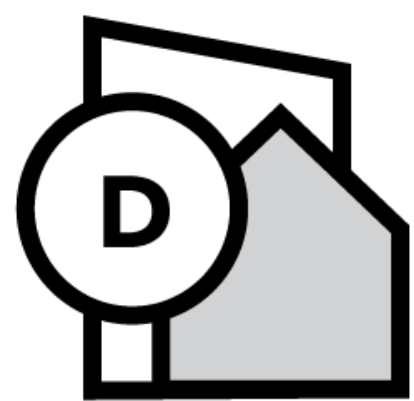


Maintaining personal relationships in couples affected by dementia

PhD trajectory



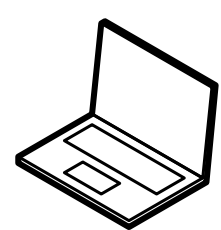
HOMEDEM
Codesigning a home
with dementia

The goal of my project is to develop an intervention to support couples in which one partner is diagnosed with dementia, to maintain their personal relationship.

Marine Markaryan, marine.markaryan@maastrichtuniversity.nl, Maastricht University

Supervisors: Dr. Sara Laureen Bartels, Maastricht University, Netherlands Prof. Dr. Marjolein de Vugt, Maastricht University, Netherlands, Prof. Dr. Niels Hendriks, LUCA School of Arts, Belgium, Adam James Cavallari, NOON care, Italy

Step 1: Gaining insight into couples' relationship needs and existing interventions



Part 1: Literature review mapping aspects affecting relationship quality against existing interventions in the field of maintaining personal relationships in couples affected by dementia.

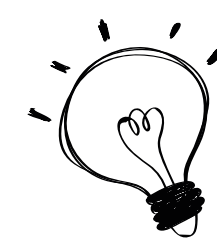
Goals:

- to identify the gaps in the field and to see which of the factors impacting the quality of relationship are not yet addressed/ poorly addressed
- to understand which "ingredients" of interventions contribute to their success

Methods:

- Step 1: Rapid review of factors impacting the relationship quality, combined with Patient & Public Involvement (PPI) events
 - 3 categories with the total of 14 factors identified by Stedje et al. (2023): i) attitudes & strategies; ii) behaviour & activities; iii) emotional connectedness.
- Step 2: Meta-narrative review to map those factors against interventions

Challenge: organizing PPI events (ethics)



Part 2: testing the hypotheses/ models derived from the literature review

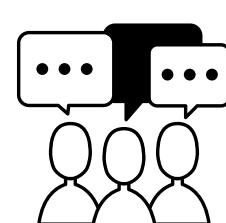
Goals: will be specified after part 1 is completed (e.g., testing the potential mechanism of action of an intervention, or prioritizing a target for an intervention)

Methods: Experience sampling method (ESM; a structured diary approach in daily life) for data collection; network/ mediation analysis for data analysis.

Challenges:

- Developing ESM items for dementia research in couples
- Dyadic ESM data analysis

Step 2: Developing an intervention



Secondment
at NOON care
in Milan

Goals: develop a new intervention/ adapt existing interventions to the context of personal relationships in couples affected by dementia. A potential intervention to adapt to the context – Acceptance and Commitment Therapy (ACT)

Methods: Iterative procedure with the elements of participatory approach and user-centered design. Repeated group discussions with the key stakeholders: people living with the diagnosis of dementia, their partners, professionals with the expertise in relationship counselling and clinical neuroscience.

Challenge: Homogeneous or heterogeneous groups? Or a combination of both? People with dementia and their partners together or separately? Experts and end users together or separately?

Step 3: Testing an intervention



Secondment at
Karolinska
Institute,
Stockholm

Methods: series of case studies (n = 3-12 dyads), with mixed-methods approach. ESM and semi-structured interviews to track both quantitative (effectiveness) and qualitative (end users experiences) aspects of intervention.

- Primary outcome - the relationship quality - will be measured with the Dyadic Adjustment Scale (DAS; Spanier & Filsinger, 1983).
- Secondary outcomes related to the wellbeing of each of the partners within the dyad (e.g., caregiver burden, stress, anxiety and depression symptoms, quality of life, sense of competence in caregivers and sense of autonomy in people living with the diagnosis of dementia) will also be measured.

Challenge: How to increase the diversity in a sample? Which characteristics to keep homogenous and in which - allow for diversity?



<https://www.homedem.eu>

References:

Spanier, G. B., & Filsinger, E. E. (1983). The dyadic adjustment scale. In E. E. Filsinger (Ed.), Marriage and family assessment: A sourcebook for family therapy (pp. 155-168). Beverly Hills: Sage Publications.

Stedje, K., Kvamme, T. K. S., Johansson, K., Stensæth, K. A., Odell-Miller, H., Bukowska, A., Tamplin, J., Wosch, T., & Baker, F. A. (2023). Influential factors of spousal relationship quality in couples living with dementia – A narrative synthesis systematic review. *Dementia*, 2023, Vol. 22(1) 281-302. DOI: 10.1177/14713012221137280



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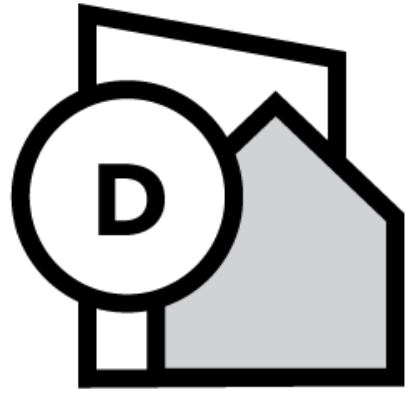
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POLITECNICO
MILANO 1863

Co-design communication products and services with PwD living at home

design for shared decision-making and autonomy



HOMEDEM
Codesigning a home with dementia

My research focuses on the evolving relationship in 'home' throughout the dementia journey. Considering person-centred care principles, my research will engage in co-design processes with PwD and their care constellation to develop products and services which foster shared decision-making communication.

Szu-Ying (Rising) Lai, rising.lai@luca-arts.be, LUCA School of Arts

Co-design communication products and services with PwD living at home

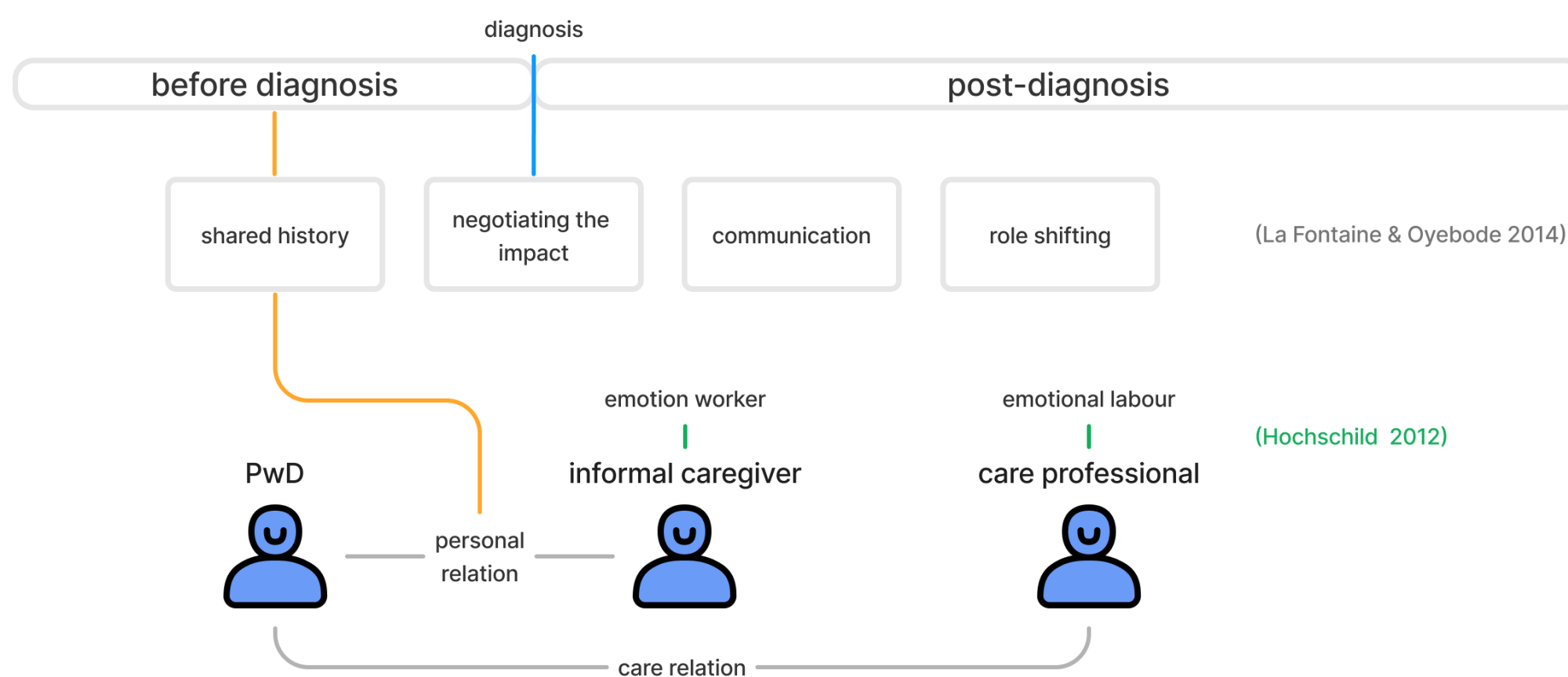
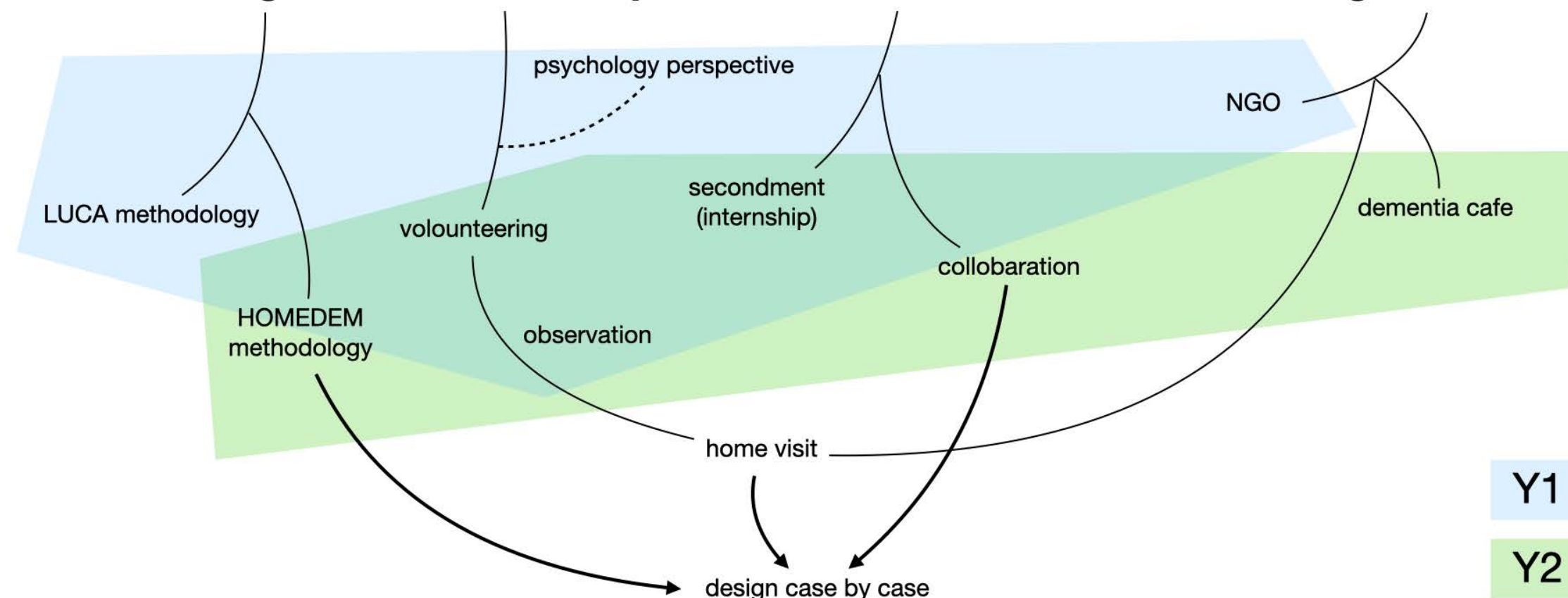


Fig. 2 Interplay between dementia and relationships.

Relationship

The shared history matters. The nature and quality of the previous relationship are important factors influencing the experience of dementia.

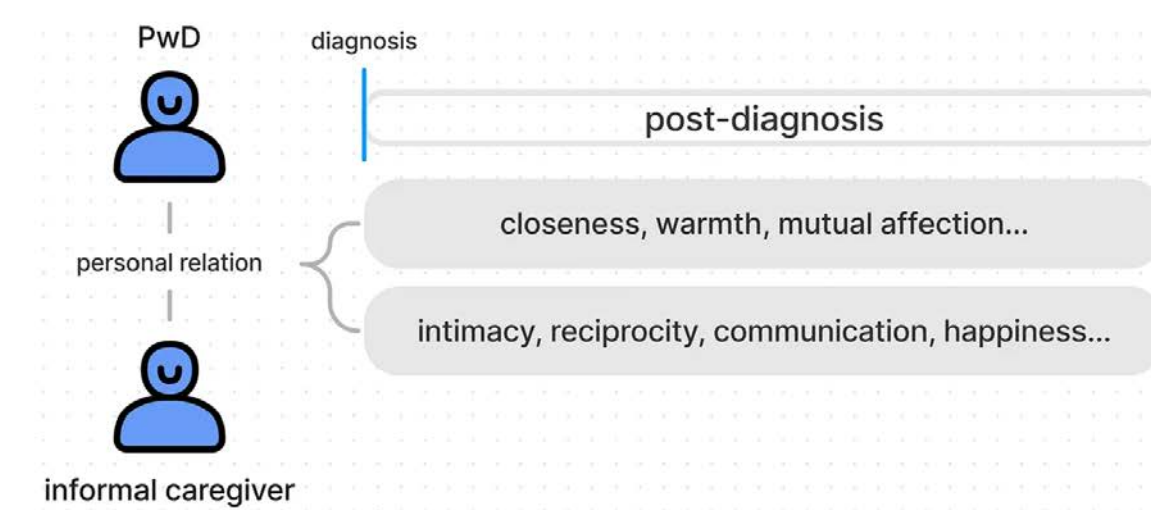


Fig. 3 Factors of relationship (quality) changes.

Decision-Making

1. Decision-making should be evaluated by the degree to which participation in the process transpires.
2. Collaborative processes and inclusive practices are needed.
3. Fostering an environment for timely decision-making.

Materiality

What role can design artefacts/products play in mediating decision-making conversations and recognising PwD's autonomy at home?

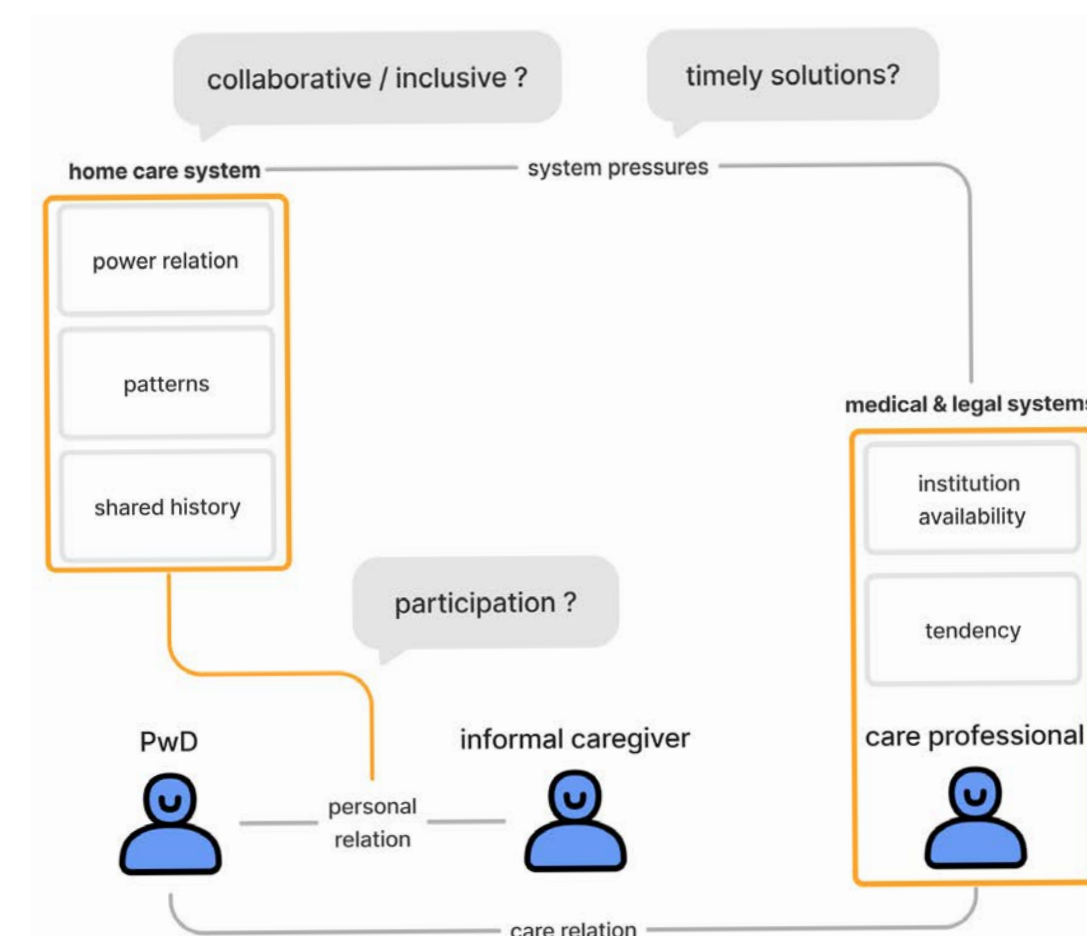


Fig. 4 Interplay between making care decisions regarding dementia care.



<https://www.homedem.eu>

References:

- La Fontaine, J and Oyeboode, J 2014. Family relationships and dementia: a synthesis of qualitative research including the person with dementia. *Ageing & Society*, 34(7), pp.1243-1272.
- Hochschild, R 2022. "The managed heart." In *Working In America*, pp. 40-48. Routledge.
- Ablitt, A, Jones, G and Muers, J 2009. Living with dementia: A systematic review of the influence of relationship factors. *Ageing & mental health*, 13(4), pp.497-511.

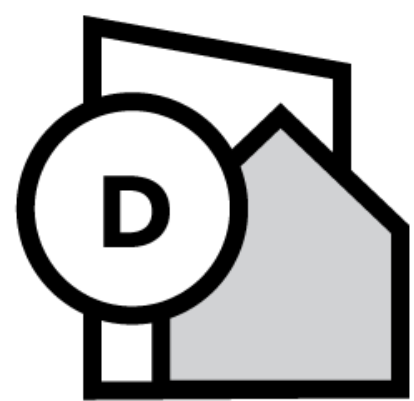


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Understanding (Un)Met Social Needs: Case Studies of Immigrant Older Adults with Dementia and Their Caregivers in Portugal

With a Focus on Migrants Originating from United Kingdom and China



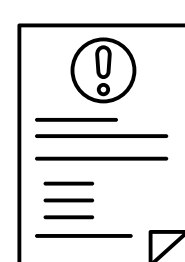
HOMEDEM

Codesigning a home with dementia

This project aims to understand how innovative tools and methods can be integrated in the interview process, to support older immigrants with dementia with varied communication capabilities and preferences, as well as their caregivers, in expressing their (un)met social needs.

Sunny Tan, sunnyt@ua.pt, University of Aveiro, Portugal

Supervisors: Liliana Sousa, Oscar Ribeiro, Rita Maldonado Branco, University of Aveiro, Portugal

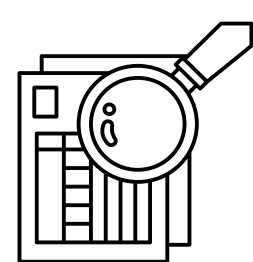


The Problem

Ageing, dementia and immigrant status each presents distinct challenges to building and maintaining relationships. Key component of 'functional abilities' crucial for enabling wellbeing in older age (WHO 'Healthy Ageing')

- Ageing and retirement : reduced opportunities for social interactions [1]
- Dementia: decline in cognitive and communication abilities further impact relationships and leisure participation [2]
- Immigrant status: additional barriers to social integration due to linguistic and cultural differences [3]
- More than 50% of community dwelling older adults with dementia report unmet social needs, such as the need for meaningful activities and companionship [4].

The understanding of what constitutes social needs, the specific social needs reported by immigrant older adults with dementia and their caregivers, and the existing solutions addressing these needs remain unclear.



Stage 1: Scoping Review: Unmet Social Needs of Community-living Older Adults with Dementia

Goal

- To map and summarize the evidence, and identify knowledge gaps in domain of met/ unmet social needs.
- To identify any variations in social needs across the disease progression.

Methods

Scoping review-

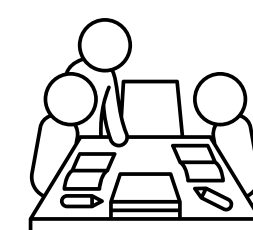
Participants: Older adults (≥65 years old) diagnosed with dementia

Concept: Met and/or unmet social needs, i.e., social and leisure activities, meaningful occupation

Context: Community- living

Challenges

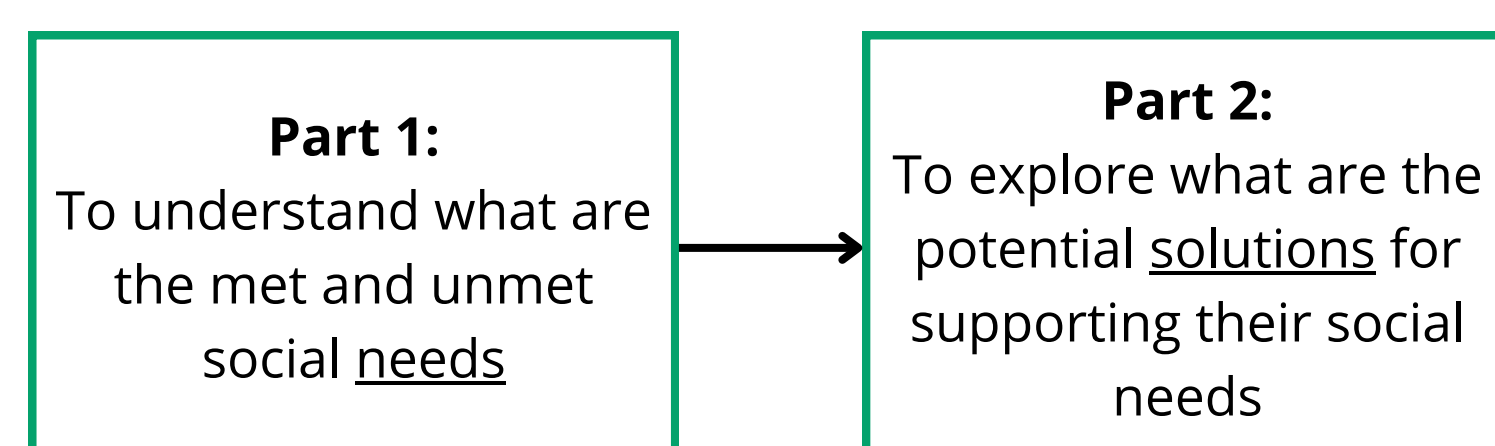
- Studies may not report type/stage of dementia, which may limit analysis of contribution by such factors.
- In studies using instruments that categorizes social needs into broad categories e.g., daytime activities, company: may limit insights on the exact type and nature of activities desired.



Stage 2: Understanding the Social Un/Met Needs of Immigrant Older Adults with Dementia and Their Caregivers: Case studies in Portugal

Goals

To understand the met and unmet social needs among immigrant older adults with dementia and their caregivers in Portugal



Methods

Case studies (n=6-10), open interviews with possible integration of innovative tools and methods, to support the varied preferences and communication abilities of each individual (e.g. walking interviews, photo-elicitation, design probes).

Challenges

- Recruitment and encouraging participation of immigrants
- Maintaining a dynamic and adaptable approach during interviews, to minimize perceptions of power imbalances.



References

- 1.Costa, S., Sousa, L., Luz, H., & Padeiro, M. (2022). Daily mobility and social interactions among community-dwelling older adults with pet dogs: a scoping review. *Journal of Applied Gerontology*, 41(12), 2609-2623.
- 2.Grand, J. H., Caspar, S., & MacDonald, S. W. (2011). Clinical features and multidisciplinary approaches to dementia care. *Journal of multidisciplinary healthcare*, 125-147.
- 3.Ciobanu, R. O., Fokkema, T., & Nedelcu, M. (2017). Ageing as a migrant: Vulnerabilities, agency and policy implications. *Journal of Ethnic and Migration Studies*, 43(2), 164-181.
- 4.Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C., & Samus, Q. M. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *Journal of the American Geriatrics Society*, 61(12), 2087-2095.

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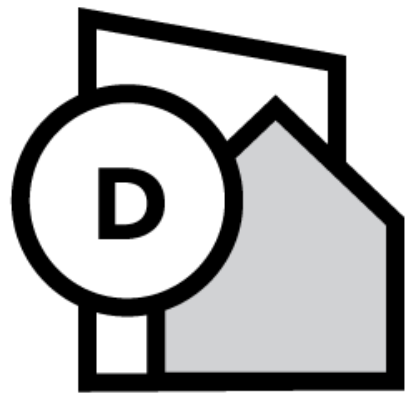


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Investigating self-directed play in the context of dementia

Exploring the experience of self-directed play for community-dwelling older adults with dementia



HOMEDEM

Codesigning a home with dementia

By gaining a deeper understanding of the role of self-directed play in the lives of people with dementia, we can develop more effective strategies and interventions to promote overall well-being and thriving for individuals with dementia in their own homes. Additionally, we can explore the potential for play in older adulthood and reimagine its significance in this stage of life.

Alicia Valencia, a.i.valencia@tue.nl, TU Eindhoven



Fig. 1
Example snap circuit building pieces by Elenco Electronics, including LEDs, motors, fans, battery pack, and jump cables [9].

Problem:

Dementia can impact the ability to maintain autonomy and live comfortably at home. More attention must be directed towards exploring the importance of self-directed engagement for PwD at home and how play can support personhood. We begin this inquiry by first investigating the nature of self-directed playful engagement and the motivations of people with dementia.

Research Questions:

1. How do opportunities from the environment inspire people with dementia to play?
2. What psychological and physical capabilities influence play in people with dementia?
3. What motivates people with dementia to play?



Fig. 1
COM-B Model of Behavior [8]



<https://www.homedem.eu>

Introduction:

Dementia can have a debilitating impact on individuals living at home [1]. As the condition progresses, they may experience a decline in initiative and motivation, affecting their quality of life and daily activities [2].

One potential approach to address this issue is self-directed play for individuals with dementia. Self-directed play refers to engaging in play activities initiated and directed by oneself without external guidance [3]. It involves freely exploring and pursuing personally interesting and enjoyable activities, allowing individuals to express their creativity and curiosity [4]. Self-directed play encourages independent thinking, problem-solving, and decision-making, promoting autonomy and agency in play experiences [5]. By providing opportunities for play, we can tap into curiosity and creativity, helping them find purpose and enjoyment in their daily lives.

However, implementing this approach effectively requires a better understanding of self-directed play for people with dementia. There is limited research on self-directed engagement for people with dementia [6]. Additionally, there is little exploration of the benefits of play in older adults [7]. This research project aims to comprehend the relationship between play, independence, and personhood to support individuals with dementia in living longer at home.

Methods and Collection:

The focus will be on gathering qualitative data to inform design probes. The experience of self-directed play for PwD, explored through interactive play workshops and interviews, will be considered based on three aspects [8]: capability, opportunity, and motivation. These three aspects are derived from the COM-B Model of Behavior theoretical framework [8]. Participants - 20 PwD.

Daycare Sessions: During a workshop, PwD will be introduced to a set of tinkering objects that can be assembled as a circuit with multiple different outcomes. Structure - a general introduction (10-15 minutes), play activity (45-60 minutes), and conclusion (10-15 minutes). In total, the interactive sessions will take place for about 1.5 hours.

Home Sessions: home activity sessions, and semi-structured interviews with PwD and their relatives or informal caregivers. This includes time with the prototype again in the context of home (60 minutes), a reflection conversation on the activity (PwD and caregivers, 30 minutes), and a follow-up interview (with just caregivers 30 minutes).

References:

1. Thoma-Lürken, T., Bleijlevens, M. H., Lexis, M. A., de Witte, L. P., & Hamers, J. P. (2018). Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatric Nursing*, 39(1), 29-38.
2. Tagariello, P., Girardi, P., & Amore, M. (2009). Depression and apathy in dementia: same syndrome or different constructs? A critical review. *Archives of gerontology and geriatrics*, 49(2), 246-249.
3. Hughes, B. (2013). *Evolutionary playwork*. Routledge.
4. Chu, J., & Schulz, L. E. (2020). Play, curiosity, and cognition. *Annual Review of Developmental Psychology*, 2, 317-343.
5. Vygotsky, L. S. (1978). *Mind in society* (M. Cole, V. John-Steiner, S. Scribner, & E. Souberman, Eds.).
6. Dopp, C. M., Drenth, H., Verkade, P. J., Francke, A. F., & Van Der Heide, I. (2021). Interventions for improving self-direction in people with dementia: a systematic review. *BMC geriatrics*, 21, 1-20.
7. Smith, P. K. (2005). What children learn from playtime, and what adults can learn from it. In *Breaktime and the school* (pp. 43-56). Routledge.
8. Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation science*, 15, 6, 42.
9. ELENCO ELECTRONICS, INC (2019)



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Maastricht University



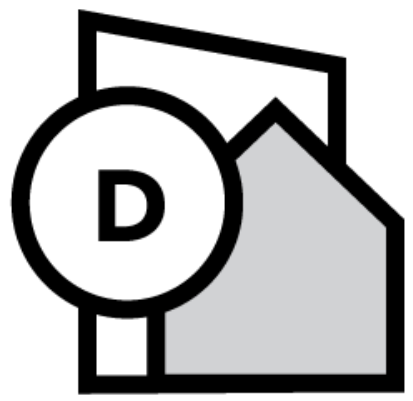
Ollscoil na Gaillimhe
UNIVERSITY OF GALWAY



POLITECNICO
MILANO 1863

Design process to explore the sense of home while creating.

Current progress : Research process map / Literature reviews / Pre-research



HOMEDEM
Codesigning a home with dementia

The primary objective of this study is to identify and facilitate home-making processes and dynamics, allowing individuals with dementia (PwD) and their care networks to establish a profound "sense of belonging" and a "sense of home" within the context of dementia villages. This research aim to contribute significantly to dementia care and home-making practices for individuals with dementia.

Natsumi Wada, natsumi.wada@polimi.it, Politecnico Di Milano

01. Research Process Map

Investigating "sense of home" and "sense of belonging"

To elucidate the methodology for investigating the sense of home and the sense of belonging, this study is anchored in the research process outlined in Figure 01. The methodology is structured around the research steps depicted in Figure 01. Specifically, the literature review will enable the identification of elements and environments contributing to the sense of home. Furthermore, to devise a novel approach to understanding the 'sense of home' and its evolution from the onset of dementia, a patient journey map will be crafted based on case studies. Pilot tests will be executed, ethical guidelines and considerations for data collection will be delineated, and comprehensive guidelines will be formulated.

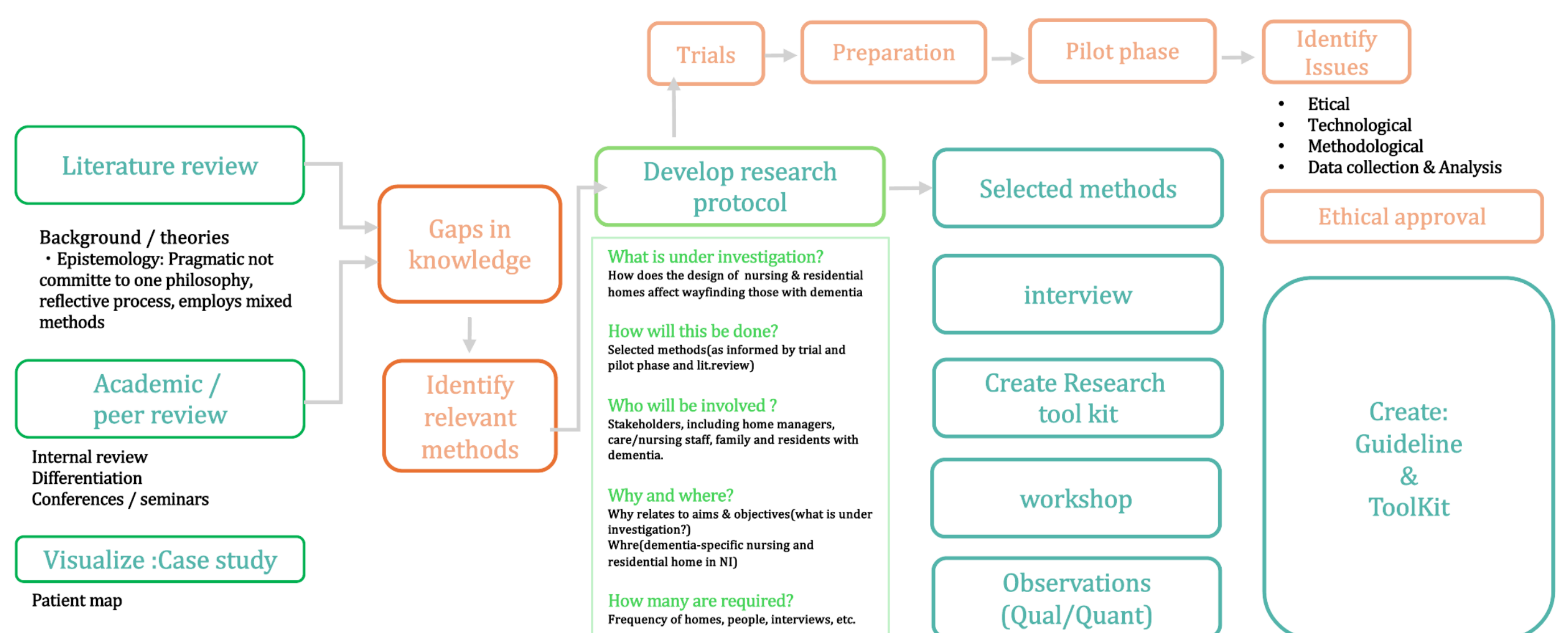


fig.1 Research Process Map

02. Literature Reviews

Framework for "Sense of Home" by literature reviews

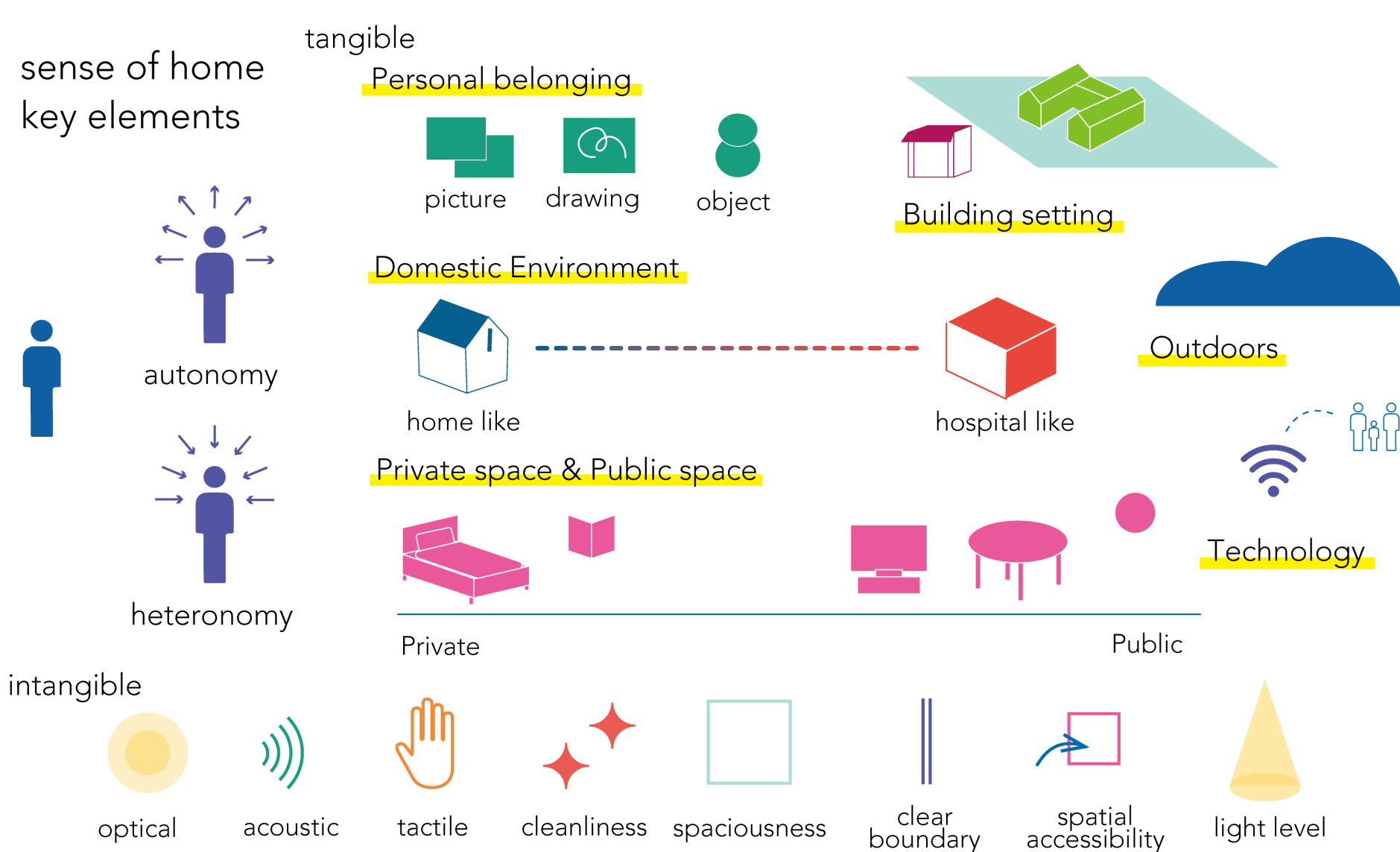


fig.2 Key elements by literature reviews (ongoing)[1]

In considering care homes and environments for people with dementia, it is important to identify how a sense of home[4] and belonging is fostered and what environmental factors are involved. The literature review will clarify how a sense of home and belonging is nurtured and built upon environmental factors[1], narrowing the focus area of this study. After a comprehensive review of previous research, the factors and relationships identified in the literature review are visualized. Based on the literature reviews, the findings, factors mentioned, and overall methodology are currently visualized and organized.

03. Pre-research : case study

Patient Journey Map

To organize the various stages of dementia and determine when to focus research attention on the overall condition, a patient map was created to offer a preliminary overview of changes over time since the onset of dementia in Japan. This map encompasses changes in individuals concerning their environment and provides a comprehensive perspective.

The map primarily includes the patient with dementia, his family, care teams, and doctors. It organizes changes over time and behavioral shifts as he transitions between six different locations, from their homes to his current care facility. In creating this map, I visualized a decade with my grandfather who had dementia. This is positioned as a comparison with the literature review and serves to organize the process of dementia and support systems in Japan. However, it should only be considered as a preliminary organization.

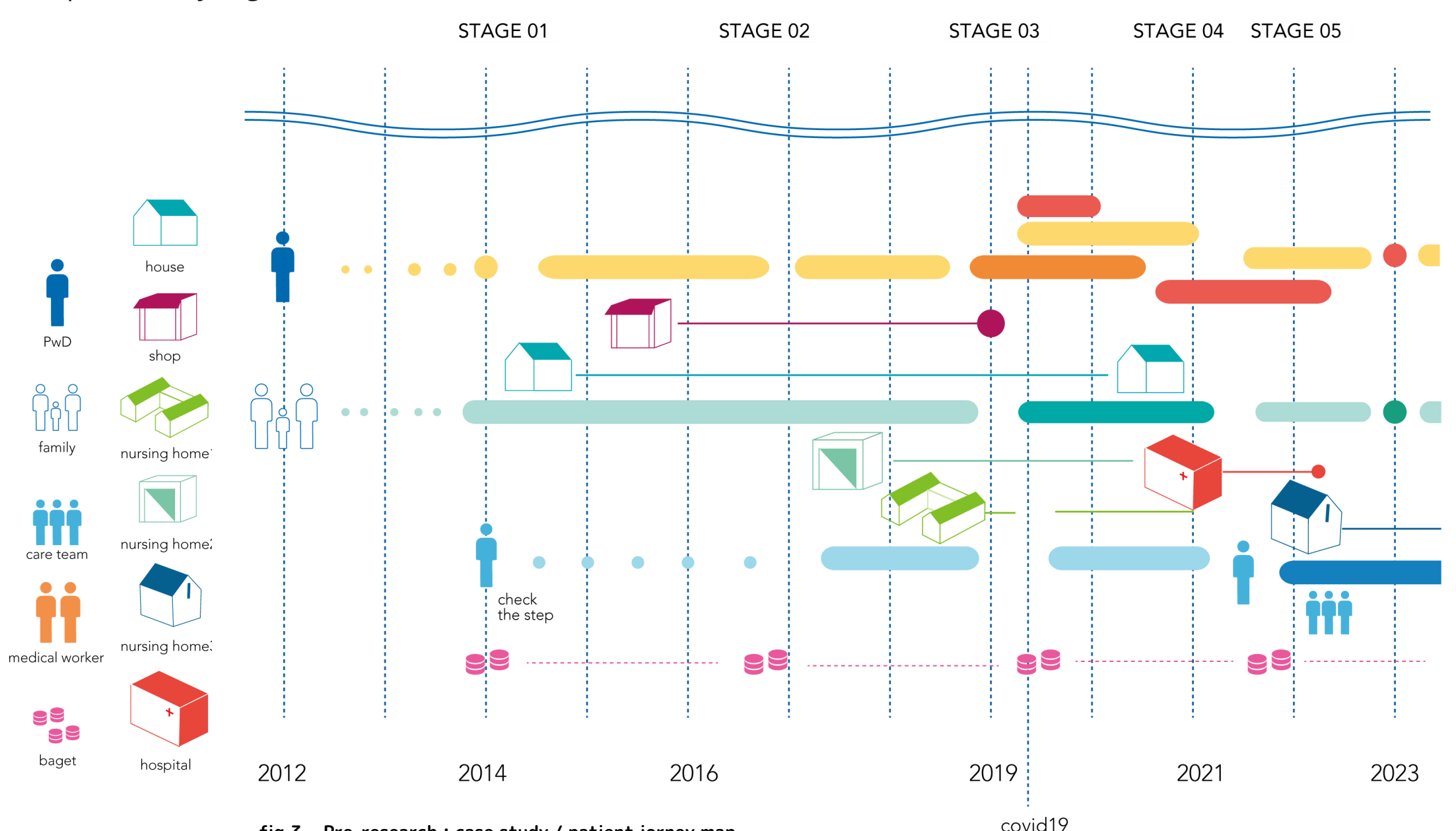


fig.3 Pre-research : case study / patient journey map



<https://www.homedem.eu>

- Chen, J.; Gramegna, S. & Biamonti, A. (2021). "Feeling at home" for people with dementia in care environments: the role of built environment factors. A critical literature review. *Convergências - Revista de Investigação e Ensino das Artes*, VOL XIV (27), 133-142. <https://doi.org/10.53681/c1514225187514391s.27.72>
- Faith, V. (2014, Jun 12). *Designing for dementia : an assessment of the impact of the physical environment on wayfinding success for residents in long term care settings.* (1 ed.) Queen's University Belfast.
- Silvia Maria Gramegna, (2021). *Interior Design as a tool for dementia care. Experiences and guidelines for the Therapeutic Habitat Model.* ISBN-13 (15)9788835115700
- Minou Gharebaglou, Hamed Beyti & Shole Rezaei Zunuz (2021): The Impact of the Sense of Home on the Quality of Life of Older Adults in Tabriz, Iran, *Journal of Aging and Environment*, DOI:10.1080/26892618.2021.1987370
- Van Dijck-Heinen, C. J. M. L., Wouters, E. J. M., Janssen, B. M., & van Hoof, J. (2014). A sense of home through the eyes of nursing home residents. *IJRST-International Journal for Innovative Research in Science & Technology*, 1, 57-69

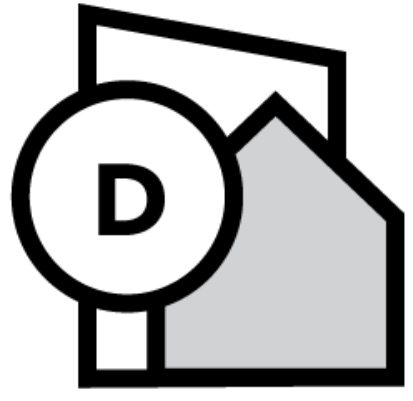


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Nightly agitation in people with dementia

Current research update and PhD trajectory



HOMEDEM
Codesigning a home
with dementia

The goal of this project is to develop a tool for nightly agitation in people with dementia to be used by their informal caregivers. The project started with a scoping review to identify behavioural characteristics of nightly agitation and come up with the definition of nightly agitation. Second step involves an ESM study targeting informal caregivers and diving into their experience of nightly agitation in people with dementia. The input from the ESM study will be used to develop a tool in collaboration with Pantón.

Ajda Flisar, ajda.flisar@kuleuven.be, KU Leuven (Centre for Care Research and Consultancy)

2023

2024

September October November December January February March April May June

Type of study: Scoping review

Title: Behavioural characteristics of nightly agitation in people with dementia living at home and in residential care homes

AIM: To identify and compare disturbing behaviours of nightly agitation in both populations and come up with a definition of nightly agitation

- RQs**
1. What are the most common disturbing behaviours of nightly agitation in people with dementia living at home and in residential care homes?
 3. Are there differences in identified common disturbing behaviours of nightly agitation between people with dementia living at home and those living in residential care homes?
 3. Could identified behaviours of nightly agitation help us coming up with a definition of nightly agitation?

Method 5408 articles screened

Searches: PubMed, Web of Science, CINAHL, Proquest, OSF for preprints

Population: Any type of dementia diagnosis

Designs: Quantitative and qualitative empirical research, case studies, intervention studies

Type of publications: Journal articles, research reports, preprints

Context: Community dwelling and residential homes setting

Extracted data: demographics, methodology and identified disturbing behaviours

2024

February March April May June July August September October November December

Type of study: ESM

Topic: Identifying disturbing nightly agitation behaviours in people with dementia from the perspective of a caregiver

AIM: Exploring the experience of nightly agitation of people with dementia in caregivers

Population: Informal caregivers

Design: 14-days of daily prompts

Mixed method design:

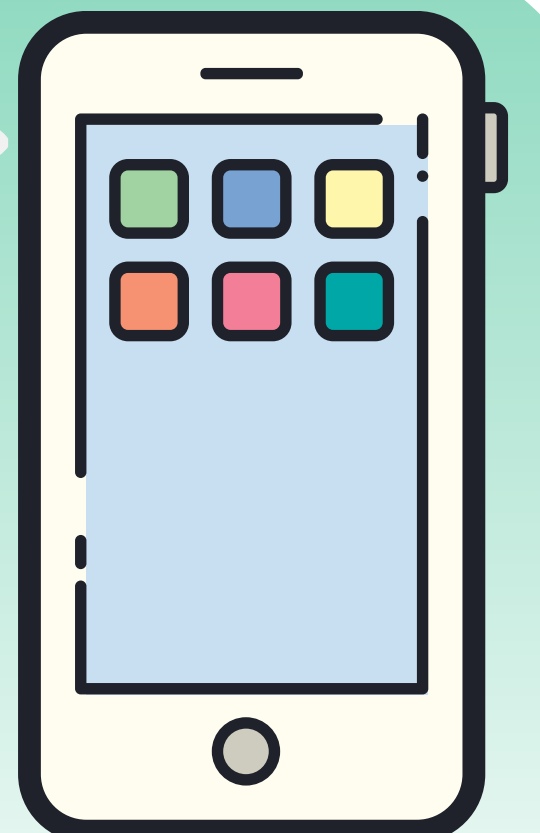
Quantitative: Which items will be used is still to be determined (ESM item repository)

Qualitative: Open-ended question as part of the ESM prompt about their needs in specific situations

- follow-up interviews

Method

Secondment at Pantón



RQs

Quantitative: to be determined based on the input from the results of the scoping review (Publication 1)

Qualitative: What are the needs of caregivers to be able to better handle the nightly agitation in home setting --> will be used for the development of the tool (Secondment at Pantón)



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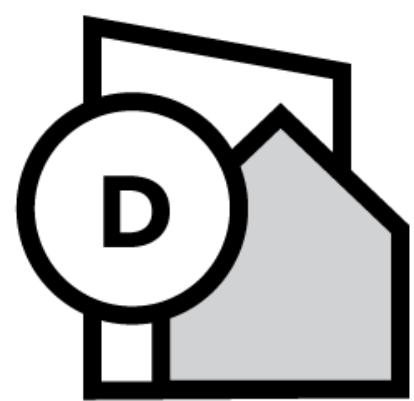


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Designing an integrated ecosystem for personalised dementia care

Current research update and PhD trajectory



HOMEDEM
Codesigning a home
with dementia

This project aims to identify service design strategies for shaping formal aged care services in a way to maximise the value co-creation across the multiple social actors and support autonomy, citizenship and personhood for people living with dementia and their care constellation.

Andrea Nakakawa Bernal, andrea.nakakawa@polimi.it, Politecnico di Milano

Supervisors: Prof. Dr. Daniela Sangiorgi, Politecnico di Milano; Prof. Dr. Eamon O'Shea, University of Galway

Context

• Navigating formal and informal services throughout the dementia care continuum can be often difficult for both people with dementia (PwD) and their informal caregivers due to a variety of reasons (e.g., **fragmented information, poor collaboration between services, lack of personalised care**) [1,2], resulting in "suboptimal care and inadequate support to caregivers" [3]

• **Autonomy, personhood and citizenship** are recognized as key values that should guide dementia care policy and service delivery [4, 5]. However, these are often hard to operationalise in practice [5,6] and difficult to support throughout the continuum of care [7].

PhD trajectory

Study 1

Goal
Develop a **framework** using a service ecosystem perspective, to integrate key values of citizenship, personhood and autonomy within formal and informal care resources.

Methods
• Narrative literature review

Study 2

Goal
Create **case studies** comparing diverse public policies and care ecosystems in Belgium and Sweden to identify how can we a) better integrate these key values throughout the continuum of care and b) improve the collaboration between formal and informal care resources in the dementia care ecosystem.

Methods
• Scoping review + archival review
• In-depth interviews (12-15) with PwD, informal and formal carers, practitioners from formal and informal care services and policy-makers
• Questionnaire: practitioners from LTC facilities and community-based services

*Sweden: PPI approach

Study 3

Goal
Develop **guidelines and recommendations for public policies and service delivery**, to maximise the value co-creation of the actors in the dementia care ecosystem and support the key values in available services.

Methods
• Participatory action research in Sweden, ideally with a pre-post method to analyze if the proposed intervention had any effect on the current service-delivery (details will be provided at a later point)
• Co-creation workshop with policy-makers

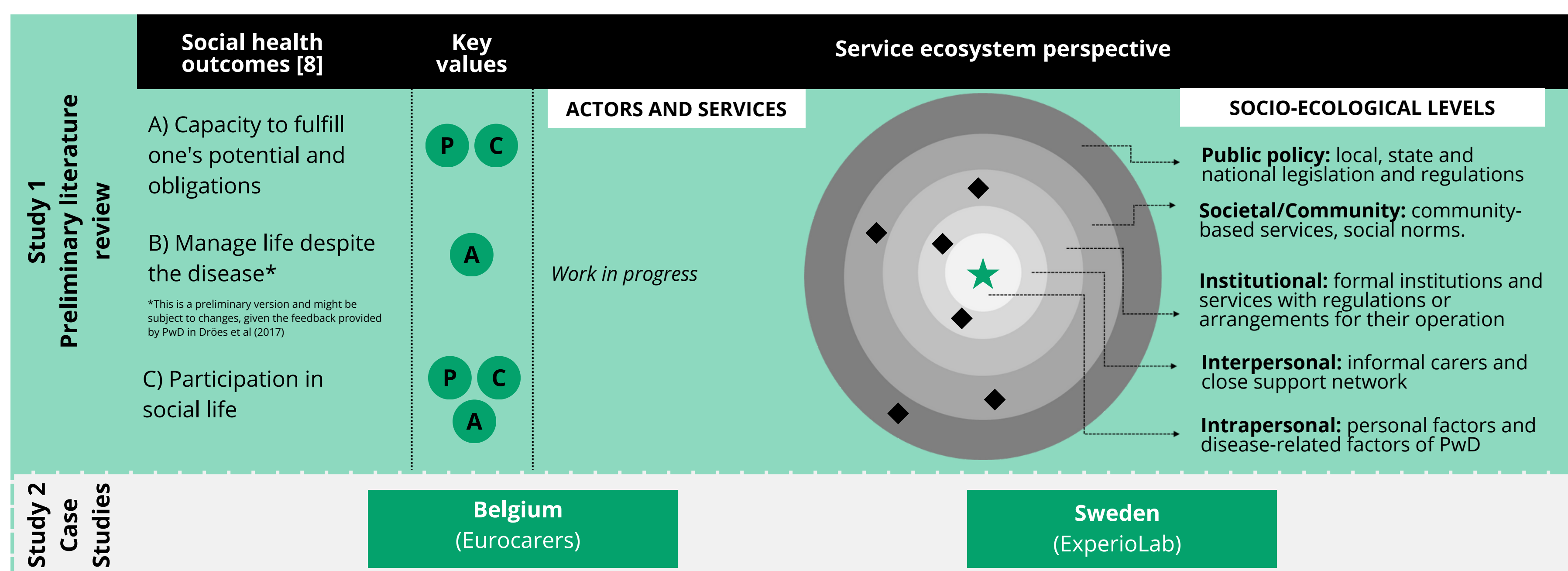


Fig. 1 Current research update



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References:

- O'Shea, E., Cahill, S. & Pierce, M. (eds.) (2017). Developing and Implementing Dementia Policy in Ireland. Galway: CESRD.
- D'Amour D, Ferrada-Videla M, San Martin Rodriguez L, Beaulieu MD. The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks. J Interprof Care. 2005 May;19 Suppl 1:116-31. doi: 10.1080/13561820500082529. PMID: 16096150.
- Super, N., & Ty, D. (2022), page 80. Multisectoral Collaboration to Improve Dementia Care. Public Policy & Aging Report, 32(2), 80-83.
- Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2021). Personhood and dementia care: a qualitative evidence synthesis of the perspectives of people with dementia. The Gerontologist, 61, 3. pp 85-100
- Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers. International Psychogeriatrics, 25(6), 949-961.
- Österholm, J., & Hydén, L.-C. (2016). Citizenship as practice: Handling communication problems in encounters between persons with dementia and social workers. Dementia, 15(6), 1457-1473.
- Keyes, S. E., Clarke, C. L., & Gibb, C. E. (2019). Living with dementia, interdependence and citizenship: Narratives of everyday decision-making. Disability & Society, 34(2), 296-319.
- Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., Verbeek, H., Vernooij-Dassen, M., Clare, L., Johannessen, A., Roes, M., Verhey, F., Charras, K., & the INTERDEM sOcial Health Taskforce. (2017). Social health and dementia: A European consensus on the operationalization of the concept and directions for research and practice. Aging & Mental Health, 21(1), 4-17.

<https://doi.org/10.1080/13607863.2016.1254596>

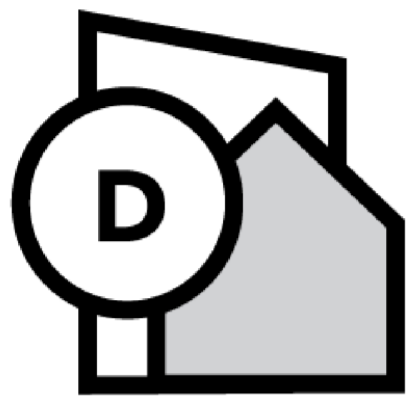


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An Economic Analysis of Autonomy-Enhancing Services and Supports for People with Dementia in Ireland

Current research update and PhD trajectory



HOMEDEM

Codesigning a home with dementia

The proposed research topic is an economic analysis of autonomy-enhancing services, supports, and infrastructure for people with dementia in Ireland. The research aims to investigate the factors influencing the cost of care and admission to long-term care for people with dementia in Ireland, as well as public preferences for home care services for people with dementia.

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Supervisors:

Dr. Sharon Walsh, University of Galway, Dr. Eamon O'Shea, University of Galway

Introduction

Dementia is a leading cause of disability in older populations that significantly impacts quality of life and ability to live independently. Supporting autonomy, choice and self-determination is crucial for the wellbeing of people with dementia. Formal care systems need to be more integrated, accessible and focused on enabling autonomy across the full continuum of care. There is limited evidence on public attitudes and willingness-to-pay for autonomy-enhancing care models.

Objectives:

1. To conduct a comparative analysis of existing policy and practice interventions that support autonomy and choice for individuals with dementia living on the boundary of care in Europe.
2. To explore the preferences and willingness-to-pay of citizens for a system of care that supports autonomy and choice for individuals with dementia, including the role of design elements.
3. To determine heterogeneity in attitudes and preferences among the general public for autonomy-enhancing services and supports for individuals with dementia, with a potential cross-country comparison.
4. To develop a common policy dialogue framework for design and dementia.

Literature Review Phase:

A comparative analysis of care systems in Europe is in progress, focusing on existing policies and practices that promote greater autonomy along the continuum of care.

Data Bases:

PubMed, Google Scholar, Web of Science, CINAHL, Grey literature, Policy documents, Evaluation studies, case studies etc

Fous:

Personhood, Design and Technology



<https://www.homedem.eu>

References: text in 15 pt Open Sans

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Methods:

The research will utilize a range of data collection methods, including:



• **Discrete Choice Experiment (DCE) Surveys:** These surveys will be meticulously designed, administered, and analyzed to discern public preferences for autonomy-enhancing care for individuals with dementia.

• **Comparative Analysis of Care Systems:** A comprehensive comparative analysis of care systems in Europe will entail the meticulous collection and analysis of policy documents, healthcare system data, and practices that foster greater autonomy along the continuum of care in selected countries.



• **Policy Dialogue Framework:** Qualitative exploration of the role of design in care systems for individuals with dementia across three countries will help to explore the potential and desirability of design-led psychosocial models of care supporting autonomy and choice at all stages of the care continuum.

• **Supplementary Questions in Surveys:** Supplementary questions in the survey questionnaire will be leveraged to scrutinize heterogeneity in attitudes and preferences among the general public for autonomy-led care and provision, potentially across different countries with varying health systems, welfare regimes, and socio-cultural norms and attitudes.



Key findings:

- Person-centered care is crucial for respecting the dignity of individuals with dementia, but it requires continuous adaptation to align with changing healthcare landscapes.
- National dementia strategies prioritize caregiver education and person-centered care training, but their effectiveness depends on factors such as institutional support and ongoing mechanisms.
- Emerging technologies like artificial intelligence and virtual reality have the potential to revolutionize dementia care, but ethical guidelines are needed to address issues of privacy, consent, and dehumanization.
- Home design plays a pivotal role in supporting personhood and autonomy for individuals with dementia, but existing national dementia strategies lack attention to technology and home design.



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