higher level.

- The development and validation of the content of the Toolkit was the first step to follow. Content triangulation of the Phase I data and consensus on the framework was reached by members of the Toolkit co-design group. After this agreement, family caregivers not included in the group were involved in two rounds of group online meetings to ask them to rate the content for its adequacy and clarity and to make suggestions to improve it.
- Even though it was planned to first validate the content, then format it and start the development later on, the steps were overlapped in order to move forward in the chronogram. Whilst the development and validation of the content of the Toolkit was ongoing, it also started to develop the prototype.
- The development of the prototype of the application was carried out by Knowledgebiz following the iterative process of co-creation.
- Once the content validation was ready, it was then formatted.
- It was necessary to adjust the content and make it accessible to the target population, following the guidelines to make it accessible for sight, mobility and literacy. Clear, responsive presentation and layout, easy navigation, keyboard control, help with bugs, and data collection automation, among others, were also considered.

In phase III, called feasibility testing, the goal will be to determine whether the intervention is appropriate for further testing, including user testing which will consist of real-world field tests to assess users' experiences with the app. This phase, in the project itself, belongs to the piloting of the toolkit. After this phase we will have a final Toolkit App version of a mobile-enabled, user-centred, culturally appropriate health app incorporating health literacy concepts. To achieve it the following steps will be taken.

- Participants involved in the testing phase will be familiar with the app environment through the phase of development and validation of the Toolkit content. Besides that, they will receive successive communications (via e-mail) to be informed of the upcoming steps in order to be able to anticipate what is coming next.
- An orientation session will be hold for the Toolkit testers. In this session the nature of the study will be explained, and participants will receive written information as well as signed an informed consent. They will be asked to fill in an information sheet including information about smartphone and internet use skills in order to have knowledge of possible barriers. All participants will have the opportunity to resolve questions and doubts.
- All participants will be given access to download the app and a demonstration on how to use the app with the direct support of the conductor. Participants will receive a copy of a prepared

- manual for mHealth app operation and use. Participants will be requested to use the app at their home for 2 weeks.
- During their use at home, the field testing, a weekly reminder will be sent, with a follow up telephone when needed. In addition, participants will be able to contact the reference persona at any time through email. Participants will maintain a logbook to record the frequency of usage, relevant experiences and challenges faced by them in use of the app.
- In order to evaluate the testing phase, all participants will access a pre/post questionnaire before carrying out the agreed period for the testing.

This phase can be found in detail in Deliverables 12-14.

2.2. Data collection methods

Focus groups

A focus group was the data collection technique chosen for an in-depth understanding of the topic but with a collective point of view. Focus groups constitute a research method that researchers organize for the purpose of collecting qualitative data, through interactive and directed discussions (Morgan, 1996). The interactivity of focus groups allows to obtain qualitative data from multiple participants, often making focus groups a relatively quick and convenient research method (Kitzinger, 1995). One informal focus group (as a tester) and two formal focus groups per country were conducted online, having between five and eight participants maximum. Formal focus groups were recorded in order to analyse afterwards.

Experts' consultation

Delphi method was the data collection technique chosen to decide from experts' point of view the content and characteristics of a mHealth application for caregivers. The Delphi method is a structured communication technique or method, originally developed as a systematic, interactive forecasting method which relies on a panel of experts (Dalkey et al., 1963; Sackman, 1974; Harold et al., 1975). Delphi is based on the principle that forecasts (or decisions) from a structured group of individuals are more accurate than those from unstructured groups (Rowe and Wright, 2001). The experts answer questionnaires in two or more rounds. After each round, a facilitator or change agent (Milbrey and McLaughlin, 1990) provides an anonymised summary of the experts' forecasts from the previous round as well as the reasons they provided for their judgments. Thus, experts are encouraged to revise their earlier answers in light of the replies of other members of their panel. It is believed that during this process the range of the answers will decrease, and the group will converge towards the "correct" answer. Finally, the process is stopped after a predefined stop criterion (e.g., number of rounds, achievement of consensus, stability of results), and the mean or median scores of the final rounds determine the results (Rowe and Wright, 1999). It is important to highlight anonymity among members of the expert group during the study to avoid possible biases related to the influence of the opinion of others. The expert's consultation consisted of three phases: 1. Formation of the committee of experts; 2. Two rounds of questionnaire (via e-mail); 3. Analysis of the results and elaboration of the conclusions through a final report by the group.

It was expected to conduct individual interviews with specific professional at the end of the round of consultations as they could have a more partial view of the caregivers' situation. However, due to the

amount of information accumulated and the type of responses received in addition to the little time available, this task did not progress.

Survey

A survey method was the data collection technique chosen to obtain descriptive and general understanding of a situation. Questionnaires were conducted in order to gather large size of information in a short period of time. The essence of survey method can be explained as "questioning individuals on a topic or topics and then describing their responses" (Jackson, 2011). This was a mail survey, which is a written survey that is self-administered (Jackson, 2011). Questionnaire was sent by email to all members accompanied by a previous presentation note with the aims, as well as the practical conditions of development of the survey (response time, guarantee of anonymity). As planned final proposal of questions was revised after conducting focus groups and experts' interviews.

Co-creation workshops

In the development of phase III, a selection of caregivers will be also involved. They will attend to workshops or seminars in which the technological tool created will be shown as well as its uses and functionalities. The workshops are conceived as an informal and agile meeting between the company developing the Toolkit and the caregivers, always with the support of the association to which they belong. It is intended to get direct feedback from their assessment of the tool development process to adjust the resource to their considerations and maximise the adaptation to their considerations in order to be useful and cover unmet needs. Up to 2 rounds of workshops can be held to gather as much information and make the platform as useful as possible.

2.3. Target groups and selection of participants

Focus groups

In the case of focus groups, the target were family caregivers of persons with Alzheimer.

The defining characteristics of an informal caregiver typically include being a person who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability (Roth, Fredman, Haley, 2015). Different studies, however, vary in their methods for defining who qualifies as a caregiver and for measuring and confirming the types of assistance provided. In some studies, caregivers are simply the co-residing spouses of persons with dementia who report providing some informal care (e.g., Kiecolt-Glaser et al., 2003; von Känel et al., 2006). Other studies more explicitly confirm that caregivers are persons who provide help with one or more ADLs or IADLs (e.g., Brown et al., 2009; Fredman et al., 2010; Schulz & Beach, 1999). Telephone survey studies have defined caregiving by asking specific questions about providing some form of assistance to a family member with a chronic illness or disability (e.g., Roth et al., 2013) or to an older adult who was unable to manage independently without help (e.g., Pruchno et al., 2008).

In our case we included primary caregivers, defined as a person who assumes responsibility for providing companionship, support, and daily care to the dementia patient; the person most frequently in the company of the patient (normally a direct relative or spouse). (Toribio-Díaz et al., 2013).

Eligibility criteria has been:

Inclusion criteria:

- Being a family/informal caregiver at the time of participating in the group
- Being older than 18
- Being able to understand and express themselves in the language in which the focus group will be done (English, Portuguese, Spanish/Catalan)
- Agree to participate with your informed consent
- Have an internet connection and a computer or other electronic device with a camera and microphone, for the development of the activity in its virtual format.
- Basic user-level knowledge of the digital environment to be able to access the video conferencing platform.
- To have participated in any caregiver care program offered by the organization (Only for Fundació Pasqual Maragall participants).
- Member of Research Network or Dementia Voice Groups (Only for Alzheimer Society participants).

Exclusion criteria:

- Being a family/informal caregiver not under the definition agreed

Participants were selected following a structural sample based on the follow classification: Novice (1-2 years' experience), advanced (3-5 years' experience), expert (+5 years' experience). We followed different procedures of selection depending on the country as follows:

- Spain: Given the inclusion and exclusion criteria, those who had been part of the Fundació Pasqual Maragall (FPM) carers programs, were contacted and informed about the focus group. Contacted by e-mail, with short information of the project, purpose of the focus group and proposed dates for it, inviting the carers to participate. A group of people (according to the agreed number) was selected between those interested, prioritizing the most representative and diverse possible for the interest and aim of the project. All interested carers received a reply thanking them or with a notification for those being selected.
- Portugal: Caregivers of People with Dementia were selected from Alzheimer Portugal (AP) services. They were invited to collaborate in the Focus Groups, and caregivers who demonstrated interest in participating were integrated into the groups. Initial contact was made by email, or by phone, with the purpose of the Focus groups being explained. Afterwards, after their demonstration of willingness to participate, further information was sent by email.
- United Kingdom: Alzheimer's Society (AS) checked with Research Network (network of volunteers of 375 members) and within their Dementia Voice Database App to identify people who met the selection criteria and had expressed an interest in taking part in online focus groups. They were invited by phone and email and received the agreed information and consent forms from Co-Care as agreed. A second focus Group was planned but invited participants had technological problems, so it had to be cancelled. They were all thanked for their interest.

An important participant in focus groups is moderator characteristics, this role was assumed by someone caregivers know from support groups in order for them to feel confident share their needs, barriers, challenges when managing their care recipients. This moderator had previous experience with this specific target population and was supported by research team member with experience in this type of groups in order to follow research principles when conducting each session.

Experts' consultation

For this target group we were looking for expert professionals in the field of caring for people with Alzheimer/dementia. After discussion, it was concluded that there are two types of professionals who needed to be consulted, those with frequent and direct contact with caregivers and those with less contact but with specific knowledge. This type of professionals varies between countries.

Those professionals with whom caregivers have more frequent contact (whom in general terms know the situation of a person with Alzheimer's and their career globally), were part of the sample that participated in data collection using the Delphi method.

Eligibility criteria was:

Inclusion criteria:

- To have five or more years of experience as their professional role.
- To have experience with persons with dementia/Alzheimer's and/or caregivers of persons with dementia/Alzheimer's.

Participants were selected following a structural sample based on gender, age and years of experience. And they will be approached with the following procedure:

- In the case of United Kingdom, a notice was posted on the Contact Help Advice and Information Network (CHAIN; https://www.networks.nhs.uk/) dementia sub-group requesting participants to take part in interviews. The CHAIN network is 150,000-member network of researchers, health and social care providers and policy makers with a shared interest in health and care improvement. The dementia sub-group has over 1000 members. To supplement this, AS made use of informal networks, e.g., LinkedIn and established relationships within their local service and policy teams to identify participants.
- In the case of Spain, professionals were contacted through the primary care centres and hospitals with specialized dementia units in the geographical area where FPM is located or with whom we have previously collaborated, prioritizing centres with large elder population and with specialized professionals caring for people diagnosed with Alzheimer and their relatives.
- In the case of Portugal: Contact with primary care professionals with previous contacts and partnerships were prioritized. In addition, contact with health local authorities was an option, in order to communicate with professionals from the area. Regarding nurses, Alzheimer Portugal has worked in different partnerships with nursing professionals at primary care settings, also nursing homes, day care centres, which facilitated this approach. In addition to Alzheimer Portugal social workers, they established a network with other professionals. Social workers working with caregivers in the community were prioritized.

Survey

In the case of survey, the target were family caregivers of persons with Alzheimer with the following eligibility criteria:

Inclusion criteria:

- Being a family/informal caregiver at the time of answering the questionnaire
- Being older than 18

The questionnaire was sent to all members of the different foundations to get as many answers as possible looking for representativeness of the sought sample will be less than a sample error of alpha error of +/- 5% and a confidence interval of 95%. The starting characteristics of the population were:

- In the case of Spain, through Fundació Pasqual Maragall, which has about 1.000 caregivers who have been part of the group programs for caregivers, being 68% of them female and 32% male, with a mean age 65 years old.
- In the case of United Kingdom, the survey was sent to a selection of carers who are registered in the Dementia Voice Database App and who have said that they would be interested in completing online surveys, who met the selection criteria and were happy to be given an ask which had a very tight turnaround time. 65% of invitees were female, 35% male. The invitees included people from ethnic minority backgrounds, of different ages, and various regions of the United Kingdom.
- In the case of Portugal, through Alzheimer Portugal, which have 13.035 members (June 2022) from 45 to 65 years old.

It was planned to gather around 155 answers in Spain, 201 in UK and 373 in Portugal.

Co-creation workshops

In the case of the workshops, the target were family caregivers of persons with Alzheimer with the following criteria:

Inclusion criteria:

- Being a family/informal caregiver at the time of assisting the workshop
- Being older than 18
- To have participated in any caregiver care program offered by the organization (Only for Fundació Pasqual Maragall participants).
- Member of Research Network or Dementia Voice Groups (Only for Alzheimer Society participants).

The aim was to be able to show them the platform, the functionalities and resources it offers, and assess it. In a second round, a new selection of caregivers was able to re-evaluate how the platform looks once the changes and recommendations of the first workshop were applied.

Participants were selected following a structural sample based on gender, age and years of experience. And they were approached with the following procedure:

- In the case of the United Kingdom: On 1 April 4 caregivers who met the selection criteria participated in the 1st workshop, of whom 50% female 50% male, different ages. They were delighted and interested to see the progress that had been made building on ideas shared at

the focus group in Nov 2021. On 6 May 4 caregivers who met the selection criteria participated in the 2nd round of the workshop, of whom 75% female 25% male. No further information about when Knowledgebiz would like the third meeting that was postponed.

- In the case of Portugal: a selection of caregivers was carried out based on their presence in previous focus groups, with basic knowledge of technology. Contacts were made by email, with an invitation to caregivers to participate in the workshop, according to their availability and interest. The first, round on March 9th, was attended by 5 caregivers (80% female and 20% male) and at the second round, on May 4th, 6 caregivers participated (83% female and 17% male). The integration of one more element in the second round, was, merely, due to the unavailability of this caregiver being in the first round.

- In the case of Spain: A selection of caregivers was done, based on those who were involved in the focus groups and had technological knowledge in order to enrich the analysis and considerations. They were contacted via email to be informed about the workshops; they were involved depending on their agenda. Different caregivers assisted to the 1st and 2nd round. On March 25th 5 caregivers who met the selection criteria participated in the 1st round, of whom 60% female, 40% male. On May 6th 6 caregivers who met the selection participated in the 2nd round, of whom 50% female and 50% male.

2.4. Data analysis

Focus groups

Thematic analysis was conducted as it is a useful method for examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights (King, 2004). Thematic analysis is also useful for summarizing key feature of a large data set, as it forces the researcher to take a well-structured approach to handling data, helping to produce a clear and organized final report (King, 2004).

Experts' consultation

In the analysis of Experts' consultation (Delphi), the main statistics used were measures of central tendency and dispersion: Mean, median, mode, maximum, minimum and standard deviation. This allowed us to have an overview of the results obtained in each of the questions, although then only the average or median was used as a value for the second round. The mean and median indicate the central trend of the distribution or set of expert response, as does mode. The maximum and the minimum indicate the extreme answers. The deviation indicates the degree of dispersion in the answers (whether or not the experts are around the average figures or not).

Survey

Descriptive analysis was conducted to organize and summarize data to see the general results in each of the questions and bivariate analysis was also carried out where the sociodemographic variables were crossed with the rest of the questions to see how the questions distributed according to age, gender, experience as a caregiver, caregiver's relationship with the person cared for and living arrangements.

3. CO-CREATION RESULTS

3.1. Phase I

In phase I, called needs assessment, the aim was to identify the needs of family caregivers, as well as professionals and contrast them with reality. To do so different data collection procedures have be done in order to have a proposal of format and content for the Toolkit.

Focus groups

An informal round of focus groups was held as an initial test of the format. Each country delivered 1 group, with a participation of between 6 and 8 people per group.

A couple of months later the formal focus groups were planned once the demographics and questions were prepared. Two focus groups were held in Portugal (16 total participants) as well as in Spain (12 total participants). One focus group was held in UK (4 total participants). One of them had experience of caring both for a parent and also for their spouse/partner. Main sociodemographic information can be seen in Table 1.

Table 1. List of the sociodemographic and profile information of the formal focus group participants.

		Spain	Portugal	UK	Total
Gender	Male	4	3	2	9
	Female	8	13	2	23
	Other	0	0	0	0
Caring experience	Novice (1-2 years' experience)	4	6	1	11
	Advanced (3-5 years' experience)	4	6	1	11
	Expert (+5 years' experience)	4	4	2	10
Relationship	Partner/Spouse	6	3	4	13
	Parent	5	12	1	18
	Sibling	0	1	0	1
	Child	0	0	0	0
	Other	1 (cousin)	0	0	1
living arrangements	lived together since before they had dementia	6	5	4	15
	Now live together to enable me to be their caregiver	4	5	0	9
	used to live together, but now live apart	0	0	1	1
	in a care home	1	2	1	4
	within short and easy travelling distance for me	1	2	0	3
	significant distance from me	0	2	1	3

When asked about the needs they identify in their everyday lives, caregivers gave multiple responses (Physical and the nursing care, Relationship with the care recipient, psychological care, among others). All three countries' caregivers coincide on the following items as the top needs, in no particular order: time for oneself and leisure, more information on the disease, the need to share their experiences and/or have peer support, and the need for more planning tools and/or support on their daily living tasks.

Some differences between countries were reported. While Spanish and Portuguese caregivers give more importance to their own psychological health and planning capacities, British caregivers prioritized information about dementia and the relationship with the care receiver.

Nonetheless, we can gather some alignments between caregivers' opinions on top needs across all countries, as seen in Table 2. The following are the top needs, in no particular order:

Table 2. Caregivers top needs

TOP NEEDS
The need to take care of oneself, both psychologically and physically[2]
Planning and juggling responsibilities
Information about professional support and formal services

Given these were their most important needs while caring for someone living with dementia, caregivers were asked about their relationship with technology; how it has helped them and how it can potentially ameliorate their everyday struggles. When asked about their good experiences with technology and how it has helped them (Table 3), they mentioned technological resources, which could be categorised in four specific groups of necessities across all countries:

Table 3. Caregivers experiences with technology

CATEGORY	EXAMPLES
Peer support	Whatsapp groups
Health Monitoring	Monitoring the caregiver's health / Monitoring the care receiver's health (Apps such as Yotecuido and My Therapy, Hospital apps, National Health System app, texts from the Pharmacy)
Planning responsibilities	Notes app, camera, storing photos, calendar…
Locating the care receiver	Tracking apps and devices, Telecare, GPS

Also named the technological aids they would like to use in the technological tool (Table 4):

Table 4. Caregivers technological aids

SPAIN	PORTUGAL	UK
Telecare: good use in case of falls, GPS in case the person leaves a specific perimeter	An app to remember, alert to do tasks (medication)	Ring (video) doorbell – to see person with dementia leaving as well as people arriving
Fall sensors	Have access to webinars	Tracker devices with GPS
Video consultations for professionals: avoid travel, but make it useful (identify improvements to be made)	An app with big letters, nice colours	SOS device worn around neck

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[2] Except the United Kingdom (UK) which prioritized nursing care and relationship with the care receiver

Electronic administration platforms that streamline documents	Tutorials to teach how to do things (even to learn how to use apps)	Texts from the pharmacy
Caregiver forums: written, online in real time	An app to contact doctor 24h/day	Calendar reminders
Alexa type for caregivers: that you can ask for things or that it alerts you to events and helps you plan tasks and events	App with health professionals and formal caregivers and their contacts (filtered by zones)	Old-fashioned phone (when person with dementia forgotten how to use mobile)
Cognitive development courses for the person being cared for	App with alimentation tips	Digital clock
Sites with useful information already filtered so you don't have to search everything that comes out of google type searches	With information's and tips about acting with a person with dementia	Digital photo frame
Being able to access temporary support services such as day centres	Simplified literature about disease	Zoom video calls
Being able to contact someone who knows their case in case of doubts and/or in case of emergencies	Strategies for caregiver to take care of her/himself	Kettle-type device that makes a cup of tea/coffee easily
	Exercises for people with Dementia	Banked voice of person with dementia so can still use her voice even when can't speak
		Mobile phone

As seen in Table 5, caregivers across all countries coincided in the following technological aids:

Table 4. Cross-country caregivers technological aids

CATEGORY	EXAMPLES
Trackers and Fall sensors	GPS, tracking devices, fall sensors, …
Consulting information	Consulting professional information on dementia related issues (general information on dementia, how to tackle certain issues, nutrition, cognitive stimulation, taking care of themselves…)
Consulting professionals	Consulting their doctors, their pharmacists
Organizing tools	Tools to help them organize, such as calendar, clock, camera, etc.

Experts' consultation

For the experts' consultation, two rounds of questions were delivered in order to gather information from the professionals which whom caregivers and their relatives living with dementia have more frequent and direct contact with. The profile of professional with frequent and direct contact with the caregiver varies from country to country as can be seen in Table 6.

Professionals, with whom caregivers have less frequency of contact, were planned to be involved in individual interview. However, this task was finally not feasible due to the volume of information collected in questionnaire as well as due to project schedule issues.

Table 5. List of professionals who intervene and/or relate to caregivers based on their frequency of contact

Contact	UK	Portugal	Spain
Frequent	GP Home-care expert Older people mental health nurse Social worker	Family GP Family Nurse (community health service) Social worker	GP Nurse Social Worker
Sporadic	IT professional form health sector Legal advisor Neurologist Neuropsychologist Nutritionist Occupational Therapist Physiotherapist Psychiatrist Psychologist Public worker related to social policies for elderly /dementia	Home-care expert IT professional form health sector Legal advisor Neurologist Neuropsychologist Nutritionist Occupational Therapist Physiotherapist Psychiatrist Psychologist Public worker related to social policies for elderly /dementia	Home-care expert IT professional form health sector Legal advisor Neurologist Neuropsychologist Nutritionist Occupational Therapist Physiotherapist Psychiatrist Psychologist Public worker related to social policies for elderly /dementia

A first round of questions was launched within a week time to answer. After the analysis of said response (for 1 week), a second round of questions was launched with another week to report back (Appendix 1). In Table 7, participation during the 2 rounds per country can be consulted.

Table 6. List of participants during the experts' consultation rounds

PARTICIPANTS (responses)						
	SPAIN		PORTUGAL		UK	
	Round 1	Round 2	Round 1	Round 2	Round 1	Round 2
Initiated questionnaires	20	10	17	9	28	4
Completed questionnaires	**13 (65%)**	**8 (80%)**	**17 (100%)**	**7 (78%)**	**17 (61%)**	**2 (50%)**
Incomplete questionnaires	7 (35%)	2 (20%)	0 (0%)	2 (22%)	11 (39%)	2 (50%)

When asked about the needs they identify in the caregivers' everyday lives, professionals from all three countries gave different opinions (Crisis Planning, Physical, nursing or personal care, Relationships with formal service providers, among others). These answers were categorized by importance. Professionals from all three countries considered the following as the most important needs, in no particular order: Psychological health of the caregiver, Relationship with the person being cared for, and Information about professional support and services.

Some differences between countries were reported. While Spanish and Portuguese professionals prioritized "Help received from others", British professionals considered "Relationships with formal service providers" to be more important.

Likewise, we can gather some alignments between the professionals' opinions on top needs across all countries, as seen in Table 8. The following are the top needs, in no particular order:

Table 7. Professionals top needs

TOP NEEDS
Psychological health of the caregiver
Relationship with the person being cared for
Information about professional support and services

As we can see, both caregivers and professionals agree on some specific needs: the psychological health of the caregiver and information about professional support and formal services.

Given these they were asked about their relationship with technology; how it can help and how it can potentially ameliorate caregivers' everyday struggles. In that sense, as seen in Table 9, when asked what needs should be prioritized when developing a technological tool, professionals from all three countries agree on the following, in no particular order:

Table 8. Cross-country professionals' prioritized needs

PRIORITIZED NEEDS
Information about dementia and dementia care
Information about professional support and services
Relationships with formal service providers
Psychological health of the caregiver

Professionals then suggested some technological examples they knew existed (Appendix 3). Also, professionals from all the three countries concurred in the following suggestions:

- In general, apps or the use of smartphones, as well as the use of GPS trackers and home speakers.
- Apps that contain information on dementia
- Apps that help caregivers support their care receiver on everyday activities: medication, cognitive stimulation, calendar, games, among others.
- Apps that let caregivers consult specialists and keep track on their relative's health as well as their own health.

From the information we have gathered on technology, we can conclude the primordial needs, which need to be in the technological tool, agreed both by professionals and by caregivers (Table 10), and the relation to the optimal technological tool are the following:

Table 9. Caregivers and professionals primordial needs and solutions

CAREGIVERS NEEDS	PROPOSED TECHNOLOGICAL SOLUTION
Information about dementia and dementia care	Apps to consult professional information on dementia

Information about professional support and services	Apps to consult directly with professionals (doctors, the pharmacy, National Health System, etc.)
Health of the care receivers	GPS, trackers, apps to consult professionals
Psychological health of the caregiver	Apps to consult professional information on how to take care of themselves
Planning and juggling responsibilities	GPS, trackers, calendar, clock, notes, camera, etc.

Professionals agree on the digital tool should include

- Training about Alzheimer disease and other dementias
- Self-care of the caregiver and support
- Care delivery, management support

Finally, when asked what it would take them to use this digital tool, for professionals across all countries, it would take having a "Strong customer support for the initial use of the technology", "Good customer service is available when the technology breaks down and troubleshooting is required", and it "Has been evaluated by healthcare professionals", or otherwise it "Has been recommended by healthcare professionals".

Caregivers Survey

The caregiver online survey was prepared to be sent to a wide number of caregivers from each of the associations (FPM, AS and AP). As planned, the questions of the survey (Appendix 2) were reviewed according to the results obtained from the focus groups and the experts' consultation. The validated survey was sent to more than 200 people and was successfully answered by 103 participants (as seen in Table 11).

Table 10. List of participants from caregivers' online survey.

PARTICIPANTS			
	SPAIN	**PORTUGAL**	**UK**
Initiated questionnaires	136	22	22
Completed questionnaires	**77 (57%)**	**18 (82%)**	**8 (36%)**
Incomplete questionnaires	59 (43%)	4 (18%)	14 (64%)

Caregivers were surveyed about their preference on device usage. Spanish and Portuguese caregivers voted phones as the best device to use, while British caregivers voted computers. Given apps are both optimal for phones and computers, this difference should not be a problem. In addition, nearly 100% of Spanish and Portuguese caregivers and 63% of British caregivers consider it useful if the digital tool were to suggest other useful sources of information to look at.

Nonetheless, when asked *"Would it be useful for you if the digital tool supported you to use technology responsibly, such as by monitoring your online time and encouraging you to take breaks?"* the majority of Spanish and Portuguese caregivers (60%) agree it would be useful, while half of British caregivers completely disagree (50%).

As we can gather caregivers agree on the digital tool should include (Table 12):

Table 11. Caregivers agreement on digital tool contents

DIGITAL TOOL SHOULD INCLUDE
Training about Alzheimer's disease and other dementias
Self-care of the caregiver
Safety, security, monitoring and reassurance (except caregivers from the UK)

Finally, yet importantly, caregivers were asked what it would take them to use this digital tool, which they considered a priority that the digital tool has been recommended and evaluated by healthcare professionals or expert caregivers. Only British caregivers give the same amount of importance to it being "free of charge".

3.2. Phase II

In Phase II the development of the Toolkit started by the technology company KnowledgeBiz with the direct participation of caregivers from each of the associations (FPM, AS, AP). In order to involve the said participants, meetings were held with a selection of caregivers (between 3 and 7 participants per session) to use a cocreation scrum-based approach, in which the caregivers have been involved since the beginning in the development of the solution, approving each one of the iterations of the Toolkit.

The plan was to have three meetings focused on the three stages of development:

1. In the first iteration a simple demonstration of what the Toolkit should be was presented. In this a plain webpage was created using the same template as CO-CARE main website, in which, the topics area and the chatbot functionalities were presented to the caregivers. Both functionalities were approved by the caregivers and suggestions about which more contents could be added were also noted for further development. Main interests and petitions can be consulted in Table 13.
2. In the second iteration, a more similar to the final version of the Toolkit was presented. In this new version, besides the functionalities presented before, it was also included a calendar, a chatroom and a journal. The caregivers validated the presented solution and asked for a vision of a shared group between caregivers that are taking care of the same person. Also, after deeper reflection it has been decided to exclude the functionality of the chatroom since most of the caregivers already use other alternatives, like regular WhatsApp. From the technical perspective, the complexity of the solution will increase and due to time, efforts and data constrains it has also been decided by the consortium to drop it. Main interests of caregivers on this iteration stage and Toolkit initial version feasible functionalities can be found in Table 14.
3. In the third and final iteration, the final version of the Toolkit will be presented to the caregivers. This should be the pre-testing phase of the Toolkit, acting the meeting as also a workshop on how to use the solution presented. The Toolkit will then become available for the caregivers to test, so that further refinement of the functionalities, bugs catching, and user experience information can be collected, closing the development of the Toolkit. This

stage did not occur due to time, logistics and development issues. However, the final version of the Toolkit will be presented to caregivers in the testing phase (detailed and explained in D12-14).

The participation of experts, formal caregivers and/or health professionals was initially planned in this phase to validate the content of the technological tool. However, due to time, logistics and development issues, it was not possible to carry out this task.

Table 12. First round meeting main highlights by country

PORTUGAL
What caregivers would like to see in the toolkit:
• Direct connection to their family doctor enabling the fast follow-up of the career
• Content adapted to the profile of the used, it is, to the stage of the disease
• Diagnosis component that will help understand the status of the career in terms of physical, mental, and state of mind health
• Agenda for booking the important things that receive notifications
• Chatbot that could guide the caregiver in moments of stress, in an easy and concise way
• Chat like whatsapp for people to communicate
• Topics with tutorials and videos
• Topics on the area of:
o Food: types of food, recipes, ways to feed the career
o Exercises (physical and cognitive) for both career and the caregiver
o Massages to help reinforce the muscles of the career
o Bureaucratic and legislation
o Wellbeing of the caregiver
How to design the toolkit
The toolkit must be simple and easy to use, with big letters and nice colouring and be easily adaptable to be seen in a pc or in a smartphone
SPAIN
What caregivers would like to see in the toolkit:
• Helplines through the chatbot
• Chat room for support with other caregivers or a similar tool as whatsapp
• Direct access to professional orientation to a telephone line
• Personal record, like a journal
• Not that impress with the suggested content, as they considered it can also be found elsewhere
• It was reported that it could be interesting just for the ones that are now starting in the process of caregiving.
How to design the toolkit
They use both PC and smartphone so it should be also transversal
UK
What caregivers would like to see in the toolkit:
• Text to speech functionality for impairment
• Helplines through the chatbot
• Chatroom not only for support but also to relax and meet up with other caregivers

• Relaxation classes and meditation
• Events like support groups available in their living area
• Personal record, like a journal
• To know what is happening in the other countries
How to design the toolkit
Simple and easy, cross platform, topics with information on the amount of time for reading them and also favourites section

Table 13. Second round meeting main interests

Functionalities	Toolkit initial version
Topics	✔
Chatbot	✔
Calendar	✔
Chatroom	X
Journal	✔
Shared group between caregivers	X

5. CONCLUSIONS

In conclusion, both caregivers and professionals across all countries consider their top needs to be: the caregiver's psychological health, their planning responsibilities, and information about dementia and professional resources. Caregivers have had good experiences with technology in areas such as peer support, health monitoring, planning and tracking their relative. At the same time, professionals' suggestions across all countries revolve about giving the caregiver information about dementia and professional support and resources, as well as tracking the caregiver's psychological health.

Both caregivers and professionals across all countries coincide in their desired technological tool would have to include tracking systems, information about dementia, information about professional support and resources, and organizing tools. Their preferred device is both phones and computers

The final version of the Toolkit included three main areas:

1. Topics: in which the technologies used to support the caregivers were presented and classified according to the consortium perception of their usage. Also, the chatbot is available to support the users in their search for information.
2. Calendar: in which the caregivers, solely or per group of caregivers of the same person, can have access to information regarding the person that they are caring after, about medication, medical appointments, regional events, among other things. Every event created can be shared to the caregiving group.
3. Journal: in which the caregivers can keep their personal records about whatever their feelings or thoughts might be, as well as information about the person that they are caring after. This information can also be shared among the group of caregivers.

The development of the Toolkit followed an iterative, co-creation approach in which the caregivers have been involved since the first version of the same. Their valuable input was of the outmost importance for the success of the implementation of the same and the consortium hopes that the tool developed will support them in their daily activities.

Some of the detected limitations of the procedure refer to:

- Reliable and consistent availability of human resources in each association for the development of tasks.
- The involvement of caregivers entailed difficulties, not because of their willingness to participate, which has always been prevalent and manifested, but because of the fluctuation of their reality because their caregiving role, altering the availability of time or energy to remain involved in the development of the Toolkit.

In relation to the limitations of the results, it would have been convenient to obtain a greater and more balanced participation (between countries) in some of the data collection methods (especially regarding the online survey).

In addition, due to the development of the project, there has been a successive delay in the established tasks that has led to a cut in the time available for testing the Toolkit. This is an important part to test the tool and its functionalities on the field and by the final users, however the progressive alteration of the schedule has forced a testing period shorter than desired (initially stipulated in 1 month, finally carried out for 15 days).

6. References

Alzheimer's Association (2012). Alzheimer's disease facts and figures. Alzheimer's & Dementia, 8, 131–68. doi: 10.1016/j.jalz.2012.02.001.

Boyce, C. & Neale, P. (2006) "Conducting in-depth Interviews: A Guide for Designing and Conducting In-Depth Interviews", Pathfinder International Tool Series

Brodaty, H. and Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience, 11, 217–228.

Brown S. L. Smith D. M. Schulz R. Kabeto M. U. Ubel P. A. Poulin M.,… Langa K. M . (2009). Caregiving behavior is associated with decreased mortality risk. Psychological Science, 20, 488–494. doi:10.1111/j.1467-9280.2009.02323.x

Chiu TML, Eysenbach G. Theorizing the health service usage behavior of family caregivers: a qualitative study of an internet-based intervention. Int J Med Inform 2011 Nov;80(11):754-764.

Cooper, C., Balamuri, T. and Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. International Psychogeriatrics, 19, 175–195. doi: 10.1017/S1041610206004297.

Dalkey, Norman; Helmer, Olaf (1963). "An Experimental Application of the Delphi Method to the use of experts". Management Science. 9 (3): 458–467.doi:10.1287/mnsc.9.3.458.

Dayer L, Heldenbrand S, Anderson P, Gubbins PO, Martin BC. Smartphone medication adherence apps: potential benefits to patients and providers. J Am Pharm Assoc 2013 Mar;53(2):172-181.

Farina, N., et al. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimer's & Dementia, 13, 572–581. doi:10.1016/j.jalz.2016.12.010.

Fredman L. Cauley J. A. Hochberg M. Ensrud K. E. Doros G . (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver study of osteoporotic fractures. Journal of the American Geriatrics Society, 58, 937–943. doi:10.1111/j.1532-5415.2010.02808.x

Frisbee KL. Variations in the use of mHealth tools: the VA mobile health study. JMIR Mhealth Uhealth 2016 Jul 19;4(3):e89

Grossman MR, Zak DK, Zelinski EM. Mobile apps for caregivers of older adults: quantitative content analysis. JMIR Mhealth Uhealth 2018 Jul 30;6(7):e162

Harold A. Linstone, Murray Turoff (1975), The Delphi Method: Techniques and Applications, Reading, Mass.: Addison-Wesley, ISBN 978-0-201-04294-8.

Jackson, S.L. (2011) "Research Methods and Statistics: A Critical Approach", 4th edition, Cengage Learning, p.17

Kiecolt-Glaser J. K. Preacher K. J. MacCallum R. C. Atkinson C. Malarkey W. B. Glaser R . (2003). Chronic stress and age-related increases in the proinflammatory cytokine IL-6. Proceedings of the National Academy of Sciences, 100, 9090–9095. doi:10.1073/pnas.1531903100

King, N. (2004). Using templates in the thematic analysis of text. In Cassell, C., Symon, G. (Eds.), Essential guide to qualitative methods in organizational research (pp. 257–270). London, UK: Sage.

Kitzinger, J. (1995-07-29). "Qualitative research. Introducing focus groups". BMJ : British Medical Journal. 311 (7000): 299–302. doi:10.1136/bmj.311.7000.299

Laks, J., Goren, A., Dueñas, H., Novick, D. and Kahle-Wrobleski, K. (2016). Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. International Journal of Geriatric Psychiatry, 31, 176–185. doi: 10.1002/gps.4309.

Milbrey W. McLaughlin (1990), The Rand Change Agent Study Revisited: Macro Perspectives and micro Realities (PDF), Stanford, CA: Stanford University

Morgan, David L. (1996). "Focus Groups". Annual Review of Sociology. 22: 129–152. doi:10.1146/annurev.soc.22.1.129. ISSN 0360-0572

Oken, B. S., Fonareva, I. F. and Wahbeh, H. (2011). Stress-related cognitive dysfunction in dementia caregivers. Journal of Geriatric Psychiatry, 24, 191–198. doi: 10.1177/0891988711422524.

Orb A, Eisenhauer, L, Wynaden D. Ethics in qualitative research. Journal of Nursing Scholarship, 2001:33 (1):93-96.

Pinto, F. N. F. R. and Barham, E. J. (2014). Bem-estar psicológico: Comparação entre cuidadores de idosos com e sem demência [Psychological wellbeing: A comparison between caregivers of older adults, with and without dementia]. Psicologia, Saúde & Doenças, 15, 635–655. doi:10.15309/14psd150307.

Portz JD, Elsbernd K, Plys E, Ford KL, Zhang X, Gore MO, et al. Elements of social convoy theory in mobile health for palliative care: scoping review. JMIR Mhealth Uhealth 2020 Jan 06;8(1)

Posner, B., Sutter, M., Perrin, P. B., Ramirez Hoyos, G., Arabia Buraye, J. and Arango-Lasprilla, J. C. (2015). Comparing dementia caregivers and healthy controls in mental health and health related quality of life in Cali, Colombia. Psicología desde el Caribe, 32, 1–26. doi: 10.14482/psdc.32.1.6273.

Pruchno R. A. Brill J. E. Shands Y. Gordon J. R. Genderson M. W. Rose M. Cartwright F . (2008). Convenience samples and caregiving research: How generalizable are the findings? The Gerontologist, 48, 820–827. doi:10.1093/geront/48.6.820

Roth D. L. Haley W. E. Hovater M. Perkins M. Wadley V. G. Judd S . (2013). Family caregiving and all-cause mortality: Findings from a population-based propensity-matched analysis. American Journal of Epidemiology, 178, 1571–1578. doi:10.1093/aje/kwt225

Roth D.L., Fredman, L., Haley, W.E., Informal Caregiving and Its Impact on Health: A Reappraisal From Population-Based Studies, The Gerontologist, Volume 55, Issue 2, April 2015, Pages 309–319, https://doi.org/10.1093/geront/gnu177

Rowe and Wright (1999): The Delphi technique as a forecasting tool: issues and analysis. International Journal of Forecasting, Volume 15, Issue 4, October 1999.

Rowe and Wright (2001): Expert Opinions in Forecasting. Role of the Delphi Technique. In: Armstrong (Ed.): Principles of Forecasting: A Handbook of Researchers and Practitioners, Boston: Kluwer Academic Publishers.

Sackman, H. (1974), "Delphi Assessment: Expert Opinion, Forecasting and Group Process", R-1283-PR, April 1974.

Saltzman M. These apps for caregivers can help you get organized, find support. American Association of Retired Persons. URL: https://www.aarp.org/home-family/personaltechnology/info-2019/top-caregiving-apps.html [accessed 2021-09-03]

Shaffer KM, Chow PI, Cohn WF, Ingersoll KS, Ritterband LM. Informal caregivers' use of internetbased health resources: an analysis of the health information national trends survey. JMIR Aging 2018 Dec 18;1(2)

Schulz R. Beach S. R . (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. JAMA, 282, 2215–2219. doi:10.1001/jama.282.23.2215Shaffer et al., 2018

Sörensen, S. and Conwell, Y. (2011). Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. American Journal of Geriatric Psychiatry, 19, 491–496. doi: 10.1097/JGP.0b013e31821c0e6e.

Takai, M., Takahashi, M., Iwamitsu, Y., Oishi, S. and Miyaoka, H. (2011). Subjective experiences of family caregivers of patients with dementia as predictive factors of quality of life. Psychogeriatrics, 11, 98–104. doi: 10.1111/j.1479-8301.2011.00354.x.

Tomomitsu, M. R. S. V., Perracini, M. R. and Neri, A. L. (2014). Fatores associados à satisfação com a vida em idosos cuidadores e não cuidadores [Factors associated with life satisfaction among elderly people who are caregivers and non-caregivers]. Ciência & Saúde Coletiva, 19, 3429–3440. doi: 10.1590/1413-81232014198.13952013.

Toribio-Díaz ME, Medrano-Martínez V, Moltó-Jordá JM, Beltrán-Blasco I. Characteristics of informal caregivers of patients with dementia in Alicante province. Neurologia. 2013 Mar;28(2):95-102. English, Spanish. doi: 10.1016/j.nrl.2012.03.010. Epub 2012 Sep 15. PMID: 22986093.

von Känel R. Dimsdale J. E. Mills P. J. Ancoli-Israel S. Patterson T. L. Mausbach B. T. Grant I . (2006). Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. Journal of Gerontology. Series A, Biological Sciences and Medical Sciences, 61, 963–969. doi:10.1093/gerona/61.9.963

Waligora, K., Bahouth, M. and Han, H. (2018). The self-care needs and behaviors of dementia informal caregivers: A systematic review. The Gerontologist, 1–9. doi: 10.1093/geront/gny076.

Wang H, Hanich K, Jiang Y, Mitchel D, Li K. Independent living needs: helping aging parents thrive. 2016. URL: https://www.parksassociates.com/marketfocus/independent-living-360vumarch2016 [accessed 2021-09-03]

Wittenberg E, Xu J, Goldsmith J, Mendoza Y. Caregiver communication about cancer: development of a mhealth resource to support family caregiver communication burden. Psychooncology 2019 Feb 11;28(2):365-371

World Health Organization (WHO) (2017). Global action plan on the public health response to dementia 2017–2025. Geneva: WHO Document Production Services.

World Health Organization (WHO) (2018). Dementia: mhGAP training of healthcare providers training manual and supporting material. Geneva: WHO Document Production Services.

APPENDIX (1)

Toolkit – Experts' Consultation

Delphi

Welcome,

Here are some questions about the needs of caregivers of people with Alzheimer's and / or dementia and how technology could do something to address them.

Thank you very much for your participation.

Needs of caregivers

Q1.- Identify the following needs that you believe a caregiver of a person with Alzheimer's has. Please mark on a scale of 1 to 5, being 1: it is not a need a caregiver of a person with Alzheimer's has and 5: it is a very important need for a caregiver of a person with Alzheimer's.

		1	2	3	4	5
Caregiving tasks	Physical, nursing, or personal care (such as medications, care, pain management, and symptoms)	☐	☐	☐	☐	☐
	Housekeeping	☐	☐	☐	☐	☐
	Supervision / support in care tasks	☐	☐	☐	☐	☐
	Help received from others (receiving support in coping with care difficulties)	☐	☐	☐	☐	☐
	Coordination (helping to organize the agenda, planning how to get to appointments, etc.)	☐	☐	☐	☐	☐
Relationships with formal service providers (exchange of information between healthcare professionals and patients with dementia and their caring relatives to maintain autonomy and continuity in their lives, multidisciplinary healthcare advice and peer communication)		☐	☐	☐	☐	☐
Adaptation of the house where they live		☐	☐	☐	☐	☐
Juggling responsibilities		☐	☐	☐	☐	☐
Financial management		☐	☐	☐	☐	☐
Personal health	Physical health of the caregiver	☐	☐	☐	☐	☐
	Psychological health of the caregiver	☐	☐	☐	☐	☐
Relationships	Relationship with the person being cared for (understanding and adapting the relationship)	☐	☐	☐	☐	☐
	Family relationship (changes in family relationships since the person is a caregiver)	☐	☐	☐	☐	☐
Planning	Crisis planning (need to anticipate crisis)	☐	☐	☐	☐	☐
	Future planning (information on evolution to anticipate decisions, organization ...)	☐	☐	☐	☐	☐
	Information about professional support and services	☐	☐	☐	☐	☐
	Information about dementia and dementia care	☐	☐	☐	☐	☐
	Information about legal matters	☐	☐	☐	☐	☐

Q1.1.- Do you miss any need that does not appear?

Q1.2.- Please, assess your own level of competence in this specific issue:

Not competent at all		Competent		Expert
1	2	3	4	5

Needs of caregivers and technology

Q2.- Of the following needs, which ones do you think are currently already covered by technology (mobile applications, electronic devices ...)? Please mark them on a scale of 1 to 5, with 1: currently not covered by technology and 5: currently fully covered by technology.

		1	2	3	4	5
Caregiving tasks	Physical, nursing, or personal care (such as medications, care, pain management, and symptoms)	☐	☐	☐	☐	☐
	Housekeeping	☐	☐	☐	☐	☐
	Supervision / support in care tasks	☐	☐	☐	☐	☐
	Help received from others (receiving support in coping with care difficulties)	☐	☐	☐	☐	☐
	Coordination (helping to organize the agenda, planning how to get to appointments, etc.)	☐	☐	☐	☐	☐
Relationships with formal service providers (exchange of information between healthcare professionals and patients with dementia and their caring relatives to maintain autonomy and continuity in their lives, multidisciplinary healthcare advice and peer communication)		☐	☐	☐	☐	☐
Adaptation of the house where they live		☐	☐	☐	☐	☐
Juggling responsibilities		☐	☐	☐	☐	☐
Financial management		☐	☐	☐	☐	☐
Personal health	Physical health of the caregiver	☐	☐	☐	☐	☐
	Psychological health of the caregiver	☐	☐	☐	☐	☐
Relationships	Relationship with the person being cared for (understanding and adapting the relationship)	☐	☐	☐	☐	☐
	Family relationship (changes in family relationships since the person is a caregiver)	☐	☐	☐	☐	☐
Planning	Crisis planning (need to anticipate crisis)	☐	☐	☐	☐	☐
	Future planning (information on evolution to anticipate decisions, organization ...)	☐	☐	☐	☐	☐
	Information about professional support and services	☐	☐	☐	☐	☐
	Information about dementia and dementia care	☐	☐	☐	☐	☐
	Information about legal matters	☐	☐	☐	☐	☐

Q3.- Of the following needs, what do you think is important that they can be covered by technology in the future? Please mark them on a scale of 1 to 5, with 1: not at all important being covered by technology and 5: prioritizing being covered by technology.

		1	2	3	4	5
Caregiving tasks	Physical, nursing, or personal care (such as medications, care, pain management, and symptoms)	☐	☐	☐	☐	☐
	Housekeeping	☐	☐	☐	☐	☐
	Supervision / support in care tasks	☐	☐	☐	☐	☐
	Help received from others (receiving support in coping with care difficulties)	☐	☐	☐	☐	☐
	Coordination (helping to organize the agenda, planning how to get to appointments, etc.)	☐	☐	☐	☐	☐
Relationships with formal service providers (exchange of information between healthcare professionals and patients with dementia and their caring relatives to maintain autonomy and continuity in their lives, multidisciplinary healthcare advice and peer communication)		☐	☐	☐	☐	☐
Adaptation of the house where they live		☐	☐	☐	☐	☐
Juggling responsibilities		☐	☐	☐	☐	☐
Financial management		☐	☐	☐	☐	☐
Personal health	Physical health of the caregiver	☐	☐	☐	☐	☐
	Psychological health of the caregiver	☐	☐	☐	☐	☐
Relationships	Relationship with the person being cared for (understanding and adapting the relationship)	☐	☐	☐	☐	☐
	Family relationship (changes in family relationships since the person is a caregiver)	☐	☐	☐	☐	☐
Planning	Crisis planning (need to anticipate crisis)	☐	☐	☐	☐	☐
	Future planning (information on evolution to anticipate decisions, organization ...)	☐	☐	☐	☐	☐
	Information about professional support and services	☐	☐	☐	☐	☐
	Information about dementia and dementia care	☐	☐	☐	☐	☐
	Information about legal matters	☐	☐	☐	☐	☐

Q2.1/3.1.- Please, assess your own level of competence in this specific issue:

Not competent at all   Competent   Expert
              1   2   3   4   5

Technology for caregivers

Q4.- Could you please list three technologies that can be useful for caregivers of persons with Alzheimer's and dementia?

1.
2.
3.

Q4.1.- Please, assess your own level of competence in this specific issue:

Not competent at all   Competent   Expert
              1   2   3   4   5

Accessible technology

Q5.- Which of the following could bring technology closer to caregivers of people with Alzheimer's? Please mark them on a scale of 1 to 5, with 1: not bringing technology closer to caregivers and 5: totally useful for bringing technology closer to caregivers.

	1	2	3	4	5
The technology is recommended by healthcare professionals	☐	☐	☐	☐	☐
That the technology has been evaluated by healthcare professionals	☐	☐	☐	☐	☐
Technology has strong customer support for the initial use of the technology (e.g., initial training)	☐	☐	☐	☐	☐
That good customer service is available when the technology breaks down and troubleshooting is required	☐	☐	☐	☐	☐
That the technology has a clear statement about the security and privacy of the data collected	☐	☐	☐	☐	☐
That the caregiver should not play an active role in interacting with technology	☐	☐	☐	☐	☐
Technology recommended by an "expert" caregiver (peer to peer)	☐	☐	☐	☐	☐
The technology is recommended by a family member	☐	☐	☐	☐	☐
The technology is free of charge	☐	☐	☐	☐	☐
Other:	_____				

Q5.1.- Please assess your own level of competence in this specific issue:

Not competent at all   Competent   Expert
          1   2   3   4   5

Toolkit for caregivers

Q6.- Do you think the following content is appropriate for a toolkit on technology solutions for caregivers of people with Alzheimer's? Please mark them on a scale of 1 to 5, with 1 being content that is not at all suitable for a toolkit for caregivers of people with Alzheimer's, and 5: is content that is totally suitable for a toolkit for caregivers of people with Alzheimer's

	1	2	3	4	5
Support with self-care and activities of daily living (of person with Alzheimer)	☐	☐	☐	☐	☐
Self-Care (of the carer)	☐	☐	☐	☐	☐
Treatments and interventions delivery	☐	☐	☐	☐	☐
Safety, security, monitoring and reassurance	☐	☐	☐	☐	☐
Training about Alzheimer's and dementia	☐	☐	☐	☐	☐
Care delivery, management and support	☐	☐	☐	☐	☐
Social interaction and networking	☐	☐	☐	☐	☐
Other:	_____				

Q6.1.- *(When clicking in 4/5 open box)*: Could you please tell us more about what you would like to see included in this particular item?

Q6.2.- Please assess your own level of competence in this specific issue:

Not competent at all   Competent   Expert
1   2   3   4   5

Q7.- Do you think the fact that the toolkit for caregivers is customizable is an added value? Please answer using a scale of 1 to 5, with 1: no value added and 5: it would be an added value for caregivers.

1   2   3   4   5
☐   ☐   ☐   ☐   ☐

Q8.- (*P8 appears if in question 7 mark 4-5*): Which of the following variables would be a possible customization element? Please answer using a scale of 1 to 5, with 1: I would not consider this item important for customizing the toolkit, and 5: This is an essential element for personalizing the navigation in the toolkit.

	1	2	3	4	5
The age of the caregiver	☐	☐	☐	☐	☐
The technological skills of the caregiver	☐	☐	☐	☐	☐
The stage of the disease of the person being cared for	☐	☐	☐	☐	☐
Other:	_____				

Q9. Would you like to add a comment?

Thank you very much for participating, your answers will be very useful to us.

APPENDIX (2)

Toolkit – Caregivers Survey Questions

> Sent by email to all members accompanied by a presentation note with the aims, as well as the practical conditions of development of the survey (response time, guarantee of anonymity)

Inclusion criteria:

- Being a family/informal caregiver at the time of answering the questionnaire
- Being older than 18

First proposal of questions after analysing focus groups and experts' interviews results:

1. If you were looking to find information, which of the following devices would you find most convenient or useful please? (Only one answer possible)
   a. *Mobile*
   b. *Computer*
   c. *Tablet*
   d. *Other – please specify*

2. Would it be useful for you if the digital tool supported you to use technology responsibly, such as by monitoring your online time and encouraging you to take breaks?

1 not useful at all	2	3	4	5 very useful

3. Would it be useful for you if the digital tool were to suggest other useful sources of information to look at - for example further information relating to your query, specific resources or specialists?)

1 not useful at all	2	3	4	5 very useful

4. Which of the following are important to be considered when choosing a technology for caregivers of people with Alzheimer's? Could you please rank them? (mark only one answer per column)

	1st	2nd	3rd	4th	5th	6th	7th	8th	9th
That it is free of charge									
That good customer service is available when the technology breaks down and troubleshooting is required									
That there is strong customer support to help getting started using the tool									

That it has been evaluated by healthcare professionals									
That it is recommended by an expert caregiver (for instance a peer family caregiver who has been in that role for a long time)									
That it is recommended by healthcare professionals									
That it has a clear statement about the security and privacy of the data collected									
That you should not play an active role in interacting with the technology (the technology suggests actions and sends you information rather than you having to search the technology for what you need)									
That it is recommended by a family member									

5. Do you think the following content is appropriate for a toolkit on technology solutions for you as a caregiver of people with Alzheimer's disease and/or other types of dementia? Please mark them on a scale of 1 to 5, with 1 being content that is not at all suitable for a toolkit for caregivers of people with Alzheimer's disease and/or other types of dementia, and 5: is content that is totally suitable for a toolkit for caregivers of people with Alzheimer's disease and/or other types of dementia

	1	2	3	4	5
Support with self-care and activities of daily living (of person with Alzheimer)					
Self-Care (of the carer)					
Treatments and interventions delivery					
Safety, security, monitoring and reassurance					
Training about Alzheimer's disease and/or other types of dementia					
Care delivery, management and support					
Social interaction and networking					
Other:					

APPENDIX (3)

Technological examples (Professionals)

Professionals suggested some technological examples they knew existed.

SPAIN	
Alexa / Specifically programmed voice assistant	Generic
App / Mobile App	
Phone / Support phone (TS, PSP…)	
Digital calendar, GPS, talking clocks	
Robot (assistants)	
Humanoid robots	
Simple Senior Phone	
Technical support: cranes	
Video conferencing	
Mobile App (Mediquo - for professionals)	Relationship and professionals
Professional app on how to care for patients	
Professional online support	
Email / Chat / Direct video call with a professional in the field to resolve issues related to new symptoms, behavioural disorders, questions…	
E-visit with health professionals / + easy to plan for the caregiver	
Instant messaging system with professionals like LMS or Whatsapp	
Telecare	
Telematic visit with image	
Visit via Whatsapp	
Chat to share worries and experiences between peers and with professionals	
Cognitive stimulation tools	To care
MyTherapy (medication)	
App of cures	
Technical support: cranes…	
Links where to find care information	Information
Websites with quality information on dementia	
Video tutorials	
Virtual help groups	Social support
Chat to share worries and experiences between peers and with professionals	
La meva salut	Health management
Telematic psychological support from home	For the caregiver
App of emotional support	

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PORTUGAL	
Applications, as Whatsapp	Generic
Applications that work on mobile phones with theoretical and practical information and with a digital assistant	
Apps / Smartphone – with applications	
Computer	
Telephone / Mobile phone	
Tablet	
Internet	
E-mail	
ISupport or mobile applications	
Digital watch and calendar	
Video-call (Skype/Zoom/etc)	
Wi-Fi	
Application for nursing care	To help with care
Application to deal with the main warning signs in dementia	
Application that allows to take a picture of the room of the house and then suggest adaptations to it, to make the environment safe	
Application that gathers information about the disease, care strategies and formal services and social supports	
Application that gathers all the health information of the person with dementia	
Support in the care	
App that includes information about social rights, informal caregiver status and other relevant legal issues and how to initiate these processes	
App that allows the caregiver to easily schedule his/her own medical appointments and his/her family member, allowing a better maintenance of their health	
App that allows access to information related to strategies toc are for the different stages of the pathology	
Communicating with healthcare professionals or clarification of doubts through bot or others	
Teleassistance equipment for the person cared for / Tele-appointments / Teleassistance	
Online training / Training	
Alarm system to prevent the risk of falls	
Support line to the person with dementia	
Automatic lights – to prevent falls / system of sensor for falls	
Home security mechanisms and devices (smart houses)	
Platform that allows caregivers to have contact with different professionals specialized in dementia (e.g., nutritionist, psychologist, social worker, speech therapist, physiotherapist)	
GPS wristband – for control by family members so that the user doesn't get lost / Support system for the possibility of the person getting lost	

UK	
3D Virtual reality	Generic
Alexa or similar	
Computer / Laptop	
Coordinate my Care	
Digital technologies connecting people ie Whatsapp	
Gaming apps	
GPS tracker / Tracking device for patient (dementia sufferer) / Tracking devices / Tracking location	
Home speaker (though as the illness progresses this could be counterproductive)	
Indoor cameras / Webcam	
Internet / websites	
iPad	
Live web chats	
Mobile	
Reminder apps	
Talking books	
Technology to allow interaction with art	
Telephone	
Television	
Zoom calls	
An easy way of connecting with other carers and professionals / Connection with other caregivers / Online group meetings with other carers and an expert in dementia / Online groups	To help caregivers
Caregiver websites	
Social media apps that caregivers can find immediate support	
Mental health first aids links – wellness action plans but with some direct contact as well	
A wearable that would detect the person with dementia's distress before it becomes visible / Something that would alert the caregiver to invisible signs of distress of the person with dementia	To help in caregiving tasks
App on phone which gives direct advice about factual things such as legal support, dementia facts, etc	
Apps to provide info about dementia to carer (Dementia guide for carers and care providers) / Clear information and advice on specific symptoms and presentations in different languages and accessible – like short videos	
Assisted technology in home to help mobility/orientation, etc. / Falls sensors / Home adaptations / Movement mats that show if a person has left their bed / Sensors to track when people are moving about at night, leaving the gas on, etc. / Sensory mats	
Automatic dispenser of medication – a better, more intuitive and connected system than the existing provision / Easier medication management other than current automatic pill dispensers / Electronic MAR charts / EMARs / Med alarm / Medication dispensers	
Electronic care planning	
Online consultations with a specialist consultant/dementia nurse	
One-stop care planning (with all related information on the person in one place)	

Pads loaded with pictures and images to stimulate or calm a PLWD	
Telecare	