Interdisciplinary Network for Dementia
Utilising Current Technology

dementia: intersectorial strategy for training and innovation network for current technology

Best Practice Guidance

Human Interaction with Technology in Dementia

Recommendations based on the research conducted in
the Marie Sklodowska Curie InnovativeTraining Network INDUCT, Deliverable D6.2 (paper version)/D6.5 (web version) V6.2 Final
and
the Marie Sklodowska Curie InnovativeTraining Network DISTINCT
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INDUCT authors: Rose-Marie Dröes, Yvette Vermeer (ESR 1), Sébastien Libert (ESR2), Sophie Gaber (ESR3), Sarah Wallcook (ESR4), Harleen Rai (ESR5), Aline Cavalcanti Barroso (ESR6), Joeke van Santen (ESR7), Floriana Mangiaracina (ESR8), Kim Beentjes (ESR 8), Sara Bartels (ESR9), Hannah Christie (ESR10), Rose Miranda (ESR11), Annelien van Dael (ESR12), Kate Shiells (ESR 13), Ángel C. Pinto Bruno (ESR 14), Angie Alejandra Diaz Baquero (ESR15), and the ESRs' supervisors Lieve Van den Block, Lara Pivodic, Louise Nygard, Manuel Franco Martin, Maria Victoria Perea Bartolomé, Paul Higgs, Iva Holmerova, Camilla Malinowsky, Franka Meiland, Henriëtte van der Roest, Justine Schneider, Annemieke van Straten, Frans Verhey, Marjolein de Vugt, Martin Orrell

DISTINCT authors: Rose-Marie Dröes, Esther Gerritsen (ESR2), Fanny Monnet (ESR3), Simone Fielding (ESR4), Golnaz Atefi (ESR5), David Neal (ESR6), Mauricio Molinari Ulate (ESR7), Jaroslav Cibulka (ESR8), Victoria Hoel (ESR9), Gianna Kohl (ESR10), Pascale Heins (ESR11), Wei-Qi-Koh (ESR12), Aysan Mahmoudi Asl (ESR 13), Josephine Tan (ESR14), Beliz Budak (ESR15), and the ESRs' supervisors Orii McDermott, Justine Schneider, Lieve Van den Block, Lara Pivodic, Martina Roes, Teake Ettema, Karin Dijkstra, Manuel Franco, Henriëtte van der Roest, Olga Stepankova, Iva Holmerova, Karin Wolf-Ostermann, Georgina Charlesworth, Paul Higgs, Marjolein de Vugt, Frans Verheij, Dympna Casey, Elaine Toomey, Martin Orrell.

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Involved organisations in INDUCT:

Research centres			
University of Nottingham	Prof. Martin Orrell Prof. Justine Schneider Harleen Rai (ESR5) Aline Cavalcanti (ESR6)	Institute of Mental Health	UK
University College London	Prof. Paul Higgs Yvette Vermeer (ESR1) Sebastien Libert (ESR2)	Division of Psychiatry	UK
Maastricht University	Prof. Frans Verhey Prof. Marjolein de Vugt Sara Bartels (ESR9) Hannah Christie (ESR10)	Dept of Psychiatry and Neuropsychology	Netherlands
Amsterdam UMC, location VU University Medical Centre	Prof. Rose-Marie Dröes Dr. Franka Meiland Joeke van der Molen (ESR 7) Floriana Mangiaracina (ESR8) Kim Beentjes (ESR8)	Dept of Psychiatry	Netherlands
VU University Amsterdam	Prof. Annemieke van Straten Dr. Annet Kleiboer Ángel Pinto Bruno (ESR14)	Deparment of clinical-, neuro-, developmental psychology	Netherlands
Vrije Universiteit Brussel (VUB)	Prof. Lieve van den Block Dr. Lara Pivodic Rose Miranda (ESR11) Annelien van Dael (ESR12)	End-of-Life Care Research Group	Belgium
Karolinska Institute	Prof. Louise Nygard Dr. Camilla Malinowsky Sophie Gaber (ESR3) Sarah Wallcook (ESR4)	Division of Occupational Therapy	Sweden
Univerzita Karlova	Prof. Iva Holmerova Prof. Olga Stepankova Kate Shiells (ESR13)	Centre of Expertise in Longevity and Long-term Care (CELLO)	Czech Republic
IDES	Pablo Gómez Prof. Manuel Franco Dr. Henriëtte van der Roest Dra. Maria Victoria Perea Bartolomé Angie Alejandra Diaz Baquero (ESR15)	I MAS D y Empleo Serviconsulting SL	Spain
WHO	Prof. Anne Margriet Pot	World Health Organisation	Switzerland
Partners			
Alzheimer Europe	Jean Georges	Alzheimer Europe	International
Alzheimer Disease International	Wendy Weidner	Alzheimer Disease International	International
World Federation of Occupational Therapists	Ritchard Ledgerd	World Federation of Occupational Therapists	International
University of Hertfordshire	Frances Bunn	Centre for Research in Primary and Community Care (CRIPACC)	UK
University of Witten	Prof. Martina Roes		Germany
SilverFit BV	Joris Wiersinga	SilverFit BV	Netherlands
Eumedianet	Lucas Vroemen	Eumedianet	Netherlands
Betawerk	Hermans	Betawerk	Netherlands

Involved organisations in DISTINCT:

Research centres			
University of Nottingham	Prof. Martin Orrell Prof. Justine Schneider Dr. Orii McDermott Lesley Garcia (ESR1) Esther Gerritzen (ESR2)	Institute of Mental Health	UK
University College London	Prof. Georgina Charlesworth Prof. Paul Higgs Gianna Kohl (ESR10)	Division of Psychiatry	UK
Maastricht University	Prof. Frans Verhey Prof. Marjolein de Vugt Golnaz Atefi (ESR5) Pascale Heins (ESR11)	Dept of Psychiatry and Neuropsychology	Netherlands
Amsterdam UMC, location VU University Medical Centre	Prof. Rose-Marie Dröes Dr. Teake Ettema David Neal (ESR6) Josephine Tan (ESR14)	Dept of Psychiatry	Netherlands
Vrije Universiteit Brussel (VUB)	Prof. Lieve van den Block Prof. Lara Pivodic Fanny Monnet (ESR3)	End-of-Life Care Research Group	Belgium
Deutsches Zentrum fuer Neurodegenerative Erkrankungen (DZNE)	Prof. Martina Roes Simone Felding (ESR4) Kubra Beliz Budak (ESR 15)	University of Witten / Herdecke	Germany
Czech Technical University in Prague (CVUT),	Prof. Lenka Lhotska Prof. Olga Stepankova Prof. Iva Holmerova Jaruslav Cibulka (ESR8)	Centre of Expertise in Longevity and Long-term Care (CELLO)	Czech Republic
IDES	Pablo Gómez Mauricio Molinari (ESR7) Aysan Maimoudi Asl (ESR13)	I MAS D y Empleo Serviconsulting SL	Spain
National University of Ireland	Prof. Dympna Casey Dr. Elaine Toomey Wei Qi Koh (ESR12)	School of Nursing and Midwifery	Ireland
University of Bremen	Prof. Karin Wolf-Ostermann Victoria Hoel (ESR9)	Department 11, Human and Health Sciences	Germany
Partners			
Alzheimer Europe	Jean Georges	Alzheimer Europe	International
Alzheimer Disease International	Paoloa Barbarino CEO	Alzheimer Disease International	International
World Federation of Occupational Therapists	Ritchard Ledgerd	World Federation of Occupational Therapists	International
Karolinska Institutet	Prof. Louise Nygard	Division of Occupational Therapy	Sweden
IBSAL	Prof. Manuel Franco Dr. Henriëtte van der Roest	IBSAL Trimbos-institute of mental health and addiction, Netherlands	Spain
University of Hertfordshire	Frances Bunn	Centre for Research in Primary and Community Care (CRIPACC)	UK
SilverFit BV	Joris Wiersinga	SilverFit BV	Netherlands
Saxion University of applied sciences	Dr. Jan Jukema Dr. Karin Dijkstra	Research group Nursing	
Eumedianet	Lucas Vroemen	Eumedianet	Netherlands

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Chapter 1 INTRODUCTION

Technology and dementia

Though the evidence is still limited, policy-makers, care professionals and researchers often see technology applications as promising solutions to promote independence and autonomy in people with dementia.

Technologies are increasingly vital in today's activities in homes and communities. Nevertheless, little attention has been given to the consequences of the increasing complexity and reliance on them, for example at home, in shops, traffic situations, meaningful activities and health care services. The users' ability to manage products and services has been largely neglected or taken for granted. People with dementia often do not use the available technology because it does not match their needs and capacities.

The rapid growth of the technological landscape and related new services have the potential to improve the overall effectiveness and cost-effectiveness of health and social services and facilitate social participation and engagement in activities. But which technology is effective and how is this evaluated best?

Successful implementation of technology in dementia care depends not merely on its effectiveness but also on other facilitating or impeding factors on a micro, meso and macro level, related to e.g. the personal living environment (privacy, autonomy and obtrusiveness); the outside world (stigma and human contact); design (personalisability, affordability and safety), and ethics on these subjects.

Best Practice Guidance Human interaction with technology in dementia

This Best Practice Guidance results from the literature and field research conducted within the INDUCT project (2016-2020), a Marie Sklodowska Curie funded Innovative Training Network, which focused on technology for people with dementia in three areas (everyday life, meaningful activities and healthcare). The main aim was to develop a multi-disciplinary, intersectorial educational research framework for Europe to improve technology and care for people with dementia, and to provide the evidence to show how technology can improve the lives of people with dementia.

In the updates of the Best Practice Guidance of December 2021, December 2022 and June 2023 the recommendations of a second Marie Sklodowska Curie funded Innovative Training Network on Technology and dementia, called DISTINCT (2019-2023) were included. The main aim of this second ITN is to provide the evidence to show how technology can improve the Social health of people living with dementia by enabling them to 1) fulfil their potential on a societal level, 2) manage their own life and 3) participate in social and meaningful activities,

Regarding the research, both the INDUCT and the DISTINCT network had (have) three main objectives:

- Identifying practical, cognitive & social factors that improve the usability of technology for people with dementia;

- Evaluating the effectiveness of specific contemporary technology; and

- Tracing facilitators & barriers for implementation of technology in dementia care.

The recommendations for improving the usability, effectiveness and implementation of technology in dementia which are presented in this Best Practice Guidance are meant to be helpful for different target groups: people with dementia, their formal and informal carers, policymakers, designers and

researchers. For this reason representatives of these target groups were consulted and involved throughout the INDUCT and DISTINCT project.

Patient and Public Involvement in INDUCT [by Kate Shiells, INDUCT ESR]

The importance of Patient and Public Involvement (PPI) in dementia research has been highlighted at a European level by Alzheimer's Europe as a way in which to enhance the 'transparency, validity and legitimacy' of research (Gove et al., 2017). PPI has been embedded throughout the INDUCT project. For instance, INDUCT was initially conceived following consultations with people with dementia and carers, who highlighted the need for the development of effective, user-friendly technologies that meet their needs in a range of environments. In addition, via Alzheimer's Europe the European Working Group of People with Dementia (EWGPWD) was consulted and provided feedback with strong support for the proposal. Since taking up their posts across Europe, Early Stage Researchers (ESRs) have then continued to involve people with dementia, their formal or informal carers and other relevant stakeholders throughout the research cycle. In particular, the European Working Group of People with Dementia (EWGPWD) has been crucial in the design, dissemination and implementation of projects. Members were present at INDUCT schools in the first and second year, where they advised ESRs on how to engage and recruit people with dementia in research, for example, by using dementia-friendly language in information sheets and consent forms. A subsequent meeting was arranged with the EWGPWD in the third year of the project to share preliminary results and gather their ideas on how best to implement and disseminate findings to appropriate stakeholders.

There are also numerous specific examples of stakeholder engagement activities within each individual project, which have assisted ESRs to develop their recommendations according to each of the three INDUCT objectives. For instance, ESR 1 conducted PPI groups with people with dementia and their carers to elicit their views on empowerment in relation to surveillance technologies, using results to form recommendations on the effectiveness of this technology (Objective 4). ESRs 3 and 4 shared data from their research on the characteristics of Everyday Technologies and the interplay with participation in public space with a PPI group of people with dementia who provided alternative interpretations of the data, leading to recommendations on the usability and implementation of these technologies (resp.Objective 3 and 5). ESR 6 carried out consultations with a PPI group, exploring their opinions of four art applications. This resulted in the selection of two art applications to be used in the proof-of-principle study, examining the barriers and facilitators of implementing digital art in touchscreen devices in nursing homes (Objective 5). Finally, second-level partners in industry have also provided valuable PPI input. For example, ESR 7 collaborated with SilverFit in the Netherlands, a company producing innovative technology to improve elderly care, who provided insight into the implementation of exergaming systems, leading to a publication on the 'do's and don'ts of exergaming for people living with dementia' (Objective 5).

Reference

Dianne Gove, Ana Diaz-Ponce, Jean Georges, Esme Moniz-Cook, Gail Mountain, Rabih Chattat, Laila Øksnebjerg & The European Working Group of People with Dementia (2017): Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement), Aging & Mental Health, DOI: 10.1080/13607863.2017.1317334

Promoting Social Health by means of enabling technology: an Occupational therapy perspective [by DISTINCT ESRs Pascale Heins and Wei Qi Koh, WFOT representatives Ritchard Ledgerd and Claudia von Zweck, and Louise Nygård, Karolinska Institute]

Occupational therapy promotes engagement in activities that people need or want to do in all domains of daily life. With this role, assistive technology is a key contributor in occupational therapy for facilitating management of such activities. In today's digitalized society, technologies are interwoven into all

activity domains. Optimising the potential for social engagement of people living with dementia therefore requires a clear understanding of how and when technology can be used to promote social health, i.e. to enable people with dementia to (1) fulfil their potential and obligations, (2) manage life with some degree of independence, and (3) participate in social activities. Therefore, this guidance provides recommendations to improve the usability, effectiveness, and implementation of technology in dementia care and research, incorporating amongst others the occupational therapy perspective.

From an occupational therapy perspective, activities are both a *means* and an *end* to facilitate people with dementia's social health. This means that occupational therapists work on mediating both the *process* of activity performance, and the *outcomes* of their participation in social activities that are meaningful to an individual. Activities are always performed within, and in interaction with, a *context*. This entails carefully deliberated attention to the transactions that unfold when people engage in activities in their daily life context. These key features of an occupational therapy perspective are also of importance when we strive to develop knowledge about how to support people with dementia through the use of technologies. It is not enough to evaluate only outcomes of a technology intervention. The 'means' (process) is equally important, where considerations regarding individuals' abilities, preferences, values, and disease trajectory, should be taken into account. Considering this, it is for current and future research in the field of technology and dementia care valuable to include people with dementia as both research participants and co-researchers, based on their expertise by experience.

Overall, taking the occupational therapy perspective into account, researchers, healthcare professionals and technology designers should aim to optimise the fit between: (1) a person with dementia's individual abilities and desire to engage in social activities, (2) the characteristics of the activity, (3) the studied or applied technology, and (4) the context. Moreover, as all of these elements interact with each other and may change throughout the course of dementia and the individual's life span, we need to be continuously prepared to revise and adapt this fit.

Chapter 2 Best Practice Guidance at a glance

<table>
<tr><td>3.1.</td><td colspan="2">Practical, cognitive & social factors to improve usability of technology for people with dementia

Technologies are increasingly vital in today’s activities in homes and communities. Nevertheless, little attention has been given to the consequences of the increasing complexity and reliance on them, for example, at home, in shops, traffic situations, meaningful activities and health care services. The users’ ability to manage products and services has been largely neglected or taken for granted. People with dementia often do not use the available technology because it does not match their needs and capacities.
This section provides recommendations to improve the usability of technology used in daily life, for meaningful activities, in healthcare and in the context of promoting the Social Health of people with dementia.</td></tr>
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The rapid growth of the technological landscape and related new services have the potential to improve the effectiveness and cost-effectiveness of health and social services and facilitate social participation and engagement in activities. But which technology is effective and how is this evaluated best? This section provides recommendations to evaluate the effectiveness of technology in daily life, meaningful activities and healthcare services as well as of technologies aimed to promote the Social Health of people with dementia. Examples of useful technologies in some of these areas are provided.</td></tr>
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<tr><td>3.3.</td><td colspan="2">Implementation of technology in dementia care: facilitators & barriers

Successful implementation of technology in dementia care depends not merely on its effectiveness but also on other facilitating or impeding factors related to e.g. the personal living environment (privacy, autonomy and obtrusiveness); the outside world (stigma and human contact); design (personalisability, affordability and safety), and ethics on these subjects. This section provides recommendations on the implementation of technology in everyday life, for meaningful activities, healthcare technology and technology promoting Social Health.</td></tr>
<tr><td></td><td>3.3.1</td><td>Technology in everyday life</td></tr>
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	3.3.3.	Healthcare technology
	3.3.4.	Social Health Domain 1: Fulfill ones potential and obligations
	3.3.5.	Social Health Domain 2: Manage ones own life and promote independence
	3.3.6.	Social Health Domain 3: Technology to promote social participation
3.4	Glossary	The glossary provides an explanation of words that are not commonly used in daily life
	INDEX 1 Thematic	This index will help you to find the recommendations of your interest based on keywords
	INDEX 2 Target group	This index will help people from different backgrounds (people with dementia, caregivers, policy makers, researchers) to find relevant recommendations for their own purpose

Chapter 3 RECOMMENDATIONS

3.1. Practical, cognitive & social factors to improve usability of technology

3.1.1. Technology in everyday life

- ***Consider selling empowering products for people with dementia and carers and avoid stigmatizing stereotypes*** [3.1.1.1]

Guidance: Providers and marketers of ST should not communicate a wanderer with dementia discourse. Rather they should focus on useful person-centred products and communicate this in a non-stigmatising way towards family carers and people living with dementia in order to provide empowering products.

Explanation and Examples: Surveillance Technology (ST), such as GPS tracking devices are used as a resilience tool to increase the safety and independence of people with dementia that portray people with dementia to sell such technologies in a way that encourages stereotypes and contribute to a misunderstanding of dementia. This in turn could also impact technology development. This qualitative research undertook three studies of production (who made what), audience reception (what do users need) and textual analysis (what media techniques are used to attract attention) focused on the UK, Sweden and the Netherlands. The production study examined 242 websites that sell ST and a wanderer discourse with dementia was found. These websites give minimum representation of people with dementia using technology but represent overburdened younger-female carers, who are in need for a locating safety product to covertly use for wandering people with dementia, children and pets. Relying on stereotypes and "not so useful" technology will hinder resilience for people with dementia. Rather, it may imply the continuous stigmatisation that occurs when people with dementia are stereotyped and disregarded as human technology users.

Keywords: Technology advertisements, textual analysis, dementia, stigma, wandering discourse

Target group: Providers, marketers of Surveillance Technology

Type of evidence
Yvette Vermeer (INDUCT ESR1)
Review of surveillance technology sold online and their marketing techniques

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Vermeer, Y., Higgs, P., Charlesworth. G. (2018) Marketing of surveillance technology in three ageing countries. Quality in Ageing and Older Adults, 20, 2019(1):20-33 https://doi.org/10.1108/QAOA-03-2018-0010

Vermeer, Y., Higgs, P., & Charlesworth, G. (2022). Selling surveillance technology: semiotic themes in advertisements for ageing in place with dementia. Social Semiotics, 32(3), 400-421. https://www.tandfonline.com/doi/full/10.1080/10350330.2020.1767399

Vermeer, Y. Analysing advertisements of older adults: controlling the senile back then and wanderers now? (submitted)

Vermeer, Y., van Santen, J., Charlesworth, G., & Higgs, P. (2020). People with dementia and carers online discussing surveillance. Journal of Enabling Technologies, 14(1), 55-70. https://doi.org/10.1108/JET-07-2019-0032

Vermeer, Y., Higgs, P., Charlesworth, G. (2019). Surveillance Technology in dementia care: implicit assumptions and unresolved tensions. In: N. Hendriks, K. Slegers, A. Wilkinson (eds.) DementiaLab 2019, Making design work: engaging with dementia in context. Springer International Publishing, p101-113.

Vermeer, Y., Higgs, P., & Charlesworth, G. (2019). What do we require from surveillance technology? A review of the needs of people with dementia and informal caregivers. Journal of Rehabilitation and Assistive Technologies Engineering, *6*. doi: 10.1177/2055668319869517

- ***Consider different needs*** [3.1.1.2]

Guidance: During the development or use of technological devices, the individual needs of the person with cognitive impairments (e.g. dementia or MCI) and carer should be considered. This includes not only everyday technology, but also surveillance technology (ST) and technology used during cognitive training sessions. Increased awareness and offered assistance is recommended.

Explanation and Examples: People with dementia tend to face more and other difficulties than people with MCI when using relevant everyday technologies such as cash machines, calling or texting with a cell phone or using a DVD player, and thus need more assistance in technology use. This may also be the case with ST and technology used for cognitive training.

For example, ST are often presented as a neutral technology, which enables carers to minimise risk. However, the views of users have not been sought by ST developers, which limits the usefulness of ST and suggests the need for the empowerment of user groups. Therefore, a study of audience reception was undertaken through focus groups, online discussions (Netherlands) and PPI (UK). Hereby people with dementia could speak for themselves, which has allowed their needs to be compared with carers. There was no clear recognition that such needs differed between people with dementia and carers, and it has not previously been recognized that this leads to a mismatch between a user's situation and the product design and how this plays out in the acceptance and use of ST. Although, carers and people with dementia have not yet reached an agreement on the privacy debate and on how the media should portray dementia, it is clear that carers often tamper with ST to make up for a lack in current designs. The results suggest that ST are being resold or rebranded by providers to use for dementia, whilst users may experience physical and cognitive barriers to using such technologies for safety reasons.

Regarding technology for cognitive training: As older people have little experience with technological devices, and so may experience problems, professionals involved in cognitive training should monitor training sessions from the outset. The professional must observe and ensure the ability of the older person to understand the instructions given through the technological device, so that the person can really benefit from the cognitive training by computer. For example, in sessions with GRADIOR, a cognitive rehabilitation program, there is always a professional in charge who helps older people to understand the exercises they may experience difficulty with.

Keywords: People with dementia, MCI, carers, needs, everyday technology, surveillance technologies, product design, assistance, usability

Target group: People with dementia; family carers; professional carers, policymakers, technology developers, researchers, clinicians, who promote the use of technology to people with cognitive impairments.

Type of evidence
Yvette Vermeer (INDUCT ESR1), Sara Bartels (INDUCT ESR9), Angie Alejandra Diaz (ESR 15)
Literature review, RCT, cross-sectional and focus group studies, online discussions, PPI

References

Vermeer Y, Higgs P, Charlesworth G. What do we require from surveillance technology? A review of the needs of people with dementia and informal caregivers. J Rehabil Assist Technol Eng. 2019 Dec 2;6. doi: 10.1177/2055668319869517.

Vermeer, Y., van Santen, J., Charlesworth, G., & Higgs, P. (2020). People with dementia and carers online discussing surveillance. Journal of Enabling Technologies, *14*(1), 55-70. https://doi.org/10.1108/JET-07-2019-0032

S. L. Bartels, S. Assander, A.-H. Patomella, J. Jamnadas-Khoda & C. Malinowsky (2019): Do you observe what I perceive? The relationship between two perspectives on the ability of people with cognitive impairments to use everyday technology, Aging & Mental Health, ePub 6May2019 https://doi.org/10.1080/13607863.2019.1609902

- ***Consider undesired side effects of dementia prevention technologies and discourses*** [3.1.1.3]

Guidance: Public health policy should more fully consider the undesired side effects of dementia prevention technologies and discourses which may reinforce the fear of dementia and imply a moral responsibility on people who cannot maintain cognition in later life due to the progression of the condition.

Explanation and Examples: A review of the literature shows there is little evidence for the effectiveness of brain training to prevent dementia. Furthermore, ethnographic research has generated evidence that engagement with it can act as a form of social exclusion by separating older people into those who have 'successfully cognitively aged' and those who have not. Indeed, the promotion of this technology implies an individual responsibility to stay cognitively healthy, implicitly reinforcing anxiety and blame around the condition and people who live with it. These side effects can reinforce the exclusion of people with the condition.

Keywords: Brain training, social exclusion, successful ageing, dementia

Target group: Researchers; policymakers

Type of evidence

Sébastien Libert (INDUCT ESR2)
Literature review, Ethnography

References

Libert, S., Charlesworth, G., & Higgs, P. (2020). Cognitive decline and distinction: A new line of fracture in later life? Ageing and Society, 40(12), 2574-2592. doi:10.1017/S0144686X19000734

- ***Adaptations to enable more accessible public transport*** [3.1.1.4]

Guidance: Public transport providers and policy-makers should be more aware of barriers to access and consider adaptations to enable better accessibility for people with cognitive issues or disabilities living with dementia.

Explanation and Examples: Everyday Technologies are required to access public transport (e.g. ticket machines, GPS, travel updates on smartphones). Research from the UK and Sweden explored how access to public transport can enable or disable a person's ability to participate in places and activities, within public space. The UK study involved 64 older people with dementia and 64 older people with no known cognitive impairment. The Swedish study included 35 older people with dementia and 34 older people with no known cognitive impairment. Transportation centres were one of the places most frequently abandoned over time by the Swedish group of people with dementia. In

both the Swedish and UK samples, compared with people without dementia significantly fewer people with dementia were drivers, so may have increased need to use public transport. Research shows they face increased barriers to using the Everyday Technologies that are required to access those services. The research is supported by consultations that were performed across London with community-based groups of older people with and without dementia, and the European Working Group of People with Dementia. The consultations revealed not only physical but also cognitive barriers to using Everyday Technologies to access public transport.

Keywords: Technology, Dementia, Transportation, Activities of Daily Living; Social Participation, Accessibility

Target group: Transportation planners, transportation operators, policy-makers.

Type of evidence

Sophie Gaber (INDUCT ESR3)
Cross sectional quantitative studies, literature review & multilevel stakeholder consultations.

References

Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., & Malinowsky, C. (2019). Everyday Technologies and Public Space Participation among People with and without Dementia. Canadian Journal of Occupational Therapy, 86(5), 400–411. https://doi.org/10.1177/0008417419837764

Gaber, S. N., Nygård, L., Kottorp, A., Charlesworth, G., Wallcook, S., & Malinowsky, C. (2020). Perceived risks, concession travel pass access and everyday technology use for out-of-home participation: cross-sectional interviews among older people in the UK. BMC Geriatrics, 20, 192. https://doi.org/10.1186/s12877-020-01565-0

- ***Addressing stigma through online and offline service options*** [3.1.1.5]

Guidance: Service providers should counter the stigmatising effect of not having access to, or not being a skilled user of, Everyday Technologies, for people with dementia and consider strategies to enhance participation, providing offline and online choices for all public services.

Explanation and Examples: Interviews were performed with 128 older people with and without dementia in the UK, and 69 people with and without dementia in Sweden. In both the UK and Swedish studies, people with dementia reported significantly lower use of Everyday Technologies compared to older people without dementia. People with dementia also reported significantly lower participation in places and activities within public space. Reduced ability to use Everyday Technologies was linked to reduced participation in places visited and activities within public space for people with dementia. Community-based consultations with older people with and without dementia across London showed that Everyday Technologies can provide opportunities to participate in services, e.g. eHealth and online banking. However, without face-to-face or written options (e.g. offline), people with dementia are at risk of stigma associated with digital exclusion. Barriers to participation in their everyday lives can lead to social isolation.

Keywords: Technology, Dementia, Activities of Daily Living, Human Rights, Stigma, Social Isolation, Health Literacy, Health Services Accessibility

Target group: Service providers e.g. retailers, transportation organisations, financial companies etc., government and voluntary services, cultural, recreational and spiritual centres, media etc.

Type of evidence

Sophie Gaber (INDUCT ESR3)
Cross sectional quantitative studies, literature review & multilevel stakeholder consultations.

References

Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., & Malinowsky, C. (2019). Everyday Technologies and Public Space Participation among People with and without Dementia. Canadian Journal of Occupational Therapy, 86(5), 400–411. https://doi.org/10.1177/0008417419837764

Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., Charlesworth, G., Wallcook, S., Malinowsky, C. (2020). Social Participation in Relation to Technology Use and Social Deprivation: A Mixed Methods Study Among Older People with and without Dementia. International Journal of Environmental Research and Public Health, 17, 4022. https://www.mdpi.com/1660-4601/17/11/4022#

- ***Design easier to use everyday ICTs (Everyday Information Communication Technologies)*** [3.1.1.6]

Guidance: Technology developers should be aware that the challenge of using everyday information communication technologies can be high for older adults, including some people with dementia. They should use inclusive design that addresses cognitive useability to reduce the level of challenge so that more people with cognitive impairments can use ICTs.

Explanation/Examples: A standardized questionnaire investigated how 35 people living with dementia and 34 people with no known cognitive impairment in Sweden perceived their ability to use 90 ETs on a 5 step rating scale. This data was analysed (in a Rasch model) to produce a *challenge measure* for each of the 31 EICTs, showing how difficult or easy they were to use. Landline telephone was the easiest EICT to use. Scores for smartphone functions (make calls, receive calls, alarm, camera) were at the easier end of the challenge hierarchy and comparable to (or lower than) the challenge of the same functions on a push button mobile phone. These smartphone functions were less relevant to the group of people with dementia than the group without. Using a computer for the full range of functions (shopping, banking, email etc.) scored in the top half of the challenge of the hierarchy and using a tablet to search the web was most difficult. No other tablet functions (i.e. banking, email) could be scored since not enough people considered those functions relevant. Several smartphone functions (i.e. game, social media, transaction) could not be scored for the same reason.

Keywords: Information Communication Technologies, Usability, Dementia, Older adults

Target group: Technology developers; e.g. designers

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Cross sectional quantitative study and literature review

References

Wallcook, S., Nygård, L., Kottorp, A. & Malinowsky, C. (2019) The use of Everyday Information Communication Technologies in the lives of older adults living with and without dementia in Sweden. Assistive Technology, 33:6, 333-340 [DOI: 10.1080/10400435.2019.1644685]

- ***Take a multi-perspective approach when procuring public space technologies to improve usability internationally*** [3.1.1.7]

Guidance: When selecting technologies for use in public spaces, procurers should involve occupational therapists and designers with expertise in dementia, and people living with dementia. Public space technologies should 1) have the most cognitively enabling and inclusive design features (i.e. minimal steps and memory demands), 2) be sited in the most supportive physical location (i.e. secure vestibule, busy thoroughfare) and 3) identify and account for wider sociocultural preferences (i.e. continued face-to-face services).

Explanation/Examples: Life outside home in most countries increasingly demands the use of everyday technologies (ETs i.e. transport ticket and parking machines, ATMs, airline self-check in machines, fuel pumps). However, ETs can present challenges, particularly for people with dementia, and differences in design and location may mean some ETs are easier to use than others. To investigate variation in the challenge of ETs; the Everyday Technology Use Questionnaire was administered with 315 people with and without dementia (73 in Sweden, 114 in the USA, 128 in England) in a cross-sectional, quantitative study. Modern statistical analysis found 5/16 public space ETs differed in challenge level between countries (specifically: ATM, airline self-check-in, bag drop, automatic ticket gates, fuel pump). These differences result from variation in design features or siting of technologies. However, they may also be due to differing habits between users in different countries (i.e. necessity and frequency of use, preference for particular modes of transport, concerns about security, embarrassment) or varying progress towards technologised rather than face-to-face services (i.e. towards cashlessness). Taking account of inter-country differences could lead to selecting the most useable technologies and services. This could improve inclusiveness of public space internationally for older adults with and without dementia.

Keywords: Everyday technology, everyday life, accessibility, useability, cultural context, transportation

Target group: Service providers e.g. retailers, transportation organisations, financial companies etc., occupational therapy educators and providers, technology developers, dementia friendly communities

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Quantitative, cross-sectional study with 315 participants in three countries.

References

Wallcook, S., Malinowsky, C., Nygård, L., Charlesworth, G., Lee, J., Walsh, R., Gaber, S.N., & Kottorp, A. (2020) The perceived challenge of everyday technologies in Sweden, the United States, and England: exploring differential item functioning in the Everyday Technology Use Questionnaire, Scandinavian Journal of Occupational Therapy, 27(8):554-566. doi: 10.1080/11038128.2020.1723685.

- ***Cashback is a replacement banking service rurally and local retailers must be aware of legal obligations to accept chip and signature cards*** [3.1.1.8]

Guidance: Due to UK bank and post office closures, local shops have a more central role in ensuring that older adults have continued, secure access to cash via face-to-face services offering card payments and cashback. Staff, managers and proprietors need to be aware of legal obligations to accept customers' chip and signature cards, which support some people with dementia to access their finances. Other countries may need to make legal provisions to ensure financial services and retailers do not discriminate against people with disabilities regarding payment methods and access to cash.

Explanation and Examples: Cash can be a preferred option among people of all ages – including some older adults with dementia - who prefer to retain visual control over their spend. Bank and post office closures have occurred across the UK, affecting particularly people in rural areas, who may now face increased travel distances to reach a branch. Technologies (ATMs and chip and PIN devices) are therefore becoming less avoidable in the process of accessing cash, however, can present problems for people living with dementia. A case study of 13 rurally dwelling older adults in the UK with mild dementia gathered data from in home interviews involving two structured questionnaires, observations, maps, and subsequent relevant document collation (i.e. public transport timetables, local news reports). The importance of local grocery shops and supermarkets in providing a trusted, face-to-face option for accessing cash was highlighted, particularly among cases who lived alone. Subsequent document analysis found some retailers were unaware of legal obligations to accept chip and signature cards leading to occasional refusals. Raising retailer awareness of the importance of card pay-

ment options rurally, and obligations to accept signature cards, could support people living with dementia to continue independently accessing their finances locally.

Keywords: Everyday life, everyday technology, rural, activities of daily living, services

Target Group: Service providers e.g. retailers, transportation organisations, financial companies etc, dementia friendly communities, voluntary services, government

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Case study of 13 rurally dwelling older adults with mild dementia in England.

References

Wallcook, S. (2021) Conditions of Everyday Technology Use and its Interplay in the Lives of Older Adults with and without Dementia. (PhD thesis) Karolinska Institutet, Stockholm. Available at: https://openarchive.ki.se/xmlui/handle/10616/47651

- ***Private surveillance car parking companies must not discriminate against drivers with dementia and must ensure useability by giving control and feedback to users*** [3.1.1.9]

Guidance: Private car parking companies that use vehicle number plate recognition and surveillance technologies must make accessible provisions that account for memory difficulties common among drivers with mild dementia. Parking facilities must allow users control and provide feedback about time of arrival. Contractors of these companies must ensure the systems they agree to are useable for their customers living with dementia.

Explanation and Examples: Driving remains essential for daily life in rural parts of the UK where public transport infrastructure is sparse. Driving also means handling continually evolving technologies: parking ticket machines (cash, cashless, SMS/app, number plate inputting), automated barriers, fuel pumps, parking surveillance systems. These technologies may increase the complexity of parking and driving, particularly for people living with dementia', and could impact some people's ability to complete everyday activities. A case study of 13 rurally dwelling older adults with mild dementia gathered data from in-home interviews involving two structured questionnaires, observations, maps, and subsequent relevant document collation (i.e. public transport timetables, local news reports). Driving was highlighted as centrally important to daily life, particularly for cases living alone. Carparks which used number plate surveillance on entry and exit were highlighted by one case as particularly problematic. These types of parking technologies offer drivers no feedback about time of arrival, nor any method by which drivers can control their own actions in relation to rules and restrictions leading to unfair discrimination. Short term memory difficulties common among people with mild dementia increase their risk of being unfairly penalised by these systems, leading to curtailed or abandoned activities, or handling complex administration of fines.

Keywords: Everyday life, everyday technology, transportation, surveillance technology, services, rural

Target Group: Service providers e.g. retailers, transportation organisations, financial companies etc, dementia friendly communities, voluntary services

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Case study of 13 rurally dwelling older adults with mild dementia in England.

References

Wallcook, S. (2021) Conditions of Everyday Technology Use and its Interplay in the Lives of Older Adults with and without Dementia. (PhD thesis) Karolinska Institutet, Stockholm. Available at: https://openarchive.ki.se/xmlui/handle/10616/47651

- ***Provide comprehensive occupational therapy assessments taking account of everyday technology use to improve identification of support needs*** [3.1.1.10]

Guidance: People with dementia reporting new difficulties using everyday technologies should be offered a comprehensive assessment by an occupational therapist. While everyday technology can be assistive to everyday activities, in some cases, a pattern of detechnologising indicates instability in the person's wider pattern of participation and may indicate a need for support, or change in housing situation.

Explanation and Examples: Everyday life, including outside home, more and more involves the use of everyday technologies (mobiles, smartphones, ATMs, transport ticket machines etc), which could even influence the places that people go to. A cross-sectional, quantitative study with 128 older adults with and without dementia in England was conducted using the Everyday Technology Use Questionnaire and the Participation in Places and Activities Outside Home questionnaire. Results of statistical analyses confirmed that for some people; going to a lower amount of places was related to perceiving a lower amount of technologies relevant in daily life and living in a relatively more deprived area. A subsequent case study was conducted with 13 rurally dwelling older adults from the same sample (using the same questionnaires with additional interview notes, observations, maps, subsequent relevant document collation i.e. mobile and internet network availability reports). Findings highlighted a person could perceive detechnologising, particularly around the home and garden, as one of several signs of vulnerability when living alone rurally. Such vulnerability was then a sign of a need for support to make living at home more tenable, including to increase safety in the grounds surrounding home, or was a sign of a need to relocate.

Keywords: Assessments, support, activities of daily living, everyday technology

Target Group: Occupational therapy educators and providers, social care and housing providers, clinicians, health care providers and patient organizations.

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Quantitative cross-sectional study with 128 UK-based participants, case study of 13 rurally dwelling older adults with mild dementia in England.

References

Wallcook, S., Nygård, L., Kottorp, A., Gaber, S., Charlesworth, G., & Malinowsky, C. (2021). Kaleidoscopic associations between life outside home and the technological environment that shape occupational injustice as revealed through cross-sectional statistical modelling. *Journal of Occupational Science*, *28*(1), 42-58.
https://www.tandfonline.com/doi/full/10.1080/14427591.2020.1818610

Wallcook, S. (2021) Conditions of Everyday Technology Use and its Interplay in the Lives of Older Adults with and without Dementia. (PhD thesis) Karolinska Institutet, Stockholm. Available at: https://openarchive.ki.se/xmlui/handle/10616/47651

3.1.2 Technology for meaningful activities

- ***Optimising the process of prototyping and usability testing*** [3.1.2.1]

Guidance: Gather feedback from people with dementia on working prototypes rather than paper prototypes.

Explanation and Examples: Work with Eumedianet and the systematic review indicated that people with dementia found it difficult to comment on paper prototypes as it did not provide them with enough knowledge on the future digital application.

Keywords: User involvement, feedback, prototyping, usability testing

Target group: Researchers involved in developing digital applications

Type of evidence

Harleen Rai (INDUCT ESR5)
Systematic review & development process of the iCST application

References

Rai, H. K., Cavalcanti Barroso, A., Yates, L., Schneider, J., & Orrell, M. Improving the involvement of people with dementia in developing technology–based interventions: a narrative synthesis review and best practice guidelines. JMIR 2020;22(12):e17531. doi.org/10.2196/17531.

Rai, H.K., Schneider, J., Orrell, M. An Individual Cognitive Stimulation Therapy App for People With Dementia: Development and Usability Study of Thinkability JMIR Aging 2020;3(2):e17105 doi: 10.2196/17105

- ***Creating a suitable user experience and design*** [3.1.2.2]

Guidance: When developing new digital applications, ensure you generate an optimal user experience and focus on sophisticated design including clear signposting and, an easy and intuitive navigation.

Explanation and Example: People using the iCST app valued the sophisticated, mature design and the clear navigation but noted the need for clearer buttons. The design should have a highly professional look and feel and be clearly orientated to adults not children.

Keywords: UX design, user experience, design, digital applications

Target group: Researchers involved in developing digital applications, UX designers.

Type of evidence

Harleen Rai (INDUCT ERS5)
Development process of the iCST application

References

Rai, H. K., Griffiths, R., Yates, L., Schneider, J., & Orrell, M. (2021). Field-testing an iCST touch-screen application with people with dementia and carers: a mixed method study. Aging & Mental Health, 25:6, 1008-1018, doi.org/10.1080/13607863.2020.1783515.

- ***Everyday fluctuations*** [3.1.2.3]

Guidance: Consider using smartphone-based experience sampling apps to measure everyday fluctuations of variables such as mood, behaviors, or cognition in people with mild cognitive impairments or carers of people with dementia to better understand variations in daily experiences.

Explanation and examples: The ‘Partner in Sight’ intervention for carers of people with dementia, the ‘Monitor-Mi’ study (feasibility of the experience sampling method (ESM) in people with MCI), and the development of two cognitive tasks (mDSST; mVSWMT), all included the experience sampling method (ESM). These studies are first steps towards a better understanding of and support for people with cognitive impairments, such as MCI or dementia, and their carers in everyday life. The results indicate positive effects on carers’ well-being, feasibility of using the ESM in people with MCI, and internal validity when assessing momentary cognition in healthy older individuals. The experience sampling method has a high ecological validity with a reduced memory bias, allows to see fluctuations, and uncovers a complex picture of affect, behaviour, and other variables in everyday life. It can be

used to increase awareness of own daily patterns and motivate behavioural changes towards more meaningful activities.

Keywords: Experience sampling, everyday life, cognition, people with MCI, carers, mood

Target group: Researchers focusing on eHealth, clinicians

Type of evidence

Sara Bartels (INDUCT ESR9)
ESM studies: 'Partner in Sight' intervention and related studies; Monitor-Mi study; Cognitive tasks (collaboration with S. Verhagen et al.).

References

Bartels SL, van Knippenberg RJM, Malinowsky C, Verhey FRJ, de Vugt ME Smartphone-Based Experience Sampling in People With Mild Cognitive Impairment: Feasibility and Usability Study. JMIR Aging 2020;3(2):e19852 doi:10.2196/19852

Van Knippenberg, R. J. M., De Vugt, M. E., Ponds, R. W., Myin-Germeys, I., van Twillert, B., & Verhey, F. R. J. (2017). Dealing with daily challenges in dementia (deal-id study): an experience sampling study to assess caregiver functioning in the flow of daily life. International journal of geriatric psychiatry, *32*(9), 949-958.

Van Knippenberg, R. J. M., De Vugt, M. E., Ponds, R. W., Myin-Germeys, I., & Verhey, F. R. J. (2018). An experience sampling method intervention for dementia caregivers: results of a randomized controlled trial. The American Journal of Geriatric Psychiatry, 26(12), 1231-1243.

Daniëls, N. E. M., Bartels, S. L., Verhagen, S. J. W., Van Knippenberg, R. J. M., De Vugt, M. E., & Delespaul, P. A. (2020). Digital assessment of working memory and processing speed in everyday life: Feasibility, validation, and lessons-learned. Internet Interventions, 19, 100300.

Verhagen, S. J., Daniëls, N. E., Bartels, S. L., Tans, S., Borkelmans, K. W., de Vugt, M. E., & Delespaul, P. A. (2019). Measuring within-day cognitive performance using the experience sampling method: A pilot study in a healthy population. PLOS ONE, 14(12), e0226409.

- ***Assessing the Ability to Use Everyday Technologies by self-perceived reports as well as observations*** [3.1.2.4]

Guidance: To understand the ability of the elderly with cognitive impairments to use everyday technology observe the interaction but also ask about their views.

Explanation and Examples: Via an observation (guided by the META), the person-technology interaction can be described in detail, e.g. does the person press buttons/the screen with an adequate force or are steps performed in a logical order. This can help to determine which elements of a specific technology are causing problems and might be particularly useful for designing intervention and the development of technology. Through a self-perceived report (S-ETUQ), the individual can reflect on a wider range of technologies and the impact of technology use to perform well in (in relation to) everyday life can be depicted. For example, if someone has problems using the ticket machine for public transport or the ATM, this might impact participating in society; if the individual has problems with using the dishwasher or vacuum cleaner, this might impact the hygiene and well-being at home.

Keywords: Everyday technology, MCI, dementia, self-perceived report, observation

Target group: Clinicians, researchers and industry evaluating technology use of people with cognitive impairments

Type of evidence

Sara Bartels (INDUCT ESR9)

Correlation study of the META and S-ETUQ (KI and UM)

References

Bartels, S.L., Assander, S., Patomella, A.H., Jamnadas-Khoda, J. & Malinowsky, C. (2020): Do you observe what I perceive? The relationship between two perspectives on the ability of people with cognitive impairments to use everyday technology, Aging & Mental Health, 24:8, 1295-1305, DOI: 10.1080/13607863.2019.1609902

3.1.3. Health care technology

- ***Portable and unobtrusive devices for electronic records are optimal for staff and residents*** [3.1.3.1]

Guidance: Nursing homes providing care for people with dementia should consider introducing portable devices in addition to desktop devices for electronic patient records (EPR). Devices should not disrupt or invade residents' privacy.

Explanation and Examples: Portable devices have been shown to increase efficiency in some instances as they allow staff to record data into the EPR at the point of care instead of at the end of the shift. This enables staff to spend more time providing care to residents, particularly for residents with dementia and complex needs. Portable devices can support person-centred care by allowing immediate access to care plans with vital information about residents, such as dementia diagnosis. Rapid access to care plans is important for staff retrieving information about individuals who are at the nursing home temporarily on respite; for those residents who may be unable to recall personal information; and for those staff who work infrequently in the home and are unfamiliar with residents. However, it should be taken into consideration that some staff may prefer desktop devices based on ease of use when completing substantial documents. During the development of portable devices for nursing homes, the impact that such devices could have on residents should be taken into account and staff should explain the purpose of EPR devices to residents and family members who may be unfamiliar with the technology.

Keywords: Device; electronic patient record; nursing home; portability.

Target group: Developers of EPR, Nursing homes

Type of evidence

Kate Shiells (INDUCT ESR 13)
Integrative literature review
Qualitative study

References

Shiells, K., Holmerova, I., Steffl, M., Stepankova, O. (2018). Electronic patient records as a tool to facilitate care provision in nursing homes: an integrative review. Informatics for Health and Social Care, 44(3), 262-277. DOI: 10.1080/17538157.2018.1496091

Shiells, K., Diaz Baquero, A. A., Stepankova, O., & Holmerova, I. (2020). Staff perspectives on the usability of electronic patient records for planning and delivering dementia care in nursing homes: a multiple case study. BMC Medical Informatics and Decision Making, 20, 159. https://doi.org/10.1186/s12911-020-01160-8

- ***Applications promoting the effective use of electronic records are required*** [3.1.3.2]

Guidance: Applications that should be incorporated into EPR systems used in nursing homes providing care for people with dementia include a spell-check, a copy and paste function and a keyword search function. Log-in processes should be rapid and secure.

Explanation and Examples: The presence of a spell-check has been described as saving time on proofreading, as well as increasing legibility and comprehension of documentation. This allows for more time to be spent with residents with dementia in direct care, and for correct care to be provided. A copy and paste function also saves time by allowing staff to easily transfer information across sections of the EPR where information is often required to be replicated. A keyword function allows staff to enter a keyword and jump to the relevant section in a resident's notes, allowing for more efficient retrieval of information, important in situations when a resident is unable to recall personal information. Rapid log-in processes should reduce barriers to using the EPR, as slow log-in processes have been found to prevent staff from accessing information about residents before delivering care, and have meant staff have been forced to pass on information about residents verbally instead of entering it into the EPR. This may mean important information regarding any sudden changes in an individual's condition might be missed.

Keywords: Applications; electronic patient record; nursing home; software

Target group: Developers of EPR, Nursing homes

Type of evidence

Kate Shiells (INDUCT ESR13)
Integrative literature review
Qualitative study

References

Shiells, K., Holmerova, I., Steffl, M., Stepankova, O. (2018). Electronic patient records as a tool to facilitate care provision in nursing homes: an integrative review. Informatics for Health and Social Care, 44(3), 262-277. DOI: 10.1080/17538157.2018.1496091

Shiells, K., Diaz Baquero, A. A., Stepankova, O., & Holmerova, I. (2020). Staff perspectives on the usability of electronic patient records for planning and delivering dementia care in nursing homes: a multiple case study. BMC Medical Informatics and Decision Making, 20, 159. https://doi.org/10.1186/s12911-020-01160-8

- ***Functionalities of electronic records should be tailored to the nursing home environment*** [3.1.3.3]

Guidance: Developers of EPR systems for dementia care should consider including a function allowing for the automated generation of graphs to show trends in data, and an accompanying function to prompt staff about changes in a resident's condition. In addition, functions allowing for the automated generation of care plans from assessment data, and alerts to prompt staff to create or update a new document in the EPR may be of value to nursing homes. Interoperability should be a goal for the future.

Explanation and Examples: Automatic generation of graphs displaying trends in a resident's condition increases visibility of changes, allowing staff to more rapidly identify and respond to changing care needs. For example, graphs showing changes in weight, which can commonly affect individuals with dementia. Furthermore, through the incorporation of artificial intelligence (AI), some EPR systems are able to analyse resident data and provide alerts to staff about potential risk factors. For instance, alerts to warn staff about potential skin breakdown, important for those residents with dementia receiving end-of-life care, who may be spending considerable amounts of time in bed and have reduced fluid intake. Automatic generation of care plans from assessment data could save staff time in administra-

tion, as well as automatic alerts incorporated into the EPR that prompt staff to update care plans, meaning optimal care can be planned and provided to individuals with dementia. Finally, EPR systems should be interoperable, so that staff can access and communicate relevant information securely over the internet with external healthcare providers, instead of using paper records.

Keywords: Alerts; artificial intelligence; electronic patient record; functionality; nursing home

Target group: Developers of EPR, Nursing homes

Type of evidence

Kate Shiells (INDUCT ESR13)
Integrative literature review
Qualitative study

References

Shiells, K., Holmerova, I., Steffl, M., Stepankova, O. (2018). Electronic patient records as a tool to facilitate care provision in nursing homes: an integrative review. Informatics for Health and Social Care, 44(3), 262-277. DOI: 10.1080/17538157.2018.1496091

Shiells, K., Diaz Baquero, A. A., Stepankova, O., & Holmerova, I. (2020). Staff perspectives on the usability of electronic patient records for planning and delivering dementia care in nursing homes: a multiple case study. BMC Medical Informatics and Decision Making, 20, 159 https://doi.org/10.1186/s12911-020-01160-8

- ***Electronic care documentation should meet the needs of nursing home staff caring for people with dementia*** [3.1.3.4]

Guidance: EPR systems should include the necessary assessment templates for use in the care of people with dementia, as well as space for entry of free text and to upload photos of residents. Electronic assessment forms and care plans for dementia care should use formalised nursing language to prompt the entry of correct information, and structured templates that guide staff through body systems, leading to comprehensive care plans.

Explanation and Examples: EPR systems in nursing homes have been found to omit the appropriate scales and assessments required by nursing staff caring for people with dementia. For instance, staff stated that they require the MMSE assessment, the QUALID scale, and the Barthel Index of Activities of Daily Living incorporated into the EPR. Furthermore, staff have identified incorrect nursing language in electronic forms, meaning important information is not recorded. For example, the omission of the term 'dementia diagnosis' from assessment forms meant that nurses were not entering this information about residents. By including the appropriate structured forms for data entry with formalised nursing language, Artificial Intelligence (AI) tools can be more successfully integrated into the EPR. Space for photos of residents is important for new staff when learning residents names and for confirming identities of residents when required, and structured body templates included into the EPR have been identified as a useful visual prompt for completing assessments. Staff also require space to enter life stories, and space for free data entry for additional notes and observations. For example, changes in the behaviour of a resident with dementia.

Keywords: Assessment; care plans; electronic patient record; nursing language; nursing home; templates

Target group: Developers of EPR, Nursing homes

Type of evidence

Kate Shiells (INDUCT ESR13)
Integrative literature review
Qualitative study

References

Shiells, K., Holmerova, I., Steffl, M., Stepankova, O. (2018). Electronic patient records as a tool to facilitate care provision in nursing homes: an integrative review. Informatics for Health and Social Care, 44(3), 262-277. DOI: 10.1080/17538157.2018.1496091

Shiells, K., Diaz Baquero, A. A., Stepankova, O., & Holmerova, I. (2020). Staff perspectives on the usability of electronic patient records for planning and delivering dementia care in nursing homes: a multiple case study. BMC Medical Informatics and Decision Making, 20, 159 https://doi.org/10.1186/s12911-020-01160-8

- ***Electronic care documentation should meet the needs of people with dementia in nursing homes*** [3.1.3.5]

Guidance: Electronic assessment forms and care plans used for planning dementia care in nursing homes should prompt staff to consider the following needs of residents: activities, maintaining previous roles, reminiscence, freedom and choice, appropriate environment, meaningful relationships, support with grief and loss, and end-of-life care.

Explanation and Examples: The themes above have been described by people with dementia in various studies exploring their self-reported needs and experiences in nursing homes. Developers should therefore consider including these themes into electronic assessment and care plan templates as prompts for nursing home staff to explore with residents.

Keywords: Assessment; care plan; electronic patient record; needs; nursing home; self-report

Target group: Developers of EPR, Nursing homes

Type of evidence

Kate Shiells (INDUCT ESR13)
Scoping literature review

References

Shiells, K., Pivodic, L., Holmerova, I., Van den Block, L. (2020). Self-reported needs and experiences of people with dementia in nursing homes: a scoping review. Aging & Mental Health, 24:10,1553-1568, DOI: 10.1080/13607863.2019.1625303

- ***Technology design focused on the characteristics of the population provides usability*** [3.1.3.6]

Guidance: To improve usability design of the technology should be developed specifically on the characteristics of the person with dementia, with respect to vision, auditory and cognitive capacities.

Explanation and Examples: Dementia is mainly suffered by elderly people. It´s well known the visual and auditorily perception changes. Shapes, colours, glares, temporal frequency of stimuli, visual acuity, and relevant visual stimuli can be bad perceived. Therefore, the design of any technology should be focused and fitted to these perceptual changes. Consequently, it is important to increase the lighting of the context of the task, the level of contrast and font size.

Equally elderly people might suffer impaired hearing, especially in sensitivity to high frequencies, discrimination of tones and differentiation of the speech of the background noise. Therefore, it is necessary for any technology to increase the intensity of the stimuli, control the background noise, avoid stimuli with high frequencies and adapt the speed of the words.

The design of the technology should take into account the cognitive impairment of a person with dementia (type, level, and deficits associated with impairment). Technology for rehabilitation must com-

prise different difficulty levels, take slow processing speed into account by extending response intervals of exercises, and an increase the variety in types of exercises.

The degree of usability of a technology will influence the user´s experience, generating a degree of satisfaction in the person with dementia that will affect their level of motivation to continue using a rehabilitation program such as Gradior.

Keywords: Visual-auditory abilities, cognitive impairment, user´s experience, degree of satisfaction, motivation, usability.

Target group: Researchers, developers, people with dementia

Type of evidence

Angie Alejandra Diaz Baquero (INDUCT ESR15)
RCT
RCT Gradior Validation
Other sources of support:

References

Toribio Guzmán, J. M., Franco Martin, M.A., Perea Bartolomé, M.V. (2015). Long Lasting Memories, an integrated ICT platform against age-related cognitive decline: usability study. (Doctoral), Department of basic psychology, psychobiology and methodology of behavioral sciences - Faculty of psychology. University of Salamanca, Spain.

- ***Consider user-centred design in the development of computer-based cognitive rehabilitation programs for people with dementia*** [3.1.3.7]

Guidance: User-centered design should be considered in the development of any technology or computer-based program for cognitive rehabilitation in people with dementia.

Explanation and Examples: User-centered design is a methodology applied in the development of programs or new technologies for cognitive rehabilitation in people with dementia. This design takes into account the target population from the beginning to the end of the development process, with the aim of investigating their needs and expectations, developing a prototype that meets these needs and evaluating the final prototype based on usability and user experience criteria.

Keywords: Dementia, computer-based program, development design, cognitive.

Target group: Researchers, developers, people with dementia, policy makers

Type of evidence

Angie Alejandra Diaz Baquero (INDUCT ESR15)
Systematic literature review.

References

Diaz Baquero, A. A., Dröes, R. M., Perea Bartolomé, M. V., Irazoki, E., Toribio-Guzmán, J. M., Franco-Martín, M. A., & van der Roest, H. (2021). Methodological Designs Applied in the Development of Computer-Based Training Programs for the Cognitive Rehabilitation in People with Mild Cognitive Impairment (MCI) and Mild Dementia. Systematic Review. Journal of clinical medicine, *10*(6), 1222. https://doi.org/10.3390/jcm10061222.

- ***Consult with end users when deciding on a mode of delivery for a digital intervention*** [3.1.3.8]

Guidance: Researchers and developers of digital psychosocial interventions for people with dementia and family carers should consult end users on the mode of delivery of their interventions to ensure its usability.

Explanation and Examples: Consensus exists that consultations with people with dementia and family carers should be carried out when developing digital complex interventions for these populations. However, with different platforms that are available to researchers and developers, it is especially important to ensure that the mode of delivery of these technologies (e.g., smartphone application, website, text messages etc.) is appropriate and useful for people who are going to use the intervention. Qualitative consultations in the form of interviews and focus groups with end users can be especially useful for this. We conducted focus groups with 17 people with dementia and family carers to establish their needs and wishes regarding the digital adaptation of an existing face-to-face intervention. Contrary to our expectations, we discovered that participants preferred a website intervention if they were going to use the intervention for a limited amount of time, for example less than four weeks. Smartphone applications were preferred if they were going to be used for a longer period. Consultations with end users are recommended to establish not just the intervention content but also its mode of delivery.

Keywords: Complex intervention, design, involvement of users, mode of delivery

Target group:

Dementia researchers, developers and designers of technological interventions

Type of evidence:

Gianna Kohl (DISTINCT ESR10)

Focus group study with 17 people with dementia and family carers

References:

Kohl, G., Cardoso, S., Heins, P., Scior, K., & Charlesworth, G. (2023). *Guidance for moving psychosocial interventions online: A worked example of adapting 'Who to tell, how and when' for people living with dementia*. Imminent manuscript submission to JMIR.

3.1.4. Social Health Domain 1: Fulfill ones potential and obligations

- ***Facilitators of online peer support groups using video meetings should provide clear guidance and support to allow people to use the platform*** [3.1.4.1/3.1.5.1/3.1.6.2]

Guidance: People with Young Onset Dementia can experience difficulties using technology or particular platforms for online peer support. Facilitators of video meetings and moderators of text-based platforms (such as Facebook groups or discussion forums) should provide clear guidance on how to use the platform and be available to offer technological assistance where needed.

Explanation and Examples: Our study, including 20 people with Young Onset Dementia across 4 focus groups, showed that most of them experienced difficulties with the online meetings at some point. This included having difficulties getting into the Zoom meeting and installing or updating the software on their devices. Some more specific recommendations included:

- The facilitator of video meetings should send out timely reminders, preferably also on the day of the meeting, including the link to the meeting. This reduces the risk that someone cannot find the link.
- The facilitator should provide a clear step-by-step guide on how to install and use the necessary software.
- The facilitator should open the meeting 10-15 minutes beforehand to allow people to get in and if needed provide remote support (e.g. via email, WhatsApp, or a phone call).

Keywords: Online intervention, people with dementia, peer support, Young Onset Dementia, video meetings

Target group: Social care providers, healthcare providers and patient organisations

Type of evidence

Esther Gerritzen (DISTINCT ESR2).
Focus groups with UK-based peer support groups that use videoconferencing platforms for their meetings.

References

Gerritzen, E. V., Kohl, G., Orrell, M., & McDermott, O. (2022). Peer support through video meetings: Experiences of people with young onset dementia. Dementia (London, England), 14713012221140468. Advance online publication. https://doi.org/10.1177/14713012221140468

- ***Facilitators and moderators of online peer support should have good listening and communication skills and a supportive attitude*** [3.1.4.2/3.1.5.2/3.1.6.3]

Guidance: It is important that the online peer support group is a safe and non-judgemental environment for everyone in the group. Most of all it is a platform for members to express themselves and support one another. It is the role of the facilitator to make everyone feel included, heard, and safe.

Explanation and Examples: Through 4 focus groups including a total of 20 people with Young Onset Dementia, and 9 individual interviews with people with Young Onset Dementia, people highlighted the importance of the role of the facilitator. Additionally, through speaking with online group facilitators, they shared what they think is important and what helps them to run a meeting well. Facilitators should:

- Have good listening skills and not take over the conversation too much, but let the group decide what to discuss and what is important.
- Make every member of the group feel included and give everyone a chance to speak. If people raise their hand, make sure to address everyone in order.
- Make sure not one person dominates the conversation.
- Call out bullying or abusive behaviour or language.
- Check in with someone after the meeting if they appeared distressed or upset, or if they left suddenly without explaining why.
- Really get to know the members, for example by meeting with them one-on-one before they join the group. In this way facilitators can learn what someone is expecting from the group, and what their needs are.

Keywords: Online intervention, people with dementia, peer support, Young Onset Dementia, facilitators

Target group: Social care providers, healthcare providers and patient organisations

Type of evidence

Esther Gerritzen (ESR2)
Focus groups, individual interviews, informal consultations.

References

Gerritzen, E. V., Kohl, G., Orrell, M., & McDermott, O. (2022). Peer support through video meetings: Experiences of people with young onset dementia. Dementia (London, England), 14713012221140468. Advance online publication. https://doi.org/10.1177/14713012221140468

- ***Use of the E-nabling Digital Co-production Framework is recommended to improve digital Patient and Public Involvement in dementia research*** [3.1.4.3]

Guidance: To better understand how digital Patient and Public Involvement (e-PPI) and blended approaches (hybrid digital and face-to-face PPI) in dementia research can be better facilitated, it is recommended to use the E-nabling Digital Co-production framework.

Explanation and Examples: Qualitative research showed that the E-nabling Digital Co-production framework (see Figure 1) is useful for researchers, PPI coordinators and public contributors in advancing understanding of the challenges and opportunities provided by e-PPI and blended (hybrid) approaches. The framework explores preferences and implications of using different modalities of PPI and it can be useful for specific populations and contexts, for example in dementia technology research. In this context, e-PPI needs to optimise engagement by taking into account participants' abilities to remember instructions on how to join the e-meeting, their levels of attention and concentration, or the need for explicit cues to the speaker. The level of support must be determined which requires specialised training for facilitators or additional supporters during the meeting. Facilitators should be aware that online meetings may deprive caregivers of respite and support that would be present face-to-face, and may exclude those who live alone or need more support. Some of the opportunities of e-PPI are related to removing geographical constraints allowing wider participation and saving resources in terms of time, not having to travel to meetings, arrange venues, catering or other coordination such as transporting PPI representatives.

Keywords: Patient and Public Involvement, e-PPI

Target group: Researchers, stakeholders, public contributors, PPI coordinators, people with dementia, and caregivers.

Type of evidence

Mauricio Molinari Ulate (DISTINCT ESR7)
Qualitative study, online focus groups, digital PPI

References

Molinari-Ulate, M., Woodcock, R., Smith, I. *et al*. Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an "E-nabling digital co-production" framework. Res Involv Engagem 8, 33 (2022). https://doi.org/10.1186/s40900-022-00371-9

- ***The application of digital Patient and Public Involvement in dementia research should take into account technological, involvementability, resources and ethical and welfare conditions*** [3.1.4.4.]

Guidance: Digital Patient and Public Involvement (e-PPI) provides opportunities, for example, in terms of saving time, not having to travel to meetings, and fewer organizational tasks, such as transporting PPI representatives to the meeting venue. However, to optimize digital Patient and Public Involvement (e-PPI) in dementia research, technological, involvement ability, resources and ethical and welfare conditions should be taken into account.

Explanation and Examples: When applying digital PPI in dementia research it is important to consider four key areas of conditions. Taking these areas into account will allow identifying improvements that

can be made to e-PPI to make it more effective and efficient, and problems avoided (see also Figure 2):

a) Technological: refers to constraints, preferences, and opportunities of the used technology.
   Improvements: virtual platforms must be considered as part of the toolkit to perform PPI; hybrid options (digital and face-to-face) must be provided.
b) Resources: is associated with personal resources such as fatigue or personal resilience; professional resources such as increased demands on conducting PPI online; and other resources such as costs of coproduction platforms, phone credit, printing, software, or budget for more frequent meetings.
   Improvements: make sure additional resources are included such as technical support staff or reimbursements for online meeting costs; face-to-face training could help participants to learn how to use the platform.
c) Involvementability: refers to requirements that are related to the success of a design task or process. How involvement differs in a digital space or how it can be translated to different populations online.
   Improvements: smaller groups can help prevent attention wandering; limit the number of people on the screen.
d) Ethical and welfare: describes aspects such as the welfare of public contributors (people with dementia and caregivers), digital exclusion, impact on social communication, data security, etc.
   Improvements: consider the configuration and history of the group when choosing which platform and approach (online, face-to-face or blended) to use; follow-up of public contributors' welfare

Keywords: Patient and Public Involvement, e-PPI

Target group: Researchers, stakeholders, public contributors, PPI coordinators, people with dementia, and caregivers.

Type of evidence

Mauricio Molinari (DISTINCT ESR7)
Qualitative study, online focus groups, digital PPI

References

Molinari-Ulate, M., Woodcock, R., Smith, I. et al. Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an "E-nabling digital co-production" framework. Res Involv Engagem 8, 33 (2022). https://doi.org/10.1186/s40900-022-00371-9

- ***Dementia associations providing information on advance care planning on their websites should not only address legal and medical information, but also provide practical communication guidance*** [3.1.4.5]

Guidance: Dementia associations' websites are an ideal place to provide advance care planning information to a wide public. If information about advance care planning is provided, dementia associations should ensure balanced content. Websites should address not only legal and medical information, but also practical guidance on how to engage in and communicate about advance care planning.

Explanation/examples: Advance care planning is a process that enables individuals to define goals and preferences for their future care. As people with dementia have a high risk of cognitive decline, advance care planning is important. Many people use the internet to find health information. Some of the most consulted sources to search for specific information about dementia are the websites of dementia associations. We conducted a content analysis of dementia associations' websites in Europe

regarding advance care planning information. We included 26 dementia associations' websites from 20 countries and one European association, covering 12 languages. Ten websites did not mention advance care planning. The information on the remaining 16 varied in terms of themes addressed and amount of information. Legal and medical themes were prominent, while other key advance care planning themes such as communication with family, communication with health professionals, sharing of decisions and the identification of personal values and life goals seem largely to be under-addressed. This is an important gap, given that the drafting of advance directives should be preceded by a process of communication between the person with dementia, their family and their healthcare providers.

Keywords: advance care planning, dementia, technology

Target groups: Health care providers and patient organizations

Type of evidence

Fanny Monnet (DISTINCT ESR3)
Content analysis of dementia associations' websites

References

Monnet, F., Pivodic, L., Dupont, C., Dröes, R.M., & Van den Block, L. (2022). Information on advance care planning on websites of dementia associations in Europe: A content analysis. Aging & Mental Health, 1–11. https://doi.org/10.1080/13607863.2022.2146051

- ***The development of web-based advance care planning support tools should involve end-users and should be based on scientific evidence*** [3.1.4.6]

Guidance: End-users should be involved in the development of web-based advance care planning support tools to ensure their usability and usefulness for end-users. Furthermore, the content of web-based advance care planning tools should be substantiated by scientific evidence.

Explanation and Examples: More and more web-based advance care planning support tools are publicly available on the internet. We conducted a systematic review of web-based interactive advance care planning support tools. We found numerous interactive web-based advance care planning support tools, varying in terms of their characteristics, functionalities, readability, quality of content, and level of evidence. Most tools were not co-developed with end users; were of low or medium quality; and, with a few exceptions, had not been evaluated in research. Tools should be evaluated through usability and effectiveness testing and should be substantiated with the most recent scientific literature.

Keywords: advance care planning, technology, design, involvement of user

Target groups: Researchers developing technology, Technology developers

Type of evidence

Fanny Monnet (DISTINCT ESR3)
Systematic review of web-based interactive ACP support tools

References

Dupont, C., Smets, T., Monnet, F., Pivodic, L., De Vleminck, A., Van Audenhove, C., & Van den Block, L. (2022). Publicly Available, Interactive Web-Based Tools to Support Advance Care Planning: Systematic Review. *J Med Internet Res*, *24*(4), e33320. https://doi.org/10.2196/33320

- ***Advance care planning websites for dementia should provide information and facilitate communication in a use-friendly manner*** [3.1.4.7]

Guidance: An advance care planning website for people with dementia and their family caregivers should focus on providing information and facilitating communication, provided in a user-friendly manner.

Explanation and Examples: Advance care planning is a process that enables individuals to define goals and preferences for their future care. Digital interactive tools, such as websites, that encourage reflection, communication and/or documentation, may support this group in the advance care planning process. However, considering the specific needs of people with dementia, it is important to develop tools that are adapted to this population. We conducted focus groups with family caregivers (serving both as potential users and proxies for people with dementia) and healthcare professionals caring for people with dementia, to determine their needs in terms of content of the advance care planning website and how this should be delivered. Some specific recommendations included:

- An advance care planning website should focus on providing advance care planning information, including but not limited to advance directives, and offer guidance on how to start an ACP conversation.
- To increase the accessibility and usability of the ACP website, the inclusion of a text-to-speech option, a print option, and the possibility to increase the font size should be considered.

Keywords: advance care planning, needs, development design

Target groups: Researchers developing technology

Type of evidence

Fanny Monnet (DISTINCT ESR3)
Focus groups with family caregivers and health professionals

References

Dupont, C., Smets, T., Monnet, F., Pivodic, L., De Vleminck, A., Van Audenhove, C., & Van den Block, L. Defining the content of a website on ACP in dementia: a focus group study with family and health professionals (Submitted in June 2022 to BMC Medical Informatics and Decision Making)

3.1.5. Social Health Domain 2: Manage ones own life and promote independence

- ***Facilitators of online peer support groups using video meetings should provide clear guidance and support to allow people to use the platform*** [3.1.5.1, see 3.1.4.1]

- ***Facilitators and moderators of online peer support should have good listening and communication skills and a supportive attitude*** [3.1.5.2, see 3.1.4.2]

- ***Privacy policies of health apps and websites should be (re-)written and (re-) designed to promote cognitive accessibility*** [3.1.5.3]

Guidance: Policy-makers and developers of apps and websites, particularly those for people with cognitive impairment or dementia, should review and improve the cognitive accessibility of privacy policies associated with apps and websites. Privacy information should be available in the official language of each country in which the app or website is available. Navigation to information should be

promoted by simple, attention-focusing user interface design. Length and linguistic complexity of information in the privacy policy should be limited, or the information should be summarized.

Explanation and Examples**:** Cognitive accessibility conceptualizes the extent to which digital services are simple, consistent, clear, multimodal, error-tolerant, and attention-focusing to use, taking into account all users.

Online data privacy is an important legal and ethical issue, and an important concern of many (potential) app-users, which may impact on their adoption of digital tools and services. The European General Data Protection Regulation (GDPR) protects people's right to access information about how their data is processed, so that they can make informed choices, but there are concerns that many privacy policies are too long, too complex and sometimes not even available. This may reduce trust in digital tools, presenting a barrier to adoption.

A cross-sectional study found that, in the Netherlands, Sweden and the UK:

- Most health and wellness apps sampled outside the UK did not have a privacy policy available in the official language of the user's country
- Almost no privacy policies met reading level benchmarks, meaning the language was too complex for the average native speaker to understand.
- The time that it would take the average adult native speaker to read each privacy policy was 10 minutes (websites) to 12 minutes (apps).

Recommendations to improve the cognitive accessibility of online privacy information have been made. An example of a privacy policy designed largely in line with these recommendations is the privacy policy of the FindMyApps project, which can be found on the project website: https://findmyapps.onderzoek.io/cognitively-accessible-privacy-information

Keywords: cognitive accessibility; applications; design

Target group: policymakers; technology developers

Type of evidence

David Neal (DISTINCT ESR 6)
Cross-sectional scoping research comparing observable properties (relating to availability, ease of navigation and readability) of privacy policies of the top health and fitness apps in the apps stores run by Apple and Google, with a purposively selected sample of websites.

References

Neal, D., Gaber, S., Joddrell, P., Brorsson, A., Dijkstra, K., & Dröes, R. M. (2023). Read and accepted? Scoping the cognitive accessibility of privacy policies of health apps and websites in three European countries. Digital health, 9, 20552076231152162.

https://doi.org/10.1177/20552076231152162

3.1.6. Social Health Domain 3: Technology to promote social participation

- ***Include social interaction elements in technological interventions that aim to promote social participation*** [3.1.6.1]

Guidance: Technological interventions aiming to promote social participation among older adults (with and without dementia) should incorporate a social interaction element.

Explanation and Examples: The number of people with dementia who live in the community and are socially isolated is growing. Social isolation can negatively affect health and well-being. Therefore, psychosocial interventions are needed to promote the social participation of people with dementia living in the community. A systematic literature review was conducted to explore the effects of technological interventions on the social participation of older adults with and without dementia. Findings from 36 studies suggest that technological interventions that include a social interaction element (e.g. face-to-face contact, phone calls, text messages) are successful in promoting social participation among older adults. Examples are group interventions that provide regular interactions within a group, or interventions that enable to connect and communicate with other people (e.g. family, friends, or other older adults).

Keywords: Social participation, designing technological interventions, social interaction, older adults, dementia

Target group: Technology developers designing technology to promote social participation. Researchers evaluating the effect of technology on social participation

Type of evidence

Pascale Heins (DISTINCT ESR11)
Systematic literature review

References

Heins, P., Boots, L.M.M., Koh, W.Q., Neven, A., Verhey, F.J., and de Vugt, M.E. (2021). The Effects of Technological Interventions on Social Participation of Community-Dwelling Older Adults with and without Dementia: A Systematic Review. Journal of Clinical Medicine, 10, 2308. doi: 10.3390/jcm10112308

- ***Facilitators of online peer support groups using video meetings should provide clear guidance and support to allow people to use the platform*** [3.1.6.2, see 3.1.4.1]

- ***Facilitators and moderators of online peer support should have good listening and communication skills and a supportive attitude*** [3.1.6.3, see 3.1.4.2]

- ***Pet robot design preferences of people with dementia need further investigation*** [3.1.6.4]

Guidance: The design of some existing pet robots for people with dementia do not sufficiently consider their preferences. For example, while some pet robots are designed to resemble unfamiliar animals such as a dinosaur or seal, people with dementia seem to prefer more familiarly designed pets, such as domestic animals like cats and dogs. As little research has been done into pet robot design preferences of people with dementia further investigation is needed.

Explanation and Examples: One of the most researched and used pet robots in dementia care is PARO, a robotic baby harp seal. The developer of PARO anticipated that users are likely to be more accepting of PARO, since they are less likely to have experiences and expectations of a seal. However, Bradwell and colleagues found that older adults including people with dementia have expressed a preference for familiar animals such as cats and dogs. A qualitative study uncovered similar findings - Care providers in nursing homes expressed that residents with dementia may prefer and react better to familiar animals. In line with a person-centred approach to care, the use of pet robots should account for the preferences and needs of people with dementia. However, there is a lack of studies that have explicitly investigated such design preferences. More studies are necessary to bridge this gap.

Keywords: Older adults, people living with dementia, dementia, social robots, low-cost pet robots, robotic pets, psychosocial impact

Target group: Social robot developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Scoping review, qualitative content analysis, qualitative study (interviews with care providers)

References:

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Bradwell, H. L., Edwards, K., Shenton, D., Winnington, R., Thill, S., & Jones, R. B. (2021). User-centered design of companion robot pets involving care home resident-robot interactions and focus groups with residents, staff, and family: Qualitative study. JMIR rehabilitation and assistive technologies, 8(4), e30337. https://rehab.jmir.org/2021/4/e30337

- ***Consider the use of digital generic photos when designing psychosocial interventions that aim to improve social interaction, mood, and quality of life*** [3.1.6.5]

Guidance: People designing psychosocial interventions for people with dementia should be aware that viewing generic, rather than personal photographs, can also be a meaningful activity for the person with dementia. Moreover, viewing these photos digitally was found to be either similar to or better than viewing conventional printed photos.

Explanation and Examples: There is evidence that using generic photos, versus personal family photos, in psychosocial interventions for people living with dementia can be more effective in promoting social interaction and eliciting stories with emotional and personal significance. Generic photos may feel less threatening compared to using personal photos in conversation with the person with dementia, the conversation that arises becomes more flexible and less demanding of remembering specific people or events. This can lead to better social interaction, mood, and eventually, better quality of life for the person with dementia. Generic photographs can be more accessible and easier to acquire, lessening the time needed to, for example, ask for and collect family photographs from relatives (if these are still available). It has the potential to be cost-effective as well (compared to other art-based activities like museum visits), and has the potential to transcend societal or cultural differences. These benefits may be even more pronounced, when generic photos are used in a digitalized format, as previous research showed that viewing digitalized photos is similar to or better (due to the pleasurable experience of using virtual reality technology; Tominari et al., 2021; Xu & Wang et al., 2020) than viewing conventional printed photos.

Keywords: social participation, people with dementia, carers, meaningful activities, generic photos, digitalized photos

Target group: care professionals, developers/designers, researchers

Type of evidence

Josephine Tan [DISTINCT ESR 14]
Systematic literature review

References

Tan, J.R.O., Boersma, P., Ettema, T.P., Planting, C.H.M., Clark, S., Gobbens, R., & Dröes, R.M. (2022). The effects of psychosocial interventions using generic photos on social interaction, mood, and quality of

life of persons with dementia: A systematic review. (Submitted)

Tominari, M., Uozumi, R., Becker, C., & Kinoshita, A. (2021). Reminiscence therapy using virtual reality technology affects cognitive function and subjective well-being in older adults with dementia. Cogent Psychology, 8(1), 1968991.

- ***Tablet-based interventions should be considered as one effective option to support social participation of community-dwelling people with mild cognitive impairment or mild dementia, but the choice to provide such an intervention should be based on user characteristics and needs*** [3.1.6.6]

Guidance: The choice for a tablet-based intervention should be based on an assessment of the characteristics of the tablet-users and their specific needs and potential to benefit from the intervention. Care providers should consider prioritizing people with MCI and younger people with MCI/mild dementia to receive tablet-based interventions.

Explanation and Examples: Evidence from the FindMyApps project showed that on average, tablet interventions could be effective to promote participation in social and other meaningful activities. However, the results also showed that tablets seem to be particularly effective for people with a diagnosis of MCI compared to those with a diagnosis of mild dementia. Regardless of the diagnosis, the results also suggest that younger people with MCI/mild dementia also benefit more from tablet-based interventions than older people. The choice for a tablet-based intervention should therefore be based on an assessment of the tablet-user characteristics, in addition to their needs and potential to benefit from it.

Keywords: tablet intervention; tablet-based intervention, FindMyApps; effectiveness; social participation, MCI, Young Onset Dementia

Target group: Professional carers, clinicians, welfare professionals, who promote the use of technology to people with cognitive impairments and dementia; family carers; people living with dementia

Type of evidence

David Neal (DISTINCT ESR6)
Results from a randomized controlled trial, conducted in the Netherlands from January 2020 to November 2022.

References

Neal D., Ettema T., Zwan M., Dijkstra K., Finnema E., Graff M., Muller M., Dröes R. M. FindMyApps compared with usual tablet use for self-management and social participation in community-dwelling people with mild dementia or mild cognitive impairment and support for informal caregivers: a randomised controlled trial. *Submitted.*

- ***Robotic platform features and applications need to be tailored to the needs and preferences of end-users before implementing them in community-based dementia care*** [3.1.6.7]

Guidance: To successfully integrate social robotic platforms in community-based dementia care, such as Meeting Centres for people with dementia and carers and daycare centres, their features and applications need to be tailored to the needs and preferences of the end-users, the dynamics of group interactions, and the Meeting Centres' activity policies and settings.

Explanation and Examples: Research through focus groups and interviews with stakeholders on potential facilitators and barriers in the implementation of the social robot MINI indicated that for a successful implementation of social robots in Meeting Centres and daycare centres for people with

dementia, it is expected to be crucial for social robot designers and developers to consider the following recommendations to guide the design of the robotic platform:

- Evaluate the needs and preferences of the participants of Meeting Centre. Qualitative research with end-users and care professionals is essential before and during the robot development phase. This will ensure the acceptance and usefulness of the robot in such contexts.
- Given the preference for group activities in Meeting Centres over individual activities, it is crucial to integrate the robot into a group setting so that it can interact with multiple users. For example, a multi-player game could allow two or more individuals to interact with a social robot at the same time.
- Avoid designing games and quiz-like activities for use on social robots to avoid, in line with the activity policy of Meeting Centres, confronting persons with dementia with their shortcomings in activities that have high cognitive and memory function demands. Instead, fun, enjoyable, and relaxing applications and games would be most appealing and beneficial.

Keywords: Social robots, community setting, Meeting Centres, dementia, daycare centres, mild cognitive impairment.

Target group: Researchers, social robot designers, and developers

Type of evidence

Aysan Mahmoudi (DISTINCT ESR13)
Original article on conditions of successful implementation of the MINI robot in Meeting Centres for people with dementia and carers

References

Mahmoudi A, Franco Martin M, Van der Roest H, Castro-González A, Kouters S, Dröes RM. (2023). Potential facilitators and barriers to implementing the MINI robot in community-based meeting centres in the Netherlands and Spain. JMIR Preprints 8/11/2022:44125.
doi: https://doi.org/10.2196/preprints.44125

3.2 Evaluating the effectiveness of specific contemporary technology

3.2.1 Technology for everyday life

- ***Ecological validity contributes to the effectiveness of a technology*** [3.2.1.1]

Guidance: The ecological validity and cultural context in which the technology will be implemented should be taken into account, to ensure it is applicable to the 'real life situation' of the person with dementia

Explanation and Examples: When cognitive rehabilitation is applied to people with dementia, it is necessary to consider the ecological validity of each tool or instrument used to perform cognitive rehabilitation, training or stimulation. Ecological validity is determined by the ability of those tools, instruments or techniques used for cognitive training to be transferred to the patient's daily life. Therefore, the patient may feel that using these techniques or tools in their daily lives can bring them benefits and influence their daily life, "beyond the rehabilitation session". For example: Gradior includes images of real objects which are well-known to the users. These objects are close to those of real life, among others: calculation exercises associated with real adult life (shopping at a supermarket), presents quizzes of daily activities (prepare a specific recipe). New technologies for rehabilitation or cognitive training

should consider ecological validity as their main objective otherwise it may not be appropriate for the person with dementia who uses it.

The context is a factor that must be considered in the design of new technologies, that is, it is not enough to delimit the population and its characteristics. For example: a technology may be applied in an urban context but not necessarily in a rural one, due to the difficulties that this context may have in terms of the existence and scope of communication systems (internet connection, presence of devices, etc.).

Consequently, Gradior was developed free of contents. This means that it is easy to change the contents of the software and objects interacting with the person with dementia. In this way, it can be fitted to different environments in an easy way. It is necessary that the exercises and objects have significance to the users.

Keywords**:** Ecological validity, cultural context, effectiveness, GRADIOR

Target group***:*** Researchers, developers, dementia people, Policy makers

Type of evidence

Angie Alejandra Diaz Baquero (INDUCT ESR15)
RCT GRADIOR

References

Diaz Baquero, A. A., Franco-Martín, M. A., Parra Vidales, E., Toribio-Guzmán, J. M., Bueno-Aguado, Y., Martínez Abad, F., Perea Bartolomé, M. V., Asl, A. M., & van der Roest, H. G. (2022). The Effectiveness of GRADIOR: A Neuropsychological Rehabilitation Program for People with Mild Cognitive Impairment and Mild Dementia. Results of a Randomized Controlled Trial After 4 and 12 Months of Treatment. Journal of Alzheimer's disease : JAD, 86(2), 711–727. https://doi.org/10.3233/JAD-215350

3.2.2 Technology for meaningful activities

- ***Pay attention to psychological coping when evaluating the impact of technology*** [3.2.2.1]

Guidance: When evaluating the impact of technology on the self-management of people with dementia, it is recommended to also evaluate how people succeed in coping psychologically and emotionally with the consequences of dementia in their daily life.

Explanation and Examples: Measures to assess self-management in people with mild dementia evaluate how people compensate for their functional disabilities in daily life, but do not rate how people cope psychologically and emotionally with the consequences of dementia in their daily life (e.g. maintaining positive thinking and relationships), which is also a component of self-management. It is recommended to use additional instruments such as the Jalowiec Coping scale (1984) or the Qualidem (Ettema et al, 2007) for these aspects when assessing the impact of technology on self-management.

Keywords: Measuring instruments, self-management, social participation, coping

Target group: Researchers and industry evaluating interventions aimed at improving the self-management of people with mild dementia living at home.

Type of evidence

Floriana Mangiaracina (INDUCT ESR8)
Systematic literature review

References

Mangiaracina F, Meiland F, Kerkhof Y, Orrell M, Graff M, Dröes RM. (2019). Self-management and social participation in community-dwelling people with mild dementia: a review of measuring instruments. International Psychogeriatrics, 31(9):1267-1285. doi: 10.1017/S1041610218001709.

- ***Personalized feedback and sustained support for carers using the experience sampling method*** [3.2.2.2]

Guidance: When using smartphone-based digital self-monitoring/experience sampling in carers of people with dementia, consider providing personalized feedback to promote emotional well-being and stimulate the undertaking of more activities they enjoy (e.g. relaxation activities).

Explanation and Examples: 'Experience sampling' (ESM)-based smartphone apps can offer solutions to raise awareness of enjoyable activities, strengthen learned coping strategies, and provide (long-term) support in everyday life. The 'Partner in Sight' intervention has been found to decrease perceived stress as well as negative affect, and to increase sense of competence in carers. However, an increase in passive relaxation activities was only achieved with personalized feedback. Long-term support could be achieved by adding additional features, such as booster sessions, micro interventions (short version of the original intervention) or ad-hoc counseling after the main intervention period, through cost-effective and common technologies (smartphone apps, webpages, emails, telephones).

Keywords: Carer coping, experience sampling method, personalized feedback, sustained support, long-term support

Target group: Researchers and clinicians supporting family carers of people with dementia in everyday life with the experience sampling method or designing interventions for caregivers of people with dementia

Type of evidence

Sara Bartels (INDUCT ESR9)
Follow-up results of the ESM 'Partner in Sight' intervention

References

Bartels, S.L., Van Knippenberg, R.J.M., Viechtbauer, 8., Simons, C.J.P., Ponds, R.W., et al. Intervention Mechanisms of an Experience Sampling Intervention for Spousal Carers of People with Dementia: A Secondary Analysis, Aging & Mental Health 2020 Dec 9:1-9. doi: 10.1080/13607863.2020.1857692.
Bartels, S. L., van Knippenberg, R. J., Köhler, S., Ponds, R. W., Myin-Germeys, I., Verhey, F. R., & de Vugt, M. E. (2019). The necessity for sustainable intervention effects: lessons-learned from an experience sampling intervention for spousal carers of people with dementia. Aging & Mental Health, 24(12)2082-2093.

Van Knippenberg, R. J. M., De Vugt, M. E., Ponds, R. W., Myin-Germeys, I., & Verhey, F. R. J. (2018). An experience sampling method intervention for dementia caregivers: results of a randomized controlled trial. The American Journal of Geriatric Psychiatry, 26(12), 1231-1243.

- ***Technical problems should be solved before evaluating the effectiveness of new tablet interventions for people with dementia*** [3.2.2.3]

Guidance: Pilot studies should be conducted to help inform and reduce technical problems and improve accuracy prior to evaluating the effectiveness of new tablet interventions

Explanation and Examples: Our feasibility study of FindMyApps, a digital programme helping people with dementia to find useful apps for self-management and meaningful activities, showed that when people experienced technical problems they were sometimes not able to provide useful feedback about FindMyApps. For instance, some participants did not use the intervention anymore after they

encountered technical problems. Even though a development and pilot study were conducted technical problems still occurred, such as: apps not being available anymore, explanation videos which did not work, personal settings not being saved, the button to go back being difficult to find, and links that did not work. To ensure that technical problems are resolved timely and do not interact with the evaluation of the tablet intervention, it is important to monitor for technical barriers by regular contact with people using the intervention in evaluation studies.

Keywords: FindMyApps, technology, tablet intervention, dementia, self-management, meaningful activities

Target group: Researchers and developers of interventions on tablets for people with mild dementia or mild cognitive impairment

Type of evidence

Kim Beentjes (INDUCT ESR8)
Pilot RCT feasibility study (Beentjes, et al., 2020)
Development study FindMyApps (Kerkhof et al., 2019)
First pilot study FindMyApps (Kerkhof et al., 2020)

References

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.(2020). Impact of the FindMyApps program on people with mild cognitive impairment or dementia and their caregivers; an exploratory pilot randomised controlled trial. Disabil Rehabil Assist Technol., Nov 27:1-13. DOI:10.1080/17483107.2020.1842918

Kerkhof, Y., Kohl, G., Veijer, M., Mangiaracina, F., Bergsma, A., Graff, M., & Dröes, R.-M. (n.d.). Randomised controlled feasibility study of FindMyApps: First evaluation of a tablet-based intervention to promote self-management and meaningful activities in people with mild dementia. Disabil Rehabil Assist Technol., 1-15. DOI:10.1080/17483107.2020.1765420.

Kerkhof, Y., Pelgrum-Keurhorst, M., Mangiaracina, F., Bergsma, A., Vrauwdeunt, G., Graff, M., & Dröes, R.-M. (2019). User-participatory development of FindMyApps; a tool to help people with mild dementia find supportive apps for self-management and meaningful activities. DIGITAL HEALTH, 5, 205520761882294. https://doi.org/10.1177/2055207618822942

- ***Pay attention to contextual, implementation, and mechanisms of impact factors when evaluating technological interventions*** [3.2.2.4]

Guidance: When evaluating the benefits of technological interventions for people with dementia and their carers it is recommended to conduct a process evaluation to understand the possible influence of contextual, implementation and mechanisms of impact factors that may have influenced the intervention outcomes. This will also provide useful information on the conditions for successful implementation of the intervention.

Explanation and Examples: In our randomised controlled exploratory pilot trial into the FindMyApps programme, a tablet-based selection tool and training to help people with dementia to find apps for better self-management and meaningful activities, we conducted a process evaluation based on the British Medical Research Council's (MRC) guidance for process evaluation of complex interventions (Moore et al., 2015). This framework highlights the possible influence that contextual, implementation and mechanisms of impact factors may have on intervention outcomes. The process evaluation in the FindMyApps study provided very relevant information. For instance, with regard to contextual factors we found that it is important that the person with dementia has someone who is easy to approach and who can help them in case of practical problems, and that a helpdesk is in place for more complicated questions and technical problems. With regard to implementation, it proved important to check if and how much a participant had experience in working with technological devices, and to adapt their

training accordingly. Additionally, it proved necessary to personalise the approach to a participants' awareness of their deficits. This was largely because some people with dementia had a more accurate understanding of their abilities and limitations with respect to their deficits than others. With regard to mechanisms of impact, we found that users who regularly practiced and who's caregivers helped them by means of the errorless learning method learned to use FindMyApps easier than users who practiced less and who's caregivers were less active in guiding them by using errorless learning. This information is not only relevant for the outcome evaluation, but also to get insight into conditions for successful implementation of FindMyApps.

Keywords: FindMyApps, technology, tablet intervention, dementia, self-management, meaningful activities, process evaluation, MRC guidance for process evaluation of complex interventions

Target group: Developers planning to design and implement eHealth interventions for caregivers of people with dementia; researchers focusing on eHealth, including tablet interventions; researchers evaluating implementation of technology for people living with dementia

Type of evidence

Kim Beentjes (INDUCT ESR8)
Process Evaluation of the FindMyApps program

References

Beentjes, K.M., . Kerkhof Y.J.F., Neal D.P., Ettema, T.I., Koppelle, M.A., Meiland, F.J.M., Graff, M., Dröes, R.M. PhD (2020). Process evaluation of the FindMyApps program trial among people with dementia or MCI and their caregivers based on the MRC guidance. Gerontechnology, 20(0), 1-15. https://doi.org/10.4017/gt.2020.20.1.406.11

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., … Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. BMJ (Online), 350. https://doi.org/10.1136/bmj.h1258

- ***In order to help people with dementia and their carers find dementia-friendly apps for self-management and meaningful activities a selection tool is desirable*** [3.2.2.5]

Guidance: People with dementia can have difficulty finding apps for self-management, meaningful activities and social participation that match their needs, interests and abilities. A tool that helps them find such apps is therefore recommended.

Explanation and Examples: People with dementia often experience unmet needs in their self-management, meaningful activities and social participation. Apps and technological interventions can potentially help them fulfil these needs and also decrease the burden for caregivers. The last decade many apps have been developed that can support people with dementia in managing daily life, engaging in activities and staying in touch with their social network. However, people with dementia may have difficulty finding apps that match their needs, interests and abilities, FindMyApps is a selection tool that aims to help people find, download and use apps for self-management and meaningful activities, which are dementia-friendly and meet their needs, interests and capabilities. A randomized controlled exploratory trial into the effectiveness of FindMyApps showed that people with dementia who were offered this tool more frequently downloaded and used apps for self-management and meaningful activities than people who did not have access to this tool. This confirmed the usefulness of the tool. Therefore, a tool such as FindMyApps is recommended for people with dementia and their caregivers to ease the search for suitable apps.

Keywords: FindMyApps, technology, tablet intervention, dementia, self-management, meaningful activities, social participation, caregiver burden

Target group: People living with dementia, family carers, Professional carers, clinicians, welfare professionals, who promote the use of technology to people with cognitive impairments and dementia, developers planning to design and implement eHealth interventions for caregivers of people with dementia; researchers focusing on eHealth, including tablet interventions; researchers evaluating implementation of technology for people living with dementia

Type of evidence

Pilot feasibility study (Kerkhof et al., 2020)
Exploratory pilot trial (INDUCT ESR8, Beentjes et al., 2020)

References

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.(2020). Impact of the FindMyApps program on people with mild cognitive impairment or dementia and their caregivers; an exploratory pilot randomised controlled trial. Disabil Rehabil Assist Technol., Nov 27:1-13.

Kerkhof, Y. J. F., Kohl, G., Veijer, M., Mangiaracina, F., Bergsma, A., Graff, M., & Dröes, R.-M. (2020). Randomised controlled feasibility study of FindMyApps: First evaluation of a tablet-based intervention to promote self-management and meaningful activities in people with mild dementia. *Disability and* Rehabilitation: Assistive Technology, Jun 19; 1-15. doi: 10.1080/17483107.2020.1765420

- ***Consider offering Exergaming as meaningful activity in day care centres for people with dementia*** [3.2.2.6]

Guidance: Meaningful activities for people with dementia have proven value for their social health. Exergaming is an innovative way of exercising in a gaming environment. This movement activity may be experienced as meaningful by the persons with dementia, is considered fun to do and has benefits for them as well as for their relatives.

Explanation and Examples: Exergaming was compared to usual activities in a cluster Randomized Controlled Trial among day care centres for people with dementia. In this study exergaming consisted of interactive cycling using a stationary bicycle (i.e. home trainer) connected to a screen. The screen displays various routes which the participant can select and this mimics the experience of cycling outside, thus offering simultaneous physical and cognitive stimulation. Positive effects in favour of exergaming were found on cognition and social functioning in people with dementia and on carers' distress related to their relative's neuropsychiatric symptoms and the carers' sense of competence. Furthermore, persons with dementia, family carers and staff were satisfied with the exergaming intervention. Exergaming can thus be considered a meaningful activity, and a good alternative when outdoor physical activities are not possible because of weather conditions or safety risks (fall incidents, wandering).

Keywords: Exergaming; effectiveness; meaningful activities, carer distress, carer sense of competence

Target group: Care organizations and professionals; Volunteers, employees and managers of day-care centres; People living with dementia; family carers

Type of evidence

Joeke van Santen (INDUCT ESR7)
Randomized Clinical Trial (RCT)

References

Van Santen, J., Dröes, R. M., Twisk, J. W., Henkemans, O. A. B., van Straten, A., & Meiland, F. J. (2020). Effects of Exergaming on Cognitive and Social Functioning of People with Dementia: A Randomized Controlled Trial. Journal of the American Medical Directors Association, 21(12):1958-1967.e5. ISSN 1525-8610, https://doi.org/10.1016/j.jamda.2020.04.018.

- ***Consider potential benefits in family carers when persons with dementia use technology*** [3.2.2.7]

Guidance: When persons with dementia use technology for meaningful activities this may not only impact their own quality of life but also the well-being of their (primary) family carers.

Explanation and Examples: In the exergaming project, people with dementia were engaged in an exergaming activity or activities as usual in day care centres. We studied the effects on persons with dementia as well as on their family carers. In carers, positive effects were found in favour of the exergaming intervention, i.e. on the carers' distress related to their relative's neuropsychiatric symptoms and the carers' sense of competence (after a three months intervention period).

Keywords: Exergaming; dementia; carers' well-being; effectiveness

Target group: Researchers, Care organizations and professionals, Volunteers, employees and managers of day-care centres

Type of evidence

Joeke van Santen (INDUCT ESR7),
Randomized Clinical Trial (RCT)

References

Van Santen, J., Dröes, R. M., Twisk, J. W., Henkemans, O. A. B., van Straten, A., & Meiland, F. J. (2020). Effects of Exergaming on Cognitive and Social Functioning of People with Dementia: A Randomized Controlled Trial. Journal of the American Medical Directors Association, 21(12):1958-1967.e5. ISSN 1525-8610, https://doi.org/10.1016/j.jamda.2020.04.018.

- ***Take actions to alleviate carers' involvement in eHealth research*** [3.2.2.8]

Guidance: Effectiveness research into eHealth interventions for community dwelling persons with dementia, often rely on information from and involvement of family carers. As they may already be (over)burdened by their caregiver tasks, participation in effectiveness research may be denied. It will be helpful to think of methods to support informal carers to participate in research.

Explanation and Examples: In the exergaming project, a bottleneck of participation of couples into the effectiveness study, was the refusal of family carers to participate because they were already (over)burdened. To accommodate caregivers they were offered support in filling out questionnaires and a little present to thank them for their contribution. This seems to have added slightly in the number of participants in our study. Other strategies to alleviate burden of participation in eHealth research may also be considered, like data logging or ecological momentary assessments.

Keywords: Exergaming; carers' well-being; effectiveness, e-Health

Target group: Researchers

Type of evidence

Joeke van Santen (INDUCT ESR7)
Randomised Controlled Trial (RCT)

References

Van Santen, J., Dröes, R. M., Twisk, J. W., Henkemans, O. A. B., van Straten, A., & Meiland, F. J. (2020). Effects of Exergaming on Cognitive and Social Functioning of People with Dementia: A Randomized Controlled Trial. Journal of the American Medical Directors Association, ISSN 1525-8610, https://doi.org/10.1016/j.jamda.2020.04.018.

Van Santen, J., Dröes, R.M., Bosmans, J.E. Blanson Henkemans, O.A. Van Bommel, S., Hakvoort, E., Valk, R., Scholten, C., Wiersinga, J., Van Straten, A., Meiland, F. (2019). The (cost-) effectiveness

of exergaming in people living with dementia and their informal caregivers: protocol for a randomized controlled trial. BMC Geriatrics 19:50, 2019. DOI:10.1186/s12877-019-1062-x

- ***Consider cost-effectiveness research into eHealth interventions*** [3.2.2.9]

Guidance: Methodological sound effectiveness research into eHealth interventions for community dwelling persons with dementia is growing. To determine the added value of such interventions, it is important to look at their effects *and* costs. This gives a balanced picture and helps policy makers to make the right decisions when deploying eHealth interventions.

Explanation and Examples: Positive effects were found of exergaming compared to usual activities in day care centres. The provision of exergaming brought additional costs related to the equipment (purchase and maintenance) and staff involvement. Compared to non-technology based interventions, especially equipment costs can be a cost driver. In the exergaming study, the participating organisations received a list of potential funders for the equipment to be used, and various funding organisations (charitable organizations) were willing to pay for it. In some cases this helped to participate in the study. Taking into account the intervention costs may help day care centres to balance the positive effects of using the eHealth interventions (for people with dementia and their carers) against the long-term costs (to be covered by own funding or external funding). This will promote a well-informed implementation and securing of the eHealth intervention.

Keywords: Exergaming; implementation; cost-effectiveness

Target group: Researchers; Care organizations and professionals; Volunteers, employees and managers of day-care centres

Type of evidence

Joeke van Santen (INDUCT ESR7)
Randomised Controlled Trial

References

Van Santen, J., Dröes, R.M., Bosmans, J.E. Blanson Henkemans, O.A. Van Bommel, S., Hakvoort, E., Valk, R., Scholten, C., Wiersinga, J., Van Straten, A., Meiland, F. (2019). The (cost-) effectiveness of exergaming in people living with dementia and their informal caregivers: protocol for a randomized controlled trial. BMC Geriatrics 19:50, 2019.

Van Santen, J., Meiland, F.J.M., Dröes, R.M., Straten, A, Bosmans, J.E. (2021). Cost-effectiveness of exergaming compared to regular Day care activities in dementia: Results of a randomised controlled trial in the Netherlands. Health and Social Care in the Community, 2021. doi.org/10.1111/hsc.13608

3.2.3. Health care technology

- ***The need for more high-quality research into development, implementation and evaluation of complex health technologies*** [3.2.3.1]

Guidance: Better research using high-quality study designs is needed to develop, implement and evaluate complex palliative care interventions (targeting whole-system change) for people with dementia living and dying at home.

Explanation and Examples: Our systematic review found that the existing evidence base remains insufficient and is generally too weak to robustly assess the effects of palliative care interventions for people with dementia living at home.

Keywords: Complex health technology, complex intervention, palliative care

Target group: Researchers, as well as policymakers to support the conduct of this kind of palliative care research

Type of evidence

Rose Miranda (INDUCT ESR11)
Systematic review of palliative care interventions for people with dementia living at home

References

Miranda R, Bunn F, Lynch J, Van den Block L, Goodman C. Palliative care for people with dementia living at home: A systematic review of interventions. Palliat Med. 2019; 33(7):726-742.

- ***Call for research on online training programs for carers' mechanisms of change to increase the quality of online training for families of people with dementia*** [3.2.3.2]

Guidance: Evaluations of the effectiveness of internet training programs should explore mechanisms of change and aspects of the intervention design, such as reliability, the type of device used and modality of the intervention.

Explanation and Examples: The systematic review (Egan et al 2018) of internet training support for familiy carers lacks detail about potential factors which may influence the effectiveness of online programs (i.e. type of connectivity, development of the intervention, usability, etc.). The quality of individual studies selected for the systematic review was limited as more than 50% of the studies showed incomplete data reporting, and 25% showed a selective reporting of outcomes according to the risk of bias assessment performed making the generalization of the results difficult. However, the systematic review reported improvements on carer's mental health outcomes by internet training.

Keywords: carer training programmes, mental health, mediators and moderators

Target group: Researchers

Type of evidence

Ángel C. Pinto Bruno (INDUCT ESR14)
Systematic literature review

References

Egan, K. J., Pinto-Bruno, A. C., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E., & Pot, A. M. (2018). Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. J Am Med Dir Assoc, 19(3), 200-206.e201. doi:10.1016/j.jamda.2017.10.023

- ***Further implementation of effective Internet-based carer training programmes recommended*** [3.2.3.3]

Guidance: Internet training programmes for family carers have potential to increase carers' well-being, to reduce distress, depression and anxiety symptoms and to increase knowledge skills.

Explanation and Examples: A systematic review (Egan et al. 2018) about online training programmes for family carers reported on two studies in which improvements in depression symptoms were demonstrated, two studies with overall improvements in anxiety and two studies showing reduction of stress symptoms. Good examples of informative websites and internet training programmes for family carers are 'Mastery over Dementia', iSupport, 'iCARE: Stress management eTraining programme' and the STAR E-Learning course.

Keywords: Carer Internet training programs, carers' well-being, carer's mental health, Mastery over Dementia, iSupport, iCARE, STAR E-Learning

Target group: Policy-makers, health care providers and patient organizations.

Type of evidence

Ángel C. Pinto Bruno (INDUCT ESR14)
Systematic literature review

References

Egan, K. J., Pinto-Bruno, A. C., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E., & Pot, A. M. (2018). Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. J Am Med Dir Assoc, 19(3), 200-206.e201. doi:10.1016/j.jamda.2017.10.023

- ***Call for research on moderators of online training programs for carers' of people with dementia*** [3.2.3.4]

Guidance: Analyses of the moderation effect of demographic characteristics of the carers and other characteristics of the person with dementia on the internet training programs outcomes should be encouraged.

Explanation and Examples: Several studies have been done to find moderators of effects of online training programs for carers of people with dementia. Some studies have demonstrated that some programs were more effective for certain subgroups of carers. However, in our analyses we could not replicate these findings. Our analyses on the effect of age, gender, level of education, relationship with the person with dementia, functional status of the person with dementia and frequency of appearance of challenging behaviour suggests that the program is equally effective for all the subgroups analysed. More research is needed before we have definitive answers. A better understanding of moderators of carers' training programs could lead to better tailoring of programs based on the specific characteristic of the carer.

Keywords: carer training programmes, mental health, mediators and moderators

Target group: Researchers

Type of evidence

Ángel C. Pinto Bruno (INDUCT ESR14)
Preliminary results of moderation analyses 'Mastery over dementia'

References

Pinto-Bruno, A. C., Blom, M., Kleiboer, A., Dröes, R-M., van Straten, A., & Pot, A. M. Moderation analyses of an online support program for carers of people with dementia. (unpublished).

- ***Consider the factors that potentially determine adherence to a computer-based cognitive rehabilitation program to generate corresponding adaptations*** [3.2.3.5]

Guidance: When evaluating adherence of people with dementia to a computer-based cognitive rehabilitation program, sociodemographic, cognitive, and psychological factors should be taken into account.

Explanation and Examples: When we consider evaluating the adherence of people with dementia to a computer-based program for cognitive rehabilitation, it is important to consider sociodemographic (age, sex, educational level), cognitive (memory, attention, executive function) and psychological factors (level of motivation, expectations, previous computer use). For this purpose, a periodic evaluation will help to evaluate these factors and their relation to the amount and the time that a person spends in using a computer program for cognitive rehabilitation. In this way, significant modifications could be made to the program, so that the program meets the needs of people with dementia.

Keywords: dementia, rehabilitation, software, computer-based program, cognition, psychology.

Target group: Researchers, people with dementia, policy makers

Type of evidence

Angie Alejandra Diaz Baquero (INDUCT ESR 15)
Study into adherence profile in people with mild cognitive impairment and mild dementia in the computer-based cognitive training program "GRADIOR"

References

Diaz Baquero, A. A., Franco-Martín, M. A., Parra Vidales, E., Toribio-Guzmán, J. M., Bueno-Aguado, Y., Martínez Abad, F., Perea Bartolomé, M. V., Asl, A. M., & van der Roest, H. G. (2022). The Effectiveness of GRADIOR: A Neuropsychological Rehabilitation Program for People with Mild Cognitive Impairment and Mild Dementia. Results of a Randomized Controlled Trial After 4 and 12 Months of Treatment. Journal of Alzheimer's disease : JAD, 86(2), 711–727. https://doi.org/10.3233/JAD-215350

3.2.4. Social Health Domain 1: Fulfill ones potential and obligations

- ***Consider recruiting people with dementia through social media platforms for the development and evaluation of technological interventions*** [3.2.4.1]

Guidance: People with dementia are active on social media platforms. For this reason, researchers recruiting participants for their studies on the development, testing or evaluation of psychosocial technological interventions should consider advertising the study details on different social media platforms.

Explanation and Examples: Devices using information and communication technology (ICT) are increasingly being used by older people, including people with dementia. We conducted an online survey with 143 people with dementia to explore if and how they use social media. Results from the survey revealed that more than half of the participants actively use social media. More people with young-onset dementia were active on social media, though a large proportion of people with dementia who were 65 years and older were actively using social media too. In addition, a large proportion of the participants themselves were recruited through Twitter and Facebook. Our results suggest that people with dementia can be reached through social media, which is of relevance for researchers looking to recruit participants for the development, testing or evaluation of psychosocial technological interventions.

Keywords: Information Communication Technologies, social media, people with dementia, Young Onset Dementia, recruitment*

Target group: Researchers recruiting people with dementia for their studies

Type of evidence

Gianna Kohl (DISTINCT ESR10)

Cross-sectional online survey with 143 people with dementia

References:

Kohl, G., Koh, W.Q., Scior, K., & Charlesworth, G. (2023). *Social media use among younger and older people with dementia: An internet-mediated mixed-methods study* (Submitted to Computers in Human Behavior.)

3.2.5. Social Health Domain 2: Manage ones own life and promote independence

- ***Technologies designed to improve social health in people with dementia should be evaluated in high quality studies to effectively support decision-making*** [3.2.5.1 /3.2.6.1]

Guidance: More high quality, ecologically valid, controlled studies must be planned, funded and executed in order to properly evaluate the effectiveness of technologies designed to be used by people with dementia and to improve social participation and self-management.

Explanation and Examples**:** A systematic review found that in the whole world only nine controlled evaluation studies with technologies designed for people with dementia have been carried out in ecologically valid settings, to assess effectiveness in improving social participation and self-management. Controlled studies are the most effective way of conducting unbiased evaluations, from which causal inference can be drawn. Policy-makers should be demanding this level of evidence as a condition of investment in such technologies. So far, studies have been conducted with VR-based technologies, other wearable technologies, and software applications. However, only a single study was found to be of good quality. Other technologies for people with dementia have not yet been the subject of a single ecologically-valid, controlled study with these outcomes (this includes, for example, social robots). In order to conduct high quality studies, researchers must ensure that studies are adequately statistically powered based on a sufficiently large sample; include active technology-based control interventions, so that is controlled for attention; and conduct and report intention-to-treat analyses, taking into account data of all participant to the study, including dropouts, and not only those who completed the intervention. Funding bodies must recognize the need to fund such studies accordingly. Clinicians, healthcare providers, policymakers and users of technology should expect and demand that such high-quality evidence is available to support decision-making.

Keywords: effectiveness; technology; self-management; social participation; ecological validity.

Target group: Clinicians; Technology developers; Commissioners; Government; Researchers.

Type of evidence

David Peter Neal (DISTINCT ESR6)
Systematic review of controlled effectiveness studies, of technologies designed for use by people with dementia to improve social health.

References

Neal, D., van den Berg, F., Planting, C., Ettema, T., Dijkstra, K., Finnema, E., Dröes, R.M. (2021). Can Use of Digital Technologies by People with Dementia Improve Self-Management and Social Participation? A Systematic Review of Effect Studies. Journal of Clinical Medicine, 10(4):604. https://doi.org/10.3390/jcm10040604

- ***Ensure the appropriate methodology for evaluating social robots*** [3.2.5.2]

Guidance: Ensure that the methodology for the evaluation of social robots for older adults with and without dementia is appropriate for the purpose of the study, to strengthen the results of the study.

Explanation and Examples: Social robots are seen promising for supporting daily functioning and promoting overall social health of cognitively impaired older people, particularly those with dementia. Our scoping review into methodologies used to study the feasibility, usability, efficacy, and effectiveness of social robots for elderly adults with and without dementia showed that, despite promising results, the quality of studies remains low due to various methodological limitations. We

have therefore formulated recommendations focusing on different types of studies that can help future researchers develop appropriate study designs to evaluate social robots, allowing for more reliable information on study outcomes:

- For *feasibility* and *usability* studies an experimental design with mixed-methods of data collection (qualitative and quantitative) are recommended. Multiple interaction sessions with the social robot are recommended as they may reveal changes in feasibility and usability, when the novelty effect gradually fades and people get used to the robot.
- Appropriate designs for *efficacy* and *effectiveness* studies are RCTs, or quasi-experimental designs when randomization is not feasible. Sample sizes should be sufficiently large, and individual interaction sessions with the social robot running for more than one month would serve best for such studies to obtain relatively robust and reliable results. Efficacy and effectiveness should only be studied in fully functioning social robots.
- It is strongly recommended not to combine different aims in one study. The preferred designs to study the feasibility and usability of a social robot, differ significantly from the designs needed to study efficacy or effectiveness.

Keywords: Social robots, community setting, methodologies, study design, feasibility, usability , efficacy, effectiveness

Target group: Researchers, social robot designers

Type of evidence

Aysan Mahmoudi (DISTINCT ESR13)
Scoping review

References

Aysan Mahmoudi Asl, Mauricio Molinari Ulate, Manuel Franco Martin; Henriëtte van der Roest (2022). Methodologies Used to Study the Feasibility, Usability, Efficacy, and Effectiveness of Social Robots For Elderly Adults: Scoping Review. J Med Internet Res 2022;24(8):e37434 https://doi.org/10.2196/37434

- ***Instruments are needed to measure self-management of people with mild cognitive impairment or mild dementia, in order to investigate the effectiveness of technological interventions*** [3.2.5.3]

Guidance: Researchers interested in Social health in dementia need to develop instruments to measure the self-management aspect of Social health. Self-management is clearly defined as one of the three domains of Social health besides the capacity to fulfil one's potential and social participation. Whilst several instruments have been proposed for the measurement of self-management, all have limitations e.g. not measuring the construct as understood in the context of Social health (managing one's own life), being too burdensome for participants, or ceiling effects on scale of total scores. Instruments which measure the construct of self-management, as understood in this context, without burdening participants and with sufficient discriminatory power for use in intervention studies are needed in order to effectively evaluate interventions aiming to improve Social health in dementia.

Explanation and Examples**:** A review of existing instruments which may be used to measure self-management found no options specifically designed to measure the construct as understood in the context of Social health in dementia (to manage one's own life). In the FindMyApps pilot study, the Self-Management Activities Scale (SMAS) was used, but proved too burdensome to administer. In the FindMyApps definitive randomized controlled trial, another option was used to measure self-management, the Adult Social Care Outcomes Toolkit (ASCOT), which was less burdensome but also less well-aligned to the construct. The usefulness of the ASCOT proved to be further limited by ceiling

effects when used in the population participating in this intervention study (people with MCI or mild dementia). Research should be undertaken to confirm consensus amongst people with dementia, their caregivers and researchers in the field on the operational definition of self-management within the context of Social health; to compose statements and scales which investigate the components of the operational definition; and to test the psychometric properties (reliability, validity, responsiveness), feasibility and discriminatory power (precision with which between- and within-subjects variation can be detected) of the resulting instrument in a population of people with MCI/mild dementia, in both an observational and interventional study setting.

Keywords: measuring instruments; self-management; Social health, self-report

Target group: researchers; researchers evaluating interventions aimed at improving the self-management of people with mild dementia living at home

Type of evidence

David Neal (DISTINCT ESR 6)
Systematic review of measuring instruments, results of a randomized controlled trial.

References

van Leeuwen KM, Bosmans JE, Jansen APD, Rand SE, Towers AM, Smith N, et al. Dutch translation and cross-cultural validation of the adult social care outcomes toolkit (ASCOT). Health Qual Life Outcomes. 2015;12:13(1).

Mangiaracina F, Meiland F, Kerkhof Y, Orrell M, Graff M, Dröes R-M. Self-management and social participation in community-dwelling people with mild dementia: a review of measuring instruments. Int Psychogeriatrics. 2019 6;1–19.

Neal D., Ettema T., Zwan M., Dijkstra K., Finnema E., Graff M., Muller M., Dröes R. M. FindMyApps compared with usual tablet use for self-management and social participation in community-dwelling people with mild dementia or mild cognitive impairment and support for informal caregivers: a randomised controlled trial. *Submitted.*

3.2.6. Social Health Domain 3: Technology to promote social participation

- ***Technologies designed to improve social health in people with dementia should be evaluated in high quality studies to effectively support decision-making*** [3.2.6.1, see 3.2.5.1]
- ***Standardised instruments for measuring social interactions and communication in dementia caregiving must be developed to ensure rigorous research into the effect of technology solutions that aim to support this*** [3.2.6.2]

Guidance:The academic community should dedicate more resources to develop and evaluate technology-driven solutions that support dyadic communication and foster social interactions in dementia caregiving dyads. Rigorous investigation is needed using standard, comparable measurements to demonstrate the effects of these technological solutions.

Explanation and Examples: A systematic literature search was conducted to comprehensively describe technology-driven interventions to prompt communication and facilitate positive social interactions between people with dementia and their conversation partners. Titles and abstracts from three databases PubMed, CINAHL and PsycINFO, were independently screened by two researchers. Quality of the included studies was assessed using the Mixed Methods Appraisal Tool. Of the 18 papers included in the review, the technology most commonly used to facilitate social interaction were tablet-computers (n=7), social robots (n=5), and personal computers (n=4). Technology-driven devices not fitting into the three other categories were labelled as ‘other’ (n = 2). Results showed that the

social technology helped: i) breaking the ice by initiating dialogue and serving as a conversational platform; ii) increase interaction frequency and duration by encouraging more involvement between the conversation partners; iii) better understand the person with dementia through reminiscence activities; and iv) reduce pressure on the conversation partner by making the communication more reciprocal. Although there is seemingly great potential in technology to facilitate social interaction and communication in dementia caregiving, the findings show that research in this area is still in an explorative phase. The diversity in study methodologies and few standardised instruments used to measure these outcomes point to a need for further research into development and validation of new assessment tools for positive outcomes in social health.

Keywords: caregiving dyads, meaningful activities, social participation, communication, dyadic relationships

Target Group: Researchers evaluating technology use of people with cognitive impairments.

Type of evidence

Viktoria Hoel (DISTINCT ESR9)
Systematic literature review

References

Hoel V, Feunou CM, Wolf-Ostermann K. Technology-driven solutions to prompt conversation, aid communication and support interaction for people with dementia and their caregivers: a systematic literature review. BMC Geriatr. (2021) 21:1 157. doi:10.1186/s12877-021-02105-0.

- ***Measure different dimensions of social participation when evaluating the effect of social technologies*** [3.2.6.3]

Guidance: Make clear how you define the outcome of social participation and assess different dimensions of this multidimensional concept when evaluating the effects of social technology on social participation.

Explanation and examples: A systematic review was conducted to gain insight into the effects of technological interventions on the social participation of older adults. A total of 36 studies was included in a narrative synthesis. A major finding was the inconsistent use of terms and concepts related to social participation among studies. Future studies should make the applied definition of social participation explicit to allow for comparison of research results.

Furthermore, a majority of the included studies measured one specific dimension of social participation, i.e: social connections (e.g. by measuring loneliness or social isolation). However, social participation is a multidimensional concept. It is not only about social connections, but also about being engaged in meaningful activities that provide social interaction with others in the community (Levasseur et al., 2010). So far, there is no outcome measure that covers all dimensions of social participation. Therefore, it is recommended to combine quantitative outcome measures with qualitative data collection methods when assessing the effect(s) of technology on social participation. In the future, research should focus on developing and validating an outcome measure that covers different dimensions of social participation.

Keywords: Social participation, effects evaluation, outcome measures, older adults, dementia, technological interventions

Target group: Industry evaluating the effect of technology on social participation; researchers evaluating the effect of technology on social participation

Type of evidence:

Pascale Heins (DISTINCT ESR11)

Systematic literature review

References

Heins, P., Boots, L.M.M., Koh, W.Q., Neven, A., Verhey, F.J., and de Vugt, M.E. (2021). The Effects of Technological Interventions on Social Participation of Community-Dwelling Older Adults with and without Dementia: A Systematic Review. Journal of Clinical Medicine, 10, 2308. doi: 10.3390/jcm10112308

Levasseur, M., Richard, L., Gauvin, L., and Raymond, É. (2010). Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. Social Science & Medicine, 71, 2141–2149. doi: 10.1016/j.socscimed.2010.09.041

- ***More studies required to investigate the impacts of low-cost pet robots in dementia care*** [3.2.6.4]

Guidance: Low-cost pet robots are a promising technology to improve the psychosocial health of people living with dementia. More high quality studies with sufficiently large sample sizes should be conducted to properly investigate their impacts.

Explanation and Examples: Pet robots are a technology-based substitute to animal assisted therapy. However, the high costs of many pet robots can hinder the use of pet robots in dementia care. A scoping review was conducted to understand the impact of using lower-cost (more affordable) pet robots. Synthesised findings from nine studies suggested that low-cost pet robots improved the communication, social interactions and other health domains of older adults and people living with dementia. However, most studies had a small sample size and were of varying quality. Moving forward, more rigorous studies are necessary to investigate their impacts.

Keywords: Older adults, dementia social robots, low-cost pet robots, robotic pets, psychosocial impact

Target group: Social robot developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Scoping review

References

Koh, W. Q., Ang, F. X. H., & Casey, D. (2021). Impacts of low-cost robotic pets for older adults and people with dementia: scoping review. JMIR Rehabilitation and assistive technologies, 8(1), e25340. DOI: 10.2196/25340

- ***Consider using low-cost pet robots to support the psychosocial health of people living with dementia and their caregivers*** [3.2.6.5]

Guidance: Low-cost pet robots demonstrate the potential to positively impact the psychosocial health of people with dementia and their caregivers. Due to their lower cost, they may be more accessible and affordable and should therefore be considered for use in dementia care.

Explanation and Examples: Although pet robots have demonstrated positive impacts on the wellbeing of people with dementia, their affordability can impede their uptake in dementia care. A scoping review, content analysis of consumer reviews and a qualitative study showed that the impacts of low-cost pet robots on people with dementia resembled the effects of other higher costed (but more advanced) pet robots. These included improved mood, companionship, increased activity engagement and reduced anxiety. Caregivers also experienced knock-on effects, such as feelings of joy and relief. Low-cost pet robots are more widely accessible to the public since they can be purchased off-the-

shelf. While promising, findings of their positive impacts are subject to bias. More rigorous studies are necessary to confirm their impacts.

Keywords: Older adults, people living with dementia, caregivers, dementia, social robots, low-cost pet robots, robotic pets, psychosocial impact

Target group: Social robot developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborator: Pascale Heins (DISTINCT ESR11), Viktoria Hoel (DISTINCT ESR9)
Scoping review, qualitative content analysis, qualitative study (interviews with care providers)

References

Koh, W. Q., Ang, F. X. H., & Casey, D. (2021). Impacts of low-cost robotic pets for older adults and people with dementia: scoping Review. JMIR rehabilitation and assistive technologies, 8(1), e25340, 1-14. https://doi.org/10.2196/25340.

Koh, W. Q., Whelan, S. A., Heins, P., Casey, D., Toomey, E., & Dröes, R.M. (2021). Usability and impact of a low-cost robotic pet for older adults and people with dementia: a qualitative content analysis of user experiences and perceptions on consumer websites. JMIR Aging, 5(1), e29224, 1-16. https://doi.org/10.2196/29224.

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

- ***The FindMyApps intervention should be preferred to usual tablet use to promote social participation in community-dwelling people with mild cognitive impairment or mild dementia as it better supports their quality of life if they are experiencing apathy, and better supports their informal caregivers' sense of competence*** [3.2.6.6]

Guidance: Care providers should consider providing people with mild cognitive impairment (MCI) or mild dementia with the FindMyApps tablet-based intervention, or even a usual tablet without Find-MyApps if accompanied with appropriate training, as an effective way of improving their social participation.

Explanation and Examples**:** Evidence from the FindMyApps project has identified increases in social participation associated with use of the tablet-based FindMyApps intervention or a usual tablet without FindMyApps, when accompanied by appropriate training. The improvements were slightly more pronounced with the FindMyApps intervention than with a tablet without FindMyApps, particularly with respect to the diversity of social activities in which people participated (as opposed to the overall frequency of social activities). Evidence was also found for people with MCI/mild dementia experiencing apathy prior to receiving the interventions having better quality of life outcomes when they received FindMyApps. All improvements found were small.

Caregivers' sense of competence refers to how well caregivers feel they can provide care for their family member with dementia or friend, and for how long. Evidence from the FindMyApps project has identified that the FindMyApps intervention is associated with a greater sense of competence for caregivers (moderate effect size) of community-dwelling people with MCI/mild dementia than a normal tablet and should therefore be implemented by preference to a normal tablet.

Keywords: tablet intervention; FindMyApps; effectiveness; social participation; carers' sense of competence

Target group: Professional caregivers, clinicians, welfare professionals, who promote the use of technology to people with cognitive impairments and dementia; family carers; people living with dementia

Type of evidence

David Neal (DISTINCT ESR6)

Results from a randomized controlled trial, conducted in the Netherlands from January 2020 to November 2022.

References

Neal D., Ettema T., Zwan M., Dijkstra K., Finnema E., Graff M., Muller M., Dröes R. M. FindMyApps compared with usual tablet use for self-management and social participation in community-dwelling people with mild dementia or mild cognitive impairment and support for informal caregivers: a randomised controlled trial. (Submitted.)

3.3 Implementation of technology in dementia care: facilitators & barriers

3.3.1. Technology in everyday life

- ***Involve diverse groups of stakeholders and consider existing contexts when designing, developing and using Everyday Technologies*** [3.3.1.1]

Guidance: Technology companies and developers should involve more diverse groups of people living with dementia or caring for people with dementia, in all stages of design, development and implementation of technologies. They should also consider existing contexts before introducing them.

Explanation and Examples: Consultations explored the ways in which Everyday Technology can be both an enabler and disabler, among people living with dementia, or providing care for people with dementia, from minority and migrant communities within the EU (Germany and Greece). The consultations highlighted the need for more contextually-relevant Everyday Technologies. This includes consideration of existing contexts before introducing technologies or technology interventions e.g. eHealth, finance or social apps. Consultees reported the need to identify existing levels of access and ability to use Everyday Technologies (e.g. possession of technological devices and digital literacy etc.) as well as access to infrastructures to support their use (e.g. internet connection, battery charging facilities and face-to-face support). Everyday Technology use is influenced by contextual and cultural factors. Technology companies and developers need to involve a more diverse group of people living with dementia or caring for people with dementia (e.g. from different cultural and socio-economic backgrounds, urban and rural environments etc.) throughout all stages of technology development.

Keywords: Every day technology; Dementia; Activities of Daily Living; Human Rights; Minority Groups; Social Isolation; Health Literacy; Health Services Accessibility

Target group: Technology developers and providers, NGOs and Think Tanks.

Type of evidence

Sophie Gaber (DISTINCT ESR3)
Multilevel stakeholder consultations & literature review.

References

Gaber, S. N. Findings presented at The Health Inequalities Research Network (HERON) Conference, London, UK, 2018. [How do Contextual Factors and Everyday Technologies Shape Inequalities in Participation among Ageing Communities Living with Health-related Vulnerabilities?]

Gaber, S. N., Nygård, L., Brorsson, A., Kottorp, A., Charlesworth, G., Wallcook, S., Malinowsky, C. (2020). Social Participation in Relation to Technology Use and Social Deprivation: A Mixed Methods Study Among Older People with and without Dementia. International Journal of Environmental Research and Public Health, 17(11), 4022. https://www.mdpi.com/1660-4601/17/11/4022#

- ***Consider involving occupational therapists to enable people with dementia to use everyday technology*** [3.3.1.2.]

Guidance: Consider involving occupational therapists in providing interventions that enable people with dementia to use the everyday information and communication technologies they have.

Explanation and Examples: A standardized questionnaire mapped how many Everyday Information & Communication Technologies (EICT) (maximum 31) were relevant to 35 people living with dementia and 34 people with no known cognitive impairment in Sweden. A relevant EICT is one that is being used, or has been used in the past, or is planned for use in future. The median amount of relevant EICTs was shown to be 11 in the group without dementia, and 7 (significantly less) in the group with dementia. Each person also rated their ability to use (maximum 90) relevant Everyday Technologies (ETs) on a 5 step rating scale. This data was analysed (in a Rasch model) to produce a score for each person's *ability to use ET*. When we compared ability to use ET with amount of relevant ETs in each group, the more EICTs a person counts as relevant, the higher was their ability to use ET. This pattern was only found in the group of people with dementia, and not the group without. The amount of relevant EICTs is affected by a person's ability to use them. So some people may need support to identify the usefulness and possibility to use an EICT function that they have access to.

Keywords: Occupational therapy, everyday life, information communication technology, activities of daily living.

Target group: Health and social care planners, digital inclusion planners, commissioners, policy makers, occupational therapy educators and organisations

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Cross sectional quantitative study with literature review

References

Wallcook, S., Malinowsky, C., Kottorp, A. & Nygård, L. (2019).The use of Everyday Information Communication Technologies in the lives of older adults living with and without dementia in Sweden. Assistive Technology, 33:6, 333-340 [https://10.1080/10400435.2019.1644685]

- ***Provide non-ICT (Information Communication Technology) options for people with dementia who need it*** [3.3.1.3]

Guidance: To avoid excluding some people with dementia, service developers should provide alternative non-ICT options when they deliver services and interventions that rely on smartphones, tablets and computers.

Explanation and Examples: A standardized questionnaire mapped how many Everyday Information & Communication Technologies (EICTs) (maximum 31) were relevant to 35 people living with dementia and 34 people with no known cognitive impairment in Sweden. In the same questionnaire, each person also rated their perceived their ability to use (maximum 90) relevant ETs on a 5 step rating scale.

A relevant EICT is one that is being used, or has been used in the past, or is planned for use in future. This data was analysed (in a Rasch model) to produce a score for each person's *ability to use ET***,** and a *challenge measure* for each of the 31 EICTs to show how difficult or easy they were to use compared to each other. EICTs on smartphones and tablets were not relevant for a high proportion of both groups. Combined with a lower ability to use ET, particularly for people in the group with dementia, and high challenge measures for computer and automated telephone service functions, this could mean some people cannot access EICT-based services and interventions on computerized devices. However, the landline telephone was easiest to use and relevant to the majority of both groups, so this, together with face-to-face options could provide viable alternatives.

The study is currently under review and will be available under open access.

Keywords: Policies, services, information communication technology

Target group: Policy makers, service developers

Type of evidence

Sarah Wallcook (INDUCT ESR4)
Cross sectional quantitative study with literature review

References

Wallcook, S., Malinowsky, C., Kottorp, A. & Nygård, L. (2019). The use of Everyday Information Communication Technologies in the lives of older adults living with and without dementia in Sweden. Assistive Technology, 33:6, 333-340 [https://10.1080/10400435.2019.1644685]

3.3.2. Technology for meaningful activities

- ***Ensure multiple employees are responsible for exergaming to ensure successful implementation of this technology*** [3.3.2.1]

Guidance: Exergaming in day care centres can be implemented more successfully by making more than one employee responsible for it.

Explanation and Examples: We have asked day-care centres for people living with dementia, which factors were important for successful implementation of Exergaming. Sometimes, only one person in the day-care centre was responsible for the Exergaming activity. If this person was not at the day-care centre, because he/she was ill or left for another job, the Exergaming activity often was forgotten.

Keywords: Exergaming, implementation, staff

Target group: Researchers and industry evaluating implementation of technology for people living with dementia, volunteers, employees and managers of day-care centres, management of care organisations, professional carers, clinicians, who promote the use of technology for people living with dementia.

Type of evidence

Joeke van der Molen (INDUCT ESR7)
Preliminary results of the process analysis

References

Joeke van Santen, Rose-Marie Dröes, Marian Schoone, Olivier A. Blanson Henkemans, Judith E. Bosmans, Sjef van Bommel, Esther Hakvoort, Ronald Valk, Carla Scholten, Joris Wiersinga, Marjolein Smit, Franka Meiland (2019). FACTSHEET Exergaming for people living with dementia: can you move along? Recommendations to promote successful implementation [in Dutch: FACTSHEET Exergaming voor mensen met dementie: beweeg je mee? Adviezen ter bevordering van succesvolle implementatie].

Van Santen J., Dröes, R.M., Blanson Henkemans, O.A., Schoone, M., van Straten, A., Valk R., Meiland F.J. A mixed-methods study into the implementation of exergaming for people living with dementia who attend day-care centres. (Submitted)

- ***Ensure the support from the management of care organisations to promote successful implementation of exergaming*** [3.3.2.2]

Guidance: Employees of care organisations should be supported by the management in their responsibility for Exergaming as a new activity. Managers should be actively engaged in Exergaming and be kept updated on any developments with regard to Exergaming (i.e. positive experiences of people with dementia practising Exergaming, any potential issues with the activity).

Explanation and Examples: We have asked day-care centres for people living with dementia, which factors played a role in successful implementation of Exergaming. The staff of these day-care centres sometimes did not feel supported by the management in supervising and implementing the Exergaming activity. This made it less likely for them to implement it.

Keywords: Exergaming, implementation, management, support.

Target group: Researchers and industry evaluating implementation of technology for people living with dementia, volunteers, employees and managers of day-care centres, management of care organisations, professional carers, clinicians, who promote the use of technology for people living with dementia.

Type of evidence

Joeke van der Molen (INDUCT ESR7)
Preliminary results of the process analysis

References

Joeke van Santen, Rose-Marie Dröes, Marian Schoone, Olivier A. Blanson Henkemans, Judith E. Bosmans, Sjef van Bommel, Esther Hakvoort, Ronald Valk, Carla Scholten, Joris Wiersinga, Marjolein Smit, Franka Meiland (2019). FACTSHEET Exergaming for people living with dementia: can you move along? Recommendations to promote successful implementation [in Dutch: FACTSHEET Exergaming voor mensen met dementie: beweeg je mee? Adviezen ter bevordering van succesvolle implementatie].

Van Santen J., Dröes, R.M., Blanson Henkemans, O.A., Schoone, M., van Straten, A., Valk R., Meiland F.J. A mixed-methods study into the implementation of exergaming for people living with dementia who attend day-care centres. (Submitted)

- ***Focus on aspects that are of interest to people with dementia when introducing a new technology***. [3.3.2.3]

Guidance: Introduce new application (app) technology to a person with dementia by focusing on aspects that are likely to encourage their interest, such as family photographs, video calls with friends and family, music, games, or art applications.

Explanation: This guidance is based on a review of the literature on the use of touchscreen technology by people with dementia and carers.

Keywords: Touchscreen technology; applications; entertainment.

Target group: Family and formal carers, and policy-makers.

Type of evidence

Aline Cavalcanti Barroso (INDUCT ESR6)
Literature review and proof of principle study

References

Cavalcanti Barroso, A., Rai, H.K., Sousa, L., Orrell, M., Schneider, J. (2020). Participatory visual arts activities for people with dementia: a review. Perspectives in Public Health, 20(10)1-10.

- ***Ensure free access to the internet for all residents in care homes*** [3.3.2.4]

Guidance: Internet should be freely available in care homes so residents with and without dementia can have access to online resources (e.g.social media, entertainment, information).

Explanation and Examples: The multi-country survey indicates that it is not common for the residents to have access to the internet in care homes, with the internet use restricted to the staff. This means that many social and leisure activities based on ICT will be inaccessible for people with dementia, depriving them of enjoyable, meaningful activities and social networks.

Keywords: Care homes; internet access

Target group: Care home and nursing home providers and policy-makers.

Type of evidence

Aline Cavalcanti Barroso (INDUCT ESR6)
Multi-country survey

References

Unpublished internal report

- ***Explore and consult with the eHealth context to facilitate implementation of eHealth interventions*** [3.3.2.5]

Guidance: To develop an eHealth intervention for caregivers of people with dementia that will be used in practice, developers should investigate the needs of the target population (people with dementia and their caregivers), and the needs of the people who will be implementing these interventions after a trial phase (such as case managers, hospital workers, volunteers or professionals associated with advocacy groups).

Explanation and examples: A systematic search was conducted into the implementation of studies including the terms ‘dementia’, ‘eHealth’, and ‘caregivers’. 2524 abstracts and 122 full texts were read, resulting in 46 studies meeting all criteria. Containing 204 statements on implementation. Most implementation statements could be grouped into 2 main themes: ‘Determinants associated with the eHealth intervention’ and ‘Determinants associated with the caregiver’. Very few statements were in the themes ‘Determinants associated with the implementing organization’ and ‘Determinants associated with the wider context’. Absence of knowledge on the contextual environment creates significant difficulties for health system planners and implementers who aim to translate these interventions into practice.

Keywords: eHealth, dementia, caregivers, implementation.

Target group: Developers planning to design and implement eHealth interventions for caregivers of people with dementia

Type of evidence

Hannah Christie (ESR10), Sara Bartels (INDUCT ESR9)
Systematic review

References

Christie, H. L., Bartels, S. L., Boots, L. M., Tange, H. J., Verhey, F. R., & de Vugt, M. E. (2018). A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia.Internet interventions, 13, 51-59.

- ***Start making eHealth financing and business plans at the start of the development phase*** [3.3.2.6]

Guidance: To ensure that the eHealth interventions for caregivers of people with dementia will continue to be available, supported, updated and compatible with changing software and hardware requirements, financing and business plans should be developed from the beginning.

Explanation and Examples: A mixed-methods study followed up on the 12 publications included in Boots et al.'s (2014) widely cited systematic review on eHealth interventions for informal caregivers of people with dementia, to explore implementation into practice. Publicly available online information, implementation readiness (ImpRess checklist scores), and survey responses were assessed. The majority of survey respondents identified commercialization and having a business plan as facilitators to implementation. There was little evidence for any of the 12 applications being put into practice.

Keywords: eHealth, dementia, caregivers, implementation, business models

Target group: Developers planning to design and implement eHealth interventions for caregivers of people with dementia

Type of evidence

Hannah Christie (INDUCT ESR10)
Follow-up study

References

Christie, H. L., Bartels, S. L., Boots, L. M., Tange, H. J., Verhey, F. R., & de Vugt, M. E. (2018). A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. Internet interventions, 13, 51-59.

- ***Implementation of technology in dementia care: facilitators & barriers*** [3.3.2.7]

Guidance: Ensure new technology is compatible with a range of relevant platforms to promote implementation.

Explanation and Examples: Findings from the feasibility trial showed that people with dementia use a range of devices with various software versions (e.g. smartphones, touch-screen tablets, and personal computers) to access apps and other services. New technology which aims to be compatible with these different devices, can lead to increased uptake and may contribute to successful implementation.

Keywords: accessibility, implementation, dementia, technology, device.

Target group: technology developers, UX designers, researchers developing technology.

Type of evidence

Harleen Rai (INDUCT ESR5)
Results from a feasibility randomised controlled trial (RCT).

References

Rai, H. K., Schneider, J., & Orrell, M. (2021). An Individual Cognitive Stimulation Therapy App for People with Dementia and Carers: Results from a Feasibility Randomized Controlled Trial (RCT). *Clinical interventions in aging, 16*, 2079–2094. https://doi.org/10.2147/CIA.S323994

Rai HK, Prasetya VGH, Sani TP, et al. (2021). Exploring the feasibility of an individual cognitive stimulation therapy application and related technology for use by people with dementia and carers in Indonesia: A mixed-method study.Dementia. doi:10.1177/14713012211018003

- ***Embedding time flexibility and social support to increase user engagement in self-help and technology-based interventions for informal caregivers*** [3.3.2.8]

Guidance: To deliver more efficient self-help and technology-based psychological interventions to informal caregivers, time flexibility and personal retention approaches should be considered to prevent a high rate of dropout. Flexible timing (i.e., self-paced instruction) and personal retention approaches, such as embedding a component of social support/interaction in the form of informational support (e.g., guidance) and/or emotional support (e.g., peer support), showed lower attrition and higher rates of engagement and satisfaction in various self-help and technology-based psychological interventions for informal caregivers.

Explanation and Examples: A systematic search was conducted into the use of psychological interventions based on acceptance and commitment therapy for informal caregivers of people with dementia or other long-term or chronic conditions. A total of 7896 abstracts and 33 full texts were read, resulting in 21 studies involving a narrative synthesis. Quantitative and qualitative data showed that flexible interventions are more amenable to caregivers' lives. Further, social or interpersonal support in various modalities (e.g., automated messaging, reminders, personal touch) might promote motivation for, uptake of and engagement in interventions. Therefore, future technology-based interventions, particularly in the form of self-help that requires little or no therapist resources, might benefit from time flexibility and embedded social support components (e.g., peer support or motivational coaching). Furthermore, employing mixed methods or embedded qualitative components. (e.g., semi-structured interviews) might provide further insight into user experience, potentially supporting decisions related to intervention design. Uncovering and preventing factors associated with high rates of dropouts will lead to more effective, adaptive and individualised interventions.

Keywords: Acceptance and commitment therapy, systematic review, informal caregivers, technology-based intervention, dementia, long-term condition

Target group: Industry evaluating the effect of online evidence-based support programs (e.g., websites/modules) on psychological outcomes; researchers designing and evaluating online (self-help) psychological interventions

Type of evidence

Golnaz Atefi (ESR5)
Systematic literature review

References

Atefi, G., M.E. De Vugt, Van Knippenberg, R.J.M., Levin, M.E., Verhey, F.R.J.1, Bartels, S.L. The use of Acceptance and Commitment Therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: A systematic review and conceptual integration. Clinical Psychology Review (under revision).

3.3.3. Health care technology

- ***Increase family carers' awareness about the use and benefits of online interventions*** [3.3.3.1]

Guidance: People involved in the provision of support to family carers, such as health professionals, patient organizations, should inform them about the potential benefits derived from the use of online interventions and actively promote their use.

Explanation and example: Despite the potential benefits of Internet carer support and training programmes, family carers are not always informed about the existence and use of online alternatives to traditional face-to-face support programmes. Extra attention should be paid to inform and motivate family carers to start and continue using Internet training programmes, especially in countries where the use of the Internet for health related purposes is not common yet. India trial (Mehta et al. 2018) Rrecruitment and adherence for a randomized controlled trial of an online support programme in India (Mehta et al. 2018) turned out to be challenging as most of the family carers were not accustomed to access to the Internet for health-related reasons.

Keywords: Online intervention, unpaid carers, informal carers.

Target group: Researchers, policy-makers, healthcare providers and patient organizations

Type of evidence

Ángel C. Pinto Bruno (INDUCT ESR14)
RCT India
Systematic review

References

Egan, K. J., Pinto-Bruno, A. C., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E., & Pot, A. M. (2018). Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. J Am Med Dir Assoc, 19(3), 200-206.e201. doi:10.1016/j.jamda.2017.10.023

Mehta, K. M., Gallagher-Thompson, D., Varghese, M., Loganathan, S., Baruah, U., Seeher, K., . . . Pot, A. M. (2018). iSupport, an online training and support program for caregivers of people with dementia: study protocol for a randomized controlled trial in India. Trials, 19(1), 271. doi:10.1186/s13063-018-2604-9

- ***Involve all users during the development process of complex health technologies*** [3.3.3.2]

Guidance: To make complex health technologies more useful and applicable for users, it is crucial to involve all users, including staff, in the early phase of development of these interventions.

Explanation and Examples: In developing complex health technologies that would be delivered by nursing staff to people with dementia, it is important to involve the nursing staff themselves in the early phase of development of such technologies. In doing so, complex health technologies can be more useful and applicable for the nursing staff.

Keywords: Complex health technologies, involvement of users.

Target group: Researchers, nursing home managers, policy-makers

Type of evidence

Rose Miranda (INDUCT ESR11)
Process evaluation of cluster RCT

References

Oosterveld-Vlug M, Onwuteaka-Philipsen BD, Ten Koppel M, Van Hout H, Smets T, Pivodic L, et al. Evaluating the implementation of the PACE Steps to Success Programme in long-term care facilities in seven countries according to the REAIM framework. Implement Sci. 2019;14:107.

- ***Make complex health technologies flexible for tailoring to local contexts*** [3.3.3.3]

Guidance: To better implement complex health technologies in complex settings such as nursing homes, it is important to make these health technologies flexible to existing situations and processes including: the specific context of the nursing homes; the needs and roles of nursing staff; and the timing and order of implementation of different intervention components (e.g. training on specific subjects).

Explanation and Examples: Nursing homes may have their own culture and own ways of working. Hence, complex health technologies should be able to fit in this context. The nursing staff may also have varying levels of knowledge and skills and complex health technologies should be flexible for tailoring so that it can be used based on the capabilities of all nursing staff. The timing and order of implementing components of the complex health technologies may not be applicable in all situations, so interventions should be flexible for nursing staff to decide when to implement certain complex health technology components.

Keywords: Tailored interventions, complex health technology.

Target group: Researchers, nursing home managers, policy-makers

Type of evidence

Rose Miranda (INDUCT ESR 11)
Process evaluation of cluster RCT
Annelien van Dael (INDUCT ESR 12)
Feasibility study; preliminary results of process evaluation of cluster RCT

References

Oosterveld-Vlug M, Onwuteaka-Philipsen BD, Ten Koppel M, Van Hout H, Smets T, Pivodic L, et al. Evaluating the implementation of the PACE Steps to Success Programme in long-term care facilities in seven countries according to the REAIM framework. Implement Sci. 2019;14:107.

- ***Ensure management engagement when implementing complex health technologies*** [3.3.3.4]

Guidance: Consider active engagement of nursing home management as a crucial component when designing complex health care technologies for nursing homes. Their commitment to the project's success will help to ensure staff have sufficient time and other resources to participate in the new programme.

Explanation and Examples: A lack of time is one of the most important barriers for implementing advance care planning (ACP) in nursing homes. Therefore, it is crucial staff gets enough time to engage and work with the intervention in order to properly implement it. When staff is given time to spend on intervention-related tasks, instead of having to spend this time on other tasks, this will increase their ownership of the intervention. In the ACP^{+} programme all nursing home managers signed a contract stating they would allow their staff to spend time on the intervention. Training sessions were held during working hours and staff got paid while attending these sessions.

Keywords: Advance care planning; management engagement; implementation

Target group: Researchers, policy makers

Type of evidence
Annelien van Dael (INDUCT ESR12)
Feasibility study; preliminary results of process evaluation of cluster RCT

References

Wendrich-van Dael, A.E. (2021). Advance care planning, dementia and nursing homes. VUBPress. ISBN: 9789461171603

- ***Target multiple levels when implementing complex health technology in a specific context*** [3.3.3.5]

Guidance: When implementing Advance care planning (ACP) as a complex health technology in a complex setting such as a nursing home, multiple levels should be targeted, including management, nurses, care staff, volunteers, visiting or residing physicians, families, cleaning or other staff.

Explanation and Examples: The implementation process will have a higher chance of succeeding when multiple levels are targeted within the nursing home. Colleagues in the nursing home can help each other to implement the intervention, creating a positive and open environment to learn and develop new skills and deliver the best care possible. In this way the intervention can produce a shift in working culture and attitudes and deliver sustainable change. The ACP+ intervention targeted not only the (head) nurses, but also other care staff and cleaning, kitchen and maintenance staff. Also, engagement of the management was required for participation in the trial. A few highly motivated people were extensively trained in conducting ACP conversations and this knowledge was past onwards to colleagues via internal training sessions. In this way the whole nursing home was involved in the intervention, leading to greater participation of all nursing home employees.

Keywords: Complex interventions, implementation, complex health care technology

Target group: Researchers and care organizations and professionals

Type of evidence

Annelien van Dael (INDUCT ESR12)

Development of advance care planning intervention (based on review, theory of change workshops and feasibility testing)

References

Gilissen, J., Pivodic, L., Wendrich-van Dael, A., Gastmans, C., Vander Stichele, R., Van Humbeeck, L., Deliens, L., & Van den Block, L. (2019). Implementing advance care planning in routine nursing home care: The development of the theory-based ACP+ program.*PloS one*, *14*(10), e0223586. https://doi.org/10.1371/journal.pone.0223586

Wendrich-van Dael, A., Gilissen, J., Van Humbeeck, L., Deliens, L., Vander Stichele, R., Gastmans, C., Pivodic, L., & Van den Block, L. (2021). Advance care planning in nursing homes: new conversation and documentation tools. *BMJ supportive & palliative care*, *11*(3), 312–317. https://doi.org/10.1136/bmjspcare-2021-003008

- ***Accessibility to technology should be ensured for all people with dementia*** [3.3.3.6]

Guidance: Cognitive rehabilitation technology should be accessible physically and in terms of cost, taking into account the mobility problems and the low income of many older people with dementia. To increase the accessibility of technology it is necessary to deliver it at low cost or promote the financing of licenses for people with dementia.

Explanation and Examples: Programs for cognitive rehabilitation for people with dementia may be inaccessible due to high costs or difficulty getting access to the location that provides the program because of mobility issues. Technology associated with cognitive rehabilitation or stimulation should be accessible to all those who could benefit from it. Technologies for cognitive rehabilitation should be accessible at home, especially in people living in rural areas or with mobility problems who are not able to travel to a center to perform cognitive rehabilitation.

Keywords: Accessibility, economic constraints, physical impairment.

Target group: Researchers, policy-makers, health technology assessment, people with dementia

Type of evidence

Angie Alejandra Diaz (INDUCT ESR15)
RCT Gradior Validation

References

Fumero Vargas, G., Franco Martin, M.A., Perea Bartolomé, M.V. (2009). Start-up and study of usability of a computer cognitive rehabilitation program "Gradior" in the treatment of neurocognitive deficits (Doctoral thesis), Department of basic psychology, psychobiology and methodology of behavioural sciences, Faculty of psychology, University of Salamanca, Spain.

- ***Take into account the level of cognitive impairment when implementing technologies*** [3.3.3.7]

Guidance: The level of cognitive impairment must be taken into account in the design of technology because people with severe dementia have different needs vs. mild dementia.

Explanation and Examples: People with severe cognitive impairment will have more problems learning to use different and new devices. They need more explanation and a longer learning time, due to limited cognitive capacities. For example, the clinical experience with Gradior shows that people with moderate and severe dementia should have the therapist as a permanent guide. According to this, Gradior possibly would have to adopt new systems and tools to become effective in people with moderate and severe dementia, and in turn, allow a level of autonomy of the person with dementia who uses this technology. Indeed, the help of a therapist in the first steps of applying a technological-based therapy is strategic for implementing and accepting the approach.

Keywords: Grade of cognitive impairment, implementation, usability.

Target group: Researchers, developers, dementia people, policy-makers

Type of evidence

Angie Alejandra Diaz (INDUCT ESR15)
RCT Gradior Validation

References

Fumero Vargas, G., Franco Martin, M.A., Perea Bartolomé, M.V. (2009). Start-up and study of usability of a computer cognitive rehabilitation program "Gradior" in the treatment of neurocognitive deficits (Doctoral thesis), Department of basic psychology, psychobiology and methodology of behavioural sciences, Faculty of psychology, University of Salamanca, Spain.

Toribio Guzmán, J. M., Franco Martin, M.A., Perea Bartolomé, M.V. (2015). Long Lasting Memories, an integrated ICT platform against age-related cognitive decline: usability study. (Doctoral thesis), Department of basic psychology, psychobiology and methodology of behavioural sciences, Faculty of psychology, University of Salamanca, Spain.

- ***Nursing home managers should ensure the appropriate conditions for implementation of EPR systems*** [3.3.3.8]

Guidance: Issues such as access to the EPR system, appropriate training and system development and support should all be considered by nursing homes before and during the implementation of EPR systems.

Explanation and Examples: Access or non-access to various parts of the EPR system should be discussed and put in place. For instance, management should consider whether auxiliary staff should be allowed to access medical information, such as dementia diagnosis, and whether this would consequently entail training in the field of dementia. Appropriate training in the EPR system according to individual staff needs is also required, as some staff may be more experienced in the use of technology than others. Training 'on the job' was found to be preferred by many over classroom-based teaching. Finally, software developers should consider working alongside nursing homes during the design of EPR systems in order to ensure software is appropriate for their needs. Developers should continue to be involved in improving the EPR following implementation, as part of an iterative cycle.

Keywords: electronic patient record; implementation; nursing home; software development; training

Target group: Developers of EPR, Nursing home management

Type of evidence

Kate Shiells (INDUCT ESR13)
Qualitative study

References

Shiells, K., Diaz Baquero, A. A., Stepankova, O., & Holmerova, I. (2020). Staff perspectives on the usability of electronic patient records for planning and delivering dementia care in nursing homes: a multiple case study. BMC Medical Informatics and Decision Making, 20, 159. https://doi.org/10.1186/s12911-020-01160-8

- ***Ensure the involvement of a dedicated trainer throughout the entire implementation of a complex health technology in nursing/care homes or other institutional settings*** [3.3.3.9]

Guidance: To improve the implementation of complex health technologies focused on training healthcare professionals in institutional settings, it is important to ensure the involvement of a dedicated trainer throughout the entire implementation process.

Explanation and Examples: For complex health technologies focused on training healthcare professionals, trainers play a crucial role. Trainers should be able to spend dedicated time to deliver the trainings in a specific facility or institution (e.g. nursing home). Hence, they should preferably be paid by a third party or, if paid by the institution, mechanisms should be in place to ensure trainers have dedicated time and training can be delivered. Ensuring the continuous and long-term involvement of such trainers (e.g. via regional collaborations) could facilitate better implementation of complex health technologies, as timing of the trainings can then be tailored to the needs in a specific context and to the learning needs of the professionals in this context.

Keywords: Complex health technology, involvement of dedicated trainers

Target group: Researchers, developers of complex health technologies, policy makers

Type of evidence

Rose Miranda (INDUCT ESR11)
Cluster RCT and process evaluation of cluster RCT
Annelien van Dael (INDUCT ESR 12)
Cluster RCT and process evaluation of cluster RCT

References

1. Oosterveld-Vlug M. Evaluating the implementation of the PACE Steps to Success Programme in long-term care facilities in seven countries according to the REAIM framework. Implement Sci. 2019;14:107.
2. Van den Block L, Honinx E, Pivodic L, Miranda R, Onwuteaka-Philipsen BD, van Hout H, et al. Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries The PACE Cluster-Randomized Clinical Trial. JAMA Intern Med. 2020;180(2):233–42
3. Pivodic, L., Wendrich-van Dael, A., Gilissen, J., Deliens, L., Vander Stichele, R., Gastmans, C. & Van den Block, L. Effectiveness of a complex advance care planning intervention in nursing homes: a cluster randomised controlled trial. Palliative Medicine, 2022, 36, 7 https://doi.org/10.1177/02692163221102
4. Wendrich-van Dael, A., Gilissen, J., Deliens, L., Vander Stichele, R., Gastmans, C., Pivodic, L. & Van den Block, L. Implementation of advance care planning in nursing homes in Flanders, Belgium: a mixed-methods process evaluation of the ACP+ trial. (Submitted)
5. Wendrich-van Dael, A.E. (2021). Advance care planning, dementia and nursing homes. VUB-Press. ISBN: 9789461171603

- ***Ensure a clear distinction of roles and responsibilities for staff when implementing complex health technologies in institutional settings*** [3.3.3.10]

Guidance: To improve the implementation of complex health technologies in institutional settings, it is important to ensure a clear distinction of roles and responsibilities for staff throughout the entire implementation process.

Explanation and Examples: To facilitate the implementation of complex health technologies in a, often complex, health care setting, a clear distinction of roles and responsibilities for staff is crucial. This clear distinction helps, 1) the staff to know what is expected of them, 2) co-workers to know what they can ask and expect of the staff involved in the implementation and 3) management to determine how much time would be needed for the staff to implement the technology in an appropriate manner.

Keywords: Complex health technology, roles and responsibilities

Target group: Researchers, developers of complex health technologies, policy makers

Type of evidence

Annelien van Dael (INDUCT ESR12)
Cluster RCT and process evaluation of cluster RCT
References

Pivodic L, Wendrich-van Dael A, Gilissen J, et al. Effects of a theory-based advance care planning intervention for nursing homes: A cluster randomized controlled trial. Palliative Medicine. 2022;36(7):1059-1071. doi:10.1177/02692163221102000

Wendrich-van Dael, A.E. (2021). Advance care planning, dementia and nursing homes. VUBPress. ISBN: 9789461171603

- ***Telehealth should be recognised as a valuable adjunct to traditional occupational therapy service provision, requiring dedicated financial, legislative and informative resources*** [3.3.3.11]

Guidance: Occupational therapists must adopt telehealth practices as a supplement to in-person occupational therapy to avoid service disruption in times of crisis. This requires legislation and public

promotion, clear strategies and guidelines for health service managers, and finally, training and continuous support for end-users.

Explanation and Examples: A global online needs-assessment survey among occupational therapists was undertaken to determine the impact of the COVID-19 pandemic on telehealth practices in occupational therapy worldwide and to get insight into facilitators and barriers in utilising this form of service delivery. The survey was circulated in the occupational therapy community by the World Federation of Occupational Therapists (WFOT) between April and July 2020, collecting responses to closed-ended questions, in addition to free-text comments. 2750 individual responses from 100 countries were received. The results revealed a significant increase in the use of telehealth strategies during COVID-19, with many reported benefits. Occupational therapists who used telehealth were more likely to score higher feelings of safety and positive work morale and perceived their employer's expectations to be reasonable. Restricted access to technology, limitations of remote practice, funding issues and slow pace of change were identified as barriers for some respondents to utilising telehealth. Facilitators included availability of supportive policy, guidelines and strategies, in addition to education and training.

Keywords: occupational therapy, accessibility, implementation, Information Communication Technologies, COVID-19

Target Group: Occupational therapy educators and organisations, policymakers.

Type of evidence
Viktoria Hoel (DISTINCT ESR 9)
An online global needs-assessment survey among occupational therapists worldwide.

References:

Hoel V, von Zweck C, Ledgerd R. Was a global pandemic needed to adopt the use of telehealth in occupational therapy? Work. (2020). doi:10.3233/wor-205268.

Hoel V, Zweck Cv, Ledgerd R. The impact of Covid-19 for occupational therapy: Findings and recommendations of a global survey. World Federation of Occupational Therapists Bulletin. (2021) 1-8. doi:10.1080/14473828.2020.1855044.

- ***Digital Health Technologies are recommended to support fully Comprehensive Geriatric Assessments, because they improve communication and data transfer of patient medical data, health decision-making, and sharing of assessment responsibility between different professionals, thereby reducing the psychological burden of individual healthcare professionals*** [3.3.3.12]

Guidance: To provide high-quality elderly and dementia care, Digital Health Technologies (DHTs) can potentially help achieve the full capacity of Comprehensive Geriatric Assessments (CGAs). In addition they can improve communication and data transfer on patients' medical and treatment plan information between care settings and stakeholders as well as improve health decision-making. Finally, they can help to share the responsibility of the geriatric assessment between professionals, thereby avoiding overloading the workload of individual users and reducing their psychological stress.

Explanation and Examples: Due to the higher rate of transitions between care settings in older populations, associated with the complexity of an ageing population and the shift from institutional care to home care, CGAs have become an important assessment tool as they encompass multiple domains and address the variety of complex problems in frail older people. They are considered as multidimensional assessments, using quantitative assessment scales, that support multidisciplinary care teams in clinical decision-making and personalized care planning to meet the needs of older people, their families and carers, focusing on functional status and quality of life.

However, to reach the full potential of CGAs, their implementation should be supported by electronic data systems, which provide relevant outputs and allow timely sharing of information within multidisciplinary teams of healthcare professionals and between different healthcare settings. The use of DHTs can potentially help them reach their full capacity and overcome the data transfer limitations between care settings and stakeholders. To improve the usability and implementation of these DHTs, the following features are recommended: a) accessibility of individual assessment by multiple healthcare professionals and the possibility of splitting sections according to professional expertise to share responsibility for assessments; b) the use of secure data storage, such as clouds; c) automatization of real-time calculation of scales and outcomes with a graphical representation of the person's profile and health status; d) automatic alerts, notifications and continuous monitoring of item completion; and e) provision of personalized care plans according to the data collected.

Well-designed digital health technologies can contribute to the safety of the potential users (e.g. healthcare professionals and stakeholders) and reduce psychological stress, including burnout and low morale, by avoiding overloading the workload of healthcare professionals. For example, by sharing the responsibility for carrying out the assessments between different professionals.

Keywords: Comprehensive Geriatric Assessment, Digital Health Technologies, implementation, older adult care, dementia care.

Target group: Researchers, stakeholders, healthcare professionals and caregivers.

Type of evidence

Mauricio Molinari-Ulate (DISTINCT ESR7)
Systematic review

References

Molinari-Ulate, M., Mahmoudi Asl, A., Franco Martin, M., & van der Roest, H. (2022). Psychometric Characteristics of Comprehensive Geriatric Assessments (CGAs) for long-term care facilities and community care: A Systematic Review. Ageing Research Reviews, 81.
doi: https://doi.org/10.1016/j.arr.2022.101742

Molinari-Ulate, M., Mahmoudi Asl, A., Parra-Vidales, E., Muñoz-Sánchez, J. L., Franco Martin, M., & van der Roest, H.. Digital Health Interventions (DHIs) supporting the application of Comprehensive Geriatric Assessments (CGAs) in long-term care settings and community care: Systematic Review (Submitted, under review).

3.3.4 Social Health Domain 1: Fulfill ones potential and obligations

- ***Health and social care professionals working with people with Young Onset Dementia should clearly signpost to online peer support as part of post-diagnostic care*** [3.3.4.1/3.3.5.1/3.3.6.4]

Guidance: Health and social care professionals working with people with Young Onset Dementia should clearly signpost to online peer support services, to help people find the support they need.

Explanation and Examples: Peer support can be highly beneficial for people with Young Onset Dementia and make the post-diagnostic period more positive. It can contribute to different aspects of social health: their ability to fulfill one's potential and obligations, management of their own life and participation in social activities. People can share experiences, information, and coping skills in these areas. This goes beyond support that health and social care professionals, or friends and family can give. Given these benefits, peer support should be accessible to every person living with Young Onset Dementia. However, access to specialised (support) services varies widely across the UK. Therefore, online peer support could offer a solution.

Our research showed that people with Young Onset Dementia experienced a severe lack of support and signposting to (peer) support services. Benefits of having peer support online included not having to travel, not having the sensory overload of being in a room full of people, and finding it comfortable to join from their own home. Having their support group gave many of them hope again, and some called it their lifeline. Our online survey showed that the main reason why people did not use online peer support was that they did not know it existed, or they did not know where to look for support. Some of those who did not have experience with online peer support would be interested if they knew where to find it. This indicates a need for professionals to clearly signpost to (online) peer support services and information.

Keywords: Online intervention, people with dementia, peer support, Young Onset Dementia

Target group: Healthcare providers and patient organisations, clinicians, professional carers

Type of evidence

Esther Gerritzen (DISTINCT ESR2). Focus groups, online survey, and individual interviews with people with Young Onset Dementia in the UK.

References

Gerritzen EV, Kohl G, Orrell M, McDermott O. Peer support through video meetings: Experiences of people with young onset dementia. Dementia. 2022;0(0). doi:10.1177/14713012221140468

- ***Moderators of online peer support groups for people with Young Onset Dementia on text-based platforms should ensure the group is closed, and provide a clear description of the purpose of the group, who it is for, and what the ground rules are*** [3.3.4.2/3.3.5.2/3.3.6.5]

Guidance: Online peer support groups on text-based platforms, such as Facebook groups or discussion forums, can have a much larger membership than in-person groups or groups using videoconferencing platforms. Moderators should provide a clear description of the purpose of the group and who it is for, and what the ground rules are.

Explanation and Examples: Findings from an extensive systematic literature research on online peer support for people with different chronic, neurodegenerative conditions, identified several elements of best practice. Online health communities, for example on social media or discussion forums can have a large membership and tend to be more anonymous in nature. To prevent access by people for whom the group is not really intended, the group should be closed. This means that the moderators need to approve before new members can join. This goes hand in hand with the purpose of the group and who it is for. For example, if the group is only for people living with a Young Onset Dementia diagnosis, moderators may want to avoid that family members, healthcare professionals, or researchers access the group. This is to allow the members to speak freely and to respect their privacy. It is also important to clearly indicate, preferably on the home page, who the group is for. Is it only for people with a diagnosis, only for carers, or for both? Finally, it is the responsibility of the moderator to intervene when someone shares harmful, misleading, or disrespectful content in the group. The moderator should delete such messages and, if possible, contact the author. In this way the moderator ensures the group remains a safe space for everyone.

The findings of the systematic literature review were echoed by people with Young Onset Dementia who took part in individual interviews and had experiences with peer support on text-based platforms.

Keywords: Online intervention, people with dementia, peer support, Young Onset Dementia, text-based platforms

Target group: Social care providers, healthcare providers and patient organisations

Type of evidence

Esther Gerritzen (DISTINCT ESR2).
Systematic literature review on online peer support for people with Parkinson's Disease, MS, and ALS.

References

Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Parkinson's Disease: Narrative synthesis systematic review. JMIR Aging, 5(3). https://doi.org/10.2196/35425 https://aging.jmir.org/2022/3/e35425

Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Multiple Sclerosis: Narrative synthesis systematic review. International Journal of MS Care 1 November 2022; 24 (6): 252–259. doi: https://doi.org/10.7224/1537-2073.2022-040

Gerritzen, E.V., Lee, A.R., McDermott, O., Coulson, N., & Orrell, M. (2022). Online peer support for people with Amyotrophic Lateral Sclerosis: Narrative synthesis systematic review. (Submitted, under review)

- ***E-learning interventions, such as the iSupport-Sp, should be considered as alternative support services to reach caregivers of people with dementia living in remote areas, thus increasing service coverage*** [3.3.4.3]

Guidance: To provide informal caregivers of people with dementia living in remote areas with alternative support services, e-learning interventions can overcome some constraints of in-person services, such as costs and transport to the venues, and might increase the reach of services. However, these e-learning interventions should follow a set of recommendations tailored to the rural context in order to be effective.

Explanation and Examples: E-learning interventions have proven effective in helping caregivers of people living with dementia, with benefits in terms of knowledge about dementia and social and emotional support. The most effective interventions are those with multiple psychotherapeutic components, such as Cognitive Behavioural Therapy and relaxation exercises, educational resources, online peer support groups, and interaction with healthcare professionals.

However, for these interventions to be successful in a specific context, such as that of rural populations, a process of cultural adaptation, co-design and implementation is needed. For example, some of the concerns expressed by the focus groups in our qualitative study into the adaptive implementation of an online support programme for caregivers, iSupport-Spanish version, concerned the local availability of technological devices or internet access in rural areas. Some recommendations that resulted from the process of co-design and cultural adaptation were:

a) make the platforms accessible through a personal link instead of a username and password;

b) make the platforms available in public spaces for those without access to Wi-Fi or technological devices, e.g. community libraries, town halls, etc.;

c) use a multiplatform format (e.g., computer, smartphone, tablets);

d) make information available through audio and text (both modalities);

e) include images and videos accompanying the text;

f) offer the possibility to personalized letter size and background colours;

g) avoid technical words (use simple language);

h) offer feedback from healthcare professionals and support groups; and

i) offer the information in slide format.

Support interventions for caregivers, such as the iSupport-Sp (available at https://learning.bluece.eu/), could improve their quality of life and the quality of care, reduce caregiver burden, improve care service delivery, and could help to cope with care responsibilities.

Keywords: Co-design, cultural adaptation, adaptive implementation, e-learning, iSupport, psychoeducation, caregivers of people living with dementia

Target group: Researchers, stakeholders, people living with dementia, and caregivers.

Type of evidence

Mauricio Molinari-Ulate (DISTINCT ESR7)

Qualitative study, online focus groups, cultural adaptation, co-design

References

Molinari-Ulate M, Guirado-Sánchez Y, Platón L, van der Roest HG, Bahillo A, Franco-Martín M. Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain. Dementia. 2023;0(0). doi:10.1177/14713012231165578

- ***Researchers and designers of web-based psychosocial interventions for people with dementia and carers are strongly recommended to collaborate with dementia support organisations as they can support implementation, dissemination, and use of these interventions*** [3.3.4.4]

Guidance: Researchers and developers of web-based psychosocial interventions for people with dementia and carers should consider working together with existing dementia charities and support organisations during the intervention development. During the implementation and dissemination phase, these charities and organisations can be supportive in informing the public about the intervention, thereby increasing its potential use.

Explanation and Examples: Existing research has shown the need for easily accessible psychosocial interventions for people with dementia and carers. Many people affected by dementia reach out to existing and well-established dementia support organisations and charities, such as Alzheimer's Society UK in the UK, after they received the diagnosis. We conducted focus groups with 17 people with dementia and family carers to inform the development of a web-based psychosocial intervention. In these consultations, several participants pointed out that the intervention needs to be easy to find. Therefore, they suggested integrating it into the online content of dementia support organisations since these organisations are often the first source of support for people with dementia and carers. For example, the dementia support organisation (e.g., Alzheimer's Society UK) could have a link on its website for people with dementia and carers that leads them to the intervention. Working together with these dementia support organisations during the intervention development phase can enhance the intervention's implementation, dissemination, and future use. It will also enable easy access to the intervention and enhance its credibility and trustworthiness.

Keywords: Dementia; implementation; online intervention; usability

Target group: Dementia researchers, developers and designers of digital interventions

Type of evidence

Gianna Kohl (DISTINCT ESR10)
Qualitative focus group study with 17 people affected by dementia

References

Kohl, G., Cardoso, S., Heins, P., Scior, K., & Charlesworth, G. (2023). Guidance for moving psychosocial interventions online: A worked example of adapting 'Who to tell, how and when' for people living with dementia. (Submitted)

3.3.5. Social Health Domain 2: Manage ones own life and promote independence

- ***Health and social care professionals working with people with Young Onset Dementia should clearly signpost to online peer support as part of post-diagnostic care*** [3.3.5.1, see 3.3.4.1]

- ***Moderators of online peer support groups for people with Young Onset Dementia on text-based platforms should ensure the group is closed, and provide a clear description of the purpose of the group, who it is for, and what the ground rules are*** [3.3.5.2, see 3.3.4.2]

- ***Researchers and technology developers developing, implementing and evaluating technological solutions promoting social health for community-dwelling dementia caregiving dyads should take on a relationship-centred approach*** [3.3.5.3]

Guidance: Researchers and technology developers should be aware of the mutual influence care recipients and caregivers have on each other, and the importance of maintaining and improving caregiving relationships. Therefore they should adopt a dyadic approach to the development, implementation and evaluation of technology-driven interventions by involving both members of the dyad.

Explanation and Examples: A mixed-methods feasibility study investigated the impact of a tablet-based activation system on nine community-dwelling caregiving dyads living with dementia, their motivations to use social technology together, and facilitating and impeding factors in the independent use of social technology at home. In light of the SARS-CoV-2 pandemic, it was clear that the extent to which the caregiving dyads were influenced by the extreme social isolation depended on how socially active they were before the pandemic, and their familiarity with social technology. The dyads' motivations for welcoming technology in their social interactions ranged from trying something new together, keeping up with society to communication support.

Identified facilitators and barriers revealed that user capabilities (care recipients' cognitive capacities and caregivers' energy to support their loved ones); user willingness (technology interest) and sufficient support (proactive, continuous and in-person) are three crucial elements in using social technology independently at home.

These contextual factors should be approached from a dyadic perspective taking into account the needs and preferences of both members of the dyad. Technology promoting social participation cannot be developed for people living with dementia without taking into account the needs of their caregivers, and vice versa.

Keywords: caregiving dyads, meaningful activities, relationship maintenance, social participation, tablet intervention

Target Group: Technology developers; Researchers; Researchers involved in developing digital applications

Type of evidence

Viktoria Hoel (DISTINCT ESR9)
Results from a mixed-methods feasibility study

References

Hoel, V., E.A. Ambugo, and K. Wolf-Ostermann, Sustaining Our Relationship: Dyadic Interactions Supported by Technology for People with Dementia and Their Informal Caregivers. International Journal of Environmental Research and Public Health, 2022. **19**(17): p. 10956.

Hoel, V., K. Wolf-Ostermann, and E.A. Ambugo, Social Isolation and the Use of Technology in Caregiving Dyads Living With Dementia During COVID-19 Restrictions. Frontiers in Public Health, 2022. 10.

- ***Recommended design and implementation framework for social assistive robotics for people with dementia*** [3.3.5.4]

Guidance: While designing social assistive robots the following recommended features should be considered to promote successful implementation: low-cost affordable design (pet robot is preferred to humanoid), language mutation for target user and integration with Smart Home IoT (including IoT security mechanisms). During the development phase co-creation should be promoted.

Explanation and Examples: These recommendations are based on the main findings of a scoping review. The scoping review investigated the state-of-the-art in social assistive robotics, i.e. the current technological advances towards a single framework for effective, safe and secure implementation of social robots for people with dementia. The scoping review qualitatively examined the literature on the use of companion robots, including both pet-like and humanoid robots, and Internet-of-Things (IoT) security, coupled with the new 5G technology for home-based elder care. A comprehensive search strategy was developed and selected databases were looked through with relevant keywords. From the 355 full-text articles found, 90 articles were selected to be examined. In order to ascertain the operation of social assistive robots in the future, remaining challenges, unused opportunities, security risks and suggested remedies are discussed, and a dementia-centred concept and implementation framework proposed.

The following set of recommendations were formulated based on the main findings:

- Consider using a pet robot instead of a humanoid assistive robot as the high cost of the latter for a similar impact and user acceptance cannot be justified.

- Consider low-cost, affordable design and various language mutations for wider deployment in practice, thus allowing more comparative studies, which could provide convincing arguments for using the robot.

- Integrate robot with Smart Home IoT to enhance its functionality towards managing ones own life and promote independence.

- Consider data security, and especially IoT security, prevention mechanisms while integrating the social robot with IoT smart home sensorics.

- Promote wider user involvement and higher level of participation (co-creation) in the development phase of the robot.

- Introduce clearly, and particularly identify, the concerns and needs of people with dementia in the design process.

- List the potential risks and misuses of IoT vulnerabilities, including their remedies, in the design process.

Keywords: Ambient assisted living technologies, Dementia, Elderly care, Internet-of-things security, Social robotics.

Target group: Assistive technology developers; social robot designers; researchers; dementia care organisations (e.g. nursing homes, day care centres) and policy-makers.

Type of evidence

Jaroslav Cibulka (DISTINCT ESR8)
Scoping review

References

Ozdemir D, Cibulka J, Stepankova O, Holmerova I. Design and implementation framework of social assistive robotics for people with dementia - a scoping review. Health and Technology. 2021;11(2):367-78. doi:https://doi.org/10.1007/s12553-021-00522-0.

- ***Signpost people with dementia to social media as accessible, virtual platforms to share experiences and information*** [3.3.5.5]

Guidance: Social media have the potential to be an additional supportive medium for people with dementia. It is recommended to signpost individuals with dementia to social media platforms to leverage their potential.

Explanation and Examples: We conducted an online survey with 143 people with dementia to explore how they used social media platforms and what kind of information they shared on their accounts. Our findings show that people with dementia use various different social media platforms like Facebook or Twitter to raise awareness, give and receive support, and to share their experiences of living with dementia. As subsequent older generations will use technology more and, consequently, will become more tech-savvy, social media platforms will become more relevant for this population. As post-diagnostic support is often lacking, social media platforms can be used as medium that is widely available and easily accessible to offer people with dementia additional (peer) support. Examples of these platforms include online forums like Talking Point by the Alzheimer's Society UK, Facebook groups run by charities or dementia organisations, or Twitter where many people with dementia are active. Signposting people with dementia to these social media platforms is therefore recommended.

Keywords: Information Communication Technologies, social media, people with dementia, Young Onset Dementia, support

Target group: People with dementia, clinicians, professional carers, dementia organisations

Type of evidence

Gianna Kohl (DISTINCT ESR10)
Cross-sectional online survey with 143 people with dementia

References

Kohl, G., Koh, W.Q., Scior, K., & Charlesworth, G. (2023). *Social media use among younger and older people with dementia: An internet-mediated mixed-methods study*. Manuscript submitted to Computers in Human Behavior.

- ***Researchers and designers of web-based psychosocial interventions for people with dementia and carers are strongly recommended to collaborate with dementia support organisations as they can support implementation, dissemination, and use of these interventions*** [3.3.5.6; see 3.3.4.4]

3.3.6. Social Health Domain 3: Technology to promote social participation

- ***Make sure social robots work well with residents and consider practical challenges when implementing social robots in nursing homes*** [3.3.6.1]

Guidance: Understanding how social robots positively impact nursing home residents as well as analysing practical challenges are important when implementing robotic assistive technology in nursing homes.

Explanation and Examples: An important *facilitating factor* to the acceptance of social robots in nursing homes is understanding and seeing how social robots positively impact residents, for example by improving the communication, decreasing loneliness, providing joy to residents, calming agitated residents or generally increasing their wellbeing. Understanding these benefits will facilitate the acceptance of social robots by staff as well as by relatives, but is also important for the resident to accept the social robot, as their acceptance will be influenced by the views and attitudes of staff and relatives.

On the other hand, one of the key *hindering factors* to the acceptance of social robots in nursing homes are practicalities of everyday life in the nursing home, such as storage, hygiene, finding a quiet place, scheduling time for robot use or the need to charge the robot.

We conclude, that applying an acceptance model of social robots (here the Almere Model) is an interesting and feasible way to trace facilitators and barriers of implementation of social technology in nursing homes, where involvement in social activities and enhancing positive experiences are important foci of interventions to improve social health.

Keywords: Acceptance, Social robots Implementation, Dementia, Nursing Home

Target group: Care Home and Nursing Home Providers, Care Organizations and Professionals, Management of Care Organisations, Nursing Homes

Type of evidence

Simone Anna Felding (DISTINCT ESR4)
Scoping review.

References

Felding, Simone Anna, Koh, Wei Qi, Teupen, Sonja, Budak, Kübra Beliz, Laporte Uribe, Franziska & Roes, Martina. A Scoping Review Using the Almere Model to Understand Factors Facilitating and Hindering the Acceptance of Social Robots in Nursing Homes. *International Journal of Social Robotics* (2023). https://doi.org/10.1007/s12369-023-01012-1.

- ***Consider different contextual factors to implement social robots in dementia care*** [3.3.6.2]

Guidance: Technology developers and researchers should be aware of the different contextual factors that can affect the translation of research on social robots to real-world use.

Explanation and Examples: Barriers and facilitators affecting the implementation of social robots can occur at different levels. For example, they relate to the social robots' features, or relate to organisational factors or external policies. A scoping review was conducted to understand the barriers and facilitators to the implementation of social robots for older adults and people living with dementia. 53 studies were included in this review. Most existing studies have disproportionately focused on understanding barriers and facilitators relating to the social robots, such as their ease of use. However, there is significantly less research that has been conducted to understand organisational factors or wider contextual factors that can affect their implementation in real-world practice. Future research should pay more attention to investigating the contextual factors, using an implementation framework, to identify barriers and facilitators on different levels to guide the further implementation of social robots.

Keywords: Implementation research, older adults, dementia social robots, pet robots, socially assistive robots, barriers and facilitators

Target group: Social robot developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)

Collaborators: Simone Felding (DISTINCT ESR4), Beliz Budak (DISTINCT ESR15)

Scoping review

References

Koh, W. Q., Felding, S. A., Budak, K. B., Toomey, E., & Casey, D. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review. BMC geriatrics, 21(1), 1-17.

- ***Loneliness should be included in future technology intervention studies as an outcome in order to study the effect of active assisted living (AAL) technologies on loneliness of people with dementia in long-term care*** [3.3.6.3]

Guidance: Implementing assistive technology could be promising in long-term care to address loneliness in dementia, but further studies are needed to tailor assistive technology to people living with dementia in different care settings and to investigate its effect on loneliness.

Explanation and Examples: Active & Assisted Living (AAL) technology aims to support coping with the consequences of dementia. A scoping review was conducted to learn if and how AAL addresses loneliness in people living with dementia in long-term care. Although, only one study focused directly on the impact of AAL technology on loneliness, findings suggest that AAL were used in the context of psychosocial interventions and proved to have had an impact on loneliness in people living with dementia. It remains unclear why loneliness was almost never included as an outcome in technology studies. Since we were not able to derive clear effects of assistive technology on loneliness from the included studies, we recommend using loneliness outcome measures in future intervention studies into AAL technology.

Keywords: Loneliness; social isolation; Active & Assisted Living technology; long-term care; dementia

Target group: Assistive technology developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence:

Beliz Budak (DISTINCT ESR15)
Scoping review

References:

Budak, K. B., Atefi, G., Hoel, V., Laporte Uribe, F., Meiland, F., Teupen, S. A., Felding, Roes, M. (2021). Can technology impact loneliness in dementia? A scoping review on the role of assistive technologies in delivering psychosocial interventions in long-term care. Disability and Rehabilitation: Assistive Technology. doi:10.1080/17483107.2021.1984594

Koh, W. Q., Felding, S. A., Budak, K. B., Toomey, E., & Casey, D. (2021). Barriers and facilitators to the implementation of social robots for older adults and people with dementia: a scoping review. BMC geriatrics, 21(1), 1-17.

- ***Health and social care professionals working with people with Young Onset Dementia should clearly signpost to online peer support as part of post-diagnostic care*** [3.3.6.4, see 3.3.4.1]

- ***Moderators of online peer support groups for people with Young Onset Dementia on text-based platforms should ensure the group is closed, and provide a clear description of the purpose of the group, who it is for, and what the ground rules are*** [3.3.6.5 see 3.3.4.2]

- ***Technological solutions to safeguard the social health of nursing home residents with dementia should be incorporated in caregiving as standard alternatives of social connections*** [3.3.6.6]

Guidance: Technological solutions that can safeguard the social health of nursing home residents with dementia should be implemented as an integrated part of caregiving procedures. This requires formally incorporated technology guidelines and continuous training of staff. As developing and implementing technology to promote social participation faces substantial barriers as long as social health is not recognized on equal terms as the physical and mental health domains, first, social health needs to be acknowledged as a priority which requires major efforts at the societal-, organizational and individual levels.

Explanation and Example: Cross-sectional data from a national online survey conducted among German nursing homes, on the impact of the COVID-19 pandemic, showed that efforts were made to ensure social participation among residents with dementia, and the use of technology in doing so.

A large proportion of respondents observed an increase in at least one Behavioural and Psychological Symptom in Dementia (BPSD) in residents with dementia. Many reported that social activities in the nursing home were cancelled, which was due to COVID-19 cases and staff shortages from 5 % and up, revealing just how easily neglectable social health strategies in nursing homes are. Half of all respondents reported having had no formal training in the use of social technology to engage their residents with dementia. Although more than 70% had provided opportunities for using technology for social purposes, the low frequency of established procedures seems to indicate ad hoc solutions to ensure the social health of residents with dementia.

At the micro-, meso- and macro level requirements were identified to promote social participation using technology. These requirements revealed that integrating technological solutions in institutional settings, requires efforts at individual-, organisational and societal level.

Keywords: COVID-19, nursing home, social isolation, social participation, social technology

Target Group: Care home and nursing home providers, Nursing homes, Policymakers

Type of evidence

Viktoria Hoel (DISTINCT ESR 9)
Cross-sectional multi-methods study.

References

Hoel, V., Seibert, K., Domhoff, D., Preuß, B., Heinze, F., Rothgang, H., Wolf-Ostermann, K. *Social* Health among German Nursing Home Residents with Dementia during the COVID-19 Pandemic, and the Role of Technology to Promote Social Participation. International Journal of Environmental Research and Public Health, 2022. 19(4): p. 1956.

- ***Assess, facilitate, tailor, monitor and evaluate the use of pet robots with individual people with dementia to minimise the risk of potential negative impacts*** [3.3.6.7]

Guidance: To minimise potential distress and negative impacts from using pet robots, researchers and care providers should assess their suitability for individuals with dementia, and facilitate their use based on each individual's preference, needs and abilities. As the needs of people with dementia can fluctuate, care providers should also monitor and re-evaluate the use of pet robots.

Explanation and Examples: Findings from a scoping review of eight studies showed that some people with dementia did not respond to pet robots. Some had negative responses such as agitation, or became jealous when the robot was shared with other residents in care facilities. An analysis of 1,327 consumer reviews on a low-cost robotic cat showed similar findings. Likewise, interviews with care providers from nursing homes revealed that they had similar experiences. To minimise the risks of

potential negative impacts, the use of pet robots for each individual has to be carefully considered. This should encompass:

- Assessment
  Assess the individual's preferences, needs, functional abilities and needs (e.g. occupational needs, and physical, cognitive, and sensory abilities). If used in a care setting, consider discussing the use of pet robots with family members.
- Facilitation and Tailoring
  Based on the assessment, provide facilitation or tailored support to individuals. For example, if the individual has difficulties initiating interactions with the pet robot, consider providing assistance
- Monitoring & Evaluating
  Monitor and evaluate the individual's reaction to pet robots, and intervene if the individual shows signs of distress. These observations should be shared with and discussed with other care providers if used in care facilities

Keywords: Older adults, dementia social robots, low-cost pet robots, robotic pets, psychosocial impact

Target group: Social robot developers, dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborator: Pascale Heins (DISTINCT ESR11)
Scoping review, qualitative content analysis, qualitative study (interviews with care providers), modified Delphi study

References

Koh, W. Q., Ang, F. X. H., & Casey, D. (2021). Impacts of low-cost robotic pets for older adults and people with dementia: scoping Review. JMIR rehabilitation and assistive technologies, 8(1), e25340, 1-14. https://doi.org/10.2196/25340.

Koh, W. Q., Whelan, S. A., Heins, P., Casey, D., Toomey, E., & Dröes, R.M. (2021). Usability and impact of a low-cost robotic pet for older adults and people with dementia: a qualitative content analysis of user experiences and perceptions on consumer websites. JMIR Aging, 5(1), e29224, 1-16. https://doi.org/10.2196/29224.

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Koh, W. Q., Hoel, V., Casey, D., & Toomey, E. (2022). Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2022.09.010

- ***Involve residents with dementia and their family members in the implementation of pet robots in long-term care settings*** [3.3.6.8.]

Guidance: Residents with dementia and their family members should be involved when planning to introduce pet robots in long-term care settings and when using pet robots.

Explanation and Examples: In a consensus-building exercise involving 56 international experts (care professionals, organisational leaders and researchers), experts established the importance of including residents with dementia and their family in the implementation of pet robots in long-term care facilities. When planning to adopt pet robots in long-term care facilities, the opinions of residents with dementia and their family members must be sought. Examples include:

- Seeking their opinions on which pet robot to purchase by showing them different pet robots, and asking or observing their reactions to each robot
- Seeking feedback on their preferred ways of using robots, such as whether they prefer the robots to be individualised or shared with other residents.

When using pet robots, residents with dementia and their family members must be supported to be actively involved. For example:

- Residents may be involved in "taking care" of robots.
- Family members could provide support or use the robots as topics of conversations during visits.

Keywords: Implementation research, implementation strategies, long-term care settings, care homes, nursing homes, older adults, dementia social robots, pet robots

Target group: dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborators: Viktoria Hoel (DISTINCT ESR9)
Qualitative study, modified Delphi study

References

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Koh, W. Q., Casey, D., Hoel, V., & Toomey, E. (2022). Strategies for implementing pet robots in care homes and nursing homes for residents with dementia: protocol for a modified Delphi study. Implementation Science Communications, 3(1), 58, 1-10. https://doi.org/10.1186/s43058-022-00308-z.

Koh, W. Q., Hoel, V., Casey, D., & Toomey, E. (2022). Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2022.09.010

- ***Before introducing pet robots in a long-term care facility, conduct stakeholder consensus discussions and assess organisational readiness*** [3.3.6.9]

Guidance: Before introducing pet robots in a long-term care facility, consensus discussions among stakeholders, such as care professionals and managers, should be conducted, to discuss whether (and why) pet robots should or should not be introduced for residents with dementia. In addition, the facility's readiness to introduce pet robots should be carefully considered.

Explanation and Examples: In a modified Delphi study involving 56 international experts (care professionals, organisational leaders and researchers), experts agreed that these strategies are critical to support the implementation of pet robots in long-term care facilities. Consensus discussions should involve all care providers who may be directly or indirectly involved in the care of residents with dementia. Examples of discussions may include:

- The importance of bringing in/using pet robots to address a chosen problem (e.g. to address residents' needs or support care staff in their delivery of care for residents with dementia)
- Appropriateness of using pet robots to address the problem(s), such as whether they align with workflows.

In addition, the organisation's readiness to implement pet robots should also be assessed. Examples include:

- Assessment of financial resources
- Assessment of manpower and logistical resources (e.g. sufficient space and charging point).

Keywords: Implementation research, implementation strategies, long-term care settings, care homes, nursing homes, older adults, dementia social robots, pet robots

Target group: dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborators: Viktoria Hoel (DISTINCT ESR9)
Qualitative study, modified Delphi study

References

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Koh, W. Q., Casey, D., Hoel, V., & Toomey, E. (2022). Strategies for implementing pet robots in care homes and nursing homes for residents with dementia: protocol for a modified Delphi study. Implementation Science Communications, 3(1), 1-10.

Koh, W. Q., Hoel, V., Casey, D., & Toomey, E. (2022). Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2022.09.010

- ***Conduct educational meetings and provide ongoing training to support care professionals to use pet robots for dementia caregiving*** [3.3.6.10]

Guidance: Care staff should be educated about the use of pet robots in dementia care through educational meetings that are tailored to the needs of different staff. In addition, they should be provided with ongoing trainings to support them in applying this knowledge as part of their delivery of dementia care.

Explanation/examples: In a modified Delphi study involving 56 international experts (care professionals, organisational leaders and researchers), educational meetings and ongoing trainings are identified as critical strategies to support the implementation of pet robots in long-term care facilities. The purpose of conducting educational meetings is to provide care staff with overall knowledge on the role of pet robots for dementia care. Such sessions should be tailored to the different needs of each care professional. Examples of content may include:

- Evidence supporting the use of pet robots in dementia care, such as information about their impacts on residents, who may benefit and who may be at risk of distress
- How pet robots can support caregiving

While the purpose of education is to provide overall knowledge about pet robots, the purpose of conducting ongoing training is to support care professionals to acquire practical skills and confidence to use pet robots in dementia care giving. Examples include:

- On-the-job training
- Structured supervision
- Training based on each staff experiences/knowledge.

Keywords: Training of care professionals, Implementation research, implementation strategies, long-term care settings, care homes, nursing homes, older adults, dementia social robots, pet robots

Target group: dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborators: Viktoria Hoel (DISTINCT ESR9)
Qualitative study, modified Delphi study

References

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Koh, W. Q., Casey, D., Hoel, V., & Toomey, E. (2022). Strategies for implementing pet robots in care homes and nursing homes for residents with dementia: protocol for a modified Delphi study. Implementation Science Communications, 3(1), 1-10. https://doi.org/10.1186/s43058-022-00308-z

Koh, W. Q., Hoel, V., Casey, D., & Toomey, E. (2022). Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2022.09.010

- ***Consider different sources of funding to support the implementation of pet robots for people with dementia within long-term care facilities*** [3.3.6.11]

Guidance: The cost of pet robots can prohibit their uptake in long-term care facilities for dementia care. There may also be additional costs involved in implementing pet robots, such as manpower and time related costs. Different funding sources need to be considered to acquire sufficient funding to support the implementation effort.

Explanation/examples: In a qualitative study involving 22 care providers from nursing homes, the cost of purchasing pet robots have been reported as a concern. Some care providers reported the use of charity funds to support the purchase of pet robots. In a modified Delphi study, experts (care professionals, organisational leaders and researchers) established that it is necessary to creatively seek and acquire funding to support the implementation of pet robots in long-term care facilities. Examples of potential funding sources may include:

- Existing funding resources
- Raising private funds (such as donations or charity)
- Shifting or (re)prioritising the use of funds within the organisation based on their impact on people with dementia

The funds may be used to support different aspects of implementation. Examples include:

- Fund the introduction and adoption of pet robots
- Support other time limited actions needed for initial implementation, such as purchasing cleaning materials
- Training (e.g. developing educational materials)

Keywords: Implementation research, implementation strategies, long-term care settings, care homes, nursing homes, older adults, dementia social robots, pet robots

Target group: dementia researchers, healthcare professionals, dementia care organisations (e.g. nursing homes, day care centres)

Type of evidence

Wei Qi Koh (DISTINCT ESR12)
Collaborators: Viktoria Hoel (DISTINCT ESR9)
Qualitative study, modified Delphi study

References

Koh, W.Q., Toomey, E., Flynn, A. & Casey, D. (2022). Determinants of implementing of pet robots in nursing homes for dementia care. BMC Geriatrics, 22(1), 457, 1-12. https://doi.org/10.1186/s12877-022-03150-z.

Koh, W. Q., Casey, D., Hoel, V., & Toomey, E. (2022). Strategies for implementing pet robots in care homes and nursing homes for residents with dementia: protocol for a modified Delphi study. Implementation Science Communications, 3(1), 1-10. https://doi.org/10.1186/s43058-022-00308-z

Koh, W. Q., Hoel, V., Casey, D., & Toomey, E. (2022). Strategies to Implement Pet Robots in Long-Term Care Facilities for Dementia Care: A Modified Delphi Study. Journal of the American Medical Directors Association. https://doi.org/10.1016/j.jamda.2022.09.010

- ***Users of tablet based interventions and care-providers should make evidence-based decisions about implementation strategy, taking into account important context, implementation and mechanisms of impact factors*** [3.3.6.12]

Guidance: There are many considerations when planning to implement technological interventions. The issues can be grouped into context, implementation and mechanism of impact factors. Evidence from the FindMyApps project has identified, within these categories, specific factors that are important for successful implementation of a tablet-based intervention, such as FindMyApps. Potential tablet-users and care providers are advised to base their decisions on this evidence.

Explanation/examples: The FindMyApps project compared the FindMyApps intervention to usual tablet use by community-dwelling people with mild cognitive impairment (MCI) or mild dementia. The following factors were identified as influencing the success of implementation of both the FindMyApps intervention and a standard tablet:

- Context:
  - People with MCI/mild dementia who previously used a tablet are more likely to use the intervention. Intensive one-on-one support is recommended to those who have never used a tablet.
  - People with MCI and younger people with MCI/mild dementia may use the intervention more. Extra support is recommended for older people with dementia.
  - People experiencing apathy may benefit more from dementia-specific tablet programmes, such as FindMyApps, which provide easy access to selected apps, than from a standard tablet.
- Implementation:
  - People with slower Wi-Fi connections may find the tablet harder to use.
  - It is often feasible to provide support by telephone and/or video-call but face-to-face contact is more suitable for those who have never used a tablet before.
  - Few people use passive support, such as a telephone helpdesk. It is therefore recommended to pro-actively offer support to those who may need it (see above).
- Mechanisms of impact:
  - Tablet-use may support social contact and engagement in meaningful activities, more than instrumental activities of daily living. It is recommended to set personal goals accordingly.
  - Limitations of specific tablet-apps (e.g. pop-up advertising, requirements for user-accounts with passwords) should be considered.
  - The *quality* of tablet-use, seems more important for social health than the *quantity* (frequency of duration) of tablet use. Set personal goals and evaluate accordingly.

Keywords: tablet intervention; process evaluation; implementation; FindMyApps

Target group: Professional carers, clinicians, welfare professionals, who promote the use of technology to people with cognitive impairments and dementia; family carers; people living with dementia

Type of evidence

David Neal (ESR6)

Mixed methods process evaluation (following UK MRC guidance) alongside a randomized controlled trial. Data collected in the Netherlands, January 2020 to November 2022, from automatically recorded observations of app usage, self- and proxy-report questionnaires, and semi-structured interviews.

References

Neal D., Kuiper L., Pistone D., Osinga C., Nijland S., Ettema T., Dijkstra K., Muller M., Dröes R. M. FindMyApps eHealth intervention improves quality, not quantity, of home tablet use by people with dementia. 2023. 10. doi: 10.3389/fmed.2023.1152077

- ***Adaptive implementation processes are required to successfully implement psychosocial applications of technology in dementia care*** [3.3.6.13]

Guidance: To successfully implement psychosocial applications of technology in dementia care, it is recommended to carry out implementation processes adapted to the context of interest and to adapt training materials socio-culturally.

Explanation/examples: A qualitative study was performed to trace facilitators and barriers to implementing an evidence-based Dutch psychosocial support programme for people with dementia and carers with greater social integration and better cost-benefit ratio, the Meeting Centres Support Programme (MCSP), in Spanish-speaking countries. Among the potential barriers identified, the most relevant were associated with the lack of adapted training materials to the sociocultural context and the difference between urban and rural populations, particularly the access to populations living in remote areas.

It is therefore recommended that an implementation process be carried out that takes into account the characteristics of the region concerned, in addition to developing actions to overcome specific barriers, such as the creation of technological tools to offer the support programme remotely to provide access to the rural population. For example, as a result of this study, the *'Introductory Online Course for the Implementation of Meeting Centres for People with Dementia and their Caregivers'* was developed and adapted for Spanish-speaking countries in the Spanish language (available at https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores). The course consists of eight modules setting out the theoretical background and practical implementation steps in the preparation, implementation and continuation phase.

Also, to offer an alternative to the face-to-face caregivers' programme included in the MCSP, the iSupport-Sp, an evidence-based training and support programme for caregivers of people with dementia, was developed in an online e-learning format in the Spanish language (available at https://learning.bluece.eu/). This platform aims to offer a support service for caregivers living in remote rural areas in Spain.

Keywords: adaptive implementation, cultural adaptation, psychosocial interventions, psychoeducation, caregivers of people with dementia, online interventions, e-learning

Target group: Researchers, stakeholders, people with dementia, and caregivers.

Type of evidence

Mauricio Molinari-Ulate (DISTINCT ESR7)
Qualitative study, online interviews, cultural adaptation, co-design

References

Molinari-Ulate, M., Vallejos, C.†, van der Roest, H., Franco Martin, M., & Dröes, R. M. (under review). Facilitadores y Barreras de la Implementación Adaptada del Meeting Centre Support Programme en Países de Habla Hispana. El Caso de España y Ecuador (submitted, under review).

Molinari-Ulate M, Guirado-Sánchez Y, Platón L, van der Roest HG, Bahillo A, Franco-Martín M. Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain. Dementia. 2023;0(0). doi:10.1177/14713012231165578

- ***Signpost people with dementia to social media as accessible, virtual platforms to share experiences and information*** [3.3.6.14; see 3.3.5.5]

- ***Researchers and designers of web-based psychosocial interventions for people with dementia and carers are strongly recommended to collaborate with dementia support organisations as they can support implementation, dissemination, and use of these interventions*** [3.3.6.15; see 3.3.4.4]

- ***Robotic platform features and applications need to be tailored to the needs and preferences of end-users before implementing them in community-based dementia care*** [3.3.6.16; see 3.1.6.7]

3.4. Glossary

Term	Definition
Active & AssistedLiving Technology	Active and Assisted Living (AAL) focuses on the use of information and communication technologies (ICT) to support people's health and safety, increasing their autonomy and well-being, by means of providing services from the automatic supervision of medication to intelligent monitoring.
Advance care planning	Continuous, dynamic process of reflection and dialogue between an individual, those close to them and their healthcare professionals, concerning the individual's preferences and values concerning future treatment and care, including end-of-life care.
Application technology	Software designed to be downloaded and used in a computer or touchscreen device (e.g. mobile phone, tablet)
Artificial Intelligence Tools (AI)	These can be incorporated into the EPR and analyse clinical data to identify patients most at risk, for example, of dehydration or pressure sores.
Barthel Index	Barthel Index of Activities of Daily Living. A measure of independence in activities of daily living.
Brain Training	Internet enabled cognitive training allowing for personal comparison with other users
Complex health technology	A complex health technology is a procedure or system developed through the application of organised knowledge and skills and aims to solve a health problem and to improve quality of lives. Examples of complex health technologies include the PACE intervention (INDUCT Project 11) and the ACP+ intervention (INDUCT Project 12)
CGA	Comprehensive Geriatric Assessment
DHT	Digital Health Technology
Electronic patient record (EPR)	An electronic set of information about a single patient
e-PPI	Electronic/digital Patient and Public Involvement
Experience Sampling Method (ESM)	Data collection method/ ‘digital diary’ using a mobile device or smartphone app to collect information on an individual’s behaviour, affect and social context in everyday life; can be used in an intervention approach to raise awareness for positivise activities through self-monitoring and to guide personalized feedback
Everyday Infor-	Commonplace information communication technologies and their functions that most people would agree are widely available in homes and society.

mation Communication Technologies	Eg. make a call from a mobile phone, receive a mobile phone call, games on a smartphone, internet banking on a tablet computer etc.
Everyday technologies	Commonplace technologies that most people would agree are widely available in homes and society. Eg. Microwave, television, ATM, ticket machine, elevator/lift, smartphone etc.
Exergaming	Physical exercise interactively combined with cognitive stimulation in a gaming environment (e.g., *Wii Fit*©). Exergaming relies on technology that tracks the participants' body movement or reactions, which are fed back into the digital game, influencing the course of the game that is shown on the screen.
Generic photos	Photos that are not personal (i.e. family photographs, or participants' own photographs)
Implementation	A set of planned, intentional activities that aim to put into practice evidence-informed policies and practices in real-world services (www.implementation.eu)
iSupport-Sp	iSupport-Spanish version
MCSP	Meeting Centres Support Programme for people with dementia and their caregivers
META	Management of Everyday Technology Assessment: Observational tool to understand the ability of an (older) individual to use everyday technology
MMSE	Mini Mental State Examination. A type of assessment used by clinicians to assist in the diagnosis of dementia, and to establish severity.
Online intervention	Internet-based programs providing information and/or training, social and mental health support.
Palliative care	Palliative care is an approach that aims to improve the quality of life of people with dementia and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, psychosocial and spiritual.
PPI	Patient and Public Involvement
QUALID Scale	Quality of life in late-stage dementia scale. An observational scale used by clinicians and caregivers to rate quality of life in persons with late-stage dementia.
S-ETUQ	Everyday Technology Use Questionnaire (Short version) Self-perceived report assessing the ability of and (older) individual to use everyday technology
ST	Surveillance Technology: Electronic tracking systems monitoring movements of wearers

Tailoring	Aligning processes. In this case; being flexible, to a certain extent, with the developed intervention-components to make them compatible with the existing processes in the nursing home.
UX	User Experience
Young Onset Dementia	Onset of dementia symptoms before the age of 65.

Chapter 4 EPILOGUE

The recommendations that were included in the first version of the Best Practice Guidance for Human Interaction with Technology in Dementia were based on the findings of research done by 15 Early Stage Researchers in the INDUCT Innovative Training Network (2016-2020) funded by the European Marie Sklodowska Curie Programme. The Best Practice Guidance 2021, 2022 and 2023 updates include also the recommendations from the Marie Sklodowska Curie funded DISTINCT Innovative Training Network (2019-2023) in which again 15 Early Stage Researchers conducted research into technology for people with dementia, with a main focus on promotion of the Social health of people living with dementia and their informal carers.

Each of the early stage researchers systematically investigated part of the literature to get a comprehensive insight in the state of the art of science regarding the usability of technology for people with dementia in daily life and in meaningful activities as well as in the application of technology in the organisation of dementia care (INDUCT), and regarding Social health, technology to support people with dementia to 1) fulfil their potential on a societal level, 2) manage their own life and 3) participate in social and meaningful activities (DISTINCT). All researchers did also scientific field work, systematically collecting new data in the mentioned areas, with a special focus on the *usability* of technology, the *evaluation* of its impact on people with dementia and their carers and/or tracing *facilitators and barriers* for the implementation of technologies in daily practice. Moreover, during their field work they involved different types of stakeholders, such as people with dementia and carers, professional health care workers, developers of technology, policy makers and researchers to get feedback on their work and findings and to get informed on the different stakeholders' perspectives. All together this resulted in a comprehensive knowledge base and in total 113 recommendations in this June 2023 update (56 from INDUCT and 57 from DISTINCT) to improve the development, usage, impact and implementation of technology for people with dementia and their application in dementia care. More specifically 39 recommendations on Practical, cognitive & social factors to improve the usability of technology for people with dementia, 25 recommendations on Evaluating the effectiveness of specific contemporary technology, and 49 recommendations on Facilitators and barriers in the implementation of technology in dementia care. Although this set of recommendations is not exhaustive it provides different stakeholders with useful state of the art information to promote the use of technology in dementia.

This Best Practice Guidance should be seen as a dynamic document that can, and will have to be, updated when new insights are available in the continuously developing technological landscape. The recommendations should therefore always be interpreted with caution. The recommendations of DISTINCT will be continued to be included in the updates of the Best Practice Guidance in the coming year.

Research into the usability, impact and implementation of technology is still in its infancy. With this Best Practice Guidance we hope to inspire and stimulate many researchers, policy makers and investors in the development of technology for people with dementia and innovation of dementia care to effectively contribute to the further development and implementation of user-friendly, useful and easy implementable technology for people with dementia and carers and dementia care in general.

INDEX 1 Themes

INDEX 2
Target groups

Care professionals/ organisations

Developers/designers

Industry

Industry evaluating the effect of online evidence-based support programs (e.g. websites/modules) on psychological outcomes [3.3.2.8]

Industry evaluating the effect of technology on social participation [3.2.6.3]

Media

Media [3.1.1.5]

Policy makers

Commissioners[3.2.5.1],[3.2.6.1],[3.3.1.2]

Dementia-friendly communities [3.1.1.7], [3.1.1.8],[3.1.1.9]

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Researchers focusing on eHealth, including tablet interventions [3.1.2.3],[3.2.2.3],[3.2.2.4]

Researchers evaluating technology use of people with cognitive impairments [3.1.2.4],[3.2.6.2]

Researchers evaluating interventions aimed at improving the self-management of people with mild dementia living at home [3.2.2.1],[3.2.5.3]

Researchers evaluating implementation of technology for people living with dementia [3.3.2.1],[3.3.2.2],[3.2.2.4]

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Researchers recruiting people with dementia for their studies [3.2.4.1]

Researchers supporting family carers of people with dementia in everyday life with the experience sampling method or designing interventions for caregivers of people with dementia [3.2.2.2]

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