2021-05

RadioMe: Challenges During the Development of a Real Time Tool to Support People With Dementia

Shakeri, G

10.1145/1122445.1122456
ACM Computing Surveys
ACM

RadioMe: challenges during the development of a real time tool to support People with Dementia

GÖZEL SHAKERI, STEPHEN BREWSTER, University of Glasgow, Scotland
SATVIK VENKATESH, DAVID MOFFAT, ALEXIS KIRKE, EDUARDO MIRANDA, SUBE BANERJEE, University of Plymouth, England
ALEX STREET, JORG FACHNER, HELEN ODELL-MILLER, Anglia Ruskin University, England

Dementia is a neurodegenerative disease which is progressive in nature. The symptoms worsen over time, leading to the deterioration of the patient's quality of life as well as their caregivers. Being diagnosed with dementia means losing one's own independence. There is no cure for such disease and its degree of progressiveness is variable. From a certain point on Persons with Dementia (PwD) need the presence of somebody that surveils their actions and needs. However, in the early phases of the disease, this need for person support is not permanent. The existence of Assistive Technologies (AT) can alert caregivers for these needs, giving much more freedom both for the patients and caregivers. Major challenges, however, exist for HCI researchers in designing ATs for PwD. Four challenges will be highlighted and discussed in this paper, and can be considered by other HCI researchers during design and development stages: 1) the stigma of being frail and old, and its consequences for HCI researchers, 2) technical, ethical, and legal issues with available smart devices, 3) lack of availability of database with annotated stress bio-signals from PwD, and 4) access to PwD in times of Covid-19. These challenges became evident during the development of the RadioMe system which aims to deliver a prototype aid that remixes a radio stream in real-time incorporating agitation reduction and reminders.

CCS Concepts: • **Human-centered computing → Collaborative and social computing devices**; **Accessibility Technologies**.

Additional Key Words and Phrases: assistive technologies, smart-home devices, wearable sensors, challenges, persons with dementia, independent living,

ACM Reference Format:
Gözel Shakeri, Stephen Brewster, Satvik Venkatesh, David Moffat, Alexis Kirke, Eduardo Miranda, Sube Banerjee, and Alex Street, Jorg Fachner, Helen Odell-Miller. 2021. RadioMe: challenges during the development of a real time tool to support People with Dementia. In *CHI '21: ACM XXX, May 08–13, 2021, Yokohama, Japan.* ACM, New York, NY, USA, 6 pages. https://doi.org/10.1145/1122445.1122456

1 INTRODUCTION

Aging is the main factor that will shape the future of a vast majority of nations [10]. The combination of a longer life and decreasing fertility rates shift demographics from the once 'normal' distribution of many young people and few older people to a population that has more 50+ year olds than children [10]. Europe already has more older people than children, and will have twice the number of older people than children in 2050 [15]. Developing countries such as China and Brazil are faced with an ever increasing older population [15], with nearly 140 million over 60 in China [10]. The

CHI '21, May 08–13, 2021, Yokohama, Japan

ACM ISBN 978-1-4503-XXXX-X/18/06…$15.00
https://doi.org/10.1145/1122445.1122456

United Nations estimate that by 2045 [21] the number of people over 60 will exceed the number of people younger than 15 - a historical first in humankind.

The unprecedented rate of aging demands societies to reshape many aspects of daily life [10]. More attention to health care and disease management is required, as well as more innovation is necessary to maintain quality of life and decrease costs imposed on healthcare systems.

With the increase in population of older adults worldwide, the number of Persons with Dementia (PwD) has also increased significantly [19]. The World Health Organisation (WHO) describes dementia a syndrome which is progressive in nature and affects memory, thinking, and cognitive abilities to perform activities of the daily life [19]. It is estimated that 50 million people live with dementia worldwide, and there are nearly 10 million new cases every year [20].

Similar to healthy older adults, PwD prefer to age in a familiar environment such as their own home [9]. However, with the progression of dementia, PwD face substantial challenges adapting to their physical, psychological, and social environments [2]. Additionally, ageing in one's own home comes with its own challenges such as loneliness, social isolation, and impaired mobility [26]. Dementia as well as ageing threaten PwDs to be displaced into non-preferred caring facilities [27].

Assistive Technologies (ATs) are promising agents in facilitating ageing-in-place for a growing number of cognitively impaired older adults [18]. ATs have been shown to support independent living [8], enhance well-being [6], and therefore promote ageing in a familiar environment [17, 18].

With the decrease in multi-generation living and the increase in nuclear families worldwide [14] innovative solutions can support and encourage independence, decision making, and communication [27] for PwD. If designed well, ATs have the potential to increase quality of life in PwD and alleviate the burden of families caring for lone-living PwD [6].

This position paper argues for the integration and extension of existing assistive systems (e.g. Amazon Alexa, smart watches) into the lives and homes of PwD, whilst highlighting challenges which come with this decision. It will further introduce and discuss the aims of the RadioMe project which will deliver a prototype aid that remixes a radio stream in real time incorporating 1) agitation reduction and 2) reminders.

2 BACKGROUND

Trends in assistive technologies provide HCI researchers with a multitude of devices to support ageing-in-place for PwD; a few examples are a) assistive robots (assistance in daily activities, communications, and social connectedness) [27], b) wearable and non-wearble sensors (e.g. gait and fall detection) [11], and 3) intelligent smart-home applications (e.g. Amazon Alexa, Google Home Hub) [4].

Wearbale sensors such as smart watches are an affordable and stigma-free way [12] of monitoring PwD's bio-signals. They can come with various pre-installed applications (e.g. fall detection) which allow general physicians and primary care givers to monitor PwD's health and offer a way of detecting health risks (e.g. data analytics) [1]. Nowadays, smart watches come with stress detection functionalities (e.g. measurements of heart rate, body temperature). Stress and agitation detection is crucial in PwD as agitated PwD can harm themselves and others. However, agitation detection in itself is not enough to support lone-living PwD; agitation intervention is necessary. Music has been shown in meta-studies to decrease arousal [22], facilitate blood pressure recovery [7], reduce anxiety [24] and aid psychophysiological recovery from stress [23]. It can be difficult for PwD to operate devices to play such interventional music, particularly when most needed.

As listening to the radio is common in the age range of PwD [25], the RadioMe system will use this medium for agitation intervention and reminders by mapping music elements onto the radio stream. The radio provides an interface involving voice and music, and one that is familiar to PwD. Market research has shown that older people are more likely to own smart-home applications

such as Amazon Alexa and Google with 33% aged 55 and over [13]. As the main usage of these smart-home devices is streaming music and the radio (71%) [13], they can be optimal tools for the RadioMe system. These devices are tested for usability, robustness, and are generally visually pleasant. And as ATs can be operationalised for multiple purposes, there might be less age-related stigma as opposed to purpose specific tools. It is very important to PwD that other people do not perceive them as old and sick [5]. Turning a device that is already sitting in people's homes into AT can have a positive impact on the lives of PwD. As Amazon Alexa and Google Hub come with developer APIs, which allow the installation of custom software, it is possible to repurpose these smart-home devices for the RadioMe project and play interventional music when most needed. However, there are major challenges we face in the development of the RadioMe project.

3 CHALLENGES

3.1 Lack of Openly Available, Annotated Stress Data from PwD

To the best of our knowledge, there is no database openly available with annotated stress bio-signals from PwD. We understand that due to ethical implications and contract constraints, researchers might not be allowed to share data. However, this lack of data poses an obstacle as other research groups are tasked with collecting stress data from PwD themselves. Collecting and annotating data from a pool of PwD is not a trivial task, very time consuming (potentially months of work), and requires the help of care givers. This issue is further aggravated by the current Covid-19 pandemic which renders physical access to vulnerable people such as PwD almost impossible.

3.2 Ethical and Legal Issues around Smart Devices

For PwD to accept a wearable sensor on their bodies, their purpose cannot be mainly an AT. The perceived loss of independence and stigma around ATs prevents PwD from feeling comfortable with these single-purpose devices which leads to abandonment of the tool. If an AT is to be worn successfully it should be in the form of a device which is acceptable to wear on the body for the majority of the day, i.e. a wrist watch [5, 12]. Readily available smart watches (e.g. Garmin, Apple watch) provide a wide range of bio-signal data, are water proof, robust, comfortable, and their appearance can generally be customised to the preference of the wearer.

An unexpected challenge we encountered was the availability of wearable sensors that provide an interface for real-time data processing as well as are affordable (e.g. Garmin's application developer fee is $40,000). Most smart watches come with their own cloud-based eco-systems (e.g. Garmin, Apple watch) where user data can be accessed through an API. However, this results in lags of potentially up to several hours as upload does not always happen immediately and most often, the wearer of the watch needs to issue the upload manually. A core requirement for the RadioMe system is agitation detection and intervention. A PwD's transition into agitation requires immediate intervention and therefore is a time critical event. Continuous, real-time access to data is imperative for the success of agitation detection and reduction. As these watches synchronise the data in the cloud via smart phone applications, it is further required that a smart phone is continuously carried on the user's body. It is not realistic to expect PwD to carry two devices on their body at all times. Therefore, a large portion of available smart watches is not appropriate for our purposes.

There are smart watch Operating systems (OS) that allow installation of custom applications and thus the synchronisation of the data with a nearby server. In pilot tests, open source OS were found to either cause non-negligible discomfort when wearing (e.g. BangleJS) or lack basic functionalities such as a properly working bluetooth connectivity (e.g. WaspOS). Google Wear OS is an operating system that allows the implementation of custom applications, is integrated in various smart watches from multiple brands, and thus allows the wearer to choose a wrist watch

according to their personal preferences. However, Wear OS watches impose major ethical concerns as it is not clear what data and how much data processing is happening on the servers. Irrespective of operating system and device (e.g. Google or Amazon) there are several issues that might be flagged by a sponsorship/ethics committee:

- will any personal identifiable be stored there (note that these companies are renowned for collecting data in the background which might be problematic).
- what data will the device collect outside of the custom application? What will the OS be able to access?
- who's Google/Amazon account will be used? Universities generally have policies about storing data on university accounts only.
- researchers are not allowed to set up accounts on people's behalf (against T&Cs), which poses the question of who will have responsible for managing, deleting the data.

The same ethical and legal concerns apply to the usage of smart-home devices. However, these come with additional privacy concerns (e.g. the perception that any spoken word is recorded) [16].

4 DISCUSSIONS AND CONCLUSION

This paper introduced the Radiome project which aims to deliver a prototype aid that remixes the radio in real-time for people with mild to moderate dementia who live alone, incorporating agitation reduction, and reminders. We argue that already available Assistive Technologies should be used when designing smart-home interfaces for Persons with Dementia, however, we are aware of multiple challenges to the integration of AT into dementia care. Despite the challenges we discussed in this paper, we believe that researchers should aim to reuse AT that are in people's households, rather than developing and integrating single purpose devices into PwD's lives. Producing single-purpose research prototypes might hinder their future usage as maintenance support might cease with the end of the research project. If the research outcome, however, is incorporated into a multi functional smart-home appliance, it might have a longer shelf life.

The concept of the RadioMe system can be applied across cultures as listening to the radio is an international past-time activity for older people. On average, listening to the radio constitutes 12.3% of daily media consumption worldwide, with stark differences between regions [3]. In Central and Eastern Europe for instance 29% of daily media content was consumed through the radio. Whereas in Pacific Asia 5.3% of consumed media content through the radio (21% in Latin America, 18.4% in North America, 20.5% in Western Europe, and 18.2% in the rest of the world) [3]. Despite ever increasing video content, the radio's usage remained stable over the last decade. A decline in radio consumption is not predicted for the near future [3] nor its replacement through television and on-demand streaming content. However, the applicability of the RadioMe system across borders might be limited due to software restrictions in certain countries (e.g. Google in China), and ethical and legal concerns regarding data collection.

5 CONCLUSION

The CHI 2021 workshop on "Designing Interactions for the Ageing Populations – Addressing Global Challenges" will provide a great opportunity to discuss the challenges mentioned in this paper, as well as whether and how research outcomes can be applied across borders.

6 ACKNOWLEDGEMENTS

This research is funded by the EPSRC, grant number EP/S026991/1.

REFERENCES

[1] Mohammed Al-Khafajiy, Thar Baker, Carl Chalmers, Muhammad Asim, Hoshang Kolivand, Muhammad Fahim, and Atif Waraich. 2019. Remote health monitoring of elderly through wearable sensors. Multimedia Tools and Applications 78, 17 (2019), 24681–24706.

[2] Alzheimer's Association. 2021. 10 Early Signs and Symptoms of Alzheimer's. https://www.alz.org/alzheimers-dementia/10_signs

[3] Anne Austin, Jonathan Barnard, Nicola Hutcheon, and David Parry. 2015. Media consumption forecasts 2015. : https://communicateonline. me/wpcontent/uploads/2016/06/Media-Consumption-Forecasts-2016. pdf (2015).

[4] Matthias Baldauf, Raffael Bösch, Christian Frei, Fabian Hautle, and Marc Jenny. 2018. Exploring Requirements and Opportunities of Conversational User Interfaces for the Cognitively Impaired. In Proceedings of the 20th International Conference on Human-Computer Interaction with Mobile Devices and Services Adjunct (Barcelona, Spain) (MobileHCI '18). Association for Computing Machinery, New York, NY, USA, 119–126. https://doi.org/10.1145/3236112.3236128

[5] Nancy A. Brooks. 1991. User's responses to assistive devices for physical disability. Social Science Medicine 32, 12 (1991), 1417–1424. https://doi.org/10.1016/0277-9536(91)90203-O

[6] Maria C. Carrillo, Eric Dishman, and Tim Plowman. 2009. Everyday technologies for Alzheimer's disease care: Research findings, directions, and challenges. Alzheimer's Dementia 5, 6 (2009), 479–488. https://doi.org/10.1016/j.jalz.2009.09.003

[7] 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 arXiv:https://bpspsychub.onlinelibrary.wiley.com/doi/pdf/10.1348/1359107041557020

[8] Saisakul Chernbumroong, Shuang Cang, Anthony Atkins, and Hongnian Yu. 2013. Elderly activities recognition and classification for applications in assisted living. Expert Systems with Applications 40, 5 (2013), 1662–1674. https://doi.org/10.1016/j.eswa.2012.09.004

[9] Carrie A. Ciro. 2014. Maximizing ADL Performance to Facilitate Aging in Place for People with Dementia. Nursing Clinics of North America 49, 2 (2014), 157 – 169. https://doi.org/10.1016/j.cnur.2014.02.004 Facilitating Aging in Place: Safe, Sound, and Secure.

[10] J. F. Coughlin, L. A. D'Ambrosio, B. Reimer, and M. R. Pratt. 2007. Older Adult Perceptions of Smart Home Technologies: Implications for Research, Policy Market Innovations in Healthcare. In 2007 29th Annual International Conference of the IEEE Engineering in Medicine and Biology Society. 1810–1815. https://doi.org/10.1109/IEMBS.2007.4352665

[11] Ana Lígia Silva De Lima, Luc JW Evers, Tim Hahn, Lauren Bataille, Jamie L Hamilton, Max A Little, Yasuyuki Okuma, Bastiaan R Bloem, and Marjan J Faber. 2017. Freezing of gait and fall detection in Parkinson's disease using wearable sensors: a systematic review. Journal of neurology 264, 8 (2017), 1642–1654.

[12] Nicolas Farina, Gina Sherlock, Serena Thomas, Ruth G. Lowry, and Sube Banerjee. 2019. Acceptability and feasibility of wearing activity monitors in community-dwelling older adults with dementia. International Journal of Geriatric Psychiatry 34, 4 (2019), 617–624. https://doi.org/10.1002/gps.5064 arXiv:https://onlinelibrary.wiley.com/doi/pdf/10.1002/gps.5064

[13] Russel Feldman. 2019. Smart speaker ownership doubles in six months. https://yougov.co.uk/topics/politics/articles-reports/2018/04/19/smart-speaker-ownership-doubles-six-months

[14] James Georgas, Kostas Mylonas, Tsabika Bafiti, Ype H. Poortinga, Sophia Christakopoulou, Cigdem Kagitcibasi, Kyunghwa Kwak, Bilge Ataca, John Berry, Sabiha Orung, Diane Sunar, Neophytos Charalambous, Robin Goodwin, Wen-Zhong Wang, Alois Angleitner, Irena Stepanikova, Susan Pick, Martha Givaudan, Irina Zhuravliova-Gionis, Rajani Konantambigi, Michele J. Gelfand, Velislava Marinova, Catherine McBride-Chang, and Yasmin Kodiç. 2001. Functional relationships in the nuclear and extended family: A 16-culture study. International Journal of Psychology 36, 5 (2001), 289–300. https://doi.org/10.1080/00207590143000045 arXiv:https://onlinelibrary.wiley.com/doi/pdf/10.1080/00207590143000045

[15] Kevin G Kinsella and David R Phillips. 2005. Global aging: The challenge of success. (2005).

[16] Josephine Lau, Benjamin Zimmerman, and Florian Schaub. 2018. Alexa, Are You Listening? Privacy Perceptions, Concerns and Privacy-Seeking Behaviors with Smart Speakers. Proc. ACM Hum.-Comput. Interact. 2, CSCW, Article 102 (Nov. 2018), 31 pages. https://doi.org/10.1145/3274371

[17] William C Mann, Kenneth J Ottenbacher, Linda Fraas, Machiko Tomita, and Carl V Granger. 1999. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly: A randomized controlled trial. Archives of family Medicine 8, 3 (1999), 210.

[18] Engineering National Academies of Sciences and Medicine. 2017. The Promise of Assistive Technology to Enhance Activity and Work Participation. The National Academies Press, Washington, DC. https://doi.org/10.17226/24740

[19] World Health Organisation. 2012. Dementia: a public health priority. https://www.who.int/mental_health/publications/dementia_report_2012/en/

[20] World Health Organisation. 2020. Dementia. https://www.who.int/news-room/fact-sheets/detail/dementia
[21] World Health Organization. 2018. Projections of mortality and causes of death, 2016 to 2060. https://www.who.int/healthinfo/global_burden_disease/projections/en/
[22] Cori L. Pelletier. 2004. The Effect of Music on Decreasing Arousal Due to Stress: A Meta-Analysis. Journal of Music Therapy 41, 3 (10 2004), 192–214. https://doi.org/10.1093/jmt/41.3.192 arXiv:https://academic.oup.com/jmt/article-pdf/41/3/192/5415296/41-3-192.pdf
[23] Mirjam Radstaak, Sabine AE Geurts, Jos F Brosschot, and Michiel AJ Kompier. 2014. Music and psychophysiological recovery from stress. Psychosomatic medicine 76, 7 (2014), 529–537.
[24] Myriam V Thoma, Martina Zemp, Lea Kreienbühl, Deborah Hofer, Patrick R Schmidlin, Thomas Attin, Ulrike Ehlert, and Urs M Nater. 2015. Effects of music listening on pre-treatment anxiety and stress levels in a dental hygiene recall population. International journal of behavioral medicine 22, 4 (2015), 498–505.
[25] BBC Trust. 2012. Service Review BBC Local Radio. http://downloads.bbc.co.uk/bbctrust/assets/files/pdf/our_work/local_radio/local_radio.pdf
[26] Janine L. Wiles, Annette Leibing, Nancy Guberman, Jeanne Reeve, and Ruth E. S. Allen. 2011. The Meaning of "Aging in Place" to Older People. The Gerontologist 52, 3 (10 2011), 357–366. https://doi.org/10.1093/geront/gnr098 arXiv:https://academic.oup.com/gerontologist/article-pdf/52/3/357/1559672/gnr098.pdf
[27] Preeti Zanwar, Patricia C. Heyn, Greg McGrew, and Mukaila Raji. 2018. Assistive Technology Megatrends to Support Persons with Alzheimer's Disease and Related Dementias Age in Habitat: Challenges for Usability, Engineering and Public Policy. In Proceedings of the Workshop on Human-Habitat for Health (H3): Human-Habitat Multimodal Interaction for Promoting Health and Well-Being in the Internet of Things Era (Boulder, Colorado) (H3 '18). Association for Computing Machinery, New York, NY, USA, Article 1, 9 pages. https://doi.org/10.1145/3279963.3279971

,