

# (RE)DESIGN OF A MOBILE INTERFACE FOR DEMENTIA: REFLECTIONS ON AN IN CONTEXT EVALUATION

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## ABSTRACT

Dementia is increasingly becoming a challenge for our society. One way to address this is by the design of interventions that improve the quality of life of people living with dementia. Yet, to do this successfully we need to actively involve them as participants. In this study we involve people with dementia and their caregivers in the evaluation of a mobile interface, to improve it, to better suit their needs. For the evaluation, ten people with dementia used a mobile interface over the course of 2 to 3 weeks. As a result we found that users are very capable of participating in such a design study. They also provided ample ammunition for redesign and new opportunity directions. However, they need to be facilitated and supported adequately to do so.

## INTRODUCTION

The number of people living with dementia is growing rapidly, posing several challenges on our society. Dementia is a collective name for diseases that progressively deteriorate the brain, Alzheimer's disease is the most common disease (~ 70 %), vascular dementia the second, with 25 % (Prince, Prina, & Guerchet, 2013). In these diseases everyday functioning declines severely. In the early stages people have issues with complex situations and short-term memory, but as the disease progresses symptoms worsen. In the mid stages people start having issues with routine tasks, and in the later stages, basic human functioning is hampered and full-time care is needed (Timlin & Rysenbry, 2010).

It is predicted that the population of people with dementia will double over the next twenty years (Prince et al., 2013). With such an increase, we need to look at alternative ways to improve their quality of life beyond political, social and economical changes.

Design can contribute to this part, especially in the early to mid stages. By the design of new (technological) interventions we can improve the quality of life of elderly who live with dementia (Horgas & Abowd, 2004). Yet, in order to achieve significant societal impact we have to carefully design these interventions, so they are user-friendly and accepted. Over the past years there have been several attempts to develop such assistive interventions for people with dementia, and many issues still remain unresolved (ie. Topo, 2009). Mostly, because existing products and services are often too difficult to be used by people diagnosed with dementia (Astell et al., 2010). Therefore, it is important that these interventions are designed with an understanding of the people behind dementia. One way to achieve this is by the active involvement of users in the design process via participatory design methods (Sanders & Stappers, 2008). Also in literature we see evidence that there is a need to involve people with dementia directly, too often caregivers or nurses are involved as spokespersons in research rather than the persons with dementia themselves, which negatively effects the design output (Topo, 2009). Furthermore, by applying participatory design methods, we can facilitate the design of interventions that fit with the needs of people living with dementia (Lindsay et al., 2012). However, such an active involvement of people with dementia in research is challenging, and a careful protocol has to be developed which respects the person with dementia and their caregivers, and does not cause a high burden (Astell et al., 2010).

We see another issue is an abundance of studies in a lab context, yet very little in everyday life. Only by conducting research in context, we can see how a concept is used over the long-term and if users integrate it in their lives (Koskinen, Zimmerman, Binder, Redström, & Wensveen, 2011). In this case it is important we give the users time to adopt a design and

adept to it, therefore these studies need to be semi to long term and involve the users in their natural context (Gent et al., 2011). The Living Lab method allows for both participatory design and studying users in context. The Living Lab approach is described as a method to expose users to innovations in a natural context (Markopoulos & Rauterberg, 2000), with the goal to develop the innovation further for a market introduction (Leminen, Westerlund, & Nyström, 2012). We rarely see people with dementia getting involved in Living Lab studies, nevertheless, they are perfectly capable to do so when adequately prepared (Suijkerbuijk, Brankaert, Kort, Snaphaan, & Den Ouden, 2015).

For this research we evaluated a mobile interface, specifically designed for elderly with dementia, to investigate how a to involve the people with dementia and their caregivers in a participatory, in context, study. The usability of this mobile interface is subsequently analysed in a qualitative way, to answer the following question:

*How can we actively involve people with dementia, and their informal caregivers, in the usability evaluation and re-design of a mobile interface for them?*

#### THE SMARTPHONE INTERFACE DESIGN

We involved the company GoCiety©, which provided the mobile interface. In addition we also involved a mental care institute who reviewed our protocol to protect the people with dementia.

The smartphone interface we evaluate in this study is the GoLivePhone© (figure 1), designed specifically for elderly. This is shown in the appearance of the menu via sizable icons, high contrast and clear pictograms. The design is kept simple, yet is adaptable to the level of the user by the informal caregiver.

In this study we want to evaluate this product together with people with dementia to make it suitable for them by redesign. The mobile interface has regular functionalities like contacts, phone and texting.

Additionally two 'new' features were added: (1) A personal navigation feature to provide support when lost in public space, and (2) a 'help button' that allows for sending out an emergency signal to a small caregiver circle, these are three informal caregivers selected together with the person with dementia. The mobile interface was setup with these five functionalities. Furthermore, a special website is provided for the informal caregivers which allows them to control the settings of the smartphone interface, and track its GPS location if it is lost.

Important is, that the functionalities provided by the mobile interface are generally accepted as positive for people with dementia. Especially keeping social contact is important for wellbeing, as is for example also shown in the COGKNOW project (Meiland et al., 2007). In addition Maki and colleagues (2009) propose seven design principles, based on universal design, for dementia. In this flexibility in use, safety and security

come forward as important. Finally, way finding is seen as contributing to the quality of life of people with dementia in general (Rasquin, Willems, de Vlioger, Geers, & Soede, 2007).



**Figure 1:** The GoLivePhone©, referred to as mobile interface.

#### ETHICAL CONSIDERATION

To increase the ecological validity (Koskinen et al., 2011) and to get insights related to the integration of a design in everyday life it is important this study was conducted in the everyday lives of people with dementia. Because of this the mobile interface was fully functional, to be used by the participants over the course of the study. As is advised for studies conducted in the homes of participants, the informed consent should not be a one-time measure, rather it is proposed to be a continuous conversation between researcher and participants (Coughlan et al., 2013). And as such we continuously reconfirmed participation. Additionally we involved a mental care hospital to function, together with the informal caregiver as a gatekeeper. The gatekeeper decides, continuously, whether participating in the research is still suitable for the person with dementia. This means we only involved people with dementia who had an informal caregivers taking care of them. Furthermore, the only data used for this study is collected via a closing interview, and documents provided freely by the participants.

#### DATA AND METHODS

In this study ten couples, each one person with dementia and one informal caregiver, participated. They used the mobile interface at their homes, over a period of 2-3 weeks. To make our participants feel comfortable, we informed them about our goal to evaluate the mobile interface and to re-design it. This ensured they were more open-minded about the design, as equal partners in the study. (*why?*)

To get an indication of the stage of dementia we used the Clinical Dementia Rating (CDR) scale (Morris, 1993). Most participants scored CDR 1.0 (early stage dementia) with one person in CDR 0.5 (very early stage) and one person CDR 2.0 (mild stage), however we did not see unusual data from the latter two.

After the study period, a reflection session was held with the couples. This session aimed to discuss and

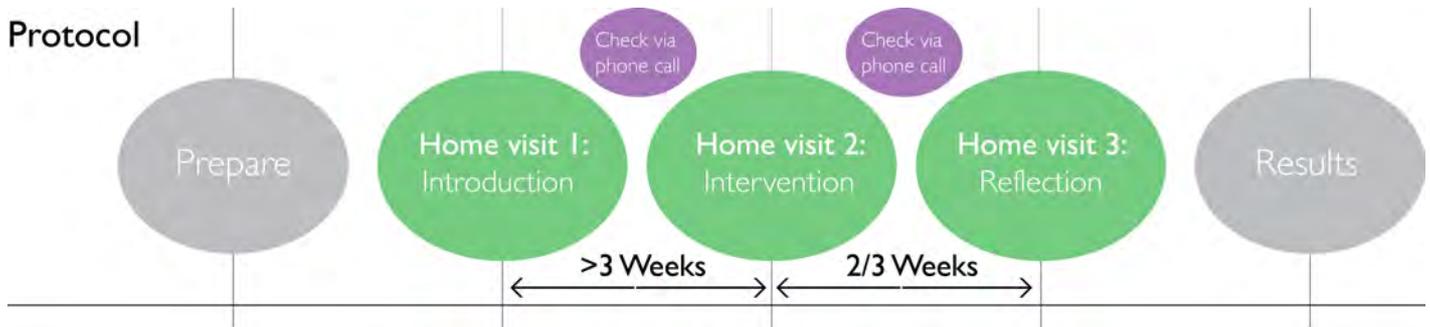


Figure 2: The participation in context protocol used during this study.

reflect upon their experience with the mobile interface concerning acceptance of the device and the contribution it made to everyday life. From this reflection session quotes were extracted and clustered in themes to find common insights (Braun & Clarke, 2006). For the reflection session we set four topics to discuss: Mobile Interaction, Device Hardware, dementia related and research protocol. The participants themselves provided the content. This means not all users commented on all aspects of the design. Also, some users provided additional text, this was also translated into quotes.

The protocol for this study was designed together with our partners in the stakeholder network. The protocol (Figure 2) aims at facilitating the study at the homes of the participants in a comfortable way.

The protocol contains the following steps:

- **Preparation:** preparation of method by researcher
- **Introduction:** The project and technology will be introduced and first questions can be answered, users can make a decision in the next period.
- **Intervention:** In this phase the researcher, together with the formal carer (from mental care institute) will visit the home and re-introduce the project and the technology. From this moment the test begins.
- **Reflection:** After an agreed period of time (2 to 3 weeks) the intervention is picked up and a reflection session is held with the couple (<1 hour).
- **Results:** The researcher analyses the results.

Additionally there are two moments, during the protocol, when the researcher checks upon the participants over the phone. This is once before the Intervention study, and once during the study ('Check via phone call', figure 2).

## EVALUATION OF DATA

The results show mainly the clusters that were found by analysing the input from the reflection session.

During the reflection sessions we noticed that mostly the informal caregivers took the lead, yet when the person with dementia was asked a direct question they were very capable to do so. This was expected, as complex social situations and discussions are often overwhelming for people with dementia (Suijkerbuijk et al., 2015). This resulted in a 2 (caregiver) : 1 (person with dementia) ratio for the input measured in quotes.

The participants were gathered carefully, and the mental care institute considered all selected participants capable to so. After this pre-selection, we visited them and introduced the project. The couples decided at this moment, if they wanted to participate. Over the course of the study we had one dropout after one week. This was mainly due to the inability of the informal caregiver to understand and use the mobile interface.

The result section uses quotes to exemplify the thematic clusters, and their contents. These are formatted as following:

"[Example quote from a participant]"-[PWD or CG]

In this quote format PWD refers to person with dementia, and CG to caregiver.

## RESULTS

Overall the usability and experience of the phone was regarded as ok. Only four participants could not use the mobile interface. The others could use it after some time, ranging from basic to expert users.

The quotes (n = 108) were provided, mostly via the reflection sessions, from the informal caregivers (n=73) and persons with dementia (n=35). First we divided the quotes in different categories based on the topics we set for the reflection session (Table 1). These were: Mobile Interface, Mobile Device, Dementia related and Other among which the research protocol is discussed. In the next part we will first describe the content of the quotes, and than reflect on the insights for redesign. Finally we will reflect on the general experience of users getting actively involved in this research based on the protocol stages described (Figure 2).

### MOBILE INTERFACE (1)

The mobile interface cluster is the most sizable from the four main cluster themes. The new functionalities were also a part of this cluster.

### GUIDE ME HOME APPLICATION

Most comments related to the 'Guide Me Home'-application, the way finding application included. Most comments pertained to a positive experience of the new feature, as for following quote exemplifies:

"I could use the [Guide me Home] Application after some tries on my own, and it worked very pleasantly." - PWD1

**Table 1:** Overview of clusters and sub-categories gathered from the reflection sessions.

<i>Cluster themes</i>	<i>Sub-theme</i>	<i>N</i>	<i>Explanation of theme:</i>
Mobile Interaction	Guide me home app	18	Describes experiences with the ‘new’ guide me home application, both positive and negative comments are found.
	Help button	8	Covers comments concerning the help me button, almost all comments are critical towards the functionality.
	General phone use	9	The general phone functions like calling, texting and adding contacts is covered here, some critical some positive.
	Menu (complexity, readability)	6	This is a cluster of comments that pertain to the difficulty to understand the (often too complex) menu structures.
	Other (language, functions, speech)	11	These are other, software related issues like language, agenda functions, text to speech and keyboard.
Device Hardware	Interaction with device	10	In this cluster mostly comments concerning the touchscreen interaction are made, like for example scrolling.
	Physical product (size)	8	This part describes comments related to the physical (non-button) part of the smartphone device.
	Physical buttons	7	This cluster contains comments concerning the external buttons on the device (volume, on/off and home).
	Battery	6	This cluster concerns complaints about the battery life.
Disease related	Addressing a need	8	Contains more general comments concerning a reflection on the general need or benefit of the mobile interface.
	Familiarity	4	Comments that are related to the concept of familiarity and recognition are clustered here.
Other	Opportunities	5	Contains new functionalities suggested by the users.
	Method comments	3	Contains comments related to the research method.
	Other comments	5	Other (reception, pre-paid, glove interaction, multi use case challenges with phone and pricing).

Some difficulties occurred as well, mostly pertaining to technological issues. Some users also tried to use the application on their bike but mentioned it was not suitable. Finally some opportunities were mentioned; a more simple map and voice feedback.

In general we could say the ‘Guide me Home’-application was considered a welcome addition. And from the reflection sessions we found participants experimented most with this application. However, the technological issues need to be solved as some of these participants put it away after the first uses.

#### HELP BUTTON FEATURE

Concerning the ‘Help’ button feature several comments were made as well, mostly critical. Participants mentioned it did not add value, that the logo was unclear, but mostly that it was often pressed by accident. We felt this functionality would have most potential, as it is simple and deemed essential in several assistive technology studies (Topo, 2009). In hindsight we were wrong, and we feel this functionality should be removed.

The participants offered several solutions, for example that it could be pressed twice, ask for a confirmation or add a telephone number to the message caregivers receive. Finally, one participant contributed a new logo suggestion for this feature (Figure 3).

#### GENERAL PHONE FUNCTIONALITY

Related to the general phone functionality, including calling, text messaging and managing contacts, especially the texting functionality was not used often and could be removed for some users. For the phone functionality we received mixed results, some mention

it went ok, whereas others mentioned it was too difficult, especially for individual participants with

dementia. Additional issues concerned erasing numbers, contacts and missed calls, furthermore someone did not succeed in adding a picture to contacts. It is difficult to re-design or discuss these functionalities, as they are a must for a mobile device to operate. However, some of these items could also potentially be hidden in the design.

#### GENERAL INTERFACE EXPERIENCE

The general interface and menu structure was mentioned to be slightly too complex, however the readability was unanimously commented on as being very good. This means the difficulty for people with dementia is conceptualizing a menu, not reading and understanding text. This happens when too much functionality are presented at once. The next quote, from a caregiver, shows this:

“The menu was a little bit too complex for [PWD], for example the message and call functionality were unnecessary.” – CG10

Reflection on the use of touchscreen is described in the second thematic cluster: device hardware.

#### OTHER INTERACTION COMMENTS

Finally, several other software issues were mentioned. Two participants mentioned that the online environment to setup the phone, and follow it was very much appreciated. Furthermore some language issues were found, and for some the volume was too loud on speaker, and too quiet on regular mode. Finally, the backlight went off too quickly. These comments are all very relevant to improve the mobile interface into an

optimal version, however do not require a new design, they are merely to be implemented.

#### DEVICE HARDWARE (2)

The second largest thematic cluster is the hardware cluster it contains four sub-categories. These mostly pertain to the physical aspects of the mobile interface we evaluated in this study.

#### PHYSICAL PRODUCT

Several comments related to the size of the device. Several participants mention it was too big, yet some mention the size is fine, and one even mentioned it was too small for typing, however, this participant had a slight visual impairment as well. Related to the material, the users preferred a casing that ensured a good grip.

#### TOUCH SCREEN INTERACTION

Most participants expressed they did not have any difficulties with the touchscreen interaction. And indeed during the first introduction session the researchers experienced that most could perform basic tasks after a short introduction. However, some participants did have difficulties, and one person mentioned the person with dementia pressed the phone rather than touch it.

"When I called my wife, sometimes my wife pressed the phone rather than touch it, in such case she would pick up the phone and also hang up the phone in one action." -CG7

#### PHYSICAL BUTTONS

Concerning the physical buttons some difficulties with the on/off button were mentioned, one of them confused it with the home button. For the volume button, two participants explicitly mentioned they experienced issues. However, in general, the participants did not often use the volume button.

#### BATTERY LIFE

Finally, related to the battery, it was unanimously mentioned it should be majorly improved when used with people with dementia. Charging is something challenging for them, and such a device should ideally go along a week. However, at least a full day cycle is a must for users to use the basic functionality when they need it. The following quote refers to this:

"Calling went ok, yet sometimes the battery wasn't properly charged (empty after half a day) and it would still not work." -CG6

#### DISEASE RELATED ISSUES (3)

As a third cluster we found some disease related issues commented on by the participants.

#### FAMILIARITY

Participants told us in the reflection sessions that the touchscreen and smartphone are something persons with dementia do not recognize as such. This could be one of the reasons it is so challenging to use for some. One person mentions that his own mobile device, an iPhone®, is easier because he is familiar with it. There might be a new generation of people with dementia on

the rise that actually knows how to use smartphones, which makes the development of such systems even more interesting. However, this was an exception, and still many people struggled with this, as can be seen in the following quote:

"My Husband [PWD] does not want to try the mobile interface, it is too challenging, and he does not recognize it." -CG8

#### ADDRESS NEEDS

Furthermore, related to whether the phone addressed a need it was mentioned several times that it 'might in the future'. One person specified it needed to be simpler to do so. Also, in literature it is confirmed that computing technologies, such as the mobile interface used in this study, should address evident needs at home for people with dementia to use them (Olsson, Engström, Skovdahl, & Lampic, 2012). In another case the caregiver could not use it, which made it unusable for the household. However, they clearly had a need for way finding and were interesting to try the help feature. This shows that only a need is not sufficient, the intervention should adequately address it in a way that fits with a certain user.

#### OTHER INSIGHTS (4)

In this cluster the remaining comments were gathered, the three sub-clusters are: Research protocol, opportunities and other comments.

#### RESEARCH PROTOCOL

Concerning the protocol, a few participants thought the introduction should have been longer and more frequent. The learning curve differs a lot for each person, and this should be integrated into the protocol. Additionally the communication could have been stronger between researchers and healthcare workers. Sometimes users were not adequately informed what our research would entail, making the introduction even more overwhelming.

#### RESEARCH PROTOCOL

Additionally, some explicit opportunities were found that did not fit with specific features of the mobile interface. It was for example, mentioned twice that the functionalities should be provided in a different way. One person mentioned there should be a feature that supports the localization of device and charger; one other user recommended this to be on the other phone (of informal carer):

"It is a pity you can not see where the other phone is on your own phone, this would have been useful." -PWD5

It is very interesting to see that the participants not only actively thought about improving features, yet, they even sought new opportunities for the devices. We believe this is facilitated because they used this as a prototype informing future design iterations.

Surprisingly, almost all participants commented on how rewarding this research felt to them, as they could

contribute to something meaningful, while having a cognitive impairment like dementia.

#### OTHER

The final cluster is a collection of comments that did not fit with the other clusters. These commented on monetary challenges and the inability to control the device with gloves.

#### DISCUSSION

The reflection sessions, and subsequent thematic analysis provided ample insight for discussion on redesign opportunities for the mobile interface. Additionally some new design directions can be distracted as well. After this we will more generally discuss the evaluation, and reflect on the involvement of people with dementia for participating in context. Finally we will discuss some limitations and further research ambitions.

#### THE MOBILE INTERFACE REDESIGN

The reflection sessions, after the studies, provided insights on different aspects of the mobile interface. We divided these in simple improvements and topics for discussion. Finally some of the reflection insights showed that a redesign would not suffice, and we have to find clues for new design directions.

Firstly, the simple improvements were direct translatable, improvements for the smartphone interface. These improvements are mostly unanimous.

Surprisingly the help feature was not appreciated. From a development perspective this is very important, as it allows for easy access in emergency situations. Ultimately, it needs a clearer presentation and more feedback when used. If it can be removed is up for debate.

Related to the general phone functionality, for some users this was just too complex. Therefore we suggest that, although basically needed for phone use, these should be hidden.

Finally, the battery needs a clear improvement. The mobile interface's battery only lasted for 15 hours, and this was experienced as too short.

Secondly, some of the elements need a deeper look, and should be discussed before redesigned. In such a case the design should perhaps be conceptualized in a different way.

Mainly the 'Guide me Home' application was very much appreciated by a few users, however sometimes confusing for others. Reflection on this feature also revealed the importance of a seamlessly working system. Some of the couples, discarded this feature because they had a bad experience during their first use. The technology should therefor work, and allow for error, as suggested in literature (Mäki & Topo, 2009). From one couple we did not receive much input because

of this reason. They experienced difficulty in connecting to a network as is shown in the following quote:

"We did not have reception from the telecom provider, therefore we could not really use the phone to call or text." – CG9

Concerning the product size and appearance the opinions were divided as well. However, this solution might be less complex, as it is something very personal. The solution might be to offer different types. However, the buttons on the mobile device were, for most users, too small to use easily. This was true for both the volume button and the on/off button. Therefore we suggest, that mobile phones, which are target specifically at elderly, are selected carefully.

In addition, some users had issues with basic touch screen interactions. For these users we have to reconsider if we want to offer a mobile interface device at all (Brankaert & den Ouden, 2013). And if we decide so, we have to look at alternative ways to offer them the functionality. Similar issues arose from the disease related reflections. However interestingly, this inability was not related to the level of the disease and might differ per person. For this group of users other opportunities might be sought.

Also in the context of familiarity it was mentioned that some people did not recognize the mobile interface as a device to use. It was stated that 'the mobile interface was too difficult' to use the functionality, this is confirmed in research, when people with dementia have to use the devices on their own (Jones, Kay, Upton, & Upton, 2013). This might guide the design of future devices. Especially for, for example, the navigation functionality and communication with friends and family, most appreciated in this study.

#### INVOLVING PEOPLE WITH DEMENTIA

As we positioned the participants as role-players in our design process, some took this role very serious and provide us with plenty of additional input and suggestions. Especially the content like for example shown in figure 3 (new logo suggestion), is very interesting and shows the participants were dedicated to contribute. As mentioned in the results, most of the participants enjoyed participating because they did something meaningful, while struggling with a disease. Some caregivers also mentioned that this might replace regular therapy sessions, as they focus too much on coping with the disease rather than living with the disease. However, this needs to be investigated further.

Additionally, some insights contributed to our general understanding of design for and with people with dementia. In literature we often see a lack of studies that involve people with dementia because it is often deemed too challenging (Topo, 2009). Yet, by giving an active role to the caregiver, the input from the person with dementia can be facilitated. As such the input from the caregiver encouraged input from the person with dementia. However, for more in-situ qualitative input

from the person with dementia, a method that collects data at home should be used (ie.. Suijkerbuijk et al. 2015). However, also the monitoring of digital data supports finding results concerning quantity of use (Brankaert, Snaphaan, & den Ouden, 2014), we have to rely on other approaches for insight in the quality of use. Results from a comparable study, involving solely dementia caregivers, confirms the difficulty of monitoring results of in context studies (Pitts et al., 2015). And show, we have to rely on indirect methods like in our case the reflection session, over direct methods often used in software evaluation.

Furthermore we noticed that the people with dementia had no issues with participating in the study. We consulted them, and the gatekeepers, continuously on whether participating was still ok. This was mainly due to two reasons: For one, we allowed the people with dementia to decide for themselves how much they would like to be involved. As a result, the involvement differed majorly per person, yet this increased the comfort of participating even more.

Also, because the study took place at their home, the participants felt more at ease. And, the home contributed to the role of the caregivers, they had a more real insight in how the design, in this case the mobile interface, is actually used over time and how it is integrated in everyday life, an important factor for technological interventions (Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009).

Most interestingly, during the introduction meeting we noticed how some participants could use the touchscreen and mobile interface when instructed how to do so, in the moment. Yet, in the reflection session some of these participants did not use the system over the course of the study, lacking initiative and guidance on how to do so (Jones et al., 2013). However, this also happened the other way around. This shows that a lab setup, in which persons with dementia are asked directly to perform an action, do not say anything about how they would perform and use the device at home.

Finally, on a stakeholder level insights were gathered as well. Cooperating with the mental healthcare institute resulted in a smooth involvement of participants. Working with industry resulted in high-quality products to conduct research with. Moreover, we saw how the care institutes and company influenced each other positively as well. For example the possibilities of technology are new to the care institute. Whereas findings related to the disease are valuable for our industry partners.

#### LIMITATIONS

Over the course of the study some limitations can be found. We saw that some participants dealt with the study as a study, meaning they never tried to integrate the device in their lives to benefit from it themselves. Nevertheless, some good design insights could be

derived from them, the actual contribution to the quality of life was not found.

Also, we noticed that the ability to interact with the interface is not fully dependent on the level of dementia. As such it is probably better to separate the results based on the skill level of the participants. Currently unable, basic and advanced users are mixed in the same results. This does provide insights for redesign, yet are not sufficient to make conclusions related to the design.

#### FURTHER RESEARCH

For future iterations we aim to research further what kind of designs work, and by doing so generate common guidelines on how to design for dementia. We will continue to pursue these studies in a real-life context of people with dementia, and improve the methods we use to measure the results. Additionally, the stakeholder collaboration was experienced as positive, this will be extended as well. Only by doing so, we can support the full range of issues caused by the disease and find design solutions that actually contribute to the societal challenge of dementia.

#### ACKNOWLEDGMENTS

We want to thank Gociety©, for providing the mobile interfaces, and the mental care institute Eindhoven (GGzE) for their expertise and support.

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