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RadioMe: Supporting Individuals with Dementia in Their Own Home... and Beyond?

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Dementia is an illness with complex health needs, varying between individuals and increasing in severity over time. Approaches to use technology to aid people with dementia are often designed for a specific environment and/or purpose, such as the RadioMe system, a system designed to detect agitation in people with mild dementia living in their own home and calming them with music when agitation is detected. Both the monitoring and intervention components could potentially be beneficially used outside of the own home to aid people with dementia and carers in everyday life. But the adaptation could put additional burdens on the carer, as many decisions and the handling of the data and software could rely on their input. In this paper we discuss thoughts on the potential role of the carer for adaptations of specified system's expansion to a larger ecosystem on the example of RadioMe.

1 INTRODUCTION

Dementia is a syndrome, a complex illness with many different causes and types. Symptoms are associated with a decline in brain functioning and they as well as their severity and progression vary between individuals and the occurrence of dementia is increasing rapidly due to the increasingly older world population[1]. The Technology Charter For People Living with Dementia in Scotland[2] categorises the benefits of technology for people with dementia (PwD) into (1) Enabling and Empowering, (2) Health and Well-being and (3) Safety and Independence. Most technologies to assist PwD focus on supporting them in activities of daily life (category (1)) and monitoring them and their environment (mostly category (3)) [4]. Assistive technologies in the homes are often introduced to enable PwD (as well as older adults without dementia) to stay in their own homes for as long as possible, as the familiar environment and the control over it can increase the well-being of people with dementia [9]. But these technical solutions are often build *for*, not necessarily *with* PwD and often do not address the concerns of carers and patients [5] or do not accommodate for the complex needs of carers [2]. Co-design including PwD can lead to approaches empowering the individual rather than focus on impairments [6] and mediate between the different views of designers and participants, encouraging a more empathetic approach [7].

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[1]World Health Organisation Website on Dementia: https://www.who.int/news-room/fact-sheets/detail/dementia (accessed 16/02/2022)
[2]Technology Charter: https://www.alzscot.org/sites/default/files/images/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf (accessed 01/03/2022)

One system for PwD, currently in development, which employs co-design for several aspects and works closely with an advisory group of carers, is RadioMe. We will use our RadioMe project as an example of how a system developed for a specific purpose and scenario of a complex illness might be expanded to fit a larger ecosystem. We will first describe the RadioMe system and then discuss what aspects could possibly be useful in other environments and touch on some challenges in enlarging the scope.

2 RADIOME SYSTEM

The RadioMe[3] system aims to support people with (mild) dementia while still living in their own home with interactive radio: reminders will be embedded into their live radio show and when agitation is detected, the music will be changed to play songs selected to calm the PwD. Music has been shown to help physiological recovery from stress [3, 10], and decrease stress-related arousal [8]. This project is conducted as a collaboration of computer music and dementia experts from the University of Plymouth, music therapy experts from the Anglia Ruskin University in Cambridge and human computer interaction researchers from the University of Glasgow. The music is selected for each individual in several sessions with the music therapist, the PwD and the carer, as reactions and preferences for music vary between individuals and there is no one size fits all approach. Agitation will be detected with wearable sensors monitoring the heart rate and sending real-time data to the computing system controlling the radio component. Machine learning algorithm are employed to detect the agitation state from the heart rate data and trigger the calming music when needed. This system aims "to support physical and mental health and wellbeing through the use of technology enabled care", one of the category (2) benefits described in the The Technology Charter For People Living with Dementia in Scotland.

The RadioMe approach combines monitoring and detection of agitation in PwD with direct intervention, adjusted to each individual person, and could aid PwD to stay more independent and ultimately keep them in their own homes longer. As most systems, RadioMe is designed for very specific environment and purpose: the system will be integrated into the home to help with every day frustration and agitation. But could the information of and experience with this in-home system be expanded to include other spaces? If this system could increase well-being of the PwD, it would be beneficial to all involved to try and use the approach in other scenarios as well. We will discuss some potential situations in which the aspects of the RadioMe system could be useful outside of the home and we will also touch upon the the additional work that would be needed to make this feasible.

3 POSSIBILITIES AND CHALLENGES OF EXPANDING THE SCOPE TO LARGER ECOSYSTEM

The RadioMe system will include both agitation monitoring and intervention with music. Both aspects provide valuable information that could be used outside of the home to support people with dementia in their tasks. We will describe two possible use cases of the two aspects and then address practical challenges arising from these.

3.1 Mobile Agitation Detection

While the RadioMe system will be integrated into the home with a laptop as main computing unit, the agitation detection will depend on wearable sensors for the physiological data. The real-time evaluation of the data could possibly be provided by a smartphone app, informing the carer or accompanying family member of rising agitation in the PwD

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[3]RadioMe Project: http://cmr.soc.plymouth.ac.uk/index.php/radiome/ (accessed 16/02/2022)

while on the move or out. This could help identify challenging situations for the person with dementia, alert to changes in their experiences and could help carers and health providers react appropriately and timely.

3.2   Intervention in Defined Spaces

The knowledge about successful music intervention for the individual with dementia (i.e. which songs work for them) could help alleviate agitation in situations that are known to be stressful for the PwD, such as, for example, a doctor's visit or a specific procedure at the hospital. This could be in combination with and adapted to the agitation detection, but could also be used as a precautionary measure in the waiting room of the general practice or similar locations on its own. This would only work for one person at a time, of course, but these specialised visits could be scheduled by the practice in advance to adapt to the needs of the most vulnerable. Headphones with the music could be another alternative with possible uses in public transport, but that would very much depend on the comfort of the PwD.

3.3   Data Handling and Updating: Additional Burden for the Carer?

There are several aspects of scaling up and using the RadioMe approach in different surroundings and situations that need to be discussed. Overall risks of technology for PwD identified by domain experts [1] include privacy concerns, potential feeling of being continually observed, and potential misuse or data leakage, among others. These hold true for this system as well. When working with people with dementia there are also ethical and moral concerns about their ability to give consent and understand specific technological systems. But we want to focus here more on the practicality of the approach.

The monitoring scenario relies on a potential smartphone app enabling the carer or accompanying person to be notified about increasing agitation of the PwD. This could potentially put additional burden on the carer, depending on what the focus of the app was and if the carer was in charge of it and needed to decide what to do with the information. If the app's focus was on monitoring changes in the illness, then someone would have to evaluate and/or label the data. Was the focus on providing opportunities for intervention, then the carer might have to decide on the type of intervention that would fit the context and environment. The symptoms and interventions might change over time and might need to be updated. Who would be in charge of that? The carer or a health professional? Would there be different versions of the app, or could anyone with the app make changes to the system or only one main carer? All of these questions become even more important if monitoring would be part of the second scenario, when interventions could take place in specific places, as the intervention would be more directly linked to the monitoring and changes in the illness could have a more direct impact. Precautionary music playing could be easily discussed vocally without technology exchanging data. However, if the PwD's agitation level was monitored in defined out-of-home spaces to trigger an intervention when necessary, the question of how the evaluated data would be exchanged with the party in charge of said space becomes important. When and how should they have access to that data? Should the carer be in charge of this exchange and make decisions an a incident to incident basis?

Considering that PwD are older adults who on average do not have much experience with technology and carers are often spouses of equal age, the burden of handling the technology could become overwhelming. Elderly carers often worry about their competence and familiarity of assistive technologies, especially when technical error occur [11]. This decision should not be made on behalf of the carer by system designers or computing scientists, but should be developed together with carers and people with dementia, as they will have to deal with the systems in the end.

4 CONCLUSIONS

People with dementia (PwD), a complex illness with varying symptoms and decline in brain functioning, can benefit widely from assistive technologies. Many of these technologies are designed for specific use cases or places, such as the RadioMe system, which aims to support PwD in their own home by detecting agitation with wearable sensors and providing music intervention to calm the PwD. Aspects of these approaches designed for those specific purposes could be very useful tools outside of the scope of their original purpose, but this adaptation could come at the cost of increasing the carer's burden.

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REFERENCES

[1] Clara Berridge, George Demiris, and Jeffrey Kaye. 2021. Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science and Engineering Ethics* 27, 1 (2021), 1–24. https://doi.org/10.1007/s11948-021-00286-w

[2] Ellen Leslie Brown, Nicole Ruggiano, Juanjuan Li, Peter J. Clarke, Emma S. Kay, and Vagelis Hristidis. 2019. Smartphone-Based Health Technologies for Dementia Care: Opportunities, Challenges, and Current Practices. *Journal of Applied Gerontology* 38, 1 (2019), 73–91. https://doi.org/10.1177/0733464817723088

[3] Sky Chafin, Michael Roy, William Gerin, and Nicholas Christenfeld. 2004. Music can facilitate blood pressure recovery from stress. *British Journal of Health Psychology* 9, 3 (2004), 393–403. https://doi.org/10.1348/1359107041557020

[4] Marcello Ienca, Jotterand Fabrice, Bernice Elger, Maurizio Caon, Alessandro Scoccia Pappagallo, Reto W. Kressig, and Tenzin Wangmo. 2017. Intelligent Assistive Technology for Alzheimer's Disease and Other Dementias: A Systematic Review. *Journal of Alzheimer's Disease* 56, 4 (2017), 1301–1340. https://doi.org/10.3233/JAD-161037

[5] Paul Ariel Kenigsberg, Jean Pierre Aquino, Alain Bérard, François Brémond, Kevin Charras, Tom Dening, Rose Marie Droës, Fabrice Gzil, Ben Hicks, Anthea Innes, Sao Mai Nguyen, Louise Nygård, Maribel Pino, Guillaume Sacco, Eric Salmon, Henriëtte van der Roest, Hervé Villet, Marion Villez, Philippe Robert, and Valeria Manera. 2019. Assistive Technologies to Address Capabilities of People with Dementia: From Research to Practice. *Dementia* 18, 4 (2019), 1568–1595. https://doi.org/10.1177/1471301217714093

[6] Cristian Leorin, Eloisa Stella, Christopher Nugent, Ian Cleland, and Cristiano Paggetti. 2019. The value of including people with dementia in the co-design of personalized ehealth technologies. *Dementia and Geriatric Cognitive Disorders* 47, 3 (2019), 164–175. https://doi.org/10.1159/000497804

[7] Stephen Lindsay, Daniel Jackson, Cas Ladha, Karim Ladha, Katie Brittain, and Patrick Olivier. 2012. Empathy, participatory design and people with dementia. *Conference on Human Factors in Computing Systems - Proceedings* (2012), 521–530. https://doi.org/10.1145/2207676.2207749

[8] Cori L. Pelletier. 2004. The effect of music on decreasing arousal due to stress: A meta-analysis. *Journal of Music Therapy* 41, 3 (2004), 192–214. https://doi.org/10.1093/jmt/41.3.192

[9] Jon Pynoos, Evelyn Cohen, and Claire Lucas. 1989. Environmental coping strategies for Alzheimer's caregivers. *American Journal of Alzheimer's Disease and Other Dementias* 4, 6 (1989), 4–8. https://doi.org/10.1177/153331758900400603

[10] Mirjam Radstaak, Sabine A.E. Geurts, Jos F.B. Rosschot, and Michiel A.J. Kompier. 2014. Music and psychophysiological recovery from stress. *Psychosomatic Medicine* 76, 7 (2014), 529–537. https://doi.org/10.1097/PSY.0000000000000094

[11] Vimal Sriram, Crispin Jenkinson, and Michele Peters. 2019. Informal carers' experience of assistive technology use in dementia care at home: A systematic review. *BMC Geriatrics* 19, 1 (2019), 1–25. https://doi.org/10.1186/s12877-019-1169-0