RelivRing: reliving social activities for people with dementia

Citation for published version (APA):

van Rijen, K., Cobbenhagen, T., Janssen, R., Olsen, M. V., Brankaert, R., Houben, M., & Lu, Y. (2020). RelivRing: reliving social activities for people with dementia. In *CHI'20 Extended Abstracts, April 25–30, 2020, Honolulu, HI, USA* [LBW045] (Conference on Human Factors in Computing Systems - Proceedings). ACM Press. <https://doi.org/10.1145/3334480.3383033>

DOI:

[10.1145/3334480.3383033](https://doi.org/10.1145/3334480.3383033)

Document status and date:

Published: 25/04/2020

Document Version:

Typeset version in publisher's lay-out, without final page, issue and volume numbers

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.tue.nl/taverne

Take down policy

If you believe that this document breaches copyright please contact us at:

openaccess@tue.nl

providing details and we will investigate your claim.

RelivRing: Reliving Social Activities for People with Dementia

Karlijn van Rijen^a
Tom Cobbenhagen^a
Rens Janssen^a
 Eindhoven University of
 Technology
 Eindhoven, 5612 AZ, NL
 k.c.a.v.rijen@student.tue.nl
 t.j.p.w.cobbenhagen@student.
 tue.nl
 r.janssen.1@student.tue.nl

Rens Brankaert
Maarten Houben
Yuan Lu
 Eindhoven University of
 Technology
 Eindhoven, 5612 AZ, NL
 r.g.a.brankaert@tue.nl
 m.houben1@tue.nl
 y.lu@tue.nl

Maria Olsen^a
 Technical University of Denmark
 Konges Lyngby, 2800, DK
 s154093@win.dtu.dk

^aThese authors contributed equally to this work

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s).

Copyright held by the owner/author(s).
CHI'20 Extended Abstracts, April 25–30, 2020, Honolulu, HI, USA
 ACM ISBN 978-1-4503-6819-3/20/04.
<https://doi.org/10.1145/3334480.3383033>

Abstract

Memory loss is one of the most frequent symptoms associated with dementia. Losing the memories of meaningful social activities, such as visits from family, can be confronting not only for the person with dementia, but also for relatives and caretakers. Through an iterative design process involving people with dementia, caretakers and relatives, the RelivRing concept was developed. The RelivRing enables people with dementia to relive the positive experience of visits from relatives. It allows relatives to leave audio messages of their visits, which the person with dementia might have otherwise forgotten. When listening to these messages, the person with dementia can re-experience the positive feeling of the visit. The design is adapted to a person with dementia's cognitive and perceptual abilities following literature research and in-context user studies. With the RelivRing, we aim to maintain and strengthen existing social relations between people with dementia and their relatives.

Author Keywords

Audio messages, Dementia, Design, Reminiscence, Social Activity

CCS Concepts

•Human-centered computing → Auditory feedback; User centered design; Accessibility technologies; Us-

ability testing; Field studies; Sound-based input / output; Haptic devices;

Introduction

Many countries are facing the challenge of dementia as their population ages [16] [20]. Dementia is a term for a range of brain conditions that affect a person's cognitive and physical abilities and often results in memory decline, impaired learning and impaired reasoning [4]. This can lead to frustration for partners or relatives [15] and may result in social isolation for the person with dementia [13], leading to loneliness and accelerating the progression of dementia [9]. This paper presents a design intervention that builds on existing research on design and dementia. Different from existing research which tends to focus on reminiscence of older memories, this paper demonstrates how design can be employed to facilitate the reliving of recent experiences, thereby providing additional insights for the field of design in context of dementia. The design process started with a literature study and expert interviews, followed by three iterations of designing and testing different prototypes with people with dementia, caretakers and family members. Research notes, video and audio recordings were collected and analysed to investigate the effects of the prototypes used in every iteration. Through an iterative process, the researchers thus devised, designed and built the RelivRing, an artefact that re-invokes the recent experience of relatives' visits through voice messages recorded by relatives. This way, people with dementia can relive the associated emotions felt while their relative was with them. The results indicate how 1) the artefact evoked meaningful emotional responses from the person with dementia, 2) made relatives feel like their visits are more appreciated (as indicated in conversations with relatives), and 3) provided an experience that can be shared between people with dementia and their caretakers.

Related Work

Multisensory technologies in dementia

Rich auditory stimulation can trigger memories, as well as enable more extrovert behaviours from people with dementia, such as initiating in conversation or cracking jokes [1] [10]. Hodge et al. [8] have also found positive emotional value in employing rich sensory stimulation. Additionally, the study showed that designing for memories obtained after the onset of dementia can contribute to the cohesiveness of a family and the affection of their interactions.

Physical considerations when designing for dementia

Using colours or contrasts to make distinctions between elements of an object can be very helpful for people with dementia to distinguish such elements from one another. Depending on the dementia type and the individual, some colours or contrasts work better than others, and care must be taken when selecting either [5]. Additionally, using lights to indicate interactive elements can help people with dementia locate them more easily. It is important that the natural couplings between action and function [19] should happen immediately, as delays can be confusing for people with dementia [5]. Moreover, tactile elements can be used as a means of guiding the person with dementia's interaction with an object, especially when the person with dementia is visually impaired [5].

Empathic actions when designing for dementia

Literature in this field has provided several design suggestions for working with people with dementia in an empathic manner:

- Avoiding the stigma of being a victim or sufferer is important to ensure that people with dementia can be comfortable and is not treated as a patient during a user study or workshop [14].

- When designing for people with dementia, it is most valuable to enhance the experiences they gain from what they still are able to do, rather than using design to plug a gap within a problem space [12].
- Products should be designed to be used as independently by people with dementia as possible in order to empower them. Empowerment is the key to gathering data: when communicating with people with dementia, researchers should prevent making them feel like patients [12].
- Hendriks et al. [7] suggests not to make exercises for people with dementia harder than what they can comprehend cognitively, to avoid stressing them out with hard tasks and to remain critical to all data gathered from people with dementia, caretakers and family. Caretakers and family might want the best for their relative, yet may not fully understand their needs [7].

Design Approach and Results

The final design followed from three iterations that all started with an analysis of literature and prior iterations, and ending with a user study.

Ethical considerations

Participants were recruited by the caretakers from the care facility. With prior and explicit consent, the participants were made aware of the purpose and related load of participation. The researchers asked permission to collect pictures, videos and audio recordings of user tests. A consent form was provided to inform the participants about the collection of personal data. Participants from early-to-mid to late stage were included in the study. Participants and their stages of dementia can be found in Table 1. Participants with early-stage were excluded in the study, as it followed

Participant ID	Gender (M/F)	Dementia stage (early/mid/late)	Test number
P01	F	Early to Mid	1
P02	F	Mid	1
P03	F	Mid	1
P04	F	Mid	1
P05	M	Mid	1
P06	F	Mid	1
P07	F	Early to Mid	2 and 3
P08	M	Mid to Late	2
P09	F	Late	2 and 3

Table 1: A table summarising all participants tested with in the pilot study, second and third study

from the expert interviews that people with early-stage dementia are often resistant to products of this nature, and mostly are not yet sent to care facilities. People with late-stage dementia were not included as they were hypothesised to not be able to reliably recognise their relatives regardless of the intervention. Moreover, communication between them and the researchers at the level required for the study would likely be impossible due to their cognitive and communicative impairments.

During the test, the tasks that participants were asked to perform were evaluated by the caretakers to avoid overloading and causing inappropriate reactions. The collected data were coded and detached from the personal data (participants' names) by assigning a number to each data set provided by the participants. The coded data were kept on a password-protected academic online platform at the Eindhoven University of Technology. Personal data collected during the project's iterations were stored offline and processed confidentially. Care was taken to ensure that partic-

Figure 1: The four products used during the pilot study

Figure 2: The prototype used during the second study

Figure 3: The setup used for the 2nd and 3rd study

ipant information would never be recognisable in publications, academic material or any other means.

1st iteration

An initial pilot study was conducted to investigate which product interactions felt natural and intuitive to people with dementia. Six participants were recruited for this test by the caretakers through convenience sampling. The test took place in a controlled environment. Residents were treated as experts and asked to show the researchers how to use a number of 'old-fashioned' products (Figure 1). The researcher and caretaker showed the four products to residents individually and in random order. Another researcher took notes on what actions appeared natural to residents during the test. This was judged by the speed and motoric ease with which residents performed certain actions, how little explanation or support the caregiver and the researcher had to give and the extent to which an action seemed to be done automatically and without the need for further thought.

Results 1st iteration

The data from the pilot study was analysed with the help of artefact models [6], sequence models [3] and a function-means-tree [17] and function analysis [11]. A rotating handle similar to a bean cutter and a phone horn emerged as the most intuitive interactions for people with dementia.

2nd iteration

The second study employed a low-fidelity prototype of the RelivRing to test the design following from the insights of the pilot study (Figure 2). It tested the positive effect of the function of the design, based on the emotional responses, together with how intuitive the interaction of the design was. As testing required voice messages from family members, recruitment of participants with dementia coincided with the recruitment of their relatives. This resulted in three partici-

pants for testing the 2nd iteration. The test was conducted in a controlled environment (Figure 3) with residents from a care facility. Researchers observed the residents perform a set of tasks communicated to them by caretakers, simulating how the final product would be used. This part of the study focused on what aspects of interacting with the device appeared natural or unnatural, and whether listening to the voice messages evoked positive emotions.

Results 2nd iteration

The second and third test were analysed using a thematic analysis [2]. Nonverbal behaviour from the video, audio transcripts and observational notes had been recorded separately and were all transcribed and coded by different researchers in the team. Using an affinity diagram [18], all observations recurring in two or more of the triangulated dimensions were clustered and conclusions were drawn.

In contrast with the first iteration, the handle did not have the desired familiarity when incorporated in a product other than a bean cutter. The phone horn did, but its inclusion was built on the assumption that the product would be used privately. In testing, residents showed more desire to share their message than to keep it to themselves. As such, both features would be removed for the third iteration.

The inclusion of a familiar element in the form of pictures of relatives in the prototype was key in making the people with dementia accept this otherwise alien product. During the second study, it was the first thing recognised by residents who had a picture provided by their relative.

With regards to the design's functionality, both residents who received a personal message from a family member reacted overwhelmingly positively by smiling enthusiastically and verbally responding to the message (quote 1).

Figure 4: The "RelivRing" used during the final study

Study Quotes

Quote 1 (while listening): *"Yes, we're going to have dinner in a minute, so... So, yeah. I'll hang up now, because we're going to have dinner... Yes? Yes, yes, yes, I remember, yes, lovely. Yes, until next time, bye. Bye."*

Quote 2 (concerning Rum-mikub): *"No, [I didn't win], W kept a bunch of pieces on his board. A one, I believe..."*

Quote 3: *"Too bad that [husband] just left..." "because otherwise he could have recorded a message?" "Yes."*

Quote 4: *"Does it help hearing your daughter's voice?" "Yes of course! Yes, yes, definitely!"*

The fact that the message was pre-recorded and unresponsive did not seem to bother or confuse the participants. Listening to the message several times also did not appear to diminish the positive effect that was experienced, and one resident was beaming so much that, according to the caretakers, even residents not involved with the test had asked what it was that had made her so happy.

The participants could be heard saying "yes, I remember [what you are talking about]" repeatedly when listening to the message, and would then explain the visit in question to the caretaker in considerable detail (quote 2). Whether the message had not only evoked positive emotions but also helped her remember it in greater detail is unclear, as it is unknown if the details were made up or true. Another resident, after the interaction design of the prototype had been explained to her, complained that her husband, who had gone home a few minutes earlier, was not there to also leave a message (quote 3).

3rd iteration

The third and final study employed a high-fidelity prototype to specifically test the usability of the design for people with dementia (Figure 4). Two of the three participants of the 2nd iteration study participated again, as shown in Table 1. The setup and data collection was the same as during the 2nd iteration. Additionally, observations focused on the extent to which the new design initiated interaction with the resident and whether the resident could interact with the design without receiving explicit explanation, as the second study had already done much to demonstrate the added value of its function.

Results 3rd iteration

The function was no longer the focal point of the test, but as it was comparable in setup and execution to the second iteration, the researchers paid attention to the resi-

dents' emotional response nonetheless, keeping in mind that changes in the prototype's form might potentially have an effect on the residents' experience of its function. None of the changes seemed to have effect on the emotions that were invoked by the prototype, however, and the responses were comparably positive (quote 4).

Both of these residents mistook the pictures that had been so easily recognised in the 2nd iteration for pictures of themselves this time, even though no changes had been made to the photos. The only notable difference was that the surrounding material of the prototype was blue instead of white, so it is assumed this remarkable contradiction is a result of the whims of dementia.

The prototype used in this iteration was very different from the 2nd, but participants still had issues interacting with it. While the physical interactions were not perceived as difficult, the design and look of the prototype itself appeared unclear to both participants. Neither of them understood what to do when asked to "press the button". Instead of a button, one participant conversely tried to press the speaker; an understandable misconception in hindsight, based on its prominent placement and material colour hiding the speaker grid. If the speaker is lowered and made out of a material that leaves the speaker grid more visible, as in the design's original vision, this issue is expected to dissolve.

The Final Design

The RelivRing (see Figure 5) is a product that helps re-invoke positive experiences in people with dementia by playing voice messages left by relatives. After visiting a relative with dementia, people can leave a voice message to a phone number, which will send it to 'their' button on the RelivRing using a WhatsApp bot. The RelivRing utilises an outer ring of slowly pulsating lights to remind the per-

Figure 5: A final prototype render

Acknowledgements

We are indebted to our participants for their time and effort in this study. We are grateful to Arjan den Hartogh, Joke and Jacqueline from Pleyade and Inge Hoogendijk from Vitalis Kronehoef their support of this work. We appreciate Rens Brankaert, Maarten Houben, Lu Yuan, Jim Steenbakker, Serge Offermans and Chet Bangaru for their insightful feedback, guidance and technical support throughout the process.

son with dementia of its presence, and if a message comes in, the button corresponding to the person leaving a message will pulse faster to draw attention and trigger a response from the person with dementia. To play the messages, the person with dementia simply presses the button that is flashing, and the message will be played through the speaker.

The speaker is centralised to ensure that sound comes directly towards the person with dementia, with a clear grid to prevent confusion about what part of the design the sound would come out of. Listening to a message of an experience they would have otherwise forgotten evokes positive emotions and helps people with dementia to remember these treasured experiences. The fact that these messages are recorded by the person they were experienced with further adds to the intimacy of the experience and supports their relationship. To accommodate for people with dementia's limited motor skills, the RelivRing has a soft outer handle that is pleasant to the touch and shields it when falling. The device is cable-powered to prevent potential issues such as battery death without caretakers noticing, and people with dementia's occasional tendencies to hoard objects of others.

Discussion

A valuable insight to take away is the variability of the target group and the difficulties that come with designing for people with dementia, as the whimsical nature of dementia makes it difficult to draw generalisable conclusions and requires an individual and sensitive approach. For instance, this was illustrated by the residents' different interpretations of the pictures of their relatives between the second and third study. Another factor contributing to this could be the studies' small sample sizes, due to the limitations of convenience sampling and the limited amount of time to set up

the tests.

When reflecting on the proposed design, it is important to acknowledge any unintended negative effects that may occur during use. One of the risks we should be aware of is the risk of reminding the user of their problems of forgetfulness, as they might realise they have forgot something only when listening to the messages. This might potentially lead to agitation, confusion or sadness. Caretakers and relatives should therefore carefully considering for whom the device is suitable. Another risk is the extra burden the RelivRing might place on caretakers in stimulating and explaining use of the device. The device should therefore allow independent use; nevertheless, it should also allow shared use between caretakers and people with dementia as it can help to foster a social connection.

Conclusion

This paper summarised the design research that explored the effect of using recorded voice messages from relatives to evoke positive emotions in people with dementia pertaining to recent visits by relatives. The most important insight from this project is that, in spite of dementia's anti-chronological nature of memory of loss, a person with dementia's recent memories can still yield an immense amount of positive emotions, even if they may be momentarily forgotten. This sets the path to a new and promising design direction in the field of design for dementia. Moreover, the project showed that the use of familiar voices in design interventions for dementia can help in invoking positive emotions and recognition. Exploring the value of familiar voices for other purposes carries potential for future research.

REFERENCES

- [1] 2018. Beleefkamer. (Aug 2018).
<https://pleyade.nl/beleefkamer>
- [2] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101. DOI:
<http://dx.doi.org/10.1191/1478088706qp063oa>
- [3] Tao Chen, Ruifeng Xu, Yulan He, Yunqing Xia, and Xuan Wang. 2016. Learning user and product distributed representations using a sequence model for sentiment analysis. *IEEE Computational Intelligence Magazine* 11, 3 (2016), 34–44.
- [4] Dementia Services Development Centre. 2013. *Improving the design of housing to assist people with dementia*. 42 pages.
- [5] Corinne Greasley-Adams, Alison Bowes, Alison Dawson, and Louise McCabe. 2014. Good practice in the design of homes and living spaces for people with dementia and sight loss. *London, UK: Pocklington Trust* (2014).
- [6] Rex Hartson and Partha S Pyla. 2012. Artifact Model. (2012). <https://www.sciencedirect.com/topics/computer-science/artifact-model>
- [7] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts*, Vol. 2. ACM, 33–36.
- [8] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring media capture of meaningful experiences to support families living with dementia. In *Conference on Human Factors in Computing Systems - Proceedings*. ACM, 1–14.
- [9] Tjalling Jan Holwerda, Dorly JH Deeg, Aartjan TF Beekman, Theo G van Tilburg, Max L Stek, Cees Jonker, and Robert A Schoevers. 2014. Feelings of loneliness, but not social isolation, predict dementia onset: results from the Amsterdam Study of the Elderly (AMSTEL). *J Neurol Neurosurg Psychiatry* 85, 2 (2014), 135–142.
- [10] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2019. Foregrounding Everyday Sounds in Dementia. In *Proceedings of the 2019 on Designing Interactive Systems Conference*. ACM, 71–83.
- [11] Raymond Jelierse, Wilfred van de Vegte, and Alex Olieman. 2008-2011. Function analysis. (2008-2011). http://wikid.io.tudelft.nl/WikID/index.php/Function_analysis
- [12] Stephen Lindsay, Katie Brittain, Daniel Jackson, Cassim Ladha, Karim Ladha, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 521–530.
- [13] Mary Lucero. 2004. Enhancing the visits of loved ones of people in late stage dementia. *Alzheimer's Care Today* 5, 2 (2004), 173–177.
- [14] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 1326–1338.

- [15] Evridiki Papastavrou, Panayiota Andreou, Nicos Middleton, Haritini Tsangari, and Savvas Papacostas. 2015. Dementia caregiver burden association with community participation aspect of social capital. *Journal of advanced nursing* 71, 12 (2015), 2898–2910.
- [16] Hannah Ritchie and Max Roser. 2019. Age Structure. (Sep 2019).
<https://ourworldindata.org/age-structure>
- [17] AJ Robotham. 2002. The use of function/means trees for modelling technical, semantic and business functions. *Journal of Engineering Design* 13, 3 (2002), 243–251.
- [18] Shun Takai and Kosuke Ishii. 2010. A Use of Subjective Clustering to Support Affinity Diagram Results in Customer Needs Analysis. *Concurrent Engineering* 18, 2 (jun 2010), 101–109. DOI :
<http://dx.doi.org/10.1177/1063293X10372792>
- [19] Stephan AG Wensveen, Johan Partomo Djajadiningrat, and CJ Overbeeke. 2004. Interaction frogger: a design framework to couple action and function through feedback and feedforward. In *Proceedings of the 5th conference on Designing interactive systems: processes, practices, methods, and techniques*. ACM, 177–184.
- [20] Martijn van Winkelhof, Gerjoke Wilmink, Philip Scheltens, Marcel Olde Rikkert, Erik Scherder, Karine, Edo Richard, Bertine Lahuis, Geert Jan Biessels, Ruben Wenselaar, and et al. 2019. Laten we de duurste ziekte aanpakken – dementie. (Oct 2019).
<https://www.nrc.nl/nieuws/2019/10/21/laten-we-de-duurste-ziekte-aanpakken-dementie-a3977408>