

AI in Dementia Care

IA no cuidado da demência

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Resumo: Existem oportunidades para tecnologias de suporte mitigarem as demandas globais sobre os cuidados com a demência. No entanto, a maioria das tecnologias de suporte são soluções pontuais, e a integração é necessária, fortalecida por Sistemas de Apoio à Decisão tanto para cuidadores formais quanto informais. A IA desempenha um papel central em interpretar os dados e tem a capacidade de identificar precocemente problemas de saúde, adaptando-se às necessidades individuais ao longo da jornada do cliente. Metodologias acessíveis e aceitas são necessárias para apoiar a pesquisa comportamental e a implementação de tecnologias, desde o co-design até a avaliação de valor e a inovação responsável no cuidado digital. É vital, no design, que nos concentremos em plataformas integradas, como a HAAL, com ecossistemas tecnológicos interoperáveis que apoiem a jornada do usuário e o trabalho dos cuidadores (in)formais.

Palavras-chave: Demência, IA, Pessoas que Vivem com Demência, Cuidadores Formais, Cuidadores Informais, Sistemas de Apoio à Decisão, Tecnologias de Suporte.

Abstract: There are opportunities for supportive technologies to mitigate the worldwide demands on dementia care. Yet, most supportive technologies are point solutions and integration is needed, strengthened by Decision Support Systems for both formal- and informal carers. AI plays a central role in making sense out of the data and has the possibility to early identify health problems and can adapt to individual needs over the client journey. Accessible and accepted methodologies are needed to support behavioral research and implementation of technologies, from co-design to value assessment to responsible innovation of digital care. It is vital in design that we focus on integrated platforms such as HAAL with interoperable technology ecosystems that support the (client) journey of the user and the work of (in)formal carers.

Keywords: Dementia, AI, People Living with Dementia, Formal Carers, Informal Carers, Decision Support Systems, Supportive Technologies.

Introduction

The total estimated worldwide cost of dementia has reached \$818 billion and will become a trillion-dollar disease (Prince et al., 2015). Due to the increasing costs in health care, decreasing number of formal carers, and changes in laws and legislations, the family of people living with dementia (PwD) will become more responsible for the care. Studies showed that supporting people with dementia places a particular burden on the informal caregiver (van der Lee et al, 2014; Lindt, van Berkel & Mulder, 2020; ADI, 2018) and involves several economic and social costs. This burden becomes heavier as the disease of the PwD progresses (Brodaty & Donkin, 2009). On the positive side, caring for a loved one can result in a sense of meaning, companionship, and improved quality of life (Yu, Cheng & Wang, 2018).

To promote independent living and support PwD to stay longer in familiar surroundings, new approaches are being embraced in Health and Care systems across Europe. In The Netherlands, the norm is: home if possible, self if possible and digital if possible (Overheid.nl, 2022). Achieving this standard will require collaboration and several years of effort from now on, also in dementia care. Active engagement is encouraged and shared responsibility for well-being, social connections, and living arrangements. The care network increasingly plays a crucial role in providing daily instrumental and social support, enhancing self-efficacy and self-management.

The world is facing challenges in respect to dementia care, yet, we can also see it as an opportunity for social- and digital innovations that contribute to independence, well-being and work pleasure. To support the sustainability of dementia care, PwD will increasingly remain in their own homes for as long as possible, with support of carers and supportive (geron)technologies. It is essential that these technologies are co-designed with the intended user groups, including PwD (Suijkerbuijk et al., 2019) and foster effective collaboration between carers, to support shared decision making, and provide care that is person-centred. We should further aim for supportive technologies that are 'warm technologies' (IJsselstein, Tummers & Brankaert, 2020), technologies that are - among others - non stigmatizing, and support well-being and the dementia client journey.

Supportive technologies can offer a solution to mitigate the worldwide burden of cognitive decline related to ageing (van der Lee et al., 2014). Additionally, these technologies can support autonomy (Yu, Cheng & Wang, 2018) and can help improve communication and information exchange among clients, informal caregivers and formal caregivers (Lindt, van Berkel, Mulder, 2020; ADI, 2018). Examples of these technologies are social robots for companionship or daytime structure, lifepattern monitoring to identify a possible

change in daily patterns of PwD and provide information about alarming situations (Nap, Buimer & Wouters, 2020). The dementia client journey can be supported by these various supportive technologies, from videocalling for PwD in the Mild Cognitive Impairment phase to robot pets for therapeutic purposes in later phases (see figure 1).

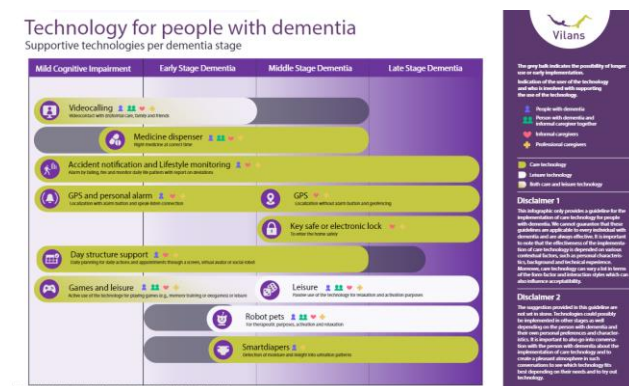


Figure 1 | Supportive technologies for people with dementia and their carers - from Mild Cognitive Impairment to Late Stage Dementia.

Ipakchian Askari S., Vasseur D., Hofstede B., Koowattanataworn P., Nap H.H. (2024). Mapping Dementia Care Technology: Tailored Digital Solutions across Stages. International Medical Education. 2024; 3(2):140-151. <https://doi.org/10.3390/ime3020012>.

Despite the positive- and valuable contribution of these supportive technologies in dementia care, all these technologies are largely point solutions, and point solutions are in the end, pointless. In research, development and implementation, we should focus more and more on stimulating integrated platforms where the relevant data from various combinations of the technologies is presented and automatically - amongst others through Artificial Intelligence (AI) - translated into actionable insights to support PwD and (in)formal carers. Positive results of these type of combinations have been found in the eWare project, that combined smart lifepattern sensors with social robotics (Casaccia et al., 2019) and the HAAL project that will be presented later. The integrated platforms, or decision support systems (DSS) - using AI algorithms - can present information about the cognitive functioning, well-being, physical activity and sleep patterns throughout the client journey. This information can be used for early detection and prevention of health and well-being related issues.

Before we further discuss the development of a DSS in the HAAL project, first a focus on what is meant by AI. AI can be defined as a "a machine-based system that, for explicit or implicit objectives, infers, from the input it receives, how to generate outputs such as predictions, content, recommendations, or decisions that can influence physical or virtual environments. Different AI systems vary in their levels of autonomy and adaptiveness after deployment." (OECD, 2024). There are different types of AI with generative AI as

the latest development (see Figure 2 for an overview). With the introduction generative AI, applications such as ChatGPT (OpenAI, 2023) revolutionize many fields, including dementia care. ChatGPT provides supportive technologies such as social robots enhanced cognitive functioning, speech, and social capabilities.

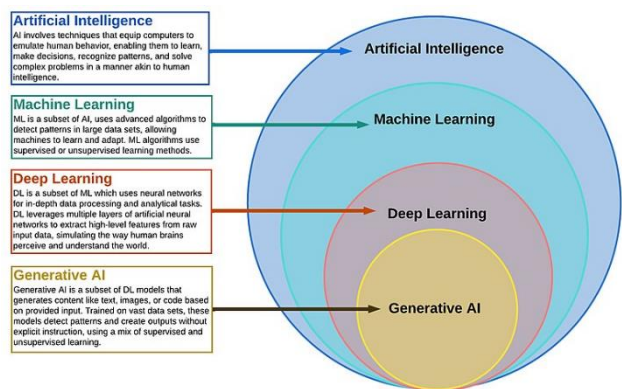


Figure 2 | Types of AI, a comparative view of AI, Machine Learning, Deep Learning, and Generative AI.

Created by L.P. Zhuhadar, 2023

HAAL project

To develop a DSS with a bundle of supportive technologies in dementia care, a multidisciplinary consortium was set up in the international HAAL (HeAlthy Aging eco-system for peoPLe with dementia) project (Nap et al., 2022) within the Active and Assisted Living (AAL) programme. Multiple organizations from the Netherlands, Denmark Italy, and Taiwan combined their expertise and experiences in the iterative development, co-design and evaluation of an AI-supported DSS for carers to gain insight into the health and wellbeing of PwD, using AI algorithms for prediction. The DSS is linked to a bundle of supportive AI-based technologies and services for PwD in various stages (Ipakchian Askari et al., 2024; see also Figure 3) and their (in)formal carers. With HAAL, the caregivers' workload can be reduced, quality of care increased, and independent living and QoL of PwD enhanced (Koowattanataworn et al., 2022). The HAAL dashboard integrates several types of data from multiple supportive technologies - using AI machine learning - collected from PwD: their physical activity, eating and sleeping patterns, cognitive functioning, social contact, and medication intake.

HAAL technologies for example include lifepattern monitoring, daytime structure, medical dispensers, GPS trackers and serious gaming (for a complete overview, see Figure 3).

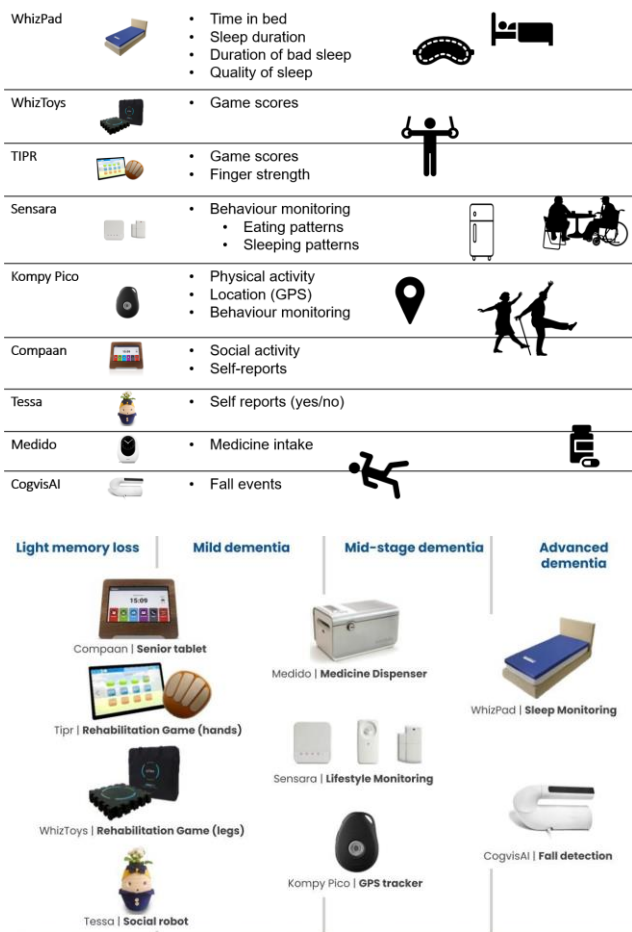


Figure 3 | Supportive Technologies used within the HAAL project.

Within HAAL, we focused on three main activities in the DSS and AI developments; 1. Co-design, 2. Value Assessment, and 3. Responsible Innovation.

Co-design

To ensure that AI based supportive technologies and the HAAL DSS are accepted and easy to use, we organized try-outs and iteratively co-designed the interface with a total of 318 end-users to match the contexts and needs. Throughout all co-design and testing activities, explicit attention was given to the views of PwD and their (in)formal carers on broader social and ethical implications of using DSSs in dementia care and how to address these issues in design and implementation. The usability of the DSS dashboard was high and matched the needs of formal carers.

Value Assessment

The HAAL DSS and bundle of supportive technologies should address quality, safety, equity, efficiency, effectiveness, accessibility, sustainability, economy, ethics and resilience in dementia care. Moreover, the supportive technologies should address different contexts, from Europe to Asia. In the HAAL evaluations, we focussed on multiple outcome measures, including - among others - cost effectiveness,

usability, quality of life, ethical acceptability, social connectedness, care burden, self-efficacy and workload. It is essential that all relevant stakeholders - from users to researchers to financiers to policy makers - agree on the measurement plan and desired impact, to prevent discussions afterwards on (accepted) value.

Responsible Innovation

Within HAAL, there was a strong focus on the responsible use of data and AI in development and the ethical values that play a role in the acceptance of care technologies (Lukkien et al., 2024). The co-design and implementation phases were strengthened by considering the ethical and societal impact of digital care. To ensure technologies to be accepted and sustainable, it is necessary to innovate responsibly during design, implementation and upscaling (i.e., 'responsible innovation').

The three main activities resulted in useful types of data visualizations within the HAAL DSS, which are summary overviews, alerts, predictions, and recommendations based on changes in the beforementioned data. The combined data from various supportive technologies predicts the physical status, sleep activity, cognitive status and general well-being of the PwD. Supervised machine learning was used to predict the user wellbeing (combination of lifepattern monitoring and social robotics). The information provided by the HAAL DSS dashboard can be used for early detection and prevention of health and wellbeing related issues and a first evaluation of HAAL can be found in Nap et al., 2024. See Figure 4 for the Beta prototype DSS dashboard.

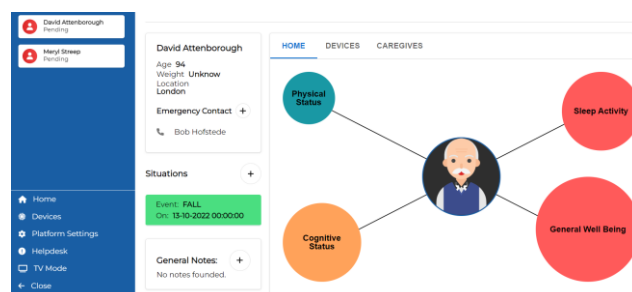


Figure 4 | HAAL DSS dashboard

Conclusion

Supportive technologies in dementia care should - with support of AI - be able to adapt to individual needs over the client journey, support integrated care and provide services accordingly. By doing so, these supportive technologies can obtain user acceptance, trust, and result in cost-effectiveness of care over time.

Accessible and accepted methodologies are needed to support behavioral research and implementation of technologies, from co-design to value assessment to

responsible innovation of digital care. It is vital in design that we focus on integrated platforms with interoperable technology ecosystems – no point solutions – that support the (client) journey of the PwD and the work of an (in)formal carer.

The use of AI and algorithms in DSSs is recommended to extract the health status of PwD and track their progression. Accordingly, supportive technologies such as lifepattern monitoring and social robots are of support and the future lays in including combinations for prediction and early detection.

Overarching the Health and Care systems, AI in dementia care should embrace positive health: people with dementia are more than their condition and their carers are more than their roles. To ensure a sustainable health care system, a focus on positive health and collaboration is key, involving loved ones, society, informal caregivers, and professionals, supported by digital platforms. Supportive technologies with DSSs and generative AI will have a large impact on dementia care. AI in dementia care can adapt to abilities, likes and wishes. AI has the potential to support the sustainability of dementia care.

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