

2024-07-10

## Designing Self-Management for and with Persons Living with Dementia OSullivan, Dympna

Dympna O'Sullivan

*Technological University Dublin, [dympna.osullivan@tudublin.ie](mailto:dympna.osullivan@tudublin.ie)*

Michael Wilson

*Dundalk Institute of Technology, [michael.wilson@dkit.ie](mailto:michael.wilson@dkit.ie)*

Damon Berry

*Technological University Dublin, [damon.berry@tudublin.ie](mailto:damon.berry@tudublin.ie)*

*See next page for additional authors*

Follow this and additional works at: <https://arrow.tudublin.ie/aircart>



Part of the [Computer Sciences Commons](#), and the [Social Work Commons](#)

---

### Recommended Citation

O'Sullivan, Dympna; Wilson, Michael; Berry, Damon; Moran, Orla; O'Neill, Siobhan; Nugent, Ciaran; Turner, Jonathan; and Doyle, Julie, "Designing Self-Management for and with Persons Living with Dementia OSullivan, Dympna" (2024). *Articles*. 15.

<https://arrow.tudublin.ie/aircart/15>

This Article is brought to you for free and open access by the Applied Intelligence Research Centre at ARROW@TU Dublin. It has been accepted for inclusion in Articles by an authorized administrator of ARROW@TU Dublin. For more information, please contact [arrow.admin@tudublin.ie](mailto:arrow.admin@tudublin.ie), [aisling.coyne@tudublin.ie](mailto:aisling.coyne@tudublin.ie), [vera.kilshaw@tudublin.ie](mailto:vera.kilshaw@tudublin.ie).



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License](#).  
Funder: Science Foundation Ireland

---

**Authors**

Dympna O'Sullivan; Michael Wilson; Damon Berry; Orla Moran; Siobhan O'Neill; Ciaran Nugent; Jonathan Turner; and Julie Doyle

# Designing Self-Management For And With Persons Living With Dementia

Dympna O’Sullivan<sup>1</sup>[0000-0003-2841-9738], Michael Wilson<sup>2</sup>[0000-0001-8642-8646], Damon Berry<sup>1</sup>[0000-0002-2290-7661], Orla Moran<sup>2</sup>[0000-0001-5831-2021], Siobhán O’Neill<sup>2</sup>[0009-0007-6809-7557], Ciaran Nugent<sup>1</sup>[0000-0003-2550-1568], Jonathan Turner<sup>1</sup>[0000-0001-9991-3130] and Julie Doyle<sup>2</sup>[0000-0003-4017-6329]

<sup>1</sup> Technological University Dublin, Dublin, Ireland

<sup>2</sup> Dundalk Institute of Technology, Dundalk, Ireland  
dympna.osullivan@tudublin.ie

**Abstract.** Promoting high quality of life for persons living with dementia has emerged as a central goal in global public health agendas. The emphasis has shifted from extending life to actively enhancing overall well-being by postponing or preventing additional disability. This represents a departure from traditional medical perspectives on dementia to a more socially-oriented approach, placing a strong focus on wellbeing.

In parallel, the concept of self-management for people with living dementia has emerged, where this is a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition. Practice recommendations for person-centered care have been recommended, which emphasize the importance of knowing and understanding the person living with dementia such that individualized choice and dignity are supported. There is also a need to include informal carers (family members or friends) in designing collaborative care planning, while balancing empowerment and active engagement for the person with living dementia in self-management with carer support. This paper describes our approach to co-designing assistive technologies for care planning with and for persons living with dementia and their caregivers.

**Keywords:** Dementia, Self-Management Technology, Codesign,

## 1 Introduction

It is estimated that close to 55 million people globally are living with dementia and that each year there are almost 10 million new cases worldwide [1]. According to research carried out by the Alzheimer Society of Ireland, an estimated 64,000 people are living with dementia in Ireland [2]. Despite a number of lifestyle and genetic risk factors, increasing age remains the strongest risk factor for dementia, with prevalence rates nearly doubling for every five years of age over the age of 65. With an ageing population, the number of people with the condition in Ireland is expected to more than double in the next 25 years to over 150,000 by 2045, representing 2.5% of the population [2].

People living with dementia (PLwD) have higher utilization of healthcare services and higher healthcare costs than those without dementia [3]. From a carer perspective, half a million people in Ireland have a family member with dementia [4]. The care burden associated with dementia is significant and a recent meta-analysis found dementia family carers to be significantly more stressed than non-dementia family carers and to suffer more serious depressive symptoms and physical problems [4]. In Ireland, the majority of PLwD (63%) live at home in the community [2], and the Irish Health Services Executive and Alzheimer Society Ireland (ASI) believe that PLwD who want to remain in their own homes should be supported to do so for as long as possible with high quality home care services. From a health services point of view, encouraging people with dementia to live at home is cost effective. One year of high-quality care in the community costs EUR11,000 less than a nursing home [5]. This is also set against a backdrop of an acute shortage of nursing home beds in Ireland [5].

There is an acute need, which digital health technologies can potentially fulfil, to provide proactive support for PLwD and their carers. However, there is limited involvement of PLwD in the design of technology to support their unique needs for independent living. Our premise is that PLwD should be at the centre of decision-making regarding care, with a shift towards active and empowered self-management facilitated by appropriately designed technology. Our research aims to co-design and co-create a holistic digital health and wellbeing platform for dementia self-management support. The platform will integrate a visual personalized care plan for PLwD, provide timely access to services and supports when required, tailored to the specific needs of PLwD and their carers, and to support them to live independently in their own homes. In developing the platform, we have engaged deeply with key stakeholders including PLwD, their formal and informal carers, dementia charity and support services. Our discussion with stakeholders reveal a number of gaps in dementia health and wellbeing services which we will describe in this paper. We will also outline our proposed participatory design work, which will translate our stakeholder requirements into an assistive technology solution that we will co-design with PLwD, their informal carers, and other stakeholders involved in their care.

## 2 State of the Art

The majority of dementia technology is focused on monitoring, security and safety. Several studies have focused on sensing technology to detect changes in patterns of behaviour that might be indicative of disease progression [6, 7]. Technology research has also focused on detection of wandering [8], and agitation [9]. The primary user of these types of technologies is typically the carer, while the PLwD is often a passive user. The literature also reveals a lack of integrated care platforms for PLwD, with current solutions each tending to focus on only a single aspect of care.

However, some research also strives for a more inclusive approach, with PLwD being more active users of technology. The Ambient Kitchen [10], makes use of an array of sensors and cameras in the kitchen to guide the PLwD through simple food preparation and cooking tasks. Other research aims to facilitate the PLwD in safe and

independent outdoor walking through the use of sensors and AI to nudge the PLwD via a sensor interface to support them in returning home independently, prior to alerting a carer [11]. However, neither the work described in [11] nor that described in [12] discuss the uptake of the systems by PLwD nor their acceptability of the systems.

Assistive technology for dementia should also strive to prolong the period of independent living and to support the maintenance of quality of life, for example through promoting engagement in meaningful activities [12]. Technologies focusing on meaningful activities can be categorized into four main purposes: reminiscence/memory support [13], behaviour management [14], stimulating engagement [15], and conversation/communication support [16]. Recent research on people with mild to moderate dementia has demonstrated the capabilities of PLwD to self-manage [17], where self-management is defined as ‘a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition’ [18]. Dixon et al conclude that “people with mild to moderate dementia are inventive creators and capable actors in self-management [17].

It is well understood that informal carers are core to supporting self-management for PLwD. The demands associated with providing full-time and unpaid care are considerable and varied, and can include including personal care, housekeeping, administration of medication and assistance with financial transactions [19]. These demands frequently result in feelings of isolation, psychological distress (anxiety, depression, and stress), loss of self-esteem, and a tendency to neglect one's own health and wellbeing due to time constraints and feelings of exhaustion [20]. These issues can then negatively affect the carer's capacity to provide adequate care, increasing the likelihood of negative health outcomes for both the carer and the care recipient [21]. As such, research has explored technology to support carers and a wide range of technological solutions now exist, including online support tools or educational programs [22], digital interventions to address burden, stress, anxiety, and depression, [23], solutions aimed at social connection and peer support [24], as well as those more focused on supporting the carer to self-manage their physical health.

### **3 Methodology**

As part of our requirements engineering for an assistive health and wellbeing platform for dementia self-management, we have interviewed over 40 dementia stakeholders. These include eight PLwD, 12 informal carers, 13 healthcare professionals who provide healthcare to PLwD and 11 persons from dementia and charity groups. These interviews were semi-structured and followed a standard guide tailored to each of the four stakeholder groups, with all interview subjects allowed the freedom to discuss topics that were of particular interest to them. It should be noted that all PLwD and all informal carers interviewed as part of this initial stage of our work were part of spousal dyads and our work to date has focused only on individuals in such dyads. During interviews with PLwD, we explored what constitutes quality of life for the PLwD, their goals in relation to future health and wellbeing, and their experiences with technology in

general, as well as technological solutions and supports for living with dementia. Interviews with informal carers focused firstly on receiving a diagnosis for the person they care for including their interactions with healthcare services, challenges they faced, and the impact on themselves and the PLwD. Secondly, we explored providing ongoing support and/or assistance for a PLwD and their carer(s) as the condition progresses including any support they accessed. While speaking to healthcare professional for PLwD, we asked them about the diagnostic and treatment process for dementia, care planning for PLwD and the role that technology can or could play in improving home-based care for PLwD.

Interviews were audio recorded using a sound recording device. Prior to analysis, the recordings were transcribed and participants’ names replaced by ID numbers. Following transcription, the audio recordings were stored securely. The transcripts were imported into NVivo qualitative data analysis software for analysis. Inductive thematic analysis was employed, using the six-step approach outlined by Braun and Clarke [25]. In the next section, we present brief highlights from our interviews in terms of requirements for assistive technology support. Further details from the interviews will be provided in an extended version of this paper.

## 4 First Results

We report on the initial phase of our research, interviews with dementia stakeholders. Results from this phase will guide the later stages of our work, in particular the codesign workshops with PLwD and the four stakeholder groups. From the stakeholder interviews, we identified several gaps in dementia care and support. These gaps will be translated into requirements for a digital platform for dementia self-management support during our planned codesign sessions with PLwD and their carers. Gaps that we particularly aim to address include:

1. Lack of dementia care plans for home-based care, particularly for modelling non-clinical aspects of care such as activities of daily living and meaningful activities. We particularly wish to address the apparent differences between clinical care plans and the requirements of PLwD and their carers for care plan content;
2. Absence of digital support for self-customization of dementia care plans and record-keeping for PLwD adherence to care plans, an absence that impedes accurate decision-making about interventions as the condition progresses;
3. Lack of support for PLwD with other chronic conditions which also require self-management;
4. Lack of insight into PLwD’s preferences for dementia self-management in particular aspects such as their preferences for privacy and sharing data with formal and informal carers, and how this may change as their disease progresses and greater levels of trust and dependence are required to be placed on the informal carer;
5. Poor understanding of informal carer requirements including support in the form of information and education about dementia and how to provide care to PLwD, as well

as support for carers' own health and wellbeing, such as details of support groups and services;

6. Challenges experienced by PLwD and their informal carers in connecting and engaging with wider dementia support services including clinical, educational and community services and an absence of support to integrate personal care plans for living at home with these wider services.

7. A lack of interoperable systems among the multiple care services required by PLwD and the resulting lack of a shared view of the PLwDs health status and care needs for formal carers. This impedes communication and decision-making and can also result in actions such as duplicate referrals for care services.

In the interviews with PLwD, it was noted that there was some positive engagement with voice-activated information and communications technology (ICT) devices (e.g., Amazon Alexa, Google Assistant) by both PLwD and their informal carers. It was further noted that for those PLwD who had used PCs, laptops or tablets, use of these devices declined as their disease progressed. This apparent increasing preference for voice-activated ICT interaction will be further explored during our codesign sessions.

## 5 Future Work

Following a full analysis of interview data, we will conduct a series of co-design workshops with dementia stakeholders to interactively explore the themes arising from the interviews. During the initial co-design sessions, PLwDs will be invited to expand further on their preferences for dementia self-management support and how that can be implemented as a digital platform. Informal carers will be asked about their requirements for support both in terms of providing care for PLwD and in how technology may support that caring role and the carers themselves. Healthcare professionals and representatives of dementia support groups and of charities will be asked to provide input that will allow to design technology in order to facilitate improved communication and shared decision making with other healthcare professionals as well as PLwD and their informal carers.

Included in the co-design workshops will be an investigation into user perceptions of, and preferences for, privacy. Technology designs emerging from co-design sessions will incorporate these preferences while being mindful of the requirements of the GDPR.

**Acknowledgments.** This material is based upon works supported by the Science Foundation Ireland under Grants No. 19/FFP/6917 and 22/NCF/OT/1124.

**Disclosure of Interests.** The authors have no competing interests to declare that are relevant to the content of this article.

## References

1. World Health Organization, <https://www.who.int/news-room/fact-sheets/detail/dementia>, last accessed 2024/01/04
2. The Alzheimer Society of Ireland, <https://alzheimer.ie/creating-change/awareness-raising/dementia-in-the-media/>, last accessed 2024/01/04
3. Aranda, M.P., Kremer, I.N., Hinton, L., Zissimopoulos, J., Whitmer, R.A., Hummel, C.H., Trejo, L., Fabius, C.: Impact of dementia: Health disparities, population trends, care interventions, and economic costs. *J Am Geriatr Soc.* **69**(7), 1774-1783 (2021). doi: 10.1111/jgs.17345.
4. Sheung-Tak, C.: Dementia Caregiver Burden: a Research Update and Critical Analysis. *Curr Psychiatry Rep* **19**(9), 64 (2017)
5. Jim Power Economics Limited. Cost Pressures in the Private and Voluntary Nursing Home Sector. Submission to the Department of Health 2017 Health Service Capacity Review, <https://dokumen.tips/documents/cost-pressures-in-the-private-voluntary-nursing-home-sector-nursing-home-care.html>, last accessed 2024/01/04
6. Enshaefar, S., Zoha, A., Markides, A., Skillman, S., Sahr, T., Elsaleh, T., Hassanpour, M., Ahrabian, A., Kenny, M., Klein, S., Rostill, H., Nilforooshan, R., Barnaghi, P.: Health management and pattern analysis of daily living activities of people with dementia using in-home sensors and machine learning techniques. *PLOS ONE* **13**(5), 1-20 (2018)
7. Qadeer, A., Seigneur, J., Choukou, M.: Recognition system for behaviour and activities of daily living among patients with dementia using smart algorithms and assistive technology. In: Choukou, M-A., Liang, H-N., Atashzar, S., Seigneur, J-M. (eds.) AH2022: 13th Augmented Human International Conference Winnipeg MB Canada 2022..
8. Tung, L., Serna, A., Aknine, A., Hurtienne, J.: Towards supporting caregivers to monitor the whereabouts of people with dementia. In: NordiCHI '16: Proceedings of the 9th Nordic Conference on Human-Computer Interaction Association for Computing Machinery, New York, NY, USA (2016)
9. Nesbitt, C., Gupta, A., Jain, S., Maly, K., Okhravi, H.: Reliability of wearable sensors to detect agitation in patients with dementia: A pilot study. In: Nakai, K., Pai, T-W. (eds.) ICBBT '18: Proceedings of the 2018 10th International Conference on Bioinformatics and Biomedical Technology pp73-77. Association for Computing Machinery, New York, NY, USA
10. Olivier, P., Xu, G., Monk, A., Hoey, J.: Ambient kitchen: Designing situated services using a high-fidelity prototyping environment. In: PETRA '09: Proceedings of the 2nd International Conference on Pervasive Technologies Related to Assistive Environments 2009. Association for Computing Machinery, New York, NY, USA
11. Ng, J., Kong, H.: Not all who wander are lost: smart tracker for people with dementia. In: CHI EA '16: Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems , pp.2241-2248. Association for Computing Machinery, New York, NY, USA
12. Tewell, J., O'Sullivan, D., Maiden, N., Lockerbie, J., Stumpf, S.: Monitoring meaningful activities using small low-cost devices in a smart home. *Pers Ubiquit Comput* **23**, 339-357 (2019) <https://doi.org/10.1007/s00779-019-01223-2>
13. Critten, V., Kucirkova, N.: 'It brings it all back, all those good times; it makes me go close to tears'. Creating digital personalised stories with people who have dementia. *Dementia* **18**(3),864-881 (2019)



## Designing Self-Management For And With Persons Living With Dementia

14. Davison, T., Nayer, K., Coxon, S., de Bono, A., Eppingstall, B., Jeon, Y., van der Ploeg, E., O'Connor, D.: A personalized multimedia device to treat agitated behavior and improve mood in people with dementia: A pilot study. *Geriatr Nurs* **37**(1), 25–29 (2016)
15. Samuelsson, C., Ekström, A.: Digital communication support in interaction involving people with dementia. *Logoped Phoniatr Vocol* **44**(1), 41–50 (2018)
16. Park, E., Owens, H., Kaufman, D., Liu, L.: Digital storytelling and dementia. In: Zhou, J., Salvendy, G. (eds.) *ITAP 2017: Human Aspects of IT for the Aged Population. Applications, Services and Contexts. ITAP 2017. Lecture Notes in Computer Science()*, vol 10298. Springer, Cham, pp. 443–451 (2017)
17. Dixon, E., Piper, A., Lazar, A.: “Taking care of myself as long as I can”: How people with dementia configure self-management systems. In: *CHI '21: Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, **2021**, 656 (2021)
18. The Dementia Engagement and Empowerment Network (DEEP). Dementia and self-management: Peer to peer resource. Available at <https://www.dementivoices.org.uk/dementia-and-self-management-peer-to-peer-resource-launched-on-6th-may-2020/>. (Accessed January 2024)
19. Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., Rosa, M. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care* **0**:1–12, (2020) doi:10.1136/bmjspcare-2020-002242
20. Hoffman, S., Sawyer, A., Witt, A., Oh, D.: The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *J Consult Clin Psychol* **78**(2), 169–199 2010.
21. Grady, P., Rosenbaum, L.. The science of caregiver health. *J Nurs Scholarsh* **47**(3), 197–199 (2015)
22. Parrav-Vidales, E., Soto-Perez, F., Perea-Bartolomé, M., Franco-Martin, M., Muñoz-Sánchez, J.: Online interventions for caregivers of people with dementia: A systematic review. *Actas Esp Psiquiatr* **45**(3), 116–126 (2017)
23. Moreno, P., Chernbumroong, S., Langensiepen, C., Lotfi, A., Gómez, E.: Virtual carer: personalized support for informal caregivers of elderly. In: *PETRA '16: Proceedings of the 9th ACM International Conference on Pervasive Technologies Related to Assistive Environments* (2016)
24. Ploeg, J., McAiney, C., Duggleby, W., Chambers, T., Lam, A., Peacock, S., Fisher, K., Forbes, D. A., Ghosh, S., Markle-Reid, M., Triscott, J., & Williams, A. :A web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: qualitative study. *J Med Internet Res* **1**(1), e2 (2018)
25. Braun, V., Clarke, V.: Using thematic analysis in psychology. *Qual Res Psychol* **3**(2), 77–101 (2006)