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Recruitment in dementia and technology research; experiences from researchers and perceptions of persons with dementia

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Abstract

Background: This paper presents the researchers' experiences with recruiting people living with dementia for a field study aimed to test or develop non-pharmacological interventions. Performing this kind of research is necessary to be able to provide appropriate and effective interventions for people with dementia.
Research aim/questions: The aim is to find out the pros and cons of recruiting PwD for field studies comprising technological innovations.
Methods: This short paper is based on the experiences of researchers during their studies, combined with a rapid literature search.
Results: Incorporating technological innovations as a non-pharmacological intervention poses a challenge to recruitment success. Several influencing factors influence the success of the recruitment process. For example, personal contact or recruitment via welfare and care organizations can be helpful.
Conclusion: Collaboration and different strategies can be helpful for the recruitment process.

Keywords: Alzheimer, enrollment, practice-based research, technological innovations

INTRODUCTION

Technological innovation is still rapidly expanding, as is the increasing number of people living with dementia at home. Currently, more than 55 million people are living with dementia worldwide (World Health Organization, 2023). They receive support from family carers and professionals. In some countries, such as the Netherlands, the provision of professional support is limited due to a shortage of staff. Therefore, the policy is based on the Framework Appropriate Care (Dutch: Kader Passende Zorg), priorities enabling individuals to remain at home as long as possible at home supported by a social network; if this is not sufficient enough with the aid of technological devices (Ministerie van Volksgezondheid, 2024). All this before admittance to a nursing home arises. There is currently no cure for dementia, so therefore there is a need to find alternative ways to support people with dementia. This is one of the reasons why studies are conducted with the objective of developing and examining technologies that can support people with dementia and their family caregivers. The design phase of these technologies offers a unique opportunity to gather enriched data. The involvement of individuals with dementia in the design phase of a study allows for the retrieval of enriched data (Kort et al., 2019). However, real-life settings are highly relevant for examining and validating the technologies. Field studies are always challenging due to limited control. For field studies on technologies for dementia research, recruitment of people with dementia (PwD) in order to consider their lived experience. To be able to provide appropriate and effective technologies that can impact the quality of life of PwD (Brankaert & Kenning, 2020). A recent review by Kirby et al. (2024) concludes the involvement is limited in breadth and depth despite the initiatives to enlarge the involvement. Kirby et al. (2024) advocate sharing more about the strategies and methods to increase the involvement and the impact of the involvement in research.

Why is the involvement of a person with dementia relevant?

Most PwD are living in their own home with support from an informal caregiver for primary care (Greenwood & Smith, 2019). The Dutch government promotes self-reliance due to the rising healthcare costs and the limited availability of professional care (Verver et al., 2018). Several studies indicate the potential of technological innovations in dementia care (e.g., Astell et al., 2019). However, different studies indicate that more research in the home context of PwD is needed to evaluate the ecological validity and success of technology (e.g. Moyle et al., 2021).

This brief reflective paper outlines the advantages and disadvantages of recruiting PwD for field studies comprising technological innovations as non-pharmacological interventions. Furthermore, the paper shares experiences and perceptions of PwD regarding their participation in these field studies.

METHOD

This reflective research is based on the authors' experiences during the recruitment for a field study to validate non-pharmacological interventions to support sleep in PwD and their informal caregivers. These experiences are combined with the experiences of other Dutch researchers who have been working with PwD and technology for the past five years. These researchers are part of our network, so the recruitment was through the network. The data is collected in the period from February to July 2024. Besides the experiences of the authors, the experiences of three researchers are collected. Their experiences are collected via online or telephone interviews or a short questionnaire via email. Topics of the consultation round were: field study explanation, intended number of participants, reached number of participants, recruitment barriers and facilitators, and reasons for not wishing to participate in the study. Notes are taken during the interviews. Finally, we conducted a rapid literature search in Google Scholar and the database HUGO (Utrecht University of Applied Sciences) on field studies conducted in the past five years in the Netherlands involving PwD and the use of technology, using the search terms: field study, dementia, and technology.

Barriers to the recruitment

Based on our and other researchers' experiences

During a field study in the PhD trajectory of Huisman, it was intended to include community-living people with dementia and their informal caregivers to test technological devices to support daily rhythm and sleep. During the recruitment period for the field study, we encountered many (care) professionals willing to engage with the research and recruitment. Although they acknowledge the usefulness and need for further development of technology to support aging in place of PwD, the recruitment process encountered obstacles and came to a halt. This was due to the high workload in the professionals' daily practice, who may perceive participation as an additional task of lower priority.

In our experience, older PwD and their caregivers lack experience in using new technologies. Consequently, there is sometimes reluctance to participate in a study involving testing technologies. In some studies where smartphone use is required (to test an application), challenges in smartphone usage lead to reluctance to participate (Heins, 2024), which may be caused by low digital literacy.

Part of the field study protocol comprises objective measurements in the indoor environment (e.g., relative humidity and air temperature). To conduct these measurements, we use small, nonintrusive sensors. But it seems that the global discussion about privacy frightens people a bit. As well as the unknown about what a sensor is and how it works. When people hear about the involvement of sensors, there is a kind of fear. At the same time, the used sensors cannot make pictures or videos. It seems very important to explain this part well to potential participants. A similar reaction was given on a tracking device (GPS) on a smartphone in the PhD trajectory of Heins, "Social participation in dementia: Experiences and the role of technology through an occupational lens" (2024).

Perceptions

When people are interested in participating in the study, obtaining written and/or oral informed consent regarding the research is mandatory. In our experience, the potential participants acknowledge the problem, in our case, sleep, what the research is focused on, but participation in the research is sometimes overwhelming. Because living with dementia and taking care of someone with dementia can be complex and can lead to physical, mental, and financial stress. Up to 50% of people with dementia at some point show some agitation (Carrarini et al., 2021), for example, due to events or changes in their lives. Agitation is something you want to avoid during the field study. Therefore, their caregivers/spouses sometimes do not wish to participate in research when changes in normal life might occur. Besides that, as already known, the care for a person with dementia can be burdensome for an informal caregiver. Being responsible for the care is, in some cases, a 24/7 job (Lindeza et al., 2020). This can be why caregivers sometimes are unable to participate in research with a longer study duration (> 1 month). Also, it was observed in the PhD trajectory of Heins (2024) that the caregiver decides about participation and makes the choice on behalf of the person with dementia. In that case, the caregiver is careful and declines participation. Van Lieshout-Dal indicates (2023) in her thesis that it might be sensible to conduct research projects with a shorter study period due to the process/nature of dementia, which is progressive.

Table 1. Overview included projects for the interviews

Recruitment region	Application	Project name
Amsterdam region	Lighting	Enlighten me project
North Netherland	Smartwatch	MOOD-Sense
South Netherland	Application on smartphone	Erop uit met Dementie

There is an increased amount of research being done with PwD. This is positive as it may contribute to the enhanced quality of life and help people to live well with dementia. However, as a result, the increasing requests to take part in research, to both care and welfare organizations but also the people with dementia and their loved ones themselves may lead some of them not to participate anymore. There is already so much burden even though the willingness is high. In some cases, this is reflected in the difficulty of contacting people. This was also found in the study of Thoolen et al. (2022), in which they tested LivingMoments, a digital communication system for people with dementia. Their experience here was that reaching potential participants only succeeds with personal contact or through care and welfare organizations. Besides that, one bad experience of participating in research can make people reluctant to participate in research again.

In a recent study by Beentjes et al. (2023) with PwD, an RCT has been performed for testing a web-based selection tool (FindMyApps). Although there was an inclusion period of 17 months, they did not include the number of participants as planned, namely 80 dyads were intended, and they included 61 PwD and 59 informal caregivers. They aimed to include people with mild dementia and/or MCI; in this last group, there is not always a diagnosis. So this group might be difficult to find (Beentjes et al., 2023). This is something researchers should be aware of or consider in the research design.

Discussion and mitigation measures

Not all research groups do have direct patient access. So, for recruitment, finding collaboration with care and welfare organizations can be helpful. These organizations and professionals directly work with PwD. Previous studies have also reported this as a strategy for recruiting PwD (Beentjes et al., 2023; Van Hoof et al., 2011; Wijma et al., 2018). For the recruitment of community-living people with dementia, it can be helpful to collaborate with several types of (care) professionals and organizations, such as meeting groups (e.g., Alzheimer cafés), community centers, home care organizations, case managers, and general practitioners. To reach out to more people, you can also use the local newspapers and social media for recruitment. On the other hand, in a recent Dutch study in the Amsterdam region with older adults, these strategies are used. Still, they did not reach their recruitment goals despite extending the recruitment period and widening the inclusion criteria (https://www.enlightenme-project.eu/). When research is not initiated by the organization, and they have no direct interest in it, the commitment is inherently lower. In a previous study with older adults by van Hoof et al. (2011), the care organization was responsible for participant recruitment. In a recent study by Janssen et al. (2023), they reported difficulties with recruiting older participants, and they faced a high dropout rate within this group. They use digital recruitment, and multiple onboarding steps were needed. They conclude collaboration with, for example, a welfare organization may lead to more in-person recruitment and support, which seems necessary in this group (Janssen et al., 2023). In Peek's (2017) study, several recruitment strategies were used, but they were not able to recruit the eligible number of participants (older adults) in the time set. So, they work with a so-called convenience sampling. Convenience and purposive sampling are used in almost all articles. Gao et al. (2019) concluded that most of the studies (people with dementia and their caregivers) included in their review often had limited reporting of sample size, inadequate evidence for sample representativeness, and insufficient description of sample characteristics (e.g., length of caregiving). They also found that only 40% of the studies had a sufficiently large sample size (Gao et al., 2019). Different recruitment strategies and collaboration may be helpful. More information about the sample size used in each study is necessary to improve transparency and facilitate further research for the use of new technologies in community living people with dementia.

The experiences of researchers and perceptions of potential participants reported above are derived from studies conducted in the Netherlands over the past five years. Although the systematic review of Gao et al. (2019) supports the findings of our study, these should be treated with caution. Because it is focused on the Dutch context and based on the experiences of several researchers in the field.

References

Astell, A. J., Bouranis, N., Hoey, J., Lindauer, A., Mihailidis, A., Nugent, C., & Robillard, J. M. (2019). Technology and Dementia: The Future is Now. In Dementia and geriatric cognitive disorders (Vol. 47, Issue 3, pp. 131–139). Karger Publishers. https://doi.org/10.1159/000497800

Beentjes, K. M., Neal, D. P., Kerkhof, Y. J. F., Broeder, C., Moeridjan, Z. D. J., Ettema, T. P., Pelkmans, W., Muller, M. M., Graff, M. J. L., & Dröes, R.-

M. (2023). Impact of the FindMyApps program on people with mild cognitive impairment or dementia and their caregivers; an exploratory pilot randomised controlled trial. Disability and Rehabilitation: Assistive Technology, 18(3), 253–265.

Brankaert, R., & Kenning, G. (2020). HCI and Design in the Context of Dementia. Springer International Publishing. https://doi.org/10.1007/978-3-030-32835-1

Carrarini, C., Russo, M., Dono, F., Barbone, F., Rispoli, M. G., Ferri, L., Di Pietro, M., Digiovanni, A., Ajdinaj, P., Speranza, R., & others. (2021). Agitation and dementia: prevention and treatment strategies in acute and chronic conditions. Frontiers in Neurology, 12, 644317.

Gao, C., Chapagain, N. Y., & Scullin, M. K. (2019). Sleep duration and sleep quality in caregivers of patients with dementia: A systematic review and meta-analysis. JAMA Network Open, 2(8), e199891–e199891.

Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. BMC Geriatrics, 19, 1–18.

Heins, P. (2024). Social participation in dementia: Experiences and the role of technology through an occupational lens. Maastricht University.

Janssen, J., Châtel, B., Den Heijer, N., Tieben, R., Deen, M., Corten, R., Peeters, G., Rikkert, M. O., & others. (2023). A digital gaming intervention to strengthen the social networks of older Dutch adults: Mixed methods process evaluation of a digitally conducted randomized controlled trial. JMIR Formative Research, 7(1), e45173.

Kirby, P., Lai, H., Horrocks, S., Harrison, M., Wilson, D., Daniels, S., Calvo, R. A., Sharp, D. J., Alexander, C. M., ... (2024). Patient and public involvement in technology-related dementia research: Scoping review. JMIR Aging, 7(1), e48292. https://doi.org/10.2196/48292

Kort, H. S. M., Steunenberg, B., & Van Hoof, J. (2019). Methods for involving people living with dementia and their informal carers as co-developers of technological solutions. Dementia and Geriatric Cognitive Disorders, 47(3), 149–156. https://doi.org/10.1159/000497802

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: a systematic review of family caregivers' perceptions. BMJ Supportive & Palliative Care.

Ministerie van Volksgezondheid, W. en S. (2024, February). Kader Passende zorg. https://www.zorginstituutnederland.nl/publicaties/adviezen/2022/06/28/kader-passende-zorg

Moyle, W., Murfield, J., & Lion, K. (2021). The effectiveness of smart home technologies to support the health outcomes of community-dwelling older adults living with dementia: A scoping review. International Journal of Medical Informatics, 153, 104513.

Thoolen, M., Toso, F., TM Peek, S., Lu, Y., & Brankaert, R. (2022). LivingMoments: Bespoke social communication for people living with dementia and their relatives. Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems, 1–18.

Van Hoof, J., Kort, H. S. M., Rutten, P. G. S., & Duijnstee, M. S. H. (2011). Ageing-in-place with the use of ambient intelligence technology: Perspectives of older users. International Journal of Medical Informatics, 80(5), 310–331.

Verver, D., Merten, H., Robben, P., & Wagner, C. (2018). Care and support for older adults in The Netherlands living independently. Health & Social Care in the Community, 26(3), e404–e414. https://doi.org/10.1111/HSC.12539

Wijma, E. M., Veerbeek, M. A., Prins, M., Pot, A. M., & Willemse, B. M. (2018). A virtual reality intervention to improve the understanding and empathy for people with dementia in informal caregivers: results of a pilot study. Aging & Mental Health, 22(9), 1121–1129.

World Health Organization. (2023, February). Dementia. https://www.who.int/news-room/fact-sheets/detail/dementia