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Methods of engagement of dementia care users in research and practice development

Edited by
W. George Kernohan, Suzanne Timmons, Anthea Innes and David Edvardsson

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Methods of engagement of dementia care users in research and practice development

Topic editors

W. George Kernohan — Ulster University, United Kingdom
Suzanne Timmons — University College Cork, Ireland
Anthea Innes — McMaster University, Canada
David Edvardsson — La Trobe University, Australia

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Wendy Moyle,
Griffith University, Australia

*CORRESPONDENCE
W. George Kernohan
wg.kernohan@ulster.ac.uk

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Editorial: Methods of engagement of dementia care users in research and practice development

W. George Kernohan[1]*, Suzanne Timmons[2], Anthea Innes[3,4] and David Edvardsson[5]

[1]Ulster University, Belfast, United Kingdom, [2]University College Cork, Cork, Ireland, [3]Centre for Rural Health Science, University of the Highlands and Islands, Inverness, United Kingdom, [4]Gilbrea Centre for Studies in Aging, Health, Aging and Society, McMaster University, Hamilton, ON, Canada, [5]Swinburne University of Technology, Hawthorn, Australia

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Editorial on the Research Topic
Methods of engagement of dementia care users in research and practice development

Introduction

Dementia is a growing global health challenge, affecting over 57 million people worldwide and placing increasing pressure on health and social care systems (World Health Organization (WHO), 2021). Despite the recognized value of involving people with dementia in coproduction and research, many researchers remain hesitant, often citing concerns about capacity, ethical complexity, or methodological limitations (Bethell et al., 2018). The imperative to involve people living with dementia and their care partners in research and practice development has gained increasing recognition in recent years. Participatory approaches, such as co-design and co-production, are now considered essential for creating interventions that are both meaningful and effective (Gove et al., 2018; Skivington et al., 2021).

The "*Methods of Engagement of Dementia Care Users in Research and Practice Development*" Research Topic in *Frontiers in Dementia* brings together articles that explore diverse strategies for involving people living with dementia and their supporters/caregivers in research and practice development. This editorial highlights the contributions of this Research Topic, aiming to explore and advance innovative methods for engaging people living with dementia and their families in the design, implementation, and evaluation of dementia care interventions. This body of work emphasizes participatory, co-design, and other collaborative approaches to research and practice development.

Setting the scene: of gaps in research

We start with Bartels et al. who present a robust opinion piece identifying key methodological gaps in psychosocial dementia research. They critique the field's

continued overreliance on RCTs, which frequently neglect context complexity, stakeholder involvement, and theory-driven mechanisms, leading to potential implementation failures and wasted resources. Their core call is for more stakeholder-informed, participatory, and mixed-method designs aligned with MRC phases. They also introduce the METHODEM initiative to systematically map and prioritize suitable methods. The paper urges methodological reform by blending conceptual clarity with suggested action. By incorporating diverse research designs and prioritizing meaningful stakeholder engagement, they and we propose a more holistic and effective approach for co-creating, evaluating and testing interventions that can be seamlessly translated into everyday practice.

Valuing lived experience and personhood

Several other papers underscore the ethical imperative of fully recognizing people with dementia as persons with human rights. This includes adopting approaches like the *intentional stance* (O'Shea et al.) and valuing emotional, social, and identity-based outcomes of participation (Seidel et al.). This reframes engagement as an ethical, relational process rather than merely a technical exercise. Drawing on a single, powerful case study, O'Shea et al. illustrate how respectful, open-ended interaction can help temporarily bridge cognitive and communicative divides. Their integration of philosophical and methodological insights provides a valuable contribution to advancing inclusive dementia research practices and challenges the norm of passive participant roles.

Lived experience was not only acknowledged but integrated to improve the relevance of tools and research design (Donnelly et al.). Indeed, our Research Topic highlights the ethical dimensions of inclusion, such as informed consent (Diaz et al.), representation across dementia stages (Snowball et al.), and the need to avoid epistemic injustice (O'Shea et al.). This reflects a move toward flexible, person-centered research methods that uphold autonomy and dignity.

On co-design and participatory methods

Co-creation of research instruments and dissemination strategies emerges as a practical and empowering method. Donnelly et al. show how co-design improved survey usability. By collaborating with a research advisory group comprising people with Lewy body dementia and their supporters/caregivers, the researchers co-designed a survey that was both accessible and relevant to the target population. Their pragmatic approach to involving people with dementia in research used a hybrid method that combined focus groups and interviews within a single event, addressing resource constraints while still capturing valuable feedback. This involvement led to tangible improvements in the survey's design, such as clearer attribute descriptions and more user-friendly presentation. De Wolf-Linder et al. illustrate co-production across all research phases, not just design or data Research Topic. They present a new model for engaging stakeholders in the dissemination of dementia research, promoting inclusivity and practical application of findings. Snowball et al. provide practical strategies for facilitating meaningful engagement, such as prioritizing accessibility and fostering an inclusive environment, underscoring the importance of integrating diverse voices to enrich the research process and outcomes.

Evaluating engagement and impact

Several studies moved beyond participation to measure the *quality and effects* of engagement. Wong et al. used PEIRS-22 to track involvement quality, while Seidel et al. explored psychosocial outcomes of advisory group participation. Their participants reported enhanced self-perception of competence, feelings of joy and wellbeing, and increased social engagement. Notably, the study also acknowledges instances of sadness and insecurity, highlighting the complex emotional landscape of such involvement. Evaluation efforts indicate an increasing emphasis on accountability and learning in engagement practices.

Enhancing communication

Effective engagement depends on reciprocal, accessible communication. Techniques like *Music Mirrors* (Edwards et al.) show the potential of integrating personalized audio-biographical cues into dementia care practices to enhance the quality of interactions. Their findings indicate that the use of Music Mirrors led to an improvement in the wellbeing of people with dementia, irrespective of the care environment.

It is clear that conversational strategies grounded in selfhood theory (O'Shea et al.) support meaningful interaction. Diaz et al. emphasize tailoring consent processes with lived-experience insight, especially in the context of new ethical challenges like AI. The authors argue that involving people with dementia and their supporters/caregivers in designing consent procedures can lead to more ethical and effective research practices, and that there is a need for more practical strategies for implementing inclusive consent processes and ensuring broader representation.

Engagement is also framed as a route to societal participation, not just research contribution. The Polish dementia campaign (Błaszkiewicz et al.) demonstrates that involvement fosters social health, belonging, and emotional wellbeing—reinforcing research as a vehicle for inclusion.

Conclusion

Across the papers, a strong convergence emerges around **inclusive, ethical, and relational approaches** to involving people with dementia across the whole spectrum of research. Authors advocate for **moving beyond tokenism** toward co-created, evaluated, and socially embedded models of research. These studies push the field to prioritize **dignity, agency, and meaningful**

connection, not only in methodology but in the broader purpose of dementia research.

Author contributions

WK: Project administration, Formal analysis, Methodology, Validation, Conceptualization, Writing – review & editing, Investigation. ST: Writing – original draft, Investigation, Formal analysis, Validation, Conceptualization, Project administration, Supervision, Writing – review & editing, Methodology. AI: Supervision, Writing – review & editing, Conceptualization, Validation. DE: Writing – review & editing, Supervision, Conceptualization, Validation.

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EDITED BY
Anthea Innes,
McMaster University, Canada

REVIEWED BY
Cinzia Coppola,
Università della Campania Luigi Vanvitelli, Italy
Angel Golimstok,
Italian Hospital of Buenos Aires, Argentina

*CORRESPONDENCE
Joey Wong
joey.wong@ubc.ca

†These authors share first authorship

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A critical reflection on using the Patient Engagement In Research Scale (PEIRS) to evaluate patient and family partners' engagement in dementia research

Joey Wong[1,2*†], Lillian Hung[1,2†], Cates Bayabay[1,2], Karen Lok Yi Wong[2,3], Annette Berndt[2], Jim Mann[2], Lily Wong[2], Lynn Jackson[2] and Mario Gregorio[2]

[1]School of Nursing, University of British Columbia, Vancouver, BC, Canada, [2]UBC IDEA Lab, School of Nursing, University of British Columbia, Vancouver, BC, Canada, [3]School of Social Work, University of British Columbia, Vancouver, BC, Canada

Introduction: Research involvement of people with lived experiences is increasing. Few tools are designed to evaluate their engagement in research. The Patient Engagement In Research Scale (PEIRS) is one of the few validated tools. Our team employed the PEIRS with patient and family partners with lived experiences of dementia every 6 months in a two-year telepresence robot project. This reflection paper reports our self-study on key learnings and proposes practical tips on using the PEIRS to evaluate patient and family partners' engagement in dementia research. It is the first to document a case using the PEIRS multiple times in a dementia research project.

Methods: Guided by Rolfe et al.'s reflective model, we conducted three team reflective sessions to examine the team's experiences using the PEIRS to improve and evaluate patient and family partners' engagement in the research. We also reviewed our meeting notes and fieldnotes documented in the research journal. A reflexive thematic analysis was performed.

Results: The team identified three key learnings: the values of using the PEIRS survey, the adaptations, and the factors influencing its implementation as an evaluation tool. Using the PEIRS provided significant benefits to the project, although some patient and family partners felt it was burdensome. The evaluation tool was enhanced with emojis and comment boxes based on suggestions from patient partners. The emojis introduced an element of fun, while the comment boxes allowed for personalized responses. Several factors influenced the PEIRS tool's effectiveness: the interviewer's identity, the confidentiality of responses and follow-ups, the timing and frequency of using the tool, and the presentation of the evaluations. These learnings led to the development of six practical tips,—"ENGAGE": Enjoyable and fun process, Never impose, Get prepared early, Adapt to the team's needs, Give people options, and Engage and reflect.

Conclusion: With the emerging trend of including people with lived experiences in dementia research, there is a need for ongoing assessment of engagement from both patient and family partners and the research team strategies. Future research can further explore survey logistics, co-development of evaluation tools, and the use of tools with people living with dementia.

KEYWORDS

patient and public involvement, aging, dementia, older adults, technology, evaluation

1 Introduction

The involvement of people with lived experiences in health research has become increasingly important and continues to gain acceptance in the research field worldwide (L'Espérance et al., 2021). Many organizations and funding bodies now mandate the involvement of these individuals—referred to as "patient partners"—throughout various stages of research [Patient-Centered Outcomes Research Institute (PCORI), 2014]. Patient partners encompass patients, persons living with the disease, caregivers, family members, and friends [Patient-Centered Outcomes Research Institute (PCORI), 2014; Strategy for Patient-Oriented Research (SPOR), 2014]. Because of the increase in patient involvement in research, it is imperative to evaluate the quality of engagement of patient partners in the process.

While numerous existing frameworks support and evaluate patient and public involvement in research (Greenhalgh et al., 2019), there is a dearth of tools specifically designed to evaluate the quality of patient partner engagement in research (Boivin et al., 2018). The Patient Engagement In Research Scale (PEIRS) is a measurement tool to evaluate the quality of engagement of patient partners in research (Hamilton et al., 2018a,b). The original 37-item PEIRS evaluation tool was shortened and validated to the 22-item (PEIRS-22) questionnaire (Hamilton et al., 2021). The PEIRS-22 is organized across eight subthemes: *procedural requirements*, *convenience*, *contributions*, *support*, *team interaction*, *research environment*, *feel valued*, and *benefits*. In a recent systematic review of tools for assessing health research partnership outcomes and impacts, the PEIRS-22 scored high in scientific rigor and usability (Mrklas et al., 2023). Besides being a one-time measurement, the PEIRS-22 can support the research team in continuously improving patient engagement in the research project (Hamilton et al., 2021). The information from the PEIRS-22 evaluation allows researchers and patient partners to work together on diverse patient engagement strategies to improve engagement experiences. The PEIRS-22 can then serve as a tool to measure and capture any improvements over the research process after applying the strategies. The PEIRS-22 allows a "feedback loop" for progress monitoring and ongoing improvements in the research team (Hamilton et al., 2021).

The PEIRS-22 tool has been used in several research studies to evaluate patient partner engagement in people living with Parkinson's Disease (Morel et al., 2023) and Down Syndrome (Chung et al., 2021). The tool has also been used to foster inclusivity of underrepresented populations in adults with congenital heart disease (Messmer et al., 2023) and Parkinson's Disease (Sanchez et al., 2022). In some studies, the PEIRS-22 was employed to assess community stakeholder engagement (Barn et al., 2022; Morse et al., 2023). Moreover, the PEIRS-22 has also been translated, culturally adapted, and linguistically validated into Danish to assess patient partner engagement in cancer patients (Christiansen et al., 2023). In all these studies, the PEIRS-22 was a pragmatic tool for researchers to appraise patient partners' experiences and engagement throughout the research process.

In Canada, the PEIRS-22 is being employed in nationwide collaborative action research to develop a Canadian evaluation framework for patient and public engagement in research (L'Espérance et al., 2021). The Strategy for Patient-Oriented Research (SPOR) Evidence Alliance, a national, multilevel organization, has utilized the PEIRS-22 during a self-study "to reflect on the experiences of patient involvement in the organization's first 3 years" (Li et al., 2022, p. 30; Wang et al., 2023).

While a number of recent studies have utilized the PEIRS-22 in evaluating patient perspectives on meaningful engagement, only one recent commentary paper was found that planned to adopt the PEIRS tool to evaluate meaningful engagement in people with lived experience of dementia who were members of the Advisory Group for the Canadian Consortium of Neurodegeneration and Aging (CCNA) in dementia research (Snowball et al., 2022). Snowball et al. (2022) shared a plan to use the PEIRS-22, with two questions from the original PEIRS-37 and free text responses for a one-time evaluation at the end of the first year of their research project, evaluating the experiences of the Advisory Group members.

To enhance patient and public engagement in our patient-oriented study on implementing telepresence robots in long-term care, our team used the PEIRS-22 questionnaire to assess the experiences of patients and family members with lived experiences of dementia as partners during the two-year partnership in the Telepresence Robot project. In the study, telepresence robots, a tablet on wheels that allows virtual communication between family members and residents, were placed in residents' rooms in four Canadian long-term care homes. Family members could call in from around the world anytime and control the robot's movement in the resident's room. The project explores the experiences of residents, family members, and staff members who have adopted telepresence robots in long-term care. The results of the project were published in another papers (Hung et al., 2023; Ren et al., 2024). The research team included people living with dementia, family partners, frontline staff, community partners, researchers and trainees. The involvement of people living with dementia and family partners started from the planning stage of the research. One person living with dementia is the project co-lead. Patient and family partners were engaged in monthly team meetings via Zoom to discuss data collection, staff engagement strategies, data analysis, manuscript preparation and conference presentations.

Before using the PEIRS-22, the research team had an orientation session on an overview of the PEIRS-22 survey and a discussion on using the PEIRS-22 tool in the Telepresence Robot project. The team decided to digitize the PEIRS-22 survey. Patient and family partners suggested supplementing the numerical rating scale of the PEIRS-22 with emojis. A comment box was added to each question for contextual or additional information. The team also talked about the interview formats. After the discussion in the orientation session, the evaluation team digitized the questionnaire using an online software application, Qualtrics, added emojis to the 5-point Likert scale and comment boxes to each question for free text responses. The research team decided to perform evaluations using the PEIRS-22 questionnaire from the start of the project. It continued every 6 months for four sessions to evaluate engagement at different time points in the project. The intention was to identify gaps and make improvements throughout the project.

The first evaluation took place with a round of interviews in the summer of 2021. This round of interviews was one-to-one conversations with each patient and family partner via Zoom at a date and time convenient to the partner. Respecting partners' autonomy and choice, subsequent evaluations were done independently through the online survey by the partners, except for one family partner who preferred Zoom evaluations. There were, in total, four rounds of evaluations. Through the evaluations, our team learnt about what worked and what did not regarding the team's engagement performance. The research team adopted different engagement strategies to improve patient and family partner engagement in the project based on the feedback received in each round of evaluations, e.g., creating newsletters for sharing the project progress and how the robots were being used at each long-term care site, providing clear tasks information and task subgroups (e.g., manuscript writing and staff engagement strategies) for partners to choose to be involved in their preferred tasks. The average total scores of the four rounds of evaluations are shown in Figure 1. A higher score indicates a greater meaningful engagement (Christiansen et al., 2023). Overall, the patient and family partners remarked positively on their experience with the research team and the project work (see Table 1).

This study aims to reflect on key lessons learned and share practical strategies for using the PEIRS-22 in evaluating the engagement of patient partners living with dementia and family partners in research. It is the first to document a case of repeated application of PEIRS-22 within a dementia research project. The study will contribute to the growing science of patient and public engagement, particularly on meaningful engagement for people with lived experiences, using engagement evaluation tools, and advancing appraisal techniques to bolster public and patient engagement in dementia research.

2 Methods

The team performed the PEIRS-22 evaluation with patient and family partners every 6 months for four sessions until July 2023. Evaluators of the scale took reflective notes after interviews. The team then reflected on the experiences of using PEIRS in evaluating patient engagement in the Telepresence Robot project. There were three 1-h reflection sessions facilitated by JW via Zoom meetings. Team members who joined the reflection included project leads LH and JM (a patient partner co-lead), patient and family partners AB, LJ, LW and MG, project coordinator JW, evaluator team lead CB, and project team member KW. People living with dementia in our project are in the early stages of dementia. JM is living with Alzheimer's disease. LJ is living with frontotemporal dementia. MG is living with vascular dementia.

Rolfe et al. (2001) reflective model guided the reflection sessions. This model was chosen because it has been widely adopted for team reflection in healthcare research. It includes three main questions: What? (What is it?), So what? (Why is it important?), and Now what? (What should we do next?) We converted these questions into questions which fit our context: "What did we do well and not so well with the PEIRS-22 evaluation?" "What worked about the PEIRS-22 in dementia research, and what didn't work?" "Why did we/the PEIRS-22 do well or not so well?" "How can we do better in the future?" "How can the PEIRS-22 or other evaluation tools be improved in the future?" Reflection sessions were audio-taped and transcribed.

Following Braun and Clarke (2022) reflexive thematic analysis, we repeatedly read the reflective notes, which are transcriptions from our reflection sessions and listened to the recording to immerse ourselves in the data. We clustered related codes into categories and arranged these into themes. Reflective notes, transcripts, codes, categories, and themes were constantly compared to ensure consistency and coherence in the analysis. The data collection and analysis processes were iterative. Preliminary findings from the data of our prior reflection session informed the questions we asked in our next reflection session.

Trustworthiness refers to the fact that readers find the findings credible (Tracy, 2010). In other words, they can believe in the findings because the findings are based on comprehensive data sources and rigorous analysis and reflection processes. We enhanced the trustworthiness of our reflection by having more than one data source (reflection notes and transcripts) and practicing reflexivity with members from diverse backgrounds, challenging each other's assumptions in the reflection process.

2.1 Ethical considerations

Ethics approval was granted from the University Ethics Boards (H21-00844). Participants provided verbal consent and were offered the option to be identified by their actual names or pseudonyms in the dissemination of findings. Each participant has reviewed and approved the contents of this article.

3 Results

Telepresence Robot research team member characteristics are summarized in Table 2. Ten research team members are male, and 17 are female. The intergenerational team involves older adults and students. Patient and family partners made up about 25% of the research team. The rest of the team included two nurses, two recreation staff, one social worker, one community partner, six undergraduate and six graduate student trainees, and two academic professors. While all team members had some research experience in general, 11 had more experience in patient-oriented research.

After the team critically reflected on using the PEIRS-22 to evaluate the engagement experiences of patient and family partners in our Telepresence Robot project, three key learnings were identified: the value of using the PEIRS survey, the adaptations, and the factors influencing its implementation as an evaluation tool.

3.1 The value of using the PEIRS survey

3.1.1 The value of the project and beyond

When reflecting on the general impression of using the PEIRS-22, two members appreciated the inclusion of this evaluation tool in the project. The different subthemes of PEIRS offered a structured framework to evaluate and improve the research team's engagement

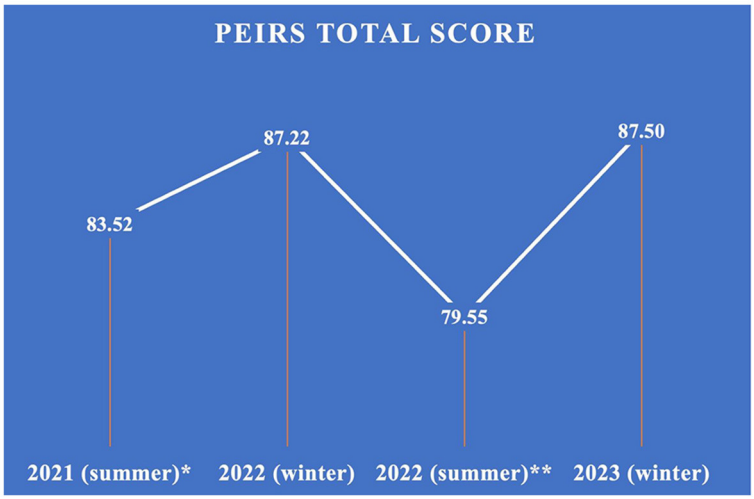

FIGURE 1
PEIRS total scores (*with 9 blank answers; **with 3 blank answers).

progress in a holistic manner throughout the research process. Our patient partner, MG, provided his comments on having the PEIRS evaluation as the project progressed, "PEIRS is an excellent way of tracking our performance [on engaging patient and family partners] on a project, and I think it is a very good tool." Our family partner, AB, also commented on the diverse aspects of engagement that PEIRS covered, "The questions do prompt you to draw your attention to things you might not have thought of otherwise." The structured framework also helped evaluate and improve the research team's engagement of patient and family partners. From the field notes of the evaluations, under the subtheme "Convenience," some partners commented at the beginning of the project on their roles in the research team: "I did not have an opportunity to discuss my role in the project… participants should be asked if they are feeling that they are useful in the project." Some partners expressed that the research team's information concerning task assignments was unclear. The research team responded by creating task subgroups and providing information on different options of the tasks that patient and family partners could join. The research team also shared information on project subgroups and tasks in the monthly newsletters. The evaluations included the voices of patient and family partners, which helped the research team enhance the research engagement process.

Besides acknowledging the positive impact that the PEIRS-22 can bring to an individual project, our patient partner project co-lead, JM, added the values of adopting PEIRS-22 beyond the Telepresence Robot project, "there are learnings [from the PEIRS] at different points. Those learning can still contribute to the field. The research lab can take that input into [the engagement strategies of] future projects, on what works and what does not." The PEIRS-22 provides a method to assess and compare patient and family involvement across research projects in our research lab and the dementia research field. Another patient-oriented project in our research lab adopted the PEIRS-22 after its use in the Telepresence Robot project. Another project lead, LH, stated, "it is not only for us [our research lab]. We can contribute to the field and promote the way we do patient-oriented research."

3.1.2 The value to patient and family partners and trainees

When asking members about how the PEIRS-22 helped individual members' engagement in the team, a family partner, AB, shared how the evaluations helped her reflect on her participation in project tasks and contributions to the research process:

> "PEIRS is a tool that is helpful in some ways in terms of awareness. Raising awareness of my engagement […] You sort of realize, okay, this is where I spent my time and how I spent it. I think that is kind of a reflection. It's actually a pretty good thing. It makes me a little bit more aware of what I am or am not doing […] It certainly enhances our understanding of the various approaches to involvement in the project."

The PEIRS-22 evaluations provided a platform for patient and family partners to share positive feedback and gaps/opportunities to improve the engagement experiences. These comments in the evaluation interviews might not often be shared in regular team meetings. The feedback encouraged and motivated student trainees in the research team to reflect, learn, improve, and use different strategies to engage patient and family partners meaningfully. For example, some comments created a positive team spirit: "I always left the meetings with a sense of optimism and "can do" spirit," and "The tasks don't take a lot of time. The tasks are very doable."

Many patients and family partners viewed the evaluation as an additional task. One member, MG, further explained, "PEIRS has nothing to do with my work in the research. It's not a reflection of my contribution to the project. It feels like just another task. It's an

TABLE 1 Examples of comments from patient and family partners.

PEIRS domains	Comments
Procedural requirements	The partners praised the research team for the level of attention, engagement and communication: "Organizers are efficient and send organized information." However, some partners voiced out that there needed to be an external source of communication besides team meetings as they might include too much information. The team moved some information in the email. After that, the team found a more innovative way than emailing, which was sharing information through our team newsletters. The team received encouraging comments: "Fabulous newsletter! Very engaging design and succinct messaging. As mentioned above, the newsletter really provided a great opportunity to get to know one another through photos and feature stories."
Convenience	In the beginning, some partners voiced that "I did not have an opportunity to discuss my role in the project… participants should be asked if they feel that they are useful in the project." Some partners found the research team's information concerning task assignments unclear. With this feedback, the research team created task subgroups and described the options of tasks that patient and family partners could join. Some partners found their involvement with the project convenient and manageable: "The team lead would always provide an option to talk over the phone at a time that was mutually convenient; also, we were welcome to email additional thoughts. The atmosphere was very friendly and forthcoming." "The tasks don't take a lot of time. The tasks are very doable." "Deadline flexibility is always appreciated."
Contributions	The partners contributed their knowledge and perspectives and felt their contributions were well received: "The voices of participants are important, and mine was included." "Being given the opportunity to share my lived-experience perspective in a constructive, forward-looking way is really why I continue to be part of this."
Team environment	The partners felt there was trust and respectful partnership within the team: "The friendliness of the research team goes a long way to foster a good environment of trust." "I'm treated with respect. We can say our view without judgement." "Everybody is very respectful. They respect the silence; there is no expectation to have something to say all the time."
Support	The partners felt well supported in their tasks and roles for the (Telepresence Robot) project: "Dr. Hamilton came in to explain the PEIRS (orientation), plus the newsletter and articles the team sends." "Whether by email or by phone (or in-person), I was always able to reach the team leader."
Feel valued	The partners felt their contributions were appreciated well and recognized through honoraria gifts, inclusion in events (e.g., conferences), and co-authorship in publications. "The Save-On and Amazon gift cards (vs. an honorarium check honorarium) are an excellent idea, although authorship is the gold standard of recognition." "My name will be mentioned along with the author, and I get gift cards. I was invited to the Christmas party and the picnic (I appreciated that I was included in these)."
Benefits	The partners found their involvement beneficial to others as well as themselves. "It is a major and much-needed confidence boost! Personally, I think it really made a huge psychological difference going forward. Thanks so much!" "I feel it's a worthwhile project for community use." "I always left the meetings with a sense of optimism and "can do" spirit." "I believe it keeps me active, and it helps my cognition." "Being involved in this project was also "therapeutic" for me in the sense that my experiences, both positive and negative, didn't just stay with me to be forgotten. Knowing that my lived experience and practical knowledge have a place to go with the potential to contribute to something positive in a field of healthcare that is often portrayed (and experienced) as negative offers hope for a better future. Society at large seems to falter in knowledge transmission, and these kinds of patient/family partnerships offer the opportunity to ensure that intergenerational, interprofessional, and other neglected interstitial connections are built up, maintained and can flourish."

evaluation." The PEIRS evaluations might seem to be burdensome to some partners. Some of them described the survey as "a chore," "tedious," and "a to-do task."

3.2 The adaptations

3.2.1 Questions in PEIRS

The PEIRS survey has 22 questions. Some members found some questions among the 22 questions to be similar. One patient partner, LJ, said, "It's repetitive. It's just tedious." Our team member, KW, one of the PEIRS-22 interviewers, said, "I think at a certain point when I was going through the survey, I was thinking why I am asking the same questions again." She further shared her concern, "There is a possibility that people may not even go through the [repeated or similar] question, because both the person asking and the person receiving may come to a consensus, 'whenever the question is similar, just skip it.'" For example, the questions under the subthemes "Procedural Requirements" and "Contributions" regarding the use of time by our partners sound similar. Another set of identical questions are related to our partners' decision making in the project under the subthemes "Benefits" and "Procedural Requirements."

Our patient partner MG raised the potential for conflicts in people's answers to similar questions: "If you answer A on the first one, and you answer C on the next similar question. Then, which answer is correct? So there is confusion and a danger [for conflict of answer] there." Our project lead, JM, commented that the interviewers could take this opportunity to learn from and build on the previous answer to a similar question. For example, interviewers can explore further when there are discrepancies in the answers to the two questions.

TABLE 2 Telepresence robot research team member characteristics.

Variable	Number ($n = 27$)
Disciplines	
Patient partner living with dementia	3
Family partner	4
Nurse	2
Undergraduate student trainee	6
Graduate student trainee	6
Academic professors	2
Community partner	1
Recreation staff	2
Social worker	1
Gender	
Female	17
Male	10
Research experience in general	
Yes	27
Experience in patient-oriented research	
Yes	11

3.2.2 Adaptations for older adults living with dementia and family partners

The team reflected on strategies to encourage people to answer the PEIRS survey. One patient partner, LJ, questioned, "I don't know how it [PEIRS] could be made more interesting so that the questions are more amiable to answer." Our patient partner, MG, appreciated the use of emojis adopted by our team for the PEIRS-22. He commented, "Using emojis makes it [PEIRS] a little bit fun to answer rather than having a series of questions, especially for people with a shorter focus and attention span." He also suggested that using an online survey tool might help design a survey that is "easier and fun to answer." Our patient partner LJ responded to MG's suggestion based on her perspective as a person living with dementia: "If we are looking for designs for people with dementia, using these online survey tools might be tricky for them to navigate and complete the survey."

Our evaluation team lead, CB, commented on the adaptations of the PEIRS-22 in our project, "At the very beginning, the team had a difficult time designing the online survey. We separated the sessions so that there are only 3 to 7 questions per page, which doesn't feel and look so long for the respondents." Our partners also liked another adaptation of adding a comment box to each question. MG said, "The comment boxes give a richer data collection because you cannot just say agree or neutral, but if you have a comment box and this adds a layer of information, I think that might be helpful." Our family partner, AB, added, "It is really good to add the comment boxes. The intention is to allow for more personalized comments."

3.3 The factors influencing its implementation as an evaluation tool

3.3.1 The interviewer's identity

One of the factors discussed by the team regarding the implementation of the PEIRS-22 is the person conducting the PEIRS interview. Some members questioned whether the participants' answers would change due to the relationships between interviewees and interviewers. Our project lead, LH, stated, "I have assumptions and a lot of positivity. If I were the person to ask for feedback, people might tell me good things and try to be polite. However, we wanted to know what matters most to them so that we can improve. People may not tell me because they try to be polite." Our evaluation team lead, CB, added the positive aspect of having arm-length interviewers to the project: "Being an outsider of the research project, the interviewer can be neutral and less likely to bring people to positive responses when asking questions. Interviewers could be more genuine, curious, and remain curious." One member also raised an interesting hypothesis on whether the participants would answer differently if the survey interviewer was an older adult or of similar cultural background: "Having similar age and cultural background may open up more conversations for feedback during the evaluations."

Some members, like AB and LJ, commented that their responses as participants would not alter based on whether they knew the person who did the interview. AB said, "I don't really think that it [who the interviewer is] would affect my responses. I generally have no problems being negative [...] It is sort of giving my impression of things."

3.3.2 The confidentiality of responses and follow-ups

Our team conducted multiple rounds of the PEIRS-22 in an anonymous format with online digitalized surveys. Except for the partner who preferred using Zoom interviews for the evaluation, the comments from other partners shared on the digitalized version were confidential. The interviewers pointed out that the anonymity made it challenging to follow up with the participants, for example, on the progress of the team engagement performance and whether the team had any improvements with participants' feedback and addressed their concerns. When the team reflected on whether we should maintain anonymity for the evaluations of engagement in the research, the participants had diverse opinions. One family partner, AB, said, "I usually choose to have my name revealed. It doesn't matter to me whether it's anonymous or not. I will probably still say the same thing." However, our patient partner, MG, was concerned about the impact on some respondents, even if they learned that their names would only be known to the interviewers. MG stated, "Revealing names to interviewers might impact the nature of feedback received... Participants may hesitate to respond freely if their identities are attached."

Our project lead, LH, reflected, "In hindsight, we didn't have a discussion about anonymity during the evaluation planning. 'Would you prefer anonymity?'" It is crucial for patients and family partners to grasp the significance of disclosing their identities, including options to remain anonymous or to be identified. They should be given the necessary information to decide for themselves

whether to reveal their identities to interviewers and research teams. For instance, the research team could illustrate how the disclosure of names to interviewers could be beneficial for follow-up actions related to team performance.

Regarding follow-up evaluations, MG, drawing on his experience with dementia, underscored the potential memory problem of participants regarding their responses, advocating for a reminder about follow-up inquiries at the PEIRS evaluation's conclusion: "A prompt at the end of the evaluation should be included to inform participants of subsequent follow-ups," he suggested. Our patient partner co-lead, JM, recommended offering follow-up options in the survey, such as "If we could follow up with you, please give us your preferred future contact." Additionally, MG proposed a system to maintain confidentiality by assigning numbers to names, enabling follow-up without revealing identities: "Assign a unique number to each participant, which will be known only to the interviewer. This allows responses to be tracked while maintaining confidentiality."

Our family partner, AB, emphasized the need to carefully consider the specific questions to follow up on: "We need to reflect on the important points that need further investigation and the ones that we are really focusing on. The evaluating team needs to take time to explore what we want to understand [. . .] which questions we want or need to dig deeper." For example, one evaluation found that patient partners were unclear about their tasks or roles. After some strategies were in place, the interviewers could follow up in the subsequent evaluation interview on whether the patient partner felt clearer about the project tasks to contribute and manage the tasks better. The interviewer, CB, noted that questions receiving a "neutral" response without additional comments should be examined more closely by the team for deeper insights.

3.3.3 The timing and frequency of using the tool

Another factor for implementing the PEIRS evaluations is the timing of conducting the PEIRS survey, as our project had multiple rounds of evaluations. The project coordinator, JW, shared that more comments and suggestions were received at the beginning: "Personally, I think the very first one [PEIRS evaluation] is the most useful because there are more comments and suggestions. We made quite a lot of changes and improvements after the first one." For example, some partners voiced out that there needed to be external sources of communication besides team meetings as there might be too much information in a meeting. The team thus moved some information in the email. After that, the team found a more innovative way than emailing, which was sharing information via monthly newsletters. The research team received an encouraging comment in the subsequent PEIR-22 evaluation: "Fabulous newsletter! Very engaging design and succinct messaging. As mentioned above, the newsletter really provided a great opportunity to get to know one another through photos and feature stories." The evaluation lead, CB, also noticed a decrease in the number of comments shared in the later rounds of the PEIRS-22, "During the third or the fourth time [of evaluation], there were not as many comments in the comment boxes." Our project lead, JM, also suggested external factors impacting the scoring of the PEIRS that might not be related to the research project, such as personal life events. The evaluation team lead, CB, echoed and shared that the third evaluation, in which the team got a lower average score, was done during a time of sustained stress during the COVID-19 pandemic. The availability of vaccines and the provincial restrictions might be potential external factors impacting patient and family partners during the third evaluation.

Some members commented on the relationships between questions and the time of evaluations. MG commented on the relevance of some questions to be asked at a certain time of the research progress: "At the beginning of the project, I thought the project was not completed yet, so why are we asking for a conclusion already on how we feel about the project?" One example regarding MG's comments is the question under the subtheme "Convenience" about the time allowed for completing his assigned tasks in the project. Our family partner LW also expressed that at the beginning of the project, she found it difficult to answer the questions regarding tasks, contributions, and workload when she was still exploring the project details and her role. One question LW mentioned regarding her contributions is under the subtheme "Procedural Requirements." These might explain some blank answers received in the survey where the questions might not be applicable during evaluation. A family partner, AB, shared that having a PEIRS survey to be conducted right after a project meeting would be helpful. She said, "It [The experience] was much fresher in my mind. My answers [to the PEIRS survey] were more relevant to the project context."

Although one family member, AB, appreciated that using the same set of standardized questions at different time points of the project could provide a basis for comparison over time, some members questioned the purpose of repeating the same questions for every evaluation. For instance, one member felt confused about the repeated questions: "There was a little bit of 'Why are they asking it again?' It's repetitive. So maybe if you do it less often, we may not find it repetitive [. . .] Say, maybe do it in the middle and the end."

3.3.4 The presentation of the evaluations

Our project's first round of the PEIRS evaluations were all one-to-one online interviews. After that, one member continued with online individual interviews, while most preferred the self-administered online survey. Our team reflected on the preferred evaluation format, whether it should be a facilitated interview or a self-administered survey, an individual or group interview, or in-person or Zoom meetings. Our patient partner, MG, emphasized the potential "side effects" of personal interviews:

"No personal interviews at all. Most people are polite. I don't want you [the interviewers] to feel offended because everybody works hard, and I don't give failing marks. If I do it at home or on paper, then it gets shown in the table, or it goes to the data. Who cares who I was talking to [. . .] I would not recommend a personal interview if you know exactly what you want and an input that is not biased."

Another member, LJ, shared her preference for completing an online self-administered survey on her own even though her answers would not be impacted by having an interviewer: "I would prefer to do an online or a paper one [survey] by myself. And you know, the interviewers, either way, if it was in person or Zoom, I don't have a problem saying how I feel, so that wouldn't be a

problem for me." Our project lead, LH, suggested the option of a group evaluation session: "Group sessions might help facilitate a better kind of conversation. So it's not as boring." Our member MG responded to the suggestion of having group evaluations: "There might be a group dynamic. They [The participants] might be persuaded by other people [in the group] to say, 'I agree'. Or sometimes when others say, 'I don't like this,' 'Yes, I don't like this either.'"

For the online option, our patient partner, MG, raised the concern of accessibility for the population our project team is engaging. He said, "We have to think about the older adults who are not conversant with technology." Our project lead, LH, echoed and reiterated the importance of having options and flexibility: "People are not homogeneous. We all have different preferences. We need to offer people options and understand what meets people's needs."

4 Discussion

There is an emerging trend to engage people with lived experience and people living with dementia in research (Miah et al., 2019; Williams et al., 2020; Vellani et al., 2023). However, there is a lack of evidence on using validated tools to evaluate the impact and process of public engagement and inclusion of people with lived experiences in dementia research (Miah et al., 2019). This reflection paper contributes to the field of dementia research by documenting how the PEIRS-22 tool can be used over multiple time points to evaluate team engagement in a dementia research project and by sharing critical team reflections on the key learnings in adopting the tool. Based on the key learnings, we will discuss (1) the need for adaptations and reflections, (2) insights for using evaluation tools with older adults living with dementia, and (3) the opportunity to build a community of learning in the field to improve engagement in dementia research. We offer practical tips and implications for future research.

One message that stood out from the team reflections is that researchers need to acknowledge that evaluation tools such as the PEIRS survey are not "one size fits all." As suggested by Mann and Hung (2019, p. 587) in the "ASK ME" framework of tips for engaging a person with dementia in research, one practical tip is "to support the person to do the best.": "It is useful to take the time to get to know the person [...] Support the person to maximize contribution and avoid exploitation. See the person with an appreciative lens helps to focus on strengths and possibilities." Despite using the same tool, researchers may need to adapt and tailor the use of the evaluation tool to support and maximize responses from the specific group of people with lived experiences in the research team. There should be flexibility and a shared informed decision-making process early in the project on how the team will work with the engagement evaluation procedures, e.g., the format and time of the evaluations and who should be performing the evaluations. These factors may have potential positive or negative influences on the evaluation and the partners' experiences in the evaluation process. Providing options and having co-developed strategies can facilitate the evaluations. Ongoing critical reflections are needed to examine the use of evaluation tools among the team. Ensuring a shared consensus and clear understanding of how and whether the evaluation tool helps the project team improve is essential. Otherwise, the initial intention behind evaluating to improve engagement may, in turn, become "a burdensome chore" to people with lived experiences. It may lead to negative engagement experiences for these individuals due to a complicated evaluation process.

For the population that our team is working with, which includes people living with dementia and older adults, several aspects need to be considered based on the critical reflections. The evaluation timing should be carefully considered when working with this population. For example, evaluations can be done right after completing specific project tasks or milestones, e.g., manuscript writing, to allow people to provide feedback regarding the engagement process to provide an "at present" feeling. The considerations of the timing of performing the evaluations echoed a recent reflection on a study using a loneliness scale for people living with dementia (Wong et al., 2022). Participants in the study tended to respond to how they felt during the interview rather than recalling their past experiences or feelings. Besides finding suitable evaluation timing, having a dementia-friendly survey can help facilitate the evaluations. The research team can refer to online resources on developing dementia-friendly surveys (Alzheimer's Society, n.d.) or co-create in-print and online surveys with people with lived experiences. Tailoring the survey to be more dementia-friendly and fun will offer individuals easier navigation of the evaluation tool and a more enjoyable evaluation experience.

This reflection underscores the significance of collective learning about the evaluation of research engagement of people with lived experiences within the field. Our team had little evidence to guide our engagement evaluations with people living with dementia at the beginning of the project. Continuous dialogues and discussions in the field are crucial to exploring what works and what does not work in the evaluation processes in various projects, how different teams adopt and adapt evaluation tools, how researchers can improve evaluation tools, what meaningful engagement means to different populations, and how the engagement experiences of patient and family partners can be better supported. The sharing of opportunities and challenges of diverse research teams allows improvements for future teams to adopt evaluation tools and contributes to the continuous development of evaluation methods to support patient and public engagement. Creating a learning community for evaluating research engagement resonates with that of a "learning health system" suggested by L'Espérance et al. (2021), which could help build capacity for implementing patient and public engagement and evaluations across the research community.

This reflection embraces assumptions, feelings and experiences of our patient and family partners and team members, which reminds our team and scholars that engagement evaluation should not only focus on the "performance" or "score." It may be more important to understand better and enhance how patients and family partners "feel," which is beyond the scores research teams obtain from validated measures.

4.1 Practical tips

Based on our key learnings, we offer the following six practical tips, "ENGAGE" (see Table 3). These tips can inform future research projects, particularly studies in the dementia field, to

TABLE 3 Description of six practical tips "ENGAGE".

E	It is an enjoyable and fun process	The evaluation enhances patient engagement experiences but not adds an extra burden on patient and family partners. It should also be beneficial and enjoyable. Adopting elements like emojis can make the evaluation process fun and more comfortable.
N	Never impose	The team needs to acknowledge that people are heterogeneous and have different preferences. The evaluation methods and process should be flexible and a shared decision among the team. Nothing should be imposed on team members.
G	Get prepared early	The preparation should involve the whole team from the beginning of the project, e.g., the aim and process of the evaluation, anonymity, the evaluation tool and the timing of evaluations. Gentle reminders from time to time on the important evaluation components (why and how) help keep people living with dementia informed and prepared.
A	Adapt to the team's needs	Different research teams may involve diverse groups of people with lived experiences who have specific needs, e.g., language barriers due to cultural backgrounds, education backgrounds and cognitive and physical challenges. For example, in our team, it was easier and fun for people living with dementia and older adults to answer the rating scale with emojis.
G	Give people options	Giving evaluation respondents options shows respect by the research teams. Individuals in the team can enjoy autonomy in deciding for themselves their preferences, e.g., being anonymous and choosing the evaluation format. This enables a person-centered approach in the evaluation process.
E	Evaluate and reflect	Teamwork and self-reflection on the engagement evaluation process are necessary to ensure that the use of the evaluation tool is meaningful and helpful in enhancing engagement experiences. Without reflection, the evaluation process of engagement experiences may become a "routine" and "wasted" task for the project team.

adopt the PEIRS-22 or other evaluation tools to enhance patient engagement experiences.

4.2 Implications for future research

In our team reflections, it was noted that some questions seemed repetitive when the PEIRS-22 evaluations were performed multiple times in a project. Future studies can explore whether there is a need to modify or omit some questions when the survey is repeated at different time points in a project. Another comment is on the impact of interviewers during the evaluation process. Future research can explore the impact of different interviewers on the evaluation results, e.g., whether it would be more beneficial to have an outsider than an insider of the project team as the evaluation interviewer.

Regarding the development and validation of evaluation tools, the PEIRS-22 has not been validated with people living with dementia. Future research developing evaluation tools for this population can engage people living with dementia and their care partners in the tool development and validation process. Including people with lived experiences can ensure the tool developed is relevant, meaningful, and accessible to the targeted population. Furthermore, our research team's patient partner co-lead is living with an early stage of Alzheimer's disease. Future research can explore the use of evaluation tools and strategies with research team members living with different types of dementia and individuals with diverse backgrounds.

5 Conclusions

Given the emerging trend of including people with lived experiences in dementia research, there is a need to continuously evaluate the engagement experiences of patient and family partners and the engagement strategies adopted by the research team. With a lack of studies documenting the use of evaluation tools and evaluation processes with people living with dementia, the key learnings from using the PEIRS-22 in a Canadian patient-oriented research study offer pragmatic insights and tips for future research teams on using engagement evaluation tools. Researchers can co-plan different aspects of the evaluation process with patient and family partners. Having ongoing critical reflections is key to more effective use of evaluation tools to enhance engagement. When more research teams share the challenges and opportunities regarding engagement evaluations, a community of practice and learning can be built to support one another on the journey of public and patient engagement in dementia research.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by UBC Behavioural Research Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article. Participants provided verbal consent and were offered the option to be identified by their actual names or pseudonyms in the dissemination of findings. Each participant has reviewed and approved the contents of this article.

Author contributions

JW: Writing – review & editing, Writing – original draft. LH: Supervision, Funding acquisition, Conceptualization, Writing – review & editing. CB: Writing – review & editing, Writing

– original draft. KW: Writing – original draft, Writing – review & editing. AB: Writing – review & editing. JM: Writing – review & editing. LW: Writing – review & editing. LJ: Writing – review & editing. MG: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Suzanne Timmons,
University College Cork, Ireland

REVIEWED BY
Nidhi Mahendra,
San Jose State University, United States

*CORRESPONDENCE
Ellen Snowball
✉ Ellen.Snowball@uhn.ca

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Engaging people with lived experience of dementia in research meetings and events: insights from multiple perspectives

Ellen Snowball[1,2]*, Christine Aiken[2], Myrna Norman[2], Wayne Hykaway[2], Zoe Dempster[2], Inbal Itzhak[3], Emily McLellan[2], Katherine S. McGilton[1,2,4] and Jennifer Bethell[1,2,5]

[1]Knowledge, Innovation, Talent, Everywhere (KITE) Research Institute, Toronto Rehabilitation Institute, University Health Network, Toronto, ON, Canada, [2]Engagement of People with Lived Experience of Dementia Program/Advisory Group, Canadian Consortium on Neurodegeneration in Aging, Montreal, QC, Canada, [3]Knowledge Translation and Exchange Program, Canadian Consortium on Neurodegeneration in Aging, Montreal, QC, Canada, [4]Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada, [5]Institute of Health Policy, Management & Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

This perspective article describes the experiences of engaging people with lived experience of dementia in research meetings and events from the perspectives of people with lived experience, researchers, trainees, audience members and others. We outline examples of engagement from different events and describe a video project, initiated by people with lived experience, conveying diverse views about becoming integral collaborators in the Canadian Consortium on Neurodegeneration in Aging (CCNA) annual Partners Forum and Science Days. We also report evaluation data from audiences and present a series of tips and strategies for facilitating this engagement, including practical considerations for supporting people with lived experience.

KEYWORDS

dementia, aging, patient and public engagement, lived experience of dementia, health research, engagement in research, multi-stakeholder, advisory group

1 Introduction

Dementia describes the symptoms related to neurodegenerative conditions, such as Alzheimer's disease, vascular dementia, Lewy body dementia, and others. These symptoms include memory loss, difficulties in thinking, problem-solving and language, and changes in mood and behavior. Dementia can impact a person's ability to perform everyday activities, such as bathing, dressing and cooking (Cipriani et al., 2020). Risk increases with age and most of those living with dementia are older adults (Canadian Institute for Health Information, 2015). Dementia is highly stigmatized (Link and Phelan, 2001). Stigmas associated with dementia, compounded by impacts of ageism and ableism, threaten social participation of people living with dementia as well as their family and friends and can be a barrier to care and support (Vernooij-Dassen et al., 2005; Werner et al., 2014; Herrmann et al., 2018).

Increasingly, patient engagement[1] in research is required by funding agencies, including in the United States, Canada, the United Kingdom (Forsythe et al., 2015; Manafo et al., 2018). The concept, rooted in HIV/AIDS research and the disability rights movement, asserts that individuals affected by publicly funded research have the right to actively participate in it (Shimmin et al., 2017). It has also been suggested to lead to better quality research with greater impact (Domecq et al., 2014; Wilson et al., 2015; Chudyk et al., 2022; Marshall et al., 2023). In the context of patient engagement in research, people with lived experience are taking on roles such as co-applicants on grants, research team members, co-authors on papers and others (Bethell et al., 2018; Snowball et al., 2022).

While much has been written about the motivations for and benefits of patient engagement, less is known about the potential challenges and risks to people with lived experience. Patient engagement activities that are not conducted ethically can pose distinct risks to people with lived experience, such as experiences of tokenism, stigmatization, re-traumatization, power imbalance, and discrimination (Hahn et al., 2016; Government of Canada, 2020; Richards et al., 2023; Zubair, 2023). Moreover, similar to participation in research on dementia (Vyas et al., 2018), racialized individuals and other marginalized groups are under-represented in patient engagement activities (Keane et al., 2023), thereby perpetuating experiences of discrimination. These experiences can harm the individual, and/or leave them disillusioned with research (Richards et al., 2023). Recommendations for patient engagement approaches, such as using anti-oppressive frameworks, would help facilitate meaningful engagement that supports the dignity and personhood of people with lived experience (Kontos, 2005; Cowdell, 2006; Kontos et al., 2017; Ontario's Patient Engagement Framework, 2017; Shimmin et al., 2017; Government of Canada, 2018, 2020; Roche et al., 2020; University Health Network, 2023; Zubair, 2023). However, there remain gaps in the literature on best practices, from the point of view of people with lived experience and specific to different research roles, venues (Poitras et al., 2020) and populations being engaged.

This article aims to describe experiences of engagement from the perspectives of people with lived experience of dementia, researchers and others, on collaborating in research meetings and events. We outline examples of engagement from different events and activities, including a video project, initiated by people with lived experience, conveying diverse views about becoming integral collaborators in the Canadian Consortium on Neurodegeneration in Aging (CCNA) annual conference. We also report evaluation data from audiences and present a series of tips and strategies for facilitating engagement in these contexts, including practical considerations for supporting people with lived experience in research events and meetings. These descriptions and findings, however, are limited to the experiences of those living with early stage dementia together with friends, family and care partners/caregivers who have collectively experienced early, middle and late stage dementia. We hope this paper will support people with lived experience in research and those seeking to involve them in similar settings.

1.1 Engagement of People with Lived Experience of Dementia Advisory Group and Cross–cutting Program

CCNA was developed to advance research on neurodegenerative diseases. It is a pan-Canadian network funded by the Canadian Institutes of Health Research and partner organizations. CCNA researchers are supported by cross-cutting programs, including the Engagement of People with Lived Experience of Dementia (EPLED)—introduced in CCNA Phase II (starting in 2019).

EPLED's objectives are to: (1) Support persons with dementia and care partners to be involved in the research process; (2) Work with research teams, cross-cutting programs and partners to develop novel mechanisms to further this collaboration; and to (3) Advance the methods of patient engagement in research through evaluation. EPLED is co-led by two academic researchers (JB and KMcG), managed by a research associate (ES), and funded by the Alzheimer Society of Canada.

In 2020, EPLED developed an Advisory Group of individuals, from across Canada, with diverse lived experiences of dementia (e.g., people living with dementia, friends, family and care partners/caregivers) who would work with CCNA researchers—not as study subjects but as collaborators in research (Snowball et al., 2022). EPLED has worked to integrate the lived experience Advisory Group members in various initiatives and to meaningfully and actively involve them in research activities.

2 Activities and roles

2.1 Canadian Consortium on Neurodegeneration in Aging Partners Forum and Science Days

CCNA Partners Forum and Science Days (PFSD) are venues to share research within the network. Previously held annually and in-person, the conference moved online due to COVID-19. In 2020, the conference agenda included a workshop to introduce EPLED. In 2021, to increase integration, EPLED Advisory Group members were invited to the planning committee. Members provided feedback on session ideas and developed roles within the program. The resulting conference agenda included two panels featuring three Advisory Group members; one about collaborating on an international research project and another about social connection and long-term care homes. In 2022, we deliberately shifted away from a lived-experience-focused session as attendance was primarily researchers already committed to patient engagement. Instead, we worked to integrate lived experience perspectives across the scientific program, including by creating new roles for members that prioritized their voices. For example, a person with

1 Canadian Institute of Health Research (2019) defines patient engagement as: "an approach that involves meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation" "Patient" is a term that refers to people with lived experience of a health issue. The authors acknowledge that using this term fails to account for people's full identities and experiences. However, for continuity, we refer to lived experience engagement in research as patient engagement throughout this paper.

dementia spoke on an opening session panel alongside CCNA's Scientific Director and Canada's Minister of Health, and a caregiver delivered the closing session. In the regular sessions, Advisory Group members participated as speakers alongside researchers and in a discussant role, where they could pose the first questions from the audience. There were other opportunities to share lived experience stories through a series of recorded videos.

2.2 Canadian Consortium on Neurodegeneration in Aging Public Events

CCNA Public Events are venues for sharing research with non-scientific audiences. In 2020, these events moved online due to COVID-19. Advisory Group members joined the planning committee in 2021. They discussed addressing the needs of care partners/caregivers, and so the event focused on "Caring and Caregiving for a Person Living with Dementia". An EPLED Advisory Group member participated as a panelist speaker alongside three researchers. EPLED and CCNA staff worked with them to prepare a recorded message for attendees. In 2022, recognizing EPLED's impact, five Advisory Group members joined the planning committee. They created a focus for the event, "Finding Hope in Dementia", around practical ways to live well with dementia. The panel included two researchers and two Advisory Group members. The webinar was structured using informal conversation and members spoke about quality of life and strategies for finding hope.

2.3 Canadian Institutes of Health Research—Institute of Aging Summer Program in Aging

In 2022, an EPLED co-lead (JB) joined the program planning committee at the Canadian Institutes of Health Research—Institute of Aging Summer Program in Aging (SPA). Advisory Group members participated in the conference program; eight joined 30-min "Coffee Breaks" with trainees, and three spoke in program sessions. An open format was used, where trainees could ask questions about EPLED engagement. These sessions were short, allowing trainees to join in-between other sessions.

2.4 Vascular training platform conference

In 2023, The Vascular Training (VAST) program integrated lived experience into their first annual in-person conference. Three EPLED Advisory Group members and one EPLED staff member (ES) were invited to join the planning committee. Advisory Group members envisioned a panel on how researchers can engage people with lived experience throughout the research process. They invited a biomedical researcher who had prior experience collaborating with them to speak from a researcher perspective. The panel was presented to an in-person research audience in Montreal, Quebec. It featured four Advisory Group members; two caregivers and two people living with dementia. Members spoke about their experiences collaborating in research, including impact on research, and barriers and enablers to engagement.

3 Methods

3.1 Evaluation data

Evaluation data were collected in online, anonymous surveys using a 5-point Likert scale (rating the helpfulness or meaningfulness of lived experience perspectives or enhanced awareness of benefits of lived experience involvement) and/or via open-ended questions (Table 1).

3.2 Experiences of EPLED Advisory Group members

3.2.1 Tips and strategies for engaging people with lived experience in research meetings and events

EPLED Advisory Group members discussed their experiences collaborating in these research events. They compiled a series of tips and strategies to encourage and assist others who might be planning research meetings and events involving people with lived experience.

3.2.2 "Successful integration of lived experience perspectives in national dementia research meetings"—Video project

> *Unless you are in a situation, you cannot relate to it. You can think about what may have happened. You can try to relate, but unless you're there living it day-to-day, you don't see what's going on –*
>
> Wayne Hykaway (1952–2024)

EPLED Advisory Group members prioritized sharing their experiences through a video project that would be accessible to diverse audiences (i.e., researchers, research funding organizations and the public, including people with lived experience). By choosing a video, they felt that more audiences would learn about the value of lived experience perspectives and strategies for supporting collaborations.

The video (https://vimeo.com/900182095) described how the EPLED Advisory Group became an important part of the CCNA community. CCNA and EPLED staff worked with Advisory Group members to develop a script and interview guide. Using open-ended questions, staff interviewed researchers, trainees, and EPLED Advisory Group members on their reflections and experiences collaborating in the CCNA conference. The recorded discussions were used to illustrate insights for researchers, research funding organizations and the public, including people with lived experience. The video shows how people with lived experience can take on multiple roles in research, and perceived benefits from the

TABLE 1 Event evaluation data collected after Advisory Group collaborations.

Event/audience	Evaluation question	Mean score	Feedback
CCNA PFSD conference (2022)/Primarily researchers, including trainees ($n = 80$ responses)	"This session featured a member from CCNA's Engagement of People with Lived Experience of Dementia (EPLED) Advisory Group. How helpful was it to hear their perspective?"	• Opening (Session 1): 4.8 out of 5 • Stress & Dementia (Session 5): 4.6 out of 5 • Closing (Session 18): 4.8 out of 5	*It was powerful to hear from someone affected by dementia who has worked in the field and is now passionate about patient engagement in research* (Session 1). *It was very helpful and moving to hear from someone with lived experience. It made the issue more real and not just an academic exercise* (Session 2). *Extremely helpful as it reminds us researchers of the importance not only to do research, publish studies and present them to conferences, but also to share the knowledge to the general public, to engage more with local groups and colleagues from other fields so that those living with dementia (and their caregivers) are never left alone and are offered all the help they deserve* (Session 18).
SPA conference (2022)/Trainees ($n = 16$ responses)	"SPA 2022 increased my awareness of the benefits of involving those with lived experience in research on age-related conditions associated with impaired cognition"	• 4.6 out of 5 • Tied for highest rating with 9/16 saying they strongly agreed	*The most important and meaningful takeaways were the many lessons and discussions with people with lived experience.* *The primary motivation to do research on neurodegeneration is to help real people with real problems, not just articles for our own career's sake.*
CCNA Public Event (2022)/General public ($n = 58$ responses)	"One of the panel members, Linda, was a caregiver who shared her experience caring for her husband with dementia. Was it helpful to include a caregiver on the panel? Please explain."	• N/A	*This was the most useful part of the presentation. Her lived experience made me feel less alone. She had excellent suggestions for advocacy and for caregiving.* *We can learn more from personal experience than a textbook.* *Oh my goodness - I learned the most from her!*
CCNA Public Event (2023)/General public ($n = 54$ responses)	"This webinar featured speakers with lived experience of dementia (a care-partner and a person with dementia). How helpful was it to hear their perspective?"	• 4.7 out of 5	*It's the first time I heard a person with dementia speak about it from their perspective.* *Hearing first hand from a patient with dementia, speaking so eloquently and clearly, broke down all my prejudices and fears about dementia.* *"Lived experience" is the strongest way to express truth, to share truth, and to live truth.*
VAST conference (2023)/Researchers and trainees ($n = 17$ responses)	"The involvement of people with lived experience was meaningful to me" "What were your favorite and least favorite sessions?"	• 99 out of 100 • 10/17 respondents mentioned the EPLED panel specifically as their favorite	*We can't forget the real people our research will benefit, not just in the future, but now!* *Working with PWLE advances not just clinical practice, but also scientific discovery.* *[I] [gained] [a] better understanding of how to explain my work to people outside of academia.*

perspectives of people with lived experience, researchers and event attendees.

4 Results

4.1 Evaluation data

Evaluation data shows that collaborations in these venues were highly rated by different audiences for increased awareness of the value of lived experience perspectives in research, and meaningfulness and helpfulness of lived experience participation (Table 1).

4.2 Tips and strategies for engaging people with lived experience in research meetings and events

4.2.1 Engage early and hold frequent meetings

Engaging EPLED Advisory Group members early in event planning meetings provided them with time to build relationships and trust with others and be meaningfully included in the planning process (Richards et al., 2023). It was important to consult with Advisory Group members on meeting time, frequency and length. Regular, online, bi-weekly or monthly one hour meetings helped to ensure that meeting agendas were not rushed, and that there was time to build rapport through informal conversation (Litherland

et al., 2018; Vellani et al., 2023). Meetings were planned around the availability of EPLED Advisory Group members, accommodating for day jobs, caregiving responsibilities, and other needs and limitations (Burton et al., 2019).

4.2.2 Provide support

Logistical support included providing email reminders of upcoming meetings, notes/recordings from meetings and assistance with forms (e.g., travel reimbursement). It also included technical support such as connecting to online meetings, troubleshooting computer problems and accessing documents (Novek and Wilkinson, 2017; Burton et al., 2019; Frank et al., 2020). Varied degrees of support were required in preparing for EPLED Advisory Group participation in meetings (e.g., preparing scripts or presentation materials). For in-person meetings, members sometimes required assistance with travel planning in advance, during and after events and, for some, a support person (e.g., friend or relative) traveled with them (Guidelines on Inclusive Travel Meetings for People with Dementia, 2024). During travel, EPLED provided a staff contact number for questions outside of business hours and collected emergency contact information. There was frequent contact between staff and Advisory Group members and opportunities to request one-on-one meetings if needed. Emotional support was provided through building relationships and trust with the EPLED and CCNA team as well as among the Advisory Group members. EPLED and the Advisory Group worked to recognize the vulnerability in sharing personal lived experiences by holding space for difficult discussions, validating people's feelings and focusing on individual strengths (Burton et al., 2019). The EPLED staff member (ES), dedicated to supporting the Advisory Group, has lived experience of dementia and Advisory Group members also brought relevant expertise to the group dynamics.

4.2.3 Create multiple roles

EPLED remained flexible on the level and nature of Advisory Group involvement. Members collaboratively created roles tailored to their varied interests, priorities, preferences, motivations, and needs (Frank et al., 2020). Roles were diversified to increase participation for Advisory Group members and engage audiences. For example, discussant roles were introduced at conference sessions, where Advisory Group members were prepared to ask the first audience question. "EPLED stories" were also introduced, where EPLED Advisory Group members recorded a short message about their lived experience. Clear descriptions and orientation on expectations and responsibilities for roles was essential.

4.2.4 Include diverse perspectives

EPLED Advisory Group members highlighted the importance of representing diverse experiences of dementia and caregiving, including with respect to age, ethnicity and gender identity. We used a consensus-based approach to reach agreement on roles, but prioritized the voices of those living with dementia. The EPLED Advisory Group collectively created a safe, trauma-informed, space to develop equitable partnerships, emphasizing trust, empathy, self-awareness, and relationship-building (Shimmin et al., 2017; Roche et al., 2020)[2]. We utilized an anti-oppressive, social justice and health equity lens to our work, recognizing vulnerability (e.g., in sharing personal lived experiences), promoting reflexivity (e.g., understanding unconscious bias), and embodied selfhood (e.g., agency beyond cognition) (Kontos, 2005; Kontos et al., 2017; Shimmin et al., 2017; Roche et al., 2020; Zubair, 2023). This approach extended to interactions in research meetings and events, where Advisory Group members recognized the vulnerability in sharing lived experiences and, even in instances of diverging opinions, supported one another in doing so. We practiced and encouraged active listening, welcoming critical feedback as opportunities for reflection and improvement.

4.2.5 Plan for informal and formal interactions

Relational strategies, such as bi-directional communication (e.g., conversations), were valued by EPLED Advisory Group members (Metz et al., 2022). During both virtual and in-person events, they enjoyed opportunities to interact with researchers, trainees and fellow lived experience members. This was seen as a way to expand their networks and learn from others' perspectives. Informal conversation was welcomed during meetings and was integrated in the programs through scheduled social time (Novek and Wilkinson, 2017).

4.2.6 Plan for frequent breaks

At online and in-person events, we planned for frequent breaks that were scheduled in agendas. For in-person meetings, we arranged private break spaces nearby, such as a quiet meeting room (Guidelines on Inclusive Travel Meetings for People with Dementia, 2024). EPLED Advisory Group members appreciated when events were held in hotels, as it allowed them to go back to their rooms as needed. We ensured that missed information was communicated as needed.

4.2.7 Encourage participation

The tips and strategies described herein are intended to encourage participation of people with lived experience. In all capacities, it was important to empower EPLED Advisory Group members with the knowledge that their lived experience was expertise and that their input was valuable. In our experience, involvement by EPLED Advisory Group members also encouraged participation from all audiences by demonstrating that different perspectives were valued. EPLED Advisory Group members contributed to various sessions, although it was key to acknowledge that some were highly technical (Burton et al., 2019). Presenting to academic and non-academic audiences can be challenging but sessions involving people with lived experience helped researchers and trainees to develop this skill set (Biglieri, 2021; Richards et al., 2023).

2 Diversity in Patient Engagement Learning Exchange. (2019). Available online at: https://www.healthcareexcellence.ca/media/xamlyars/dle-report-e-final-ua.pdf.

FIGURE 1
EPLED tip sheet infographic.

4.2.8 Provide compensation and prepay expenses

Offering compensation helps to recognize the expertise, time and contributions of people with lived experience (Litherland et al., 2018). Referring to patient engagement compensation guidelines can provide guidance, such as payment based on type of engagement (Government of Canada, 2019, 2022)[3]. However, compensation should also be individualized according to unique needs and circumstances. Further, payment for travel expenses should be reimbursed. To minimize out-of-pocket expenses incurred by EPLED Advisory Group members and wait time for reimbursement, we prepaid expenses to the extent possible by booking travel, arranging hotel rooms and ground transportation (Guidelines on Inclusive Travel Meetings for People with Dementia, 2024).

4.2.9 Use accessible language and spaces

Using accessible, person-centered language in all communications and venues helped EPLED Advisory Group members to feel included. The EPLED Advisory Group provided recommendations that advised researchers and trainees to tailor their communications, including using language that was jargon and acronym-free and, where possible, circulating material within the group at least 1-week in advance of meetings (https://www.epled.ca/s/Suggestions-For-Researchers). For in-person events, dementia-friendly guidelines were helpful, such as choosing locations that were accessible (e.g., had ramps and elevators), had break spaces (e.g., close to hotel rooms or designated quiet rooms), and were familiar and close to parking and public transit (Parkes et al., 2022)[4]. Because people with dementia can experience sensory overstimulation, choosing venues with lower noise (e.g., carpeted floors), with evenly and well-lit spaces and using clear,

3 Patient and Public Partner Appreciation Policy and Protocol, SPOR Evidence Alliance. (2022). Available online at: https://sporevidencealliance.ca/wp-content/uploads/2022/01/SPOREA_Patient-and-Public-Appreciation-Policy_2021.01.14-1.pdf.

4 DEEP Guide Choosing a dementia-friendly meeting space (2013). Available online at: https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf.

large signage was helpful (Dewing, 2009). For online events, we used videoconference applications that had accessibility features, such as closed captioning and recording capabilities. We provided visual supports when needed and clear cues when moving onto one agenda item to the next.

4.2.10 Evaluate from different perspectives

After meetings and events, organizers evaluated the contributions of the lived experience perspectives by inviting audience feedback. Typically, this consisted of brief online surveys that included questions about the perceived usefulness and impact of including people with lived experience in the program. We shared these data with Advisory Group members to recognize their contributions, expertise and growth as well as discuss opportunities for improvement.

4.3 Dissemination

We posted the co-produced EPLED video and tip sheet infographic (Figure 1) online. We screened two versions of the video at the Pride in Patient Engagement in Research (PiPER) Research Day (October 2023 in Toronto): a 5-min version during a conference session, and the full 15-min video in a gallery space. We presented the infographic and evaluation data in a poster at the Canadian Association on Gerontology conference (October 2023 in Toronto). We also screened the 15-min version of the video and infographic at the Canadian Conference on Dementia (November 2023 in Toronto). In January 2024, EPLED and CCNA hosted a webinar, "'Yes, It's Possible!': Top Tips for Engaging People with Lived Experience" (https://vimeo.com/905754604), featuring EPLED Advisory Group members, co-leads and CCNA staff. The video was screened during the opening session at CCNA Partners Forum and Science Days (March 2024 in Montreal).

5 Conclusion and future directions

In this perspective article, we described experiences of engaging people with lived experience of dementia in national research meetings and events. The article was written with people with lived experience who participated in those events, however, while this included people living with early stage dementia, we also acknowledge that perspectives of middle and late stage dementia were those of friends, family and care partners/caregivers. As patient engagement becomes more prominent in research, we anticipate an increase in resources on best practices on engaging diverse individuals and groups of people with lived experience, including those at different stages of dementia, racialized individuals and groups and 2SLGBTQIA+ communities. It is important that efforts in this area are informed by the perspectives of both researchers and people with lived experience. Guidelines that are not developed collaboratively, alongside people with lived experience, risk prioritizing academic perspectives and perpetuating negative experiences of tokenism and stigma. We hope this article can serve as a guide to those planning to engage people with lived experience in national research meetings and events.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: the data were collected as part of program evaluation activities. Further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent was not required to participate in this study in accordance with the local legislation and institutional requirements.

Author contributions

ES: Conceptualization, Investigation, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing. CA: Conceptualization, Writing – review & editing. MN: Conceptualization, Writing – review & editing. WH: Conceptualization, Writing – review & editing. ZD: Conceptualization, Writing – review & editing. II: Conceptualization, Writing – review & editing. EM: Conceptualization, Writing – review & editing. KM: Investigation, Writing – review & editing. JB: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Visualization, Writing – original draft, Writing – review & editing.

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In memoriam

This paper is dedicated to the memory of Wayne Hykaway who passed away on May 17, 2024.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Suzanne Timmons,
University College Cork, Ireland

REVIEWED BY
Nidhi Mahendra,
San Jose State University, United States
Sharon Walsh,
University of Galway, Ireland

*CORRESPONDENCE
Joseph P. M. Kane
✉ joseph.kane@qub.ac.uk

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Developing a person-centered stated preference survey for dementia with Lewy bodies: value of a personal and public involvement process

Paula Sinead Donnelly[1], Aoife Sweeney[1], Emily Wilson[2], Anthony Peter Passmore[1], Noleen K. McCorry[1], Marco Boeri[1,3] and Joseph P. M. Kane[1]*

[1]Centre for Public Health, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, Belfast, United Kingdom, [2]Northern Ireland Lewy Body Dementia Research Advisory Group, Queen's University Belfast, Belfast, United Kingdom, [3]Patient-Centered Outcomes, OPEN Health, London, United Kingdom

Introduction: The development of high-quality stated preference (SP) surveys requires a rigorous design process involving engagement with representatives from the target population. However, while transparency in the reporting of the development of SP surveys is encouraged, few studies report on this process and the outcomes. Recommended stages of instrument development includes both steps for stakeholder/end-user engagement and pretesting. Pretesting typically involves interviews, often across multiple waves, with improvements made at each wave; pretesting is therefore resource intensive. The aims of this paper are to report on the outcomes of collaboration with a Lewy body dementia research advisory group during the design phase of a SP survey. We also evaluate an alternative approach to instrument development, necessitated by a resource constrained context.

Method: The approach involved conducting the stages of end-user engagement and pretesting together during a public involvement event. A hybrid approach involving a focus group with breakout interviews was employed. Feedback from contributors informed the evolution of the survey instrument.

Results: Changes to the survey instrument were organized into four categories: attribute modifications; choice task presentation and understanding; information presentation, clarity and content; and best-best scaling presentation. The hybrid approach facilitated group brainstorming while still allowing the researcher to assess the feasibility of choice tasks in an interview setting. However, greater individual exploration and the opportunity to trial iterative improvements across waves was not feasible with this approach.

Discussion: Involvement of the research advisory group resulted in a more person-centered survey design. In a context constrained by time and budget, and with consideration of the capacity and vulnerability of the target population, the approach taken was a feasible and pragmatic mechanism for improving the design of a SP survey.

KEYWORDS

patient and public involvement, dementia with Lewy bodies, stated preference survey, discrete choice experiment, best-worst scaling, patient perspective, preferences, pretesting

1 Introduction

Lewy body dementia (LBD), encompassing both dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD), is recognized as the second most common dementia subtype (Vann Jones and O'Brien, 2014; McKeith et al., 2017; Kane et al., 2018). DLB is characterized by four "core" clinical features/symptoms: fluctuating cognition, recurrent visual hallucinations, REM sleep behavior disorder, and spontaneous parkinsonism (McKeith et al., 2017). However, additional symptoms may include severe neuroleptic sensitivity, postural instability, repeated falls, syncope, severe autonomic dysfunction, hypersomnia, hyposmia, hallucinations in other modalities, systematized delusions, apathy, anxiety and depression. There is no staging system for DLB and experiences are diverse, however the disease course is invariably progressive (Matar et al., 2021) and associated with a poorer prognosis than for other forms of dementia (Mueller et al., 2017).

Understanding patient preferences is critical for pursuing meaningful and relevant avenues of research. Health preference research aims to understand the values and preferences of key stakeholders to inform person-centered care, research and policy. Within this realm, stated preference (SP) methods have emerged as a means of quantifying patient preference information (Soekhai et al., 2019b). Two well-established SP methods in healthcare research are discrete choice experiments (DCEs) and best-worst scaling (BWS) (Soekhai et al., 2019a; Hollin et al., 2022). DCEs present respondents with a series of hypothetical alternatives (e.g., hypothetical treatment A or B) and ask them to select their preferred option, aiming to elicit preferences, explore the relative importance of attributes (e.g., cost, efficacy, and risk), and understand which tradeoffs respondents are willing to accept between the benefits and risks of adverse events or cost (e.g., a willingness to accept a higher risk of side effects for greater treatment efficacy). Each DCE choice task typically includes two or three alternatives, which might or might not also contain an opt-out alternative (e.g., choosing no treatment) or the standard of care (e.g., treatment as usual). On the other hand, BWS requires respondents to identify the "best" and "worst" items from a set of items (for example, side-effects, mode of administration and frequency of administration). Each BWS choice task typically includes three, five or seven items. Elicited preferences are contingent on how the scenario and the attributes (or items) are described. Ensuring the appropriate specification of the attributes is therefore essential for designing a valid instrument and collecting reliable preference data.

The recommended steps in the instrument development process of SP surveys are evidence synthesis, expert input, end-user engagement, pretest interviews and pilot testing (Janssen et al., 2016; Campoamor et al., 2024). The aim of end-user engagement is to improve an instrument's person-centeredness. This may involve establishing an advisory board, comprising key stakeholders, who are actively involved throughout the study (Janssen et al., 2016). This step is reflective of the shifting paradigm toward person-centered research as well as personal and public involvement (PPI) in research.

There is a clear theoretical framework supporting PPI in healthcare research (Rose, 2014; Frith, 2023). In dementia research, the Alzheimer's Society Research Network, formerly known as the Quality Research in Dementia (QRD) network, was founded on the principle that individuals with dementia and care partners can provide unique and valuable contributions to research (Alzheimer's Society, 2019). This network has served as a beacon for PPI in dementia research. Work associated with the Edinburgh Centre for Research on the Experience of Dementia (ECRED) has also exemplified the value of including a research advisory group (RAG) early in a study (e.g., Watchman et al., 2024). Guidelines and resources have been established to assist researchers in effectively integrating meaningful PPI in their research (Crowe et al., 2020; UK Research and Innovation, 2024). There is also increasing recognition of the potential for preference research to benefit from PPI (Aguiar et al., 2021; Shields et al., 2021). However, despite the importance of PPI in health economics and preference research, there is no guidance on establishing effective PPI in preference studies.

Pretesting is a flexible process where representatives from the target population are engaged in improving the validity, reliability, and relevance of the survey (Campoamor et al., 2024). This is achieved by, for example, refining the survey's content and structure, reducing sources of unnecessary burden and advising on potential ethical issues. Pretest interviews involve presenting the survey instrument to people similar to the final respondents, asking them to respond to the survey thinking out loud. The survey instrument is then updated based on feedback. The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Task Force therefore recommends pretesting as part of a rigorous design process (Bridges et al., 2011). However, despite the importance of pretesting and calls for transparency in the survey development process, there are few studies detailing the process and outcomes (Vass et al., 2017; Pearce et al., 2021).

Both qualitative and quantitative methods have been recommended in pretesting (Johnston et al., 2017; Vass et al., 2017; Hollin et al., 2020). Cognitive interviewing utilizing a verbal protocol analytical technique called "*think aloud*" is one pretesting approach, while focus groups and observations of participants silently completing survey tasks represent other approaches (Mariel et al., 2021; Pearce et al., 2021; Haggar et al., 2022; Campoamor et al., 2024). Co-design approaches, wherein respondents actively participate to solve issues together with the research team, may also be utilized (Aguiar et al., 2021; Campoamor et al., 2024). In this regard, pretesting is a collaborative process and has been aptly described as a "codevelopment type of engagement" (Campoamor et al., 2024).

The necessary extent of pretesting is case-specific (Mariel et al., 2021); however, pretesting typically occurs across multiple waves of survey administration, with improvements iteratively incorporated at each wave. For DCEs in environmental valuation (i.e., DCEs exploring environmental resources), it has been suggested that around two to eight focus groups, five to ten cognitive interviews, and one to two pilot surveys is sufficient (Mariel et al., 2021). Traditional approaches to pretesting are therefore resource intensive in terms of time, recruitment and costs associated with remunerating participants for their time. Participants may also experience significant demands on their time and potential burden. Furthermore, whereas in traditional

pretesting different members of the target population are involved at each wave, DLB is a hard-to-reach population which has led to challenges with research participation (Goldman et al., 2020).

In a reflexive essay, drawing on insights from academic researchers at the ECRED, as well as firsthand experiences of a person living with dementia actively involved in research and a facilitator of the ECREDibles- a group of people living with dementia who share an interest in research- the authors emphasize the critical importance of prioritizing the wellbeing of individuals with dementia in research endeavors (Warran et al., 2023). This highlights the necessity of balancing the importance of pretesting with the potential burden traditional approaches may impose on a vulnerable population of individuals with DLB. Consequently, we opted for an alternative approach to the instrument development process.

In this study, the alternative approach to the instrument development process involved conducting the stages of end-user engagement and pretesting simultaneously with a PPI RAG. A co-design approach was adopted with RAG contributors actively encouraged to provide input to refine the survey. The aims of this paper are to (1) report on the outcomes of collaboration with the PPI RAG during the design phase of a SP survey incorporating a DCE and best-best scaling [BBS; a variation of BWS (Huls et al., 2022)], that measured treatment preferences of individuals with DLB and their care partners, and (2) evaluate the strengths and limitations of this alternative approach to instrument development as a pragmatic alternative to traditional design approaches for SP surveys. This was a unique circumstance given that DCEs and BBS have not yet been used with this population, and consideration of the potential burden that extensive pretesting approaches may impose on this vulnerable population was required.

2 Materials and methods

2.1 Personal and public involvement

To facilitate the development of a SP survey instrument for individuals with DLB and their care partners, input from the Northern Ireland Lewy Body Dementia Research Advisory Group (LBD RAG) was sought during the design phase of the survey. The LBD RAG, comprising individuals with LBD and their care partners, assessed the patient-centeredness, acceptability and accessibility of the survey instrument and provided advice on ethical considerations.

The LBD RAG contributors were recruited through advertisements in local Psychiatry of Old Age services, including a LBD clinic, and social media networks. There were no exclusion criteria applied for membership in the RAG in order to capture a wide range of perspectives and experiences. Interested individuals provided contact information to their clinician, who was a member of the research team (JK). Subsequently, the study coordinator (PSD) contacted potential contributors to explain the PPI initiative and the role of the RAG within the study. Ten RAG contributors, comprising four individuals diagnosed with LBD and six care partners, one of whom is a co-author (EW), attended the involvement event.

Guidelines set forth by the National Institute for Health Research (NIHR) were followed regarding the remuneration of individuals' time and reimbursement of expenses (NIHR, 2023). The Guidance for Reporting Involvement of Patients and the Public 2 Short Form (GRIPP2-SF) (Staniszewska et al., 2017) was used to summarize PPI involvement in the current study (Table 1).

2.2 The draft survey instrument

A draft survey instrument was developed to address the research question, "Which symptoms would individuals with DLB and their care partners most like to see improved upon by a potential therapy?" Specifically, the survey instrument was designed to assess the relative importance of DLB symptoms regarding priorities for treatment, how individuals trade off between different symptoms and risks when considering treatment options, and preferences for treatment characteristics and the trade-offs that individuals are willing to accept between treatment efficacy and the risk of adverse events.

The initial section of the survey instrument included a Participant Information Sheet (PIS). This was followed by consent procedures and a differentiation question asking respondents to specify whether they are an individual with DLB or care partner (current or former). Logic branching was then applied to present individuals with DLB and care partners with personalized screening and demographic questions.

The subsequent section provided detailed information on the DCE attributes and related questions to assess comprehension. The six DCE attributes described in the draft survey instrument were: "risk of overall memory, thinking, and functional decline in the next 18 months," "impact of visual hallucinations," "impact of parkinsonism," "impact of sleep behaviors," "impact of fluctuations," and "risk of brain-related side effects in the next 18 months." The first five attributes are related to the four core diagnostic symptoms of DLB together with dementia (McKeith et al., 2017). The final attribute concerns the risk of amyloid-related imaging abnormalities (ARIA). ARIA are a reported side effect of anti-amyloid therapies in clinical trials for patients with Alzheimer's disease (AD) (Sperling et al., 2011; Filippi et al., 2022; Jeong et al., 2022). ARIA are commonly transient and clinically asymptomatic; however, ARIA can lead to exacerbation or emergence of symptoms. Severe manifestations of ARIA, including seizures, stroke and meningitis have been documented (Salloway et al., 2022; Atwood and Perry, 2023; Sims et al., 2023; van Dyck et al., 2023). ARIA of this severe nature have the potential to be reversed; however, they may require hospitalization and can be fatal (VandeVrede et al., 2020; Filippi et al., 2022; Reish et al., 2023; Solopova et al., 2023). Given that DLB pathology commonly co-occurs with AD pathology (Irwin and Hurtig, 2018), it is expected that anti-amyloid therapies will be trialed in DLB populations. The final attribute was therefore included to understand the risk tolerance of people affected by DLB.

While including all relevant possible attributes in a DCE is ideal, it can increase survey complexity and participant burden. To balance comprehensiveness and feasibility, we therefore selected a subset of possible attributes, ensuring that those central to the

TABLE 1 Patient (personal) and public involvement in the development of a stated preference survey reported using GRIPP2-SF.

Section and topic	Item
1. Aim/s	The aim of personal and public Involvement (PPI) in the study was to co-design a person-centered stated preference (SP) survey that was acceptable to, and accessible for, people with dementia with Lewy bodies (DLB) and their care partners.
2. Methods	Involvement of the Northern Ireland Lewy Body Dementia Research Advisory Group (LBD RAG), which comprises individuals with LBD and their care partners, took place as a half-day event in September 2023. RAG contributors were recruited through advertisements in local Psychiatry of Old Age services, including a LBD clinic, and social media networks. Ten RAG contributors, comprising four individuals diagnosed with LBD and six care partners, attended the involvement event. A focus group with breakout interviews was carried out. The focus group involved improving the content and clarity of key study documentation. The interviews involved RAG contributors completing example choice tasks and providing feedback on how the accessibility of the tasks could be improved for potential participants. Modifications arising from RAG recommendations were categorized *post-hoc*. Feedback from the contributors on their experience of involvement was collected informally through phone calls conducted by the study coordinator (PSD). Guidelines set forth by the National Institute for Health Research (NIHR) were adhered to regarding the remuneration of individuals' time and reimbursement of expenses. One care partner from the RAG is a co-author on this paper (EW) having made valuable contributions to paper edits.
3. Results	RAG contributors contributed significantly to the evolution of the survey instrument. The ways in which contributors informed the study included: • Providing recommendations aimed at enhancing the clarity of the discrete choice experiment (DCE) attribute descriptions. • Suggesting improvements to make the presentation of the DCE and best-best scaling (BBS) choice tasks more user-friendly. • Sharing their preferences regarding the presentation of information. • Offering advice on enhancing the survey's clarity and usability. • Providing suggestions for new questions or items that are relevant to the research question. • Advising on mitigating potential ethical issues. • Recommending ways to reduce sources of unnecessary burden within the survey. • Suggesting suitable ways to explain the study to potential participants.
4. Discussion	Involvement of the RAG at this stage of the study was very effective and influenced the evolution of the survey instrument, based on the impacts in Section 3. The RAG suggested changes to and highlighted issues within the survey, leading to a more person-centered SP survey that better met the needs of people with DLB. Given that the reliability of findings from preference studies is reliant on the quality of the choice methods, partnership with the RAG will ultimately lead to more accurate preference findings. Improving the acceptability and accessibility of the design will also ultimately benefit recruitment to the study. RAG contributors were informed about the research methods used in the study which likely positively contributed to the quality of the feedback they provided. In addition, possible power imbalances were managed by offering contributors reimbursement for their expenses and remuneration for their time. At the outset of the involvement event, the research team emphasized that the nature of the partnership would be shaped through communication between the researchers and lay members. This helped to create a positive environment which may also have ensured contributors felt confident and supported in sharing their views. However, there were limitations. Challenges with conducting PPI in the design of preference studies has been acknowledged, including the need for adequate training in preference research methods (Goodwin et al., 2018; Al-Janabi et al., 2021). In the current study, RAG contributors were introduced to the concept of DCEs and BBS, but they were not provided with structured training on these methods. It is therefore possible that this limited the input from contributors. Additionally, some care partners reported reluctance to express or elaborate on their opinions in the presence of the individual with DLB. Future studies may consider utilizing individual interviews or focus groups to overcome this.
5. Reflections	The RAG partnership played a critical role in informing the design of the SP survey. Partnership was sought during the end-user engagement and pretesting phase of the study, but ideally, RAG contributors would have contributed toward the design of the DCE attributes or earlier in the formulation of the research question. However, due to the extensive range of possible DLB symptoms and the resulting complexity it would impose on the DCE design if all possible symptoms were included as attributes, this approach was deemed impractical. Consequently, advisory input was sought at a subsequent stage, and the DCE design was informed by clinical experts with a focus on the key diagnostic symptoms of DLB. Nonetheless, the RAG contributors in this study contributed to the evolution of the study design and influenced its progression, thereby contributing meaningfully to the study. We will continue to collaborate with the LBD RAG throughout the research study. Although all RAG contributors shared positive reflections on the involvement process, some contributors reported feeling fatigued during the event. We are aware that this might have limited the extent to which some contributors were able to engage. Some individuals with more advanced cognitive impairment may have also found it more challenging to contribute fully to the focus group discussions. However, we felt that the breakout interviews helped to ensure that those wanting to share their views had an opportunity to do so. This therefore facilitated more inclusive opportunities for people at different stages of DLB to express their views and contribute to the survey evolution.

research question and decision context were included. Guided by our research question, evidence synthesis and consultation with clinical experts, we focused on the four core diagnostic symptoms of DLB, along with global cognitive and functional decline, due to their clinical significance. Together with a final attribute related to the risk of ARIA, this resulted in six final attributes, aligning with current practices in health-related DCEs (Soekhai et al., 2019a). However, with consideration of the capacity and vulnerability of our target population, we made additional considerations by restricting the number of levels and using color-coding which has been reported to reduce DCE choice task complexity (Jonker et al., 2019). Since DCEs and BBS are novel for this population, we are also interested in the tolerability of these methods.

After the description of three attributes, a practice DCE task with a reduced number of attributes was introduced. Subsequently, descriptions of the remaining attributes were provided, followed by eight DCE choice tasks (Figure 1). Each DCE choice task featured three hypothetical treatment alternatives. The alternatives were described by the six attributes which varied across different levels. Across the choice tasks, the attribute levels describing two

of the alternatives (treatment A and treatment B) varied, while the attribute levels describing the third alternative (no treatment) remained fixed. The "no treatment" alternative acted as an opt-out.

The next section began with an overview of the six items included in the BBS: "motor and movement difficulties," "memory and thinking," "autonomic dysfunction," "neuropsychiatric and psychological symptoms," "sleep-related concerns," and "fluctuating cognition." Following this description, six BBS choice tasks were presented (Figure 2). Each BBS choice task displays a subset of three items from the full set of six items. Respondents always select from a choice of three items in each BBS choice task. The items in each task vary across the choice tasks, providing the analyst with a relative ranking of all the items. In each task, respondents were first asked to select their most preferred (i.e., best) symptom group to prioritize for treatment. Next, respondents were asked to choose their most preferred symptom group to prioritize for treatment from the remaining two options (i.e., second-best). Following both choice experiments, respondents viewed a series of questions about their preferences for treatment characteristics and their tolerance of fatal risks resulting from adverse events associated with a hypothetical treatment.

2.3 Involvement event

Involvement of the LBD RAG at this stage of the study was conducted as a half-day event in September 2023, held in person on university premises. An alternative approach to the instrument development process was employed whereby end-user engagement and pretesting were carried out simultaneously during the involvement event. A co-design approach was adopted with RAG contributors actively providing input to refine the survey. A hybrid approach utilizing a focus group discussion with breakout interviews was employed to capture substantial input from contributors within a resource-limited context. The procedures for the focus group and interviews are detailed below. As the purpose was to inform the evolution of the survey instrument rather than to collect qualitative data, neither the focus group discussion nor the interviews were audio-recorded nor transcribed verbatim.

As recommended during pretesting, peer-review by other scientists was also conducted (Johnston et al., 2017). This occurred following LBD RAG input. Two internal peer-reviewers, selected for their relevant specialist interests, their clinical experience with our target population and the absence of identified conflicts of interest, independently reviewed the study documentation and provided feedback from a methodological perspective on the survey instrument's ability to address the research aims.

2.3.1 Focus group procedure

The focus group, facilitated by three members of the research team, lasted ~150 min, with breaks incorporated and refreshments provided. All RAG contributors participated in the discussion as a single group. During the discussion, one researcher (observer) was assigned specifically to take notes, and two research nurses offered practical support to RAG contributors. Before the focus group commenced, all RAG contributors were briefed on the study's aims and objectives as well as the importance of PPI in the research. This was followed by an introduction to DCEs and BBS. The focus group discussion was semi-structured, and RAG contributors were given paper copies of the study documentation, supplemented by a PowerPoint presentation.

First, each DCE attribute description was reviewed in turn to seek advice on comprehensibility and accuracy based on the lived experiences of the RAG contributors. The RAG contributors were also asked to provide feedback on the appropriateness of the graphics used to represent each attribute (shown in Figure 1). The researchers developed the graphics by utilizing a blend of freely available graphics sourced online and Microsoft's Image Creator, an image generation tool. After reading each attribute description, contributors were invited to respond to questions such as, "What do you think we are communicating" or "Is there anything missing in the description or that is inaccurate?" When feedback was provided by someone, the other contributors were asked if they agreed. If there was disagreement, the group collaborated to suggest improvements.

The discussion of the DCE attribute descriptions was followed by a review of key study documentation including the PIS, screening and demographic questions and BBS attribute descriptions and tasks. Finally, RAG contributors discussed the end-of-survey questions regarding important treatment characteristics and risk tolerance for fatal adverse events.

2.3.2 Face-to-face interview procedure

Following the initial whole group discussion of the DCE attribute descriptions involving all RAG members, breakout face-to-face interviews commenced in an adjacent room. These interviews ran parallel to the ongoing focus group. RAG contributors, either as patient-care partner dyads or individually, sequentially withdrew from the focus group to complete the interviews. Two researchers, who also left the focus group, facilitated these interviews, leaving one researcher to continue leading the focus group discussion. Upon completing their interview, the contributors rejoined the ongoing focus group discussion.

The interviews were conducted to pretest example DCE choice tasks. The aim was to assess the feasibility of the tasks and collect feedback from the RAG contributors on the accessibility and acceptability of the choice tasks. Printed copies of six choice tasks were provided, and contributors completed them in the presence of two researchers, one of whom took notes. The order of the choice tasks was designed to progressively increase in complexity to determine the point at which respondents experienced fatigue or resorted to the use of simplifying heuristics i.e., decision-making strategies which allow individuals to make choices with less cognitive effort, such as choosing to ignore some attributes (Veldwijk et al., 2023).

To capture feedback, observations were made regarding contributors' reactions to the information presented, such as signs of confusion or hesitation. In addition, think-aloud and concurrent and retrospective probes were used. This included questions

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Imagine that you are talking to the doctor about treatment options for DLB symptoms. They offer you a choice between two treatments (A or B) or no treatment at all. If you choose no treatment, symptoms will continue to worsen overtime. Please tick the box for the treatment option that you prefer more (A, B or no treatment).

Characteristics of the treatment	Treatment A	Treatment B	No Treatment
(A) Rate of overall memory, thinking and functional decline in the next 18 months	**(L) Little or no change** in memory, thinking and **independence** for doing daily activities like bathing, toileting or medications. 	**(L) Worsening** of memory and thinking. **Greater assistance** required with daily tasks like bathing, toileting or medications. 	**(L) Worsening** of memory and thinking. **Greater assistance** required with daily tasks like bathing, toileting or medications. 
(B) Impact of visual hallucinations	**(L)** Hallucinations occur **less** often and are **not** frightening. 	**(L)** Hallucinations occur **more** often and are frightening. 	**(L)** Hallucinations occur **more** often and are frightening. 
(C) Impact of parkinsonism	**(L)** Motor & movement difficulties begin to **interfere** with functioning. Assistance is **often** needed. 	**(L)** Motor & movement difficulties **improve**. Assistance is **sometimes** needed. 	**(L)** Motor & movement difficulties begin to **interfere** with functioning. Assistance is **often** needed. 
(D) Impact of sleep behaviors	**(L)** Sleep behaviors become **more** disruptive. They happen **more** often. The risk of injury **increases**. 	**(L)** Sleep behaviors become **less** disruptive. They happen **less** often. The risk of injury **decreases**. 	**(L)** Sleep behaviors become **more** disruptive. They happen **more** often. The risk of injury **increases**. 
(E) Impact of fluctuations	**(L) Less** daytime sleepiness. Able to keep attention. 	**(L) More** daytime sleepiness. Difficulty keeping attention. 	**(L) More** daytime sleepiness. Difficulty keeping attention. 
(F) Risk of brain-related side effects in the next 18 months	 **(L) 2** out of 10 people will develop brain changes	 **(L) 3** out of 10 people will develop brain changes	 **(L) 0** out of 10 people will develop brain changes
Which option would you choose?	**Treatment A** ☐	**Treatment B** ☐	**No Treatment** ☐

FIGURE 1
Example discrete choice experiment choice task from the draft survey instrument. The three alternatives were described by six attributes (labeled "A–F" in the example). The attributes varied across different levels (labeled "L" in the example).

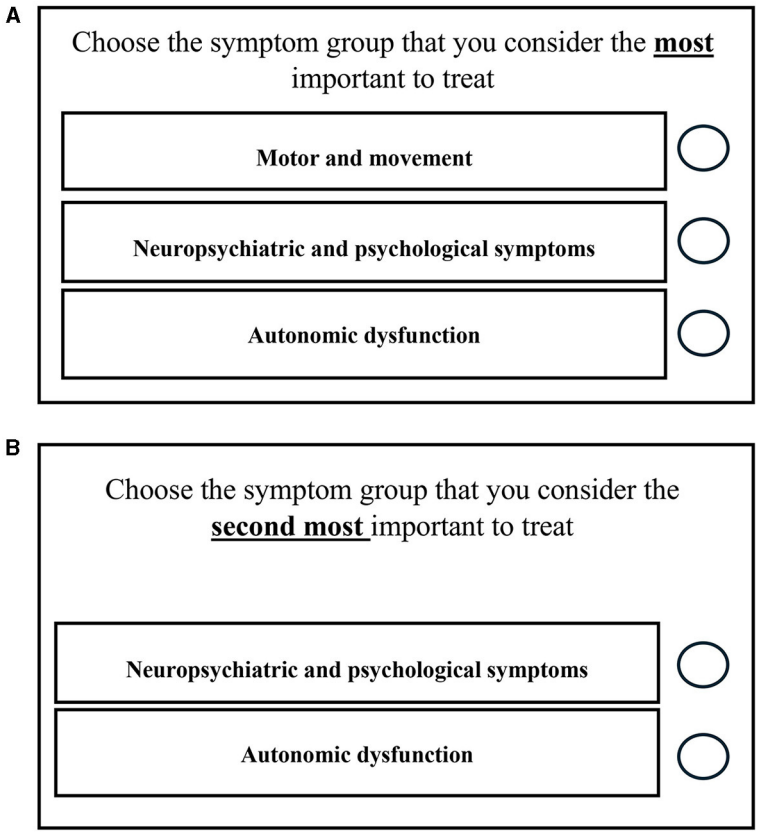

FIGURE 2
Example best-best scaling choice task from the draft survey instrument. Once the participant selects the most important symptom group (item) to treat in the first part of the task **(A)**, this item will disappear. The participant is then asked to choose the most important symptom group to treat from the remaining two items **(B)**. In the example provided, one option has been removed to show what it would look like if the participant selected "motor and movement" in the first part of the task.

such as, "How did you reach that answer?" and "Did you find that easy or difficult to answer?" Think-aloud feedback allowed the researcher to assess choice validity by evaluating whether contributors practiced compensatory decision-making (trading attributes against each other), or whether they used simplifying heuristics which would impose challenges for modeling. If think-aloud data was not provided, a researcher probed contributors on their decision process. During the interviews, RAG contributors also highlighted challenging or confusing aspects of the choice tasks. This led to discussions between the two researchers present during the interview and the contributors on possible amendments to clarify areas of confusion.

After completing five-six DCE choice tasks, RAG contributors were asked about the difficulty of the tasks, the appropriateness of the hypothetical scenario, and whether they perceived eight choice tasks to be manageable.

2.4 Feedback and improvements

Although one researcher was assigned to note-taking, all three researchers made notes throughout the event. After the session, the three research team members collated the written information they had collected, and notes were cross-referenced for triangulation. Considering that only one researcher was facilitating the focus group at one point, and therefore only their notes were available for that part of the discussion, we conducted member checking with the RAG contributor who is included as a co-author on the paper (EW). This contributor reviewed the paper to verify the accuracy of the reported outcomes.

The recommendations arising from RAG input were then categorized *post-hoc*. The day following the involvement event, the study coordinator, who was involved in the event, contacted contributors to express gratitude for their participation and inquired if they had any feedback on the PPI experience. These phone calls were conversational in nature and not recorded for the purpose of data collection; rather, informal feedback served to provide guidance for the research team on future PPI activities in the study.

3 Results

Overall, RAG contributors provided positive feedback about the proposed research, and peer-reviewers were satisfied from a methodological perspective. In total, one focus group, two

individual interviews and four dyadic interviews were conducted. The feedback provided by the RAG was considered by the research team, and changes to the SP methods and survey instrument were made as appropriate. The full list of changes that arose based on feedback from the RAG is displayed in Figure 3 according to their respective category.

3.1 Improvements to the survey design

RAG contributors valued the PIS. Although they found it lengthy, they acknowledged the necessity of the information. However, RAG contributors requested that the "purpose of the study" section of the PIS highlight that while there is currently an absence of treatments that alter the disease course in DLB, the study aims to inform the design of future studies for new treatments. This additional information was incorporated.

With regards to the feasibility of the DCE, RAG contributors felt that, for individuals with mild DLB, eight choice tasks would be manageable if there was the option to pause the survey and when care partner support was available. Figure 3A illustrates the amendments aimed at improving respondents' understanding of the DCE attributes. All attribute descriptions underwent revisions, except for the "impact of visual hallucinations" attribute. An important change was made to the "risk of brain-related side effects in the next 18 months" attribute. Consultation was sought from the RAG to address this attribute with sensitivity and clarity. Initially described as "brain changes," some RAG contributors expressed concerns about potential misinterpretations of clinically beneficial brain changes. Consequently, clarifications were made indicating that treatments could lead to adverse or unintended changes to the brain, such as edema and/or stroke. These examples were informed by the manifestations of ARIA in clinical trials investigating monoclonal antibodies for AD (VandeVrede et al., 2020; Filippi et al., 2022; Reish et al., 2023; Sims et al., 2023). Given ethical considerations regarding discussing serious adverse events (SAE), the research team also consulted the RAG for their perspectives on the appropriateness of this attribute and the examples of SAE. Contributors were asked whether discussions of adverse events caused distress, and although varying levels of comfort were noted, there was a consensus on the importance of acknowledging potential adverse events because it is an important factor influencing treatment preferences. To mitigate potential distress for prospective participants, RAG contributors suggested including additional contextual information within the attribute description describing how these risks would be managed. Therefore, in the attribute description we clarified that individuals receiving treatment with a risk of SAE would be closely monitored by their clinician. This was based on the monitoring practices employed in phase 2 and 3 clinical trials to detect and manage ARIA in AD patients (Cummings et al., 2022, 2023).

Figure 3B lists the modifications aimed at improving the presentation and understanding of DCE choice tasks. Given that people with DLB may experience visuoperceptual difficulties, there was consensus that the colored text used for the attribute levels was difficult to read (Figure 1). Following RAG advice, the colored font was switched to black text for improved legibility, while retaining color-coding in the supporting graphics. Contributors did not express any concerns regarding font size or style. RAG contributors also highlighted the potential difficulty for individuals with dementia to interpret the information in the DCE when it is presented in columns. Given that the use of a matrix in DCEs necessitates a columnar presentation, the research team worked with RAG contributors to develop clear instructions on how to read the choice task.

During the pretest interviews, confusion arose among some RAG contributors regarding whether they should disregard attributes (symptoms) that are currently not relevant to them or their loved one. Changes to improve the understanding of the choice question therefore included improving instructional clarity. RAG contributors were asked if they felt it was possible to imagine having all the symptoms before making a choice, which they felt was feasible. This addition aimed to address possible attribute non-attendance and any misinterpretations that the appearance of worsening symptoms in the choice tasks, currently not experienced by them or their loved one, was indicative of developing new symptoms.

However, although RAG members could make choices as though they were experiencing all the symptoms, the researcher conducting the interview observed that certain members expressed apprehension regarding symptoms not presently affecting them. Consequently, they often opted for the "no treatment" alternative. Although selecting the opt-out provides valuable insights for the analyst, it may diminish statistical power as attribute level information is not collected from every respondent. Therefore, a significant adjustment resulting from the pretesting phase was the inclusion of a forced-choice question after a respondent chose "no treatment", prompting them to indicate their preference if only treatment A or B were available.

Figure 3C lists the changes made to meet RAG contributors' preferences for how information was presented, to improve the clarity of the information presented, and to add additional content suggested by RAG contributors. In particular, RAG contributors were consulted about whether they felt that the consideration of fatal risks associated with treatments could be distressing for potential participants. All RAG contributors felt that this was not distressing; however, they preferred that the highest risk be presented first. Input from the RAG also prompted the inclusion of new content in the survey (Figure 3C). This included the addition of a question concerning financial dependents, identified during focus group discussions as a potential influence of treatment preferences. Also, it was unanimously recognized that support from care partners may be required for individuals with DLB to complete the survey. This led to the inclusion of a question that captured the extent of support provided by care partners to individuals with DLB when completing the survey. In addition, RAG contributors referred to the importance of the treatment administration route as an important determinant of treatment acceptance. This led to its inclusion in a question on important treatment characteristics.

The RAG felt that the BBS tasks were accessible and would not burden participants. However, as illustrated in Figure 3D, contributors recommended including example symptoms related to each symptom domain within the choice task.

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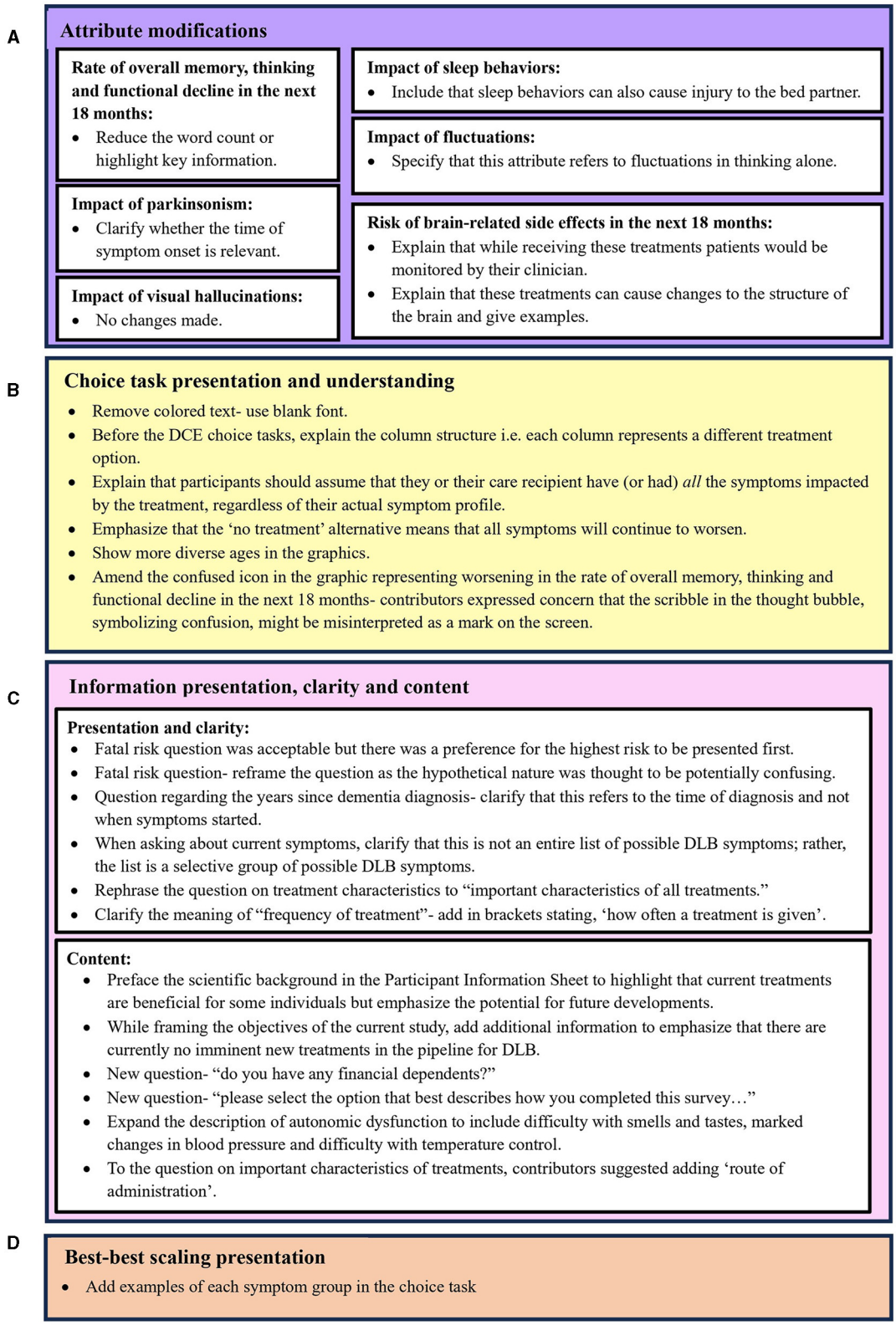

FIGURE 3
Improvements to survey instrument arising from contributor feedback across four categories: **(A)** Attribute modifications, **(B)** Choice task presentation and understanding, **(C)** Information presentation, clarity and content, and **(D)** Best-best scaling presentation.

3.2 Feedback on the personal and public involvement experience

Feedback obtained from RAG contributors on their experience of being involved during the design of the study was overall positive. Feedback during the telephone calls and discussions among the research team revealed a mutually beneficial relationship arising from the PPI process (Figure 4). However, some challenges were expressed by RAG contributors including difficulty for care partners to express their opinions in the presence of care recipients, and feelings of fatigue among some members with LBD. Despite these challenges, all RAG contributors expressed an interest in continuing to act as study contributors.

4 Discussion

In this study, an alternative approach to survey instrument development was employed to gain valuable insights tailored to individuals with DLB and their care partners. The alternative survey development approach, which combined recommended steps for end-user engagement and pretesting (Janssen et al., 2016; Campoamor et al., 2024), was necessitated by resource constraints and the vulnerable nature of the population. The approach is detailed alongside the specific outcomes resulting from involvement.

Inclusion of patient and public partners in the development of preference elicitation methods is increasingly acknowledged as a valuable mechanism for informing methodological choices and improving the relevance of preference research (Aguiar et al., 2021; Shields et al., 2021). However, PPI is rarely reported in preference studies despite often being mandated by funders (Shields et al., 2021). By providing a comprehensive report on the development process of our survey instrument, we not only foster transparency but also acknowledge the substantial value of PPI input in preference research.

The co-design process undertaken during survey development resulted in tangible modifications to the survey instrument. For example, we encountered unexpected challenges with the color-coding of the DCE text among RAG contributors experiencing visuoperceptual difficulties due to DLB. This contrasted prior findings suggesting potential benefits of color-coding for reducing DCE task complexity (Jonker et al., 2019). While contributors demonstrated a good understanding of the DCE attributes and BBS symptom domains, understanding the DCE attribute related to brain-related side effects posed some difficulty, prompting collaboration to refine the attribute description. Additionally, RAG input proved invaluable in reducing the risk of potential participant distress associated with this attribute. Ensuring appropriate communication of this risk attribute was crucial. Experiential knowledge and perspectives from RAG contributors played a critical role in achieving this. Collaborating with contributors, the decision was made to include an explanation that close monitoring would be carried out by clinicians during treatment, as is stated in the appropriate use recommendations for emerging monoclonal antibodies for AD (Cummings et al., 2022, 2023).

The involvement of RAG contributors went beyond refining the survey. RAG contributors also generated additional ideas, reflecting an actively engaged, co-design approach that significantly contributed to the relevance of the survey instrument. By involving those directly impacted by DLB, we ensured that the survey captured essential perspectives and was person-centered, a quality indicator of stated preference methods (Janssen et al., 2017). While this led to direct benefits to the research, benefits for both the research team and contributors were also noted (Figure 4). These echoed previous reports of the mutual benefits of PPI in research (Aries et al., 2021).

The effective partnership may have been facilitated by efforts made to minimize power imbalances, an inherent issue in PPI (O'Shea et al., 2019). This included offering remuneration for contributors' time and reimbursement for their expenses. We also implemented recommendations whenever possible and reached compromises when necessary. Adaptations were also made to support contributors with cognitive impairment, including the provision of communication cards and frequent breaks. Since individuals affected by DLB may encounter challenges with speech fluency (Ash et al., 2012), the communication support cards (which read "I would like to speak") served as non-verbal cues that contributors could display during discussion to express their desire to contribute. However, none of the contributors utilized the communication support cards on this occasion. Nevertheless, these efforts likely contributed to fostering a positive environment that encouraged contributors to share their views.

Inclusive opportunity is a key standard outlined in the UK standards for public involvement (Crowe et al., 2020). Rather than intensive pretesting across multiple waves which could burden individuals with cognitive impairment, involvement across a single half-day event enabled inclusive opportunity for people at both mild and moderate stages of dementia. This avoided the need to rely on a homogenous sample of individuals at the early stage of dementia. Training for PPI contributors is also encouraged in the UK standards (Crowe et al., 2020). Challenges with conducting PPI in the design of preference elicitation surveys has been related to the appropriate level of training provided to contributors (Al-Janabi et al., 2021; Shields et al., 2021). In the current study, RAG contributors were introduced to the concept of DCEs and BBS, but they were not provided with structured training on these methods. It is therefore possible that this limited the input from contributors. Nevertheless, it is essential to discuss training expectations with contributors, especially in vulnerable populations.

We opted for informal, unstructured conversations to evaluate the impact of PPI input at this stage of the study because we believed it would be the least burdensome approach for contributors. However, use of existing tools such as a public involvement log or the Public Involvement Impact Assessment Framework could have enhanced the evaluative process (The PiiAF Study Group, 2014). Further discussion of the challenges and reflections on PPI in the study are reported using the GRIPP2-SF (Table 1).

The objective of this paper is not to assess the strengths and limitations of focus groups and interviews as research methods or to evaluate the integration of these methods for data collection. Instead, the focus is on evaluating the value of the alternative

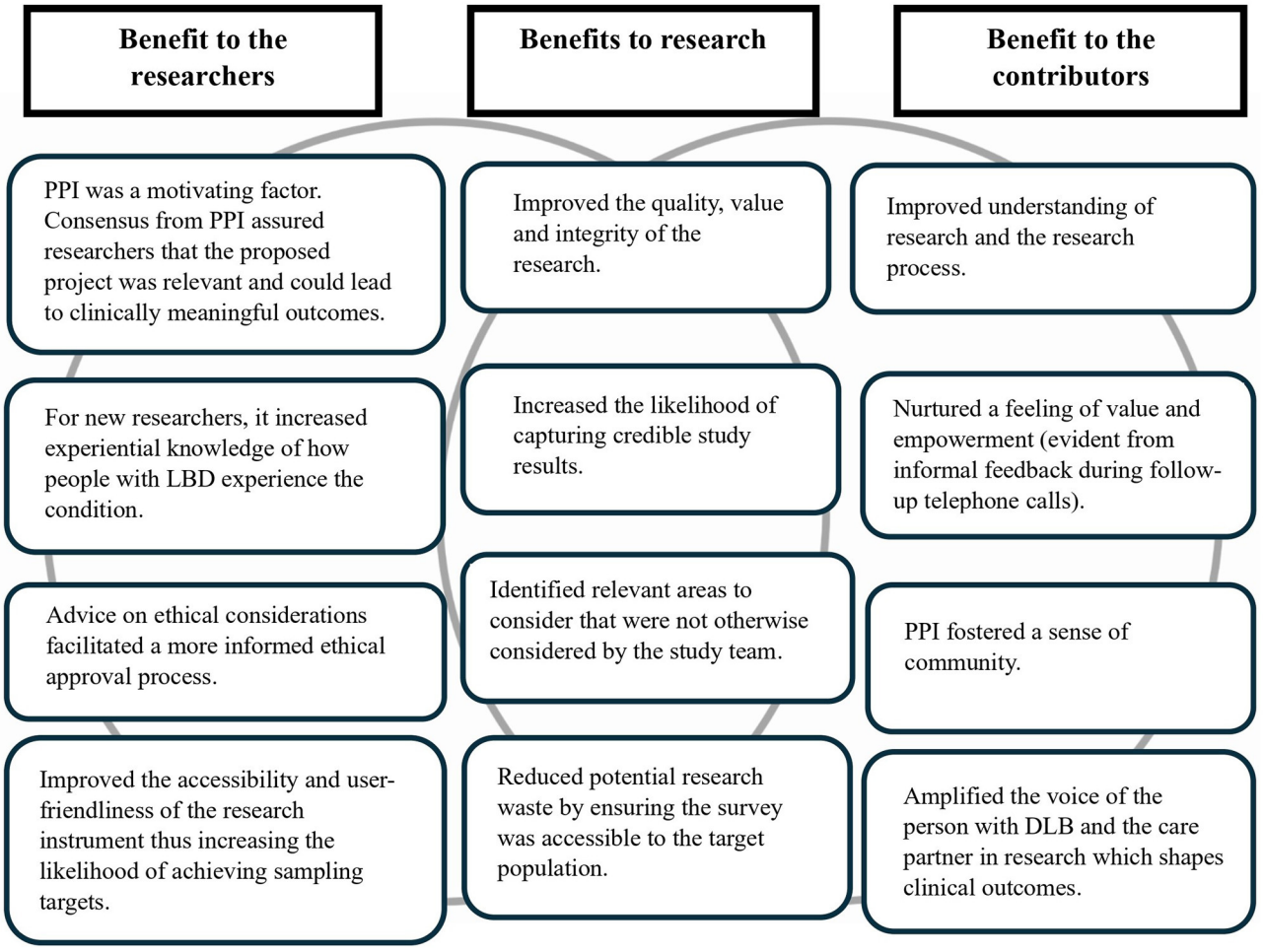

FIGURE 4
Mutual benefits of the personal and public involvement activity.

survey development approach within a resource-limited context. The reported benefit of focus groups as a flexible, efficient method for discussing concepts and language was evident in this study (Johnston et al., 2017). Additionally, the heterogeneity of perspectives in the focus group enhanced the richness of feedback received and fostered a sense of community among PPI contributors which was observable in their interactions. While focus groups have been criticized for their lack of ability to facilitate individual exploration and "groupthink" (Busetto et al., 2020), we were able to offset this through utilizing simultaneous breakout interviews. The breakout interviews allowed for independence of individuals responses and reduced the time between discussion and recall for people with cognitive impairment.

4.1 Limitations and future directions

The traditional pretesting process of implementing iterative changes across waves was not feasible using the current approach. While iterative modifications are advantageous because they allow for revisions to be assessed, it was felt that, in the current context, extensive pretesting would impose burden on contributors and compromise the heterogeneity of the RAG by forcing reliance on people at earlier stages of dementia. Future studies may explore the benefits of two sequential focus groups with iterative changes made following session one and reviewed at session two. However, the potential benefit of employing this approach, in contrast to the methodology adopted in this study, should be weighed against the associated risks of burden and should take account of the constraints of PPI budgeting.

Future studies may also consider individual interviews for care partners and people with DLB to potentially capture richer responses. However, the dyadic nature of the interviews reflects real-life clinical situations where the patient's cognitive, behavioral and functional capacities are often discussed with patient and care partner dyads. If individual interviews are considered, investigators should work with contributors to determine their preferences and to avoid the risk of causing unnecessary stress or anxiety for individuals with DLB.

Moreover, sociodemographic and clinical data were not collected on LBD RAG contributors. However, the LBD RAG is a local RAG comprising individuals recruited exclusively from

Northern Ireland and so the opinions of individuals with DLB and their care partners from other geographical locations were not adequately represented. Similarly, all RAG contributors with DLB resided at home, thus excluding the perspectives of individuals with DLB in care settings, who may have more advanced dementia. Academic researchers at the ECRED have highlighted the ethical challenges associated with including individuals from care settings, particularly in circumstances lacking resources such as transportation to facilitate their participation (Warran et al., 2023). Future studies could consider using video conferencing platforms or arranging transport to facilitate the participation of those residing in care settings to participate in PPI initiatives. DLB is also a highly heterogeneous disease (McKeith et al., 2017) and, as with all involvement work, the views of the RAG may not reflect the views of all individuals with DLB and their care partners.

We also acknowledge that the fatigue experienced by some contributors could have limited their engagement. To address this, future studies could consider conducting interviews and the focus group across 2 days or offering fatigued individuals the option to complete interviews on a subsequent day, either in person or virtually. This approach may also be supportive given that people with DLB can experience fluctuating cognition.

Finally, while it is felt that the outcomes reported informed a survey instrument capable of more accurate data collection, there is no evidence to support a connection between the implemented modifications and the quality of the resulting data.

5 Conclusion

This work contributes to the emerging literature on pretesting in SP surveys and the value of PPI in SP research. Involvement of the PPI RAG resulted in a more valid and reliable survey design that better addressed the needs and preferences of individuals with DLB and their care partners. In a resource-limited context, the approach taken was a feasible and pragmatic mechanism for improving the survey design through feedback from the target population. As recognition of the value of SP methods to inform regulatory decision-making continues to increase, their use in DLB and other dementia populations is expected to increase. Future studies should further explore collaborative survey development approaches with this population, with authors encouraged to share their strategies and outcomes to inform best practice.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the patients/participants was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

PD: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Visualization, Writing – original draft, Writing – review & editing. AS: Writing – review & editing, Investigation. EW: Writing – review & editing. AP: Conceptualization, Supervision, Writing – review & editing. NM: Conceptualization, Supervision, Writing – review & editing. MB: Conceptualization, Methodology, Resources, Supervision, Validation, Writing – review & editing. JK: Conceptualization, Funding acquisition, Investigation, Methodology, Resources, Supervision, Validation, Writing – review & editing.

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Conflict of interest

MB was employed by company OPEN Health.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
W. George Kernohan,
Ulster University, United Kingdom

REVIEWED BY
Stefanie Auer,
University for Continuing Education Krems, Austria
Jolanta Dorszewska,
Poznan University of Medical Sciences, Poland

*CORRESPONDENCE
Katja Seidel
katja.seidel@uni-siegen.de

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The psychological effects of research participation on people with dementia: findings from a German exploratory interview study

Katja Seidel[1,2]*, Claudia Winiarski[1], Jochen René Thyrian[2,3] and Julia Haberstroh[1]

[1]Department of Psychology, Psychological Aging Research, Faculty V: School of Life Sciences, University of Siegen, Siegen, Germany, [2]German Center for Neurodegenerative Diseases (DZNE), Greifswald, Germany, [3]Institute for Community Medicine, University of Greifswald, Greifswald, Germany

The German National Dementia Strategy aims to engage people with dementia in research projects. However, the effects of such research participation on experience and behavior have been insufficiently explored. This study aimed to investigate the psychological effect of research participation on people living with dementia. In a qualitative, exploratory approach, guideline-based interviews were conducted with four persons with dementia who had served as co-researchers on an advisory board in a health services research study for 8 months at that time. The analysis revealed predominantly positive effects of research participation at all levels of experience and behavior. Most effects were reported by the co-researchers on a cognitive level. Both the perception of being competent and of making a positive contribution to oneself and/or others are key effects of research participation. The main effects on an emotional level were joy and wellbeing and on a behavioral level were positive social contacts and social communication. Sadness and insecurity represent the sole negative effects. Nuanced focal points of effects among the individual interviews were found. The results align with existing research highlighting the positive effects of participation on people with dementia. Through advancing an interdisciplinary perspective on their research involvement, we advocate for heightened attention to this topic within the realm of psychology.

KEYWORDS

patient participation, participatory research, dementia, psychology, qualitative research, patient engagement, stakeholder engagement, patient and public involvement

1 Introduction

Although the *UN Convention on the Rights of Persons with Disabilities* guarantees their right to equal participation and codetermination in political and social decision-making processes, people with dementia, as well as people with other forms of disability, still experience exclusion from decision-making, especially on issues that affect their own lives (Hirschberg, 2010). Participation—in the broader sense understood as access to and involvement in activities, decisions and processes that affect the shaping of social conditions (Arbeitskreis Kritische Gerontologie der DGGG, 2016)—is a human right and a political and civic mandate (Hirschberg, 2010). Persons living with dementia are too

often denied the ability to make self-determined decisions about their medical treatment (Wied et al., 2019, 2021) or are excluded from considerations about their own care without the opportunity to address this exclusion (Thraves, 2015). Furthermore, despite growing interest, they are still excluded from many areas of research and are rarely given the opportunity to participate in projects as co-researchers (Rivett, 2017). However, when it comes to health research, there is a scientific approach in the form of participatory health research (PHR) (Wright et al., 2016, 2021) that aims to maximize participation for people whose areas of life or health problems are the subject of research. PHR specifically regards target groups as co-researchers who need to be involved in research processes as equal partners to generate relevant knowledge in the co-production process (Wright et al., 2016, 2021). This should lead to greater health equity (Wright et al., 2016, 2021). This is also reflected in the German National Dementia Strategy (NDS), which aims to "improve health services and the quality of life of people with dementia in line with their needs and requirements" through a variety of activities (p. 132) (BMFSFJ, 2020, p. 132). And Vinay and Biller-Andorno (2023) showed that most of the National Dementia Strategies they included in their evaluation contain patient empowerment as a key ethical aspect. An important field of action within the NDS is to open research in terms of content and methodology by involving persons with dementia in participatory research projects (BMFSFJ, 2020).

Consistent with academic perspectives and scientific evidence, the involvement of people with lived experience is associated with a greater likelihood of positive research outcomes, increased likelihood of applicability and sustainable implementation of healthcare projects (Di Lorito et al., 2017; Bethell et al., 2018; Gregory et al., 2018; Burton et al., 2019; Clar and Wright, 2020; Dening et al., 2020; Schlechter et al., 2021; Brooke, 2019; Tanner, 2012). Alongside the ethical and moral obligation and the instrumental benefit of involving those who are affected in research projects that concern their lives, another perspective on participation can also be adopted.

From a psychological perspective, participation is not only a means of enriching and improving research results through the personal experience of people with dementia. Rather, it can also positively influence the experience and behavior of the people involved. Qualitative studies have reported that they experience positive social relationships as part of their involvement in research projects; feel pride in meaningful activities; report intellectual stimulation, joy, feelings of appreciation, and meaning in life; feel dignity; and perceive their own lives as meaningful despite their illness (Tanner, 2012; Ashcroft et al., 2016; Brooke, 2019; Dening et al., 2020). Participation is also already being used specifically as a means of promoting recovery due to its beneficial effects (Ashcroft et al., 2016). Based on this, it could be assumed that by influencing a person's mental processes and states in a beneficial way, participation can be understood as a (psychological) intervention, defined as "the act of interfering with the outcome or course especially of a condition or process (as to prevent harm or improve functioning)" (Merriam-Webster, (n.d.b)). However, these findings usually appear to be embedded in other questions and tend to be more of a narrative nature. Furthermore, these publications often have methodological shortcomings, particularly regarding the description of the type and extent of participation and are rarely published in renowned journals (Bethell et al., 2018).

There has been an increase in the literature on participatory methods in the field of dementia research, especially since 2019 (Reyes et al., 2023), and a general increase in research activities in the field of participatory research. In the field of PHR, there are a few recent framework models that attempt to structure the potential impact dimensions of participation (Staley, 2015; Banks et al., 2017; Kongats et al., 2018). Any form of research participation can be viewed as a complex intervention with various dimensions of impact, whereby the effects themselves are multifactorial, i.e., influenced, for example, by the project objectives, the commitment of the participants, the group dynamics, and the communication style (Weidekamp-Maicher, 2021). Nevertheless, there is a lack of reliable findings on the question of the psychological effects in terms of benefits for persons with dementia (Ashcroft et al., 2016; Bethell et al., 2018; Brooke, 2019). To the best of our knowledge, there are no empirical studies in which concrete psychological constructs have been specifically derived or systematically determined.

Therefore, in the current research we focus on the effects on the subjective experience of people with dementia. The aim is to gain a better understanding of the psychological effects and potential benefits of research participation for them. Specifically, the effects of participation will be investigated from a psychological background using an exploratory approach. In the context of the present work, it seems crucial to emphasize that people with dementia are a particularly vulnerable group in the context of research activities. Cognitive impairments, above all those affecting memory, the planning and control of actions, a limited ability to abstract and the loss of communication skills can cause methodological problems when conducting projects and research with people with dementia (Slegers et al., 2015; Di Lorito et al., 2017). People with cognitive impairments may perceive their world and share their experiences differently, which can present challenges when carrying out projects together with them (Slegers et al., 2015). Another limitation for their participation is the concern about their ability to give informed consent to research (Swaffer, 2016). These challenges concern not only the research process itself, but also the resulting research findings, which may be affected. When investigating our research question, we try to take these challenges into account.

2 Materials and methods

2.1 Study design

The analysis of the psychological effects of participation follows a qualitative, exploratory design using semi-structured, guideline-supported interviews. The reporting of the methods applied in this study is aligned with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) and the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

2.2 The participatory research project as a framework

In cooperation with a local Alzheimer Association (AlzA), two advisory boards (persons with dementia and relatives of persons with dementia) were established in 2021 as part of the *Participatory Pilot Study DelpHi-SW* (Dementia: lifeworld-oriented and person-centered support in Siegen-Wittgenstein). DelpHi-SW tested a structured participatory approach to adapt the evidence-based complex dementia care management intervention (DeCM) (Thyrian et al., 2017) to an exemplary regional setting in Germany (Seidel et al., 2022) and prepared it for a subsequent implementation study (Purwins et al., 2023). The advisory board members (ABM) advised on and helped shape the regional and cross-sectoral adaptation and implementation of the DeCM. Their responsibilities included setting topics for DeCM, revising information materials and survey instruments, and discussing issues relating to the concrete implementation of the study. Feedback was reported to other stakeholders and the project team and was incorporated into the DeCM study. The advisory board meetings have been held once a month since July 2021, each lasting 1.5 h They were held in a more familiar setting, accompanied by two academic researchers (KS, female psychologist) and moderated by two experienced AlzA moderators. In the course of dementia, there is an increasing loss of cognitive performance. Alzheimer's disease in particular leads to progressive losses in communicative abilities along the four communication steps of *Presentation*, *Attention*, *Comprehension*, and *Remembering*, as described in more detail in the *TANDEM communication model* by Haberstroh et al. (2011). Disease-related language limitations therefore represent a potential barrier when working with persons with dementia as research partners. Strategies are already available, such as the evidence-based training program *TANDEM* by Haberstroh and Pantel (2011). The following communicative strategies, amongst others, appeared to be relevant for the work within the advisory board: linking to old memories and life themes, linking to universal experiences, "What for?" questions, biography work, helping to find the thread again, attentive posture, responding to unfamiliar words in a non-concrete way (Haberstroh and Pantel, 2011).

2.3 Participants

The exploratory interview study was conducted with $N = 4$ participants (two females) who were between 45 and 80 years old and had a mild degree of dementia of various types with only slightly pronounced psychological and behavioral symptoms. Prior to the collaboration with the ABM and before the interview study, we made the decision not to assess the degree of dementia development. We believe that such an approach would not have been appropriate because it would have been associated with a deficit-oriented attitude toward our co-researchers, would have reminded them more of a patient role and would have made anonymization even more difficult. The psychological and behavioral symptoms became evident during the meetings, e.g., in the form of slight memory loss, difficulty finding the right words for something and/or following complex conversations, attentional fluctuations, or mild mood swings (sadness, impatience). At this point, all interviewees had been ABM for 8 months. All interviewees had sufficient hearing and vision. Interview participation was voluntary, and no financial or other compensation was granted. Ethical review and approval were obtained from the Council for Research Ethics at the University of Siegen (ER_27/2021).

2.4 Materials

Due to the lack of systematic research on the psychological impact of research participation on persons with dementia, no established questionnaire could be used. We therefore developed an interview guide (see Supplementary Table 1) using the so-called *SPSS method* (German language abbreviation for collect, check, sort, subsume) (Helfferich, 2011). First, as many questions as possible on the participatory effect of the advisory board's activities were collected. These questions were then critically checked by the academic researchers to determine whether, for example, they stimulate narration, touch on the relevance systems of the co-researchers and do not ask for facts (Helfferich, 2011). The remaining questions were then bundled and sorted by content. The interview partners were not involved in the development of the interview guidelines.

2.5 Data collection

The four individual and audio recorded interviews took place in March 2022 in the home setting of the four ABMs without the presence of third parties. The interviews lasted 47, 30, 54, and 10 min and were conducted by the academic researcher (KS). The interviewees were informed orally and in writing about the content, aim, potential risks, and audio recording of the interview study. To ensure informed consent, relevant material was adapted regarding dementia-sensitive language and based on documents already drafted by the advisory board members. The consent of the interviewees was continuously checked throughout the entire interview process so that the interviews could be terminated in the event of discomfort, stress, or unwillingness. In two interviews, the academic researcher and the interviewee jointly decided to end the interview due to increasing emotional arousal. Both interviews were included in the analysis, as the main topics had already been addressed in both interviews. Both persons accepted the offer of a consecutive stabilizing conversation. Depending on the particular needs of the interviewees, they were able to express and/or verbalize their emotions in this conversation. With reference to statements already made, the focus was then directed to existing resources or further services. After the interviews, postscripts with additional information on the interview situations were created.

2.6 Data preparation and analysis

To capture speech delays, word-finding inhibitions, and simultaneous speech, all interviews were transcribed (CW,

psychologist) according to the extended content-semantic transcription system (Dresing and Pehl, 2015). The transcripts were checked against the audio recordings by the interviewer and supplemented with para- and non-verbal aspects. In the end, a total of 19,095 words were generated. The transcripts were then anonymized according to *Bochumer Anonymisierungsmodell* (*Bochum anonymization model*; Richter et al., 2021) via a combination of factual and absolute anonymization.

Qualitative data were analyzed according to structuring content analysis by Kuckartz and Rädiker (2022) using the software MAXQDA.[1] For this purpose, after (1) initiating text work, both researchers independently and inductively (2) developed thematic main categories, (3) coded the entire material accordingly, (4) summarized the text sections with the same coding, (5) inductively formed subcategories, (6) coded the entire material again with the main and subcategories, and (7) analyzed the data. This involved a category-based analysis along the lines of the main categories, an examination of correlations between the interviews and particularities at the individual case level. Divergent coding was critically discussed, and final coding was conducted by consensus.

3 Results

Overall, 23 main categories were created from 246 text units, whereby text passages were also assigned to several categories. These main categories can be classified along three dimensions: *emotional level*, *cognitive level,* and *behavioral level*. With 104 text units (42%), most of the codes are assigned to eight main categories of the cognitive level, 81 text units (33%) to nine main categories of the emotional level, and 61 text units (25%) to six main categories of the behavioral level. Table 1 presents the overall results of the coding process.

While the three most frequently mentioned main categories of the dimensions of emotion (*Joy*, *Wellbeing*, *Sense of belonging and integration*) and cognition (*Competence experience*, *Making a positive contribution*, *Satisfaction with advisory board activity*) can be found in all interviews, the distribution and focus of the other categories differed across the four interviews. Therefore, the following results, structured by dimension, focus on the three aspects of experience and behavior that were most frequently described by the respondents in connection with their participation as an ABM. All other categories with sample statements are shown in Supplementary Table 2. Additionally, specifics at the individual case level are also reported. All quotations are presented linguistically in their original form and capitalization is used to make special linguistic emphases visible.

TABLE 1 Overall results of the coding process: main categories and their subcategories sorted by dimensions.

Main category*	*n*	%**
Emotional level	**81**	
Joy	20	25
Anticipation of the advisory board	4	
Through participation in the form of the advisory board	16	
Wellbeing	17	21
Sense of belonging and integration	12	15
Pride	12	15
Emotional relief	7	9
Feeling supported	6	7
Security	3	4
Sadness	2	2
Insecurity	2	2
Cognitive level	**104**	
Competence experience	24	23
Making a positive contribution	19	18
For oneself	4	
For others	15	
Satisfaction with advisory board activity	15	14
Cognitive stimulation	14	13
Reflection on one's own needs	13	13
Reflection on one's own dementia disease	11	11
Dementia as part of the self	5	
Perception of deficits within the advisory board	6	
Confidence	5	5
Curiosity	3	3
Behavioral level	**61**	
Social communication	26	43
Within the advisory board	20	
About the advisory board	6	
Social contacts	12	20
Contributing resources	8	13
Other activities	6	10
Being authentic	6	10
Social participation	3	5

$N = 246$ text units.
*Subcategories are right aligned.
**The proportion of main categories and subcategories within the respective dimension.

3.1 Emotional level

3.1.1 Joy

This category refers to a feeling of pleasure and happiness that, in contrast to wellbeing, does not describe a global feeling but rather a feeling that is linked to concrete events (Wirtz, n.d.). Our results show that joy can refer to the anticipation of the advisory board and to the enjoyment caused by participation in the advisory board itself. The initial anticipation was already evident with the request to join the advisory board:

"You know what, right away. I didn't even think about it, right away yes" (Interview 2, pos. 61–64).

1 MAXQDA [Computer software] (2022). *VERBI Software*.

This joy remained even after the start of the project. When asked how they felt when they knew it was the day of the advisory board meeting, the interviewees stated:

"Well, actually I'm always looking forward to it like hell" (Interview 2, pos. 136–139).

"I always find it, am always somewhere actually, when these appointments are, um yes, in such a positive tension" (Interview 3, pos. 31–33).

Joy is also reported in connection with participation in the advisory board itself. The reasons for this are manifold. First, the work itself is enjoyable.

"Therefore, it was just the self-help group, but then I'm really proud, say [name of partner], 'I have worked hard again!'" (Interview 2, pos. 205-207).

"Well, I, I, you see, I am coming out of my shell.... That makes me happy." (Interview 1, pos. 648–651).

Joint communication in advisory board meetings is also a pleasure. For example, one interviewee "simply enjoys being able to talk to open people" (Interview 1, pos. 346–347). Another emphasizes this aspect:

"And that was a very short, but VERY intense statement, where I thought: great, amazing, good." (Interview 3, pos. 298–303).

After all, it is also their own advisory board work that gives them pleasure. When asked how it felt to know that their own suggestions would be considered in the study project, one advisory board member replied:

"Very, very, very, very, very, very, very, VERY nice. Yes." (Interview 2, pos. 310–313).

3.1.2 Wellbeing

This category includes all text units in which the interviewees describe the perception of being happy and generally satisfied, frequently experiencing positive and rarely negative experiences and feelings (Eid, 2021). Most of the interview statements encoded refer to the advisory board in general. Descriptions such as "incredibly pleasant" (Interview 1, position 634); "pleasant atmosphere" (Interview 3, position 41–42); "such a very um very pleasant atmosphere" (Interview 3, pos. 41–42); "how well one is feeling" (Interview 2, pos. 658); or "I truly LIKE going there" (Interview 1, pos. 250) were often used. One interviewee described it more vividly:

"Almost as if in God's hands." (Interview 1, pos. 645).

According to a smaller number of codes, *Wellbeing* is explicitly linked to the personal commitment of the academic researchers, who are perceived, for example, as "nice and kind" (Interview 1, pos. 684).

3.1.3 Sense of belonging and integration

This category refers to the feeling of belonging and being integrated into a group and/or topic on an equal level (Merriam-Webster (ed.), (n.d.a)). The co-researching ABM felt that they belong, e.g., to "like-minded people" (Interview 4, pos. 25), to "people affected [by dementia]" (Interview 3, pos. 36) to "other colleagues" (Interview 1, pos. 446), or to people with whom "you can talk about something like that [dementia]" (Interview 1, pos. 207).

"But um, it was nice, they were all people with dementia.... And talking to them and such. I thought it was nice... With like-minded people like that" (Interview 4, pos. 19–25).

The perception of *belonging and integration* also occurs when the ABM perceive themselves as actively involved in the board activities. Thus, praised the "openness" (Interview 1, pos. 148) to collaboration, saying that one could "suddenly participate on a completely different level" (Interview 1, pos. 525–526). When asked how to recognize good involvement, one interviewee replied:

"You know what, you all ask us. Everyone can add their two cents" (Interview 2, pos. 271–272).

3.2 Cognitive level

3.2.1 Competence experience

Perceiving oneself as competent is the most frequently assigned main category on a cognitive level. The co-researchers felt that they were able to successfully fulfill the tasks and performance requirements of the advisory board through their own actions (Wirtz, 2021). This impact of participation can be seen in various aspects. First, in the realization that they are competent, -for example, "in an area that I can still follow relatively well" (Interview 3, pos. 182). After the meetings, one advisory board member "had the feeling that I had done something good for the advisory board and for myself" (Interview 2, pos. 147–148). Second, the perception of being asked for advice also signaled an attribution of competence:

"So, we are not stupid, we are still quite alive" (Interview 1, pos. 668–670).

Third, all four co-researchers also explicitly confirmed that they did not feel overwhelmed by their participation in the advisory board. One person reported:

"Yes, I feel a bit challenged. Not that it's too much for me" (Interview 1, pos. 517–518).

Challenged without being overwhelmed is also how this advisory board member sees it:

"I noticed that when we did something. I did notice that, right.... Yes, always a bit. But you know, I was [at work] before. I was physically exhausted and mentally exhausted. That was ideal" (Interview 2, pos. 483–489).

Regarding their advisory board activities, the co-researchers not only perceived themselves as competent in real-life situations but also saw themselves as capable in the future:

"Well, I think I'm still someone who can contribute good ideas and has the fantasy to do so. Or simply, um, yes, all these stories that you have somehow experienced" (Interview 3, pos. 433).

When asked whether they would have thought that participation would be possible despite the health restrictions, one person resolutely answered "Yes, I think so" (Interview 4, pos. 190). The four co-researchers not only felt capable, but also, in some cases, attributed a value to their own actions, as explained in the following category.

3.2.2 Making a positive contribution

According to the co-researcher's definition, this main category is based on the realization that their own advisory board activities contribute to a result that they personally perceive as valuable. A further distinction can be made between the positive contributions for oneself and for other people or circumstances (as subcategories). The former can be seen in statements such as:

"Yes, but that also has something that helps me to say where I am now on my path" (Interview 3, pos. 249).

"And it also helps me at the same time" (Interview 1, pos. 293).

Being a co-researcher also provides access to relevant information and "that is also important for us, not just for you" (Interview 2, pos. 30–31).

However, most of the coded statements relate to the positive effect of one's own activity on others.

"Yes, um I have the feeling that despite everything I can somehow still contribute and somehow still pass on certain things" (Interview 3, pos. 612–613).

The positive aspects can also be directed toward the other co-researchers, for example, when their own strengths are brought into the advisory board:

"Yes, that means a bit, I'm doing well. And, I can see from the applause that it does the others good too" (Interview 1, pos. 329–331).

3.2.3 Satisfaction with advisory board activity

This category refers to all text segments in which the co-researchers' perception is expressed that the expected and achieved personal goals within the framework of the advisory board activity coincide (Zufriedenheit [satisfaction], 2000). When asked whether their own expectations had been met, one person replied:

"And HOW!" (Interview 2, pos. 678)

"In any case, in EVERY case" (Interview 2, pos. 67).

In some cases, satisfaction is explicitly linked to the framework conditions perceived as harmonious, for example, regarding the frequency of the advisory board meetings (Interview 2, pos. 693–694; Interview 3, pos. 28–31) or the interpersonal atmosphere (Interview 1, pos. 546–548). Indirectly, the level of satisfaction of the ABM with their participation can be deduced if they recommend participation to other people with disabilities.

"Yes, I can only say what I thought was right for me. And, please, help yourselves." (Interview 1, pos. 354–355)

"Well, everything here was super great. The people should come." (Interview 2, pos. 655–656).

3.3 Behavioral level

3.3.1 Social communication

At the behavioral level, the effects of participation are predominantly evident in the category of social communication, understood as the mutual exchange of information about thoughts and feelings (Bierhoff, n.d.). The results suggest a further differentiation between communication outside the advisory board about the advisory board and communication within the advisory board on general and disease-related topics (as subcategories). In the context of disease-related topics, the central value of participation in the advisory board becomes apparent.

"You can talk about it....How it goes for everyone and what they do" (Interview 4, pos. 42–44).

"I always think it's good that all these people come together. That we can talk to each other. Because one person does it one way and another person does it differently." (Interview 4, pos. 75–78).

One would "simply enjoy being able to talk to open people." (Interview 1, pos. 346–347), and it would be "so relaxed and nice about such an UNpleasant … topic" (Interview 1, pos. 306).

The individual's responsibility as an advisory board member is formulated as follows:

"That I also say um difficult things... and that helps me, of course, that I can get it off my chest." (Interview 1, pos. 49–55).

The open, inviting culture of discussion is emphasized by the statement that the advisory board is about "mental work and, um, telling stories" (Interview 2, pos. 368) and that everyone can "add their two cents" (Interview 2, pos. 271–272). In the context of non-illness-related communication, the possibility of so-called wellbeing rounds is appreciated.

Outside of the advisory board, the main contacts for discussion of advisory board topics are not only partners and family but also work colleagues. In addition, the advisory board also becomes a topic among friends:

"A lot of people know about me, um, that I have Alzheimer disease somewhere... Um, and with individual friends... where it goes a bit further, um, I also gave them details." (Interview 3, pos. 544–548).

3.3.2 Social contacts

Our results show that the advisory board offers all co-researchers the opportunity to make positive social contacts. On the one hand, this refers to the academic researchers.

"I feel comfortable with you... You are nice and kind." (Interview 1, pos. 380–382).

However, above all, the advisory board is described, for example, as a "nice group" (Interview 3, pos. 51).

"They were all people with dementia.... And, talking to them and all that. I thought it was nice… We were just among ourselves." (Interview 4, pos. 19–59).

3.3.3 Contributing resources

On the advisory board, the co-researchers were able to contribute their own resources, for example, personal topics, abilities, and skills. This concerns, for example, "All these stories that you have somehow experienced, um, as a [profession]." (Interview 3, pos. 433).

"Well, I think I'm still someone who can come up with good ideas somewhere, and has the imagination to do so." (Interview 3, pos. 433).

3.4 Additional findings

There are distinct subcategories for the main categories of *Joy*, *Reflection on one's own dementia disease*, and *Social*

communication, which do not overlap in the coding. This is not the case for the perception of *Making a positive contribution*. Here, the co-researchers think simultaneously about making a positive contribution both for themselves and for others. For example, when speaking of a "…win–win situation. I would like to help the other people and help myself too." (Interview 2, pos. 26–27).

Furthermore, there are connections between the different main and sub-categories. A text segment can address several thematic aspects, which is why several main and sub-categories can overlap or nest within one another. Such overlap can be observed particularly frequently in the behavioral category of *Social communication within the advisory board*. This applies, for example, to the combination of *Social communication* and *Being authentic*. Furthermore, *Social communication* is often flanked by emotional experience components. Several text segments on internal advisory board communication are also labeled with the main code *Emotional relief*. In this way, members of the advisory board can "talk things out" (Interview 4, pos. 42) and "get rid of stressful thoughts" (Interview 1, pos. 54, pos. 137–138). A *Sense of belonging and integration* is also often described when the ABM talk to each other. This generally applies when the co-researchers are among "like-minded people" (Interview 4, pos. 22–27) with whom they can talk about their own dementia. Both, *Social communication within the advisory board* and the *Sense of belonging and integration* are closely linked to the behavioral category of positive *Social contacts*. For the latter, the results often show a connection with the emotional category of *Wellbeing*. This applies both to contact between co-researchers and academic researchers and to contact among the ABM. The cognitive category *Competence experience* was also frequently coded together with other categories, such as the category *Making a positive contribution to others*. In the corresponding text segments, the co-researchers reported, for example, that they "did something good" for the advisory board (Interview 2, pos. 147–148) or "helped to help others" (Interview 1, pos. 732–733). On an emotional level, this perception of expertise is often accompanied by *Pride*. For example, when the co-researchers "worked hard again" (Interview 2, pos. 207) or participated "on a completely different level" (Interview 1, pos. 525–526) in the board meetings.

Regarding the psychological effects of participation as an ABM, different central themes can be identified for each co-researcher. In interview 4, statements coded to the three categories *Social contacts*, *Social communication within the advisory board*, and *Sense of belonging and integration* are mentioned particularly often and are interwoven with each other. This combination of categories accounts for more than half of the codes in this interview. For this co-researcher, the advisory board primarily offers the opportunity to *communicate with other people about dementia*, to make positive *social contacts* and to behave *authentically*. On an emotional level, this person feels disproportionately comfortable, particularly *relieved* and *supported*. Interview 2 focused on cognitive aspects, and the advisory board was equated with *cognitive stimulation* with striking frequency. On an emotional level, this is accompanied by great *joy* and *pride*. In interview 3, the differentiated *reflection on needs and dementia* was striking. Only this co-researcher talks about the negatively connoted perception of deficits in the context of the board's work and describes negative feelings of *insecurity* and *sadness*. On the other hand, this person feels *confident* and often *competent*. This experience of competence is linked to the two categories of *contributing resources* and the perception of *making a positive contribution to others*. On a personal level, participation in the advisory board had such predominantly positive effects that the person decided to be involved in other working groups as well.

4 Discussion

As one of the first studies from an explicitly psychological perspective, this project investigated the psychological effects of research participation on persons with dementia. We found various psychological effects along the three dimensions of emotion, cognition, and behavior, with a focus on the cognitive level across all interviews. As expected, and in line with the literature, the present study also shows that the impact of advisory board activity on co-researchers is of significant importance (Staley, 2015; Swarbrick et al., 2019). For reasons of clarity, we discuss the results according to the dimensions found.

4.1 Cognitive effects of research participation

On a cognitive level, it is noticeable that the co-researching ABM often perceive themselves as competent and are able to verbalize this. This finding is consistent with previous literature and can be found both in general studies about research partnerships (Hoekstra et al., 2020) as well as in studies involving people with dementia (Clare et al., 2008; Tanner, 2012; Littlechild et al., 2015; McConnell et al., 2019). In the context of research participation, a minimum level of skill, such as in spatial orientation, attention, and language, is required (van Baalen et al., 2011). In terms of language skills, mildly affected persons are more likely to understand rather simple verbal messages, and memory and word finding may already be impaired, but grammar and attention are still largely intact (Kuemmel et al., 2014). With suitable methods, people with dementia with early-onset impairments in particular can therefore formulate and represent their thoughts, feelings, and interests themselves (Aggarwal et al., 2003; Wißmann, 2021).

The cognitively stimulating character of the advisory board meetings is perceived positively by the co-researchers and, in their view, distinguishes the advisory board from the meetings of the self-help group. Ashcroft and colleagues (Ashcroft et al., 2016) were previously able to identify intellectual stimulation as a positive effect of participatory involvement. This is relevant because wide-ranging cognitive stimulation, which includes sensory experiences, positive memories, communication, and social contact, can help to preserve the remaining cognitive resources of persons living with dementia (Ivemeyer and Zerfaß, 2006). It is also noticeable that the ABMs not only perceive themselves as competent but also attribute positive value to their actions. The perception of making a positive, meaningful contribution to oneself and/or others in the context of research participation has already been extensively document-ed in the literature (Fudge et al., 2007; Steeman et al., 2007; Littlechild et al., 2015; Ashcroft et al., 2016; Waite et al., 2019). Some of the statements made also describe a *give and take* in the context of their advisory board activities. If those affected give back the support they

receive through their own contributions, this can in turn have a positive effect on their subjective wellbeing—a fact that could also be expanded as part of targeted interventions (Godde et al., 2016).

Our results also show the emancipatory potential of participatory projects discussed in the literature (Clare et al., 2008; Arbeitskreis Kritische Gerontologie der DGGG, 2016; McConnell et al., 2019). In this way, the co-researchers continue to experience themselves as effective by contributing their individual competences and strengths and experience themselves as competent in the sense of self-efficacy and making a positive contribution to themselves and others. This is a relevant aspect, as the personal resources of the co-researching persons are understood as protective factors that can support coping with their disease and improve their quality of life and wellbeing (Arbeitskreis Kritische Gerontologie der DGGG, 2016; Gruber, 2020).

4.2 Behavioral effects of research participation

A very significant, positive effect of the advisory board's activities can be seen at the behavioral level in the form of social communication and positive social contacts. This finding is also not surprising, as a positively perceived expansion of the social network has already been documented (Fudge et al., 2007; Litherland et al., 2018; Hoekstra et al., 2020). As our findings show, the co-researchers even feel encouraged to be able to behave authentically among people with the same condition. Participating in interesting projects together with others also prevents from withdrawing at home.

4.3 Emotional effects of research participation

On an emotional level, the advisory board represents joy and wellbeing for the co-researchers with almost half of all coding in the interviews falling into these two categories. How central a shared joyful experience is for people with disabilities is shown by the fact that fun is considered one of the key therapeutic principles of *cognitive stimulation therapy* (Aguirre et al., 2018). Our results also confirm findings showing that people living with dementia have a great need for appreciation and recognition (Niebuhr, 2010). This relates to biographical and life experiences, which serve as personal resources for the advisory board, as well as participation in the advisory board itself. The ABMs describe being proud when they receive positive feedback on their participatory involvement, both within and outside the advisory board. Previous studies have shown that co-researchers experience appreciation as part of their research participation (Fudge et al., 2007; Litherland et al., 2018; Hoekstra et al., 2020).

A special feature of research with people with dementia is that co-researchers are inevitably confronted with their dementia as part of their advisory board activities. As described by the ABMs, this stimulates reflection processes that involve an active examination of the condition and the course of their own illness. This has already been considered as an opportunity for individuals to come to terms with their illness (Ashcroft et al., 2016). Providing participatory support for dementia research can even give life with this disease a new, independent value (Clare et al., 2008). However, confrontation with dementia can also have negative, stressful effects on co-researchers. This is particularly true when those affected perceive increasing disease-related limitations and losses (Span et al., 2018). In the interviews, sadness and insecurity were found to be negatively connoted feelings and deficits in the context of the advisory board activity. Interesting, but congruent with previous findings, is the fact that these negative thoughts and feelings do not appear to carry much weight in the overall view of research participation (Ashcroft et al., 2016; Weidekamp-Maicher, 2021). The ABM seem to be able to allow and balance these opposing feelings in the context of their advisory board activities and successfully self-integrate the negative feelings, so that a view of the positively perceived aspects of the advisory board becomes clear again. Other negatively connoted thoughts or feelings, as described in the literature, such as dissatisfaction, the feeling of not being heard and appreciated, or feeling overwhelmed (Ashcroft et al., 2016; Hoekstra et al., 2020) were not addressed by the ABM. On the contrary, the co-researchers reported great satisfaction with the frequency of the meetings, the composition of the advisory board, the working nature of the meetings, and the results of their own advisory board activities.

4.4 Additional findings

Our results show a strong connection between social and emotional components. This suggests that the advisory board seems to fulfill basic psychosocial needs. We would like to combine this result with current findings that social and, above all, emotional support are important protective factors for the life expectancy of people living with dementia (Blotenberg et al., 2024). An absence of both appears to be a risk factor for shorter life expectancy, over and above other known clinical factors. Participation can be one way to find social and emotional support. Therefore, our results strengthen the call for greater attention to be given to the psychosocial needs of people with disabilities (Blotenberg et al., 2024).

In the context of research, older people, even those without dementia, are assumed to be uncooperative or uninterested in research (Wanka and Urbaniak, 2023). In contrast, our results show a strong need among ABM to reassure themselves of their remaining competencies by repeatedly addressing their own skills and participative contributions. However, it appears that the application of remaining skills seems to be the central issue. An increase in skills, as described in several studies on patient and public involvement (Fudge et al., 2007; Baldwin et al., 2018; Hoekstra et al., 2020), was not explicitly addressed in the interviews.

Our results show distinct inter-individual differences in the motivation to participate in advisory boards and the psychological impact of research participation. This speaks to the importance of continuing to see persons living with dementia as individuals despite having the same condition and, above all, taking their individual needs and personality into account when working with them as co-researchers.

4.5 Strengths and limitations

With the content analysis method according to Kuckartz and Rädiker (2022), a method was chosen that allows *a priori* category formation from empirical data and guidelines as well as inductive, explorative category formation on the material or a combination of both variants. This allowed a previously little investigated research subject to be comprehensively illuminated and described in greater depth. Both the data generation and evaluation followed strict quality criteria. This applies above all to intersubjective traceability, which was ensured above all through detailed procedural documentation, consistent verification by both researchers regarding coding, and the explication and documentation of all research steps. The standardization of procedures, e.g., interview guidelines, transcription, anonymization, and coding rules, increases procedural reliability, i.e., trust in the data and its interpretation. The different perspectives of the two coders are seen as a further strength. While one was an active part of the interviews, the other only knew the interview situation from the audio recordings and postscripts. Critically reflecting on deviating coding and ultimately reaching a consensus on assignments, therefore, meant a very intensive examination of the data material and contributed to internal consistency. The interviews were partly characterized by very long units of meaning, interjections, and digressions regarding the individual characteristics of the interviewees' speech production and comprehension. Communicative validation during the interviews, i.e., summarizing or reflecting the statements to the interviewees, clarified comprehension difficulties and increased the probability that what was said corresponded to what was meant.

Four interviews were not and are not intended to generate results representative of the entire group of persons living with dementia. However, in contrast to the principle of external validity in quantitative research, the focus in qualitative research is on authentic or comprehensive representation (Kruse, 2015). Nevertheless, the characteristics of individual interviewees may have played a greater role in the overall presentation of the results. This is another reason why impact analysis at the individual case level is so important. In line with other literature (Arbeitskreis Kritische Gerontologie der DGGG, 2016), the group of co-researching persons with dementia was also found to have a relatively high level of formal education, socioeconomic status, and no migration background. This is another reason why the results do not aim to generalize and represent a specific group of people. As only people with mild dementia were interviewed, no statement can be made about the experience and behavior of people with more severe dementia. Furthermore, the practical support provided by the personal environment and the AlzA favored the participation of the co-researchers. This indicates that they therefore have considerable social capital (James and Buffel, 2023), which is not the case for the general population of people with dementia. The interviews were conducted by an academic researcher who was known to the co-researchers from the advisory board meetings. Although existing trust and mutual sympathy promote a pleasant and open discussion atmosphere, such an established relationship between speakers could also lead to distortions in response behavior during an interview, e.g., in the sense of social desirability. This applies here in particular because the interviews took place in the middle of the project period, and both parties were interested in a positive evaluation. Unwanted power dynamics between academics and co-researchers must also be considered.

4.6 Practical implications

In terms of an interdisciplinary view of participation and, above all, research participation of persons with dementia, we advocate greater consideration of the topic in the realm of psychology. The biopsychosocial model can provide an integrative framework to explain the psychological effects of participation on the co-researchers using established psychological theories. People in the later stages of dementia, those with a migration background and those with insufficient social resources must also be given access to research projects and thus also to the associated positive psychological effects. Based on the findings on the high socioeconomic status of most co-researchers in participatory research projects, this also touches on the ethical issue of perpetuating existing inequalities through participatory research.

In addition, a procedure for dealing with emotionally stressful interview situations with people with dementia should be developed and empirically evaluated.

5 Conclusion

The largely positive feedback from the advisory board members shows that people with dementia are very happy to be involved in research efforts and contribute to the knowledge gained as experts of their own lives. Nonetheless, various circumstances must be considered when conducting research with them to enable them to have a positive experience of participation. It is particularly important to create conditions that allow co-researchers to experience the positive effects of their participatory engagement, that they are challenged but not overwhelmed, and that negative emotional reactions to perceived disease-related losses are appropriately addressed. Despite the increasing number of participatory research projects with people with dementia, the impact of research participation on those affected is still not extensively considered (Backhouse et al., 2016; Rivett, 2017; Bethell et al., 2018; Harris et al., 2018). With our study, we would like to contribute to psychology's involvement in the topic.

Data availability statement

The datasets presented in this article are not readily available because for data protection purposes, no raw data can be made available, as it is highly likely that conclusions could be drawn about individual interviewees from these data. Requests to access the datasets should be directed to katja.seidel@uni-siegen.de.

Ethics statement

The studies involving humans were approved by Council for Research Ethics at the University of Siegen (ER_27/2021). The

studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

KS: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Visualization, Writing – original draft, Writing – review & editing. CW: Formal analysis, Writing – original draft. JT: Funding acquisition, Writing – review & editing. JH: Funding acquisition, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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EDITED BY
Anthea Innes,
McMaster University, Canada

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Karin Wolf-Ostermann,
University of Bremen, Germany
Leszek Koczanowicz,
University of Social Sciences and Humanities, Poland

*CORRESPONDENCE
M. Błaszkiewicz
✉ maria.mackowiak@student.umw.edu.pl

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Fostering social health of people with dementia: evaluation of *the Razem przed siebie* dementia awareness campaign in Poland

M. Błaszkiewicz[1]*, D. Szcześniak[1], M. Ciułkowicz[1], Julia Ewa Rymaszewska[2], L.-F. Low[3], H. Brodaty[4] and J. Rymaszewska[5]

[1]Department of Psychiatry, Wroclaw Medical University, Wrocław, Poland, [2]Department and Clinic of Dermatology, Allergology and Venerology, Wrocław Medical University, Wrocław, Poland, [3]Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia, [4]Centre for Healthy Brain Ageing, Discipline of Psychiatry and Mental Health, School of Clinical Medicine, University of New South Wales, Sydney, NSW, Australia, [5]Department of Clinical Neuroscience, Wroclaw University of Science and Technology, Wrocław, Poland

Background: Due to the need to increase social awareness about dementia and the needs of patients living with dementia in Poland, the *Razem przed siebie* (eng. *Forward with Dementia*) campaign was created. The aim of the study was to evaluate its effectiveness.

Methods: To disseminate key campaign messages to the target audiences (people with dementia, carers, health and social care professionals [HSCP] and general public) a website, social and traditional media promotions, webinars and social activities were created. The campaign ran between September 2021 and April 2022. Mixed methods (online survey, reach estimates and interviews) were used to evaluate the campaign.

Results: Almost 1,300 people visited the website during the campaign period. Of these, 55 carers and HSCP responded to the online survey. The most read section of the website was *Understanding the diagnosis* (carers [56% of 25] and HSCP [80% out of 30]). The website was mostly accessed by carers (68%) and HSCP (66.7%) through word-of-mouth recommendations. 80% carers and 90% HSCP found the website very or extremely helpful. Over 90% of carers and HSCP expressed an intention to revisit the website. Based on 31 interviews, campaign effects, change mechanisms and limitations were identified. Campaign events elicited positive emotions among people with dementia, providing them with a feeling of belonging and engagement. Esteeming personal interactions over informational campaign materials, those with dementia felt acknowledged and empowered by the events. Carers also reported positive experiences and increased interest and knowledge, though they expressed disappointment with the lack of respite care, an issue beyond the campaign's scope. HSCP perceived the campaign events positively and identified significant gaps in the dementia care system.

Conclusion: Evaluation of the *Razem przed siebie* campaign revealed successes and limitations. While effectively incorporating anti-stigma campaign recommendations and enhancing social health for individuals with dementia, the campaign clearly showed the pressing need for systemic solutions. Despite positive perception of the campaign, there is a need for a better diagnostic and post-diagnostic support for people with dementia and their carers.

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KEYWORDS

dementia, campaign, social health, evaluation research, stigma

1 Introduction

The WHO Global Dementia Action Plan 2017–2025 (1) recognizes social campaigning as a crucial means to raise awareness and friendliness about dementia. The recommended key messages of such actions are: to spread reliable knowledge about dementia, its subtypes, early symptoms and risk factors, as well as to counteract stigmatization and discrimination and to plead in favor of the human rights of people with dementia (1). In 2021, only 21% of WHO members had implemented dementia awareness campaigns (2).

Furthermore, reports from studies assessing the effectiveness of the dementia campaigns are sparse and not directly comparable due to different campaign goals, target groups, communication channels, societal contexts, and evaluation strategies (3–8). Available evaluation results of mass media campaigns on dementia from the Netherlands (4, 5), Belgium (5), and Australia (7) indicate only a partial change in the campaign goals, e.g., increased awareness of dementia risk factors among general public. The increase in knowledge was observed only in better educated demographic strata (5). Active participation by general public in the campaign events (not just exposure to promotional materials) allowed for better recognition of the campaign's key messages (4). Australian *Forward with Dementia* (8) and Canadian *Not If, But When* (6) web-based resources aimed at health and social care professionals (HSCP) only partially influenced their attitudes regarding respectively: (1) diagnostic conversation for dementia and referral for post-diagnostic support, and (2) comfort in assessing driving risk in dementia, indicating that a social campaign is not a complete remedy for systemic barriers.

In Poland, according to estimates, there are currently over 500,000 people living with dementia, many of whom lack a formal diagnosis (9). Poland has yet to implement a national dementia strategy, and the health and social care systems function independently, complicating access to appropriate care (10). Informal carers, who often handle the coordination of treatment and care, have limited respite options (11). The few scientific studies on the social situation of people with dementia in Poland reveal that awareness of dementia is generally low among the general population as well as HSCP (12–14). Given the rising number of dementia cases, this lack of awareness constitutes a serious barrier to improving the situation for people with dementia in Poland (12). Despite calls from national advocacy organizations (15) and scientific reports (16) emphasizing the necessity of a nationwide social campaign addressing dementia, no such initiative had been undertaken until the commencement of this study. Prior sporadic health promotion initiatives related to dementia were typically confined to local efforts, and their efficacy remains unreported.

As meta-analyses show, there is no single recipe for campaign success (3). Their effectiveness is determined by a multitude of factors that require further research (3). Moreover, examination of many campaigns aimed at raising awareness and destigmatizing mental illnesses has shown that they often bring no benefits or, worse still, unintentional adverse effects (17, 18). For instance, concentrating on enhancing understanding of the biomedical aspects of a particular illness, while it diminished the tendency to blame patients for their condition, led to a rise in the perception that the disease is not amenable to therapy (18). Recognizing these failures allowed the researchers and activists to formulate guidelines to support effectiveness of public health campaigns (17–20). Advice included empowering individuals with firsthand experiences of mental health problems to spearhead grassroots social movements and to share their lived-experience; concentration on rights and dignity of those who have faced stigma and discrimination; substituting notions of incapacity and dangerousness with narratives of hope and competence. The context of the health care system and its limitations also needed to be addressed (17, 19). Interestingly, applying these indications to the context of dementia demonstrates their compatibility with the concept of social health (21). The paradigm of social health is one of the most prominent frameworks for explaining health for people with dementia, defining it as a dynamic process involving adaptation and coping with a chronic disease in social life (21, 22). Maintaining social health means balancing the deficits and limitations resulting from disease with personal and social resources, and environmental conditions (22). Social health depends on both how person with dementia interacts with the social environment and how the social milieu reciprocally interacts with them (21). A threat to this balance and reciprocity is societal stigma, which—within the social health concept—can be understood as depriving a person with dementia of: obligations, rights, and participation, i.e., essential elements of social health. Importantly, social health is regarded as a modifiable risk factor for cognitive decline (21), implicated in the pace of progression of dementia (23). It therefore appears that awareness campaigns may have the potential to enhance some aspects of social health in dementia (24).

The previously outlined strategies for impactful anti-stigma campaigns (18, 20) address changes at the individual level (as posited in the social health framework) (21). This involves empowering individuals in terms of their capabilities, social participation, and independence. The reinforcement of individuality, achieved through initiatives such as social campaigns, is intended to bring about transformations in the social environment, leading to, e.g., a reduction in stigma. In turn, decreased stigma may, like a feedback loop, bolster the individuality of those navigating the challenges of the disease.

Because the concept of social health is a priority in research on the health of people with dementia (21) and corresponds directly to recommendations for conducting anti-stigma campaigns (20), we utilize it as a conceptual framework for post-hoc analysis of the effects of introducing in Poland a dementia awareness campaign and website *Razem przed siebie* (in English-speaking countries, the campaign slogan was *Forward with dementia*) in the perception of dementia among the target groups. The aim of this study was to evaluate effects of social campaign *Razem przed siebie* in Poland using qualitative and quantitative methodological attitude including mapping campaign effects onto the social health conceptual framework.

2 Materials and methods

2.1 Intervention

Razem przed siebie campaign and website were part of an international Co-Designing Dementia Diagnosis & Post-diagnostic Care (COGNISANCE) project. An international consortium composed of five countries (Australia, Canada, United Kingdom, the Netherlands and Poland) developed the generic dementia awareness intervention. Based on close cooperation between researchers, a marketing company and local working groups composed of people with dementia, carers, HSCP and key stakeholders developed the branding and website design. The co-designing process and website user-testing have been described (25). The English name *Forward with dementia*, key messages and content of the website were translated and adapted to the Polish context. Through further cooperation between Polish research team, and local working group a campaign strategy was prepared. The leading team conducting the campaign consisted of four researchers and two volunteers from the Wroclaw Medical University, diverse in age, gender, educational background (psychiatrists, psychologists and medical students) and years of experience (both early career researchers and experienced independent researchers).

2.1.1 Target audiences

There were four target audiences of the intervention in Poland: people with dementia, carers, HSCP and general public. Key messages were:

1 Dementia is a disease which needs to be diagnosed and treated.
2 Dementia diagnosis is the first step to starting appropriate therapy.
3 It is possible to live a positive life with dementia.
4 There are things that can be done to live well with dementia.

2.1.2 Website

The campaign website was a resource about dementia for three groups of recipients: people with dementia, carers and HSCP. It contains articles on: the diagnosis process, acceptance of the diagnosis, coping with symptoms, living well with dementia, plans and decisions for the future, tailored in content to each recipient group. Additionally, the website presents personal stories of people with dementia and contained news and promotions on campaign events.

2.1.3 Campaign

In Poland the campaign ran from 21st September 2021 to 7th April 2022. The main activities were concentrated in Wrocław and Lower Silesia. Key messages of the campaign were promoted via a range of educational and participatory activities (Figure 1) such as: social media marketing (Facebook, Instagram, YouTube), media coverage (local and nationwide press, radio and TV), distribution of printed leaflets, posters and gadgets (pens, badges, bags, reflective bands), promotional spots on public transport and regional railways, campaign bus covered with the campaign slogans, illumination of important buildings, webinars for carers and HSCP, exhibitions of paintings by a local artist living with dementia, speeches by campaign ambassadors (person with dementia and carer), mobile screening points, lectures in schools, senior councils, Universities of the Third Age, meeting centers for people with dementia, information stand at the seniors' festival and final music concert. The campaign received honorary patronage from: the Polish Minister of Health; the Deputy Marshal of Lower Silesia; the Voivode of Lower Silesia; the President of the City of Wrocław; the city of Wrocław; the president of the Polish Alzheimer's Foundation, Wrocław Women's Council and the Rector of the Wrocław Medical University. A collection of photographs capturing various campaign events has been provided as the Supplementary material.

2.2 Intervention evaluation

2.2.1 Design

A mixed-method approach was applied to assess the effects of introducing a dementia awareness intervention. Outcome measures were: website usability (operationalized by: time spent on the website, information read, website helpfulness, website information source, ease of use, plan to visit the website again and reach) and effects of the campaign among people with dementia, carers and HSCP. Quantitative design was used to evaluate the website usability among carers and HSCP and to estimate the reach of selected campaign activities. Qualitative study was aimed to assess the effects of the campaign among people with dementia, carers and HSCP. Study procedures were conducted in accordance with the Helsinki Declaration (26) and approved by the Ethics Committee of the Wroclaw Medical University (No. KB – 928/2021).

2.2.2 Recruitment process and data collection

2.2.2.1 Quantitative data

The website evaluation survey was conducted throughout the whole duration of the campaign. The survey was available on the *Razem przed siebie* website under the button *Rate the website* located on the top navigation bar. Incentives to participate in the study were also published on the *Razem przed siebie* social media channels.

Visitors to the website were invited to complete the questionnaire; after clicking *Rate the website* they were redirected to the online survey on the Survio® platform. After entering the link to the survey, participants were informed that completion was equivalent to agreeing to participate in the study. The survey included multiple choice questions regarding the general opinion about the *Razem przed siebie* website, user experience, time spent on website and general demographic information, including participant's role, i.e., family & friend of a person with dementia, HSCP, person with dementia or other. Additionally, each subsection of the questionnaire comprised of an optional segment where respondents had the opportunity to provide open-ended comments.

The reach of selected campaign activities was counted on the basis of: data from Google Analytics (website visitors), data from the marketing company (reach of the press release: online and printed publications); number of page views and likes (posts on social networking sites and webinars), counting participants of certain events (number of tickets for a concert, number of people examined at diagnostic mobile points), number of distributed printed materials (leaflets, posters).

2.2.2.2 Qualitative data

For the qualitative part of the research convenience sampling strategy was used. Representatives from the campaign's target groups,

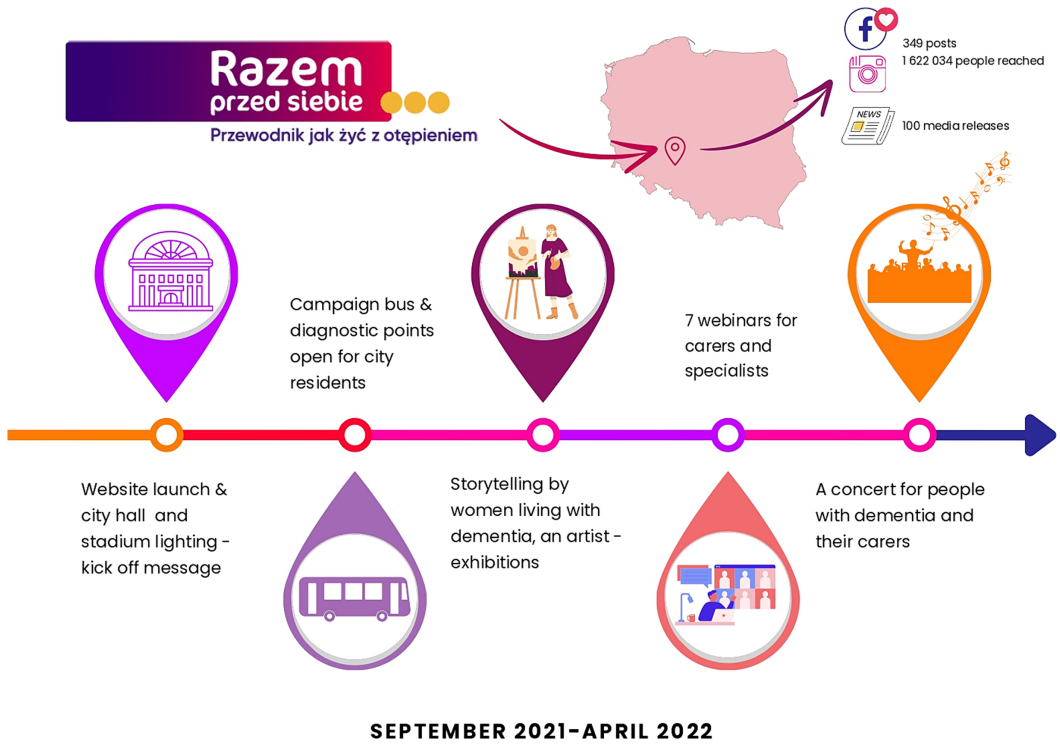

FIGURE 1
Highlights from the *Razem przed siebie* campaign and the Polish logo.

including people with dementia, carers, and HSCP, who attended the events were invited to take part in the research. During the events, researchers invited participants to take part in interviews and share their impressions of the campaign. Those who expressed interest in the study were contacted via phone or email, and interview dates were scheduled individually. Interviews with people with dementia were conducted at day meeting centers that organized outings to campaign events. Prior to interviews, the purpose was reiterated and informed consent was obtained from all participants involved. Interview guide included questions about general experiences with the *Razem przed siebie* initiative, brand perception, dissemination channels, personal impressions and feelings, relevance of key messages, impact of the campaign and website on knowledge, attitudes, and behaviors toward dementia. The interviews were conducted and audio-recorded by research team members experienced in qualitative data collection (MB, MC, JER). Demographic data were collected and stored in password-protected files.

2.2.3 Data analysis

2.2.3.1 Quantitative data

Descriptive statistics were presented as mean, standard deviation or counts and percentages. Calculations were made using the R package for Windows (version 4.3.2) (27).

2.2.3.2 Qualitative data

Recorded interviews were transcribed into verbatim scripts by the research team members skilled in preparing materials for qualitative analyses. Before analysis, the transcripts underwent anonymization and proofreading. The review of transcripts for accuracy served as an initial step in the authors' familiarization with the data. Four researchers—one psychologist, two psychiatry residents and one medical student—conducted data analysis. Thematic analysis, incorporating inductive and deductive approaches (28), was employed to analyze the transcripts in relation to the primary analytical question: what are the effects of introducing a dementia awareness campaign and website *Razem przed siebie* in the perception of dementia. During the initial phase, the most information-rich transcripts from interviews with people with dementia, carers and HSCP were independently analyzed by two researchers who generated initial codes answering the study questions through inductive analysis. Through discussion between the researchers, the codes were standardized and compiled into a codebook. Subsequently, the remaining material was analyzed by one researcher using deductive analysis based on the jointly-developed codebook. During the brainstorming session, two researchers (MB, DS) engaged in the previous stages of the analysis examined similarities and differences between the studied groups and clustered individual codes into themes and sub-themes. The relevance and naming of the formulated themes and sub-themes were discussed until a consensus was reached. Themes and subthemes were then analyzed post-hoc from the perspective of the social health concept and its specific markers. Through discussion between researchers (MB, DS), it was determined which of the previously formulated sub-themes aligned with markers of social health.

The interviews, transcription and analysis were carried out in Polish, while the results are presented in English. Each quoted excerpt was translated independently by two researchers. The translations were then compared and a discussed to ensure accurate conveyance of meaning between languages.

3 Results

3.1 Participants demographics

Fifty-five individuals, including family and friends of people with dementia and HSCP, responded to the online survey between November 2021 and June 2022 (Table 1). No people with dementia filled out the survey. Out of the 323 individuals who accessed the survey link, only 55 completed the survey, resulting in a completion rate of 17%.

Thirty-one interviews were conducted between March and September 2022 with people with dementia [$N = 14$], carers [$N = 9$] and HSCP [$N = 8$] (Table 1). The time since dementia diagnosis in participants with dementia ranged from 1 month to 8 years. In the group of carers, the time since the diagnosis of their relative ranged from: 8 months to 20 years. Eight carers stated that they provide the main care for a person with dementia. The group of carers included: spouse [$N = 3$], sibling [$N = 1$], children [$N = 4$] and grandchild [$N = 1$]. Six HSCP were healthcare providers and two social care providers. All interviewees were Poles, living in Wroclaw, Poland.

3.2 Quantitative data

3.2.1 Survey

The average time spent on the website (Figure 2A), both for carers and HSCP, was most often above 5 min and below 30 min. Only one carer and three HSCP spent less than 5 min on the website. The rest of the participants declared that they spent more than 30 min on the website.

The most read section of the page (Figure 2B) was *Dementia diagnosis*, both for carers (56%) and HSCP (80%). Carers also showed interest in the *Coping with the symptoms* section and *Campaign news* (40% each), and—to a lesser extent—in the *Good life with dementia*, *Accepting the diagnosis*, *Plans and decisions* and *Stories* (24% each). The HSCP expressed approximately equal interest in all the remaining sections.

The majority of carers (68%) found the website very helpful (Figure 2C). 12% claimed the website was extremely helpful; for 16% it was moderately helpful. One carer answered the website was only slightly helpful. Most of HSCP rate the website as extremely helpful (53.3%) or very helpful (36.7%). For 10% of HSCP the website was moderately helpful. None of the participants acknowledged that the website was entirely unhelpful.

The most common source of information about the website (Figure 2D) for carers was family and friends (68%), for HSCP—their colleagues (i.e., other professionals—36.7%, and family and friends—30%). Only 12% of carers learned about the website from HSCP. For carers, the next most frequent sources of information were: social media, posters, Internet, and—to a lesser extent—traditional media

TABLE 1 Surveys and interviews: the demographic information of the participants.

Surveys					
	N	Sex	Age (years)		
People with Dementia	0	$N = 0$	N/A		
Family & Friends	25 (45%)	Female $N = 19$ Male $N = 5$ Non-binary $N = 1$	Mean – 46 (SD = 18)		
HSCP	30 (55%)	Female $N = 22$ Male $N = 8$	Mean – 38 (SD = 16)		
Interviews					
				Living Arrangements	Time since the diagnosis of dementia (years)
People with Dementia	14	Female $N = 8$ Male $N = 6$	Mean – 79	Alone $N = 6$ With family $N = 8$	Mean – 2.5
Carers	9	Female $N = 8$ Male $N = 1$	Mean – 64	Alone $N = 2$ With family $N = 7$	Mean – 7
HSCP	8	Female $N = 7$ Male $N = 1$	Mean – 41	N/A	N/A

HSCP, Health and Social Care Professional; N, number; N/A, not applicable.

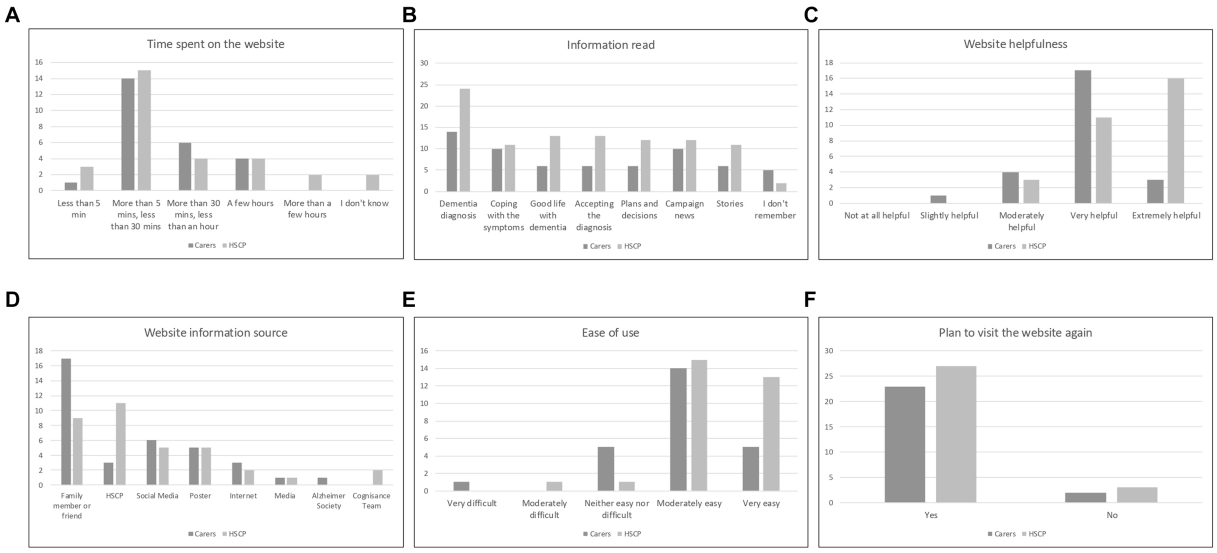

FIGURE 2
Survey data. **(A)** Time spent on the website; **(B)** Information read; **(C)** Website helpfulness; **(D)** Website information source; **(E)** Ease of use; **(F)** Plan to visit the website again.

TABLE 2 The reach of selected campaign activities.

Activity	Reach (at the end of the campaign)
Website visitors	1,282 visitors
Media release (91 internet publications, 8 printed publications, 1 TV coverage)	reach 1,503,000, 00
Distributed printed materials	900 leaflets 100 posters 1,150 gadgets
Social media channels Facebook Instagram	reach 1,622,034, 00 387 likes 61 followers
Webinars (on YouTube channel)	873 views (the most popular webinar on social health watched by 273 people)
Five mobile screening points	300 people examined
Music final concert	350 participants

and Alzheimer's society. For HSCP, other common sources of information were: social media and posters, Internet and Cognisance Team members.

56% of carers claimed that the website is moderately easy to use (Figure 2E) and for further 20% it was even very easy. Also 20% agreed that the website is neither easy nor difficult to use. Only one carer found the website very difficult to use. For majority of HSCP the website was moderately (50%) or very easy (43.3%) to use. The vast majority of the visitors expressed an intention to revisit the website (over 90% for both carers and HSCP; Figure 2F). Less than 10% of all participants indicated that they would not visit the website again.

3.2.2 Reach

The reach of selected activities, those which could be quantified, are presented in Table 2. The values provided apply only to the campaign period. Many participants might have had numerous interactions with campaign messages via various channels. Due to the wide array of events encompassed within the campaign and its promotion through numerous partners, we could not estimate the reach of all promotional activities.

3.3 Qualitative data

The thematic analysis resulted in the identification of: (1) campaign effects and (2) underlying change mechanisms, individually for each of the studied groups. Additionally, factors that were external to the campaign, but influenced its effectiveness were distinguished. Arrangement of these themes is illustrated in Figure 3. The most representative quotes are presented in the text.

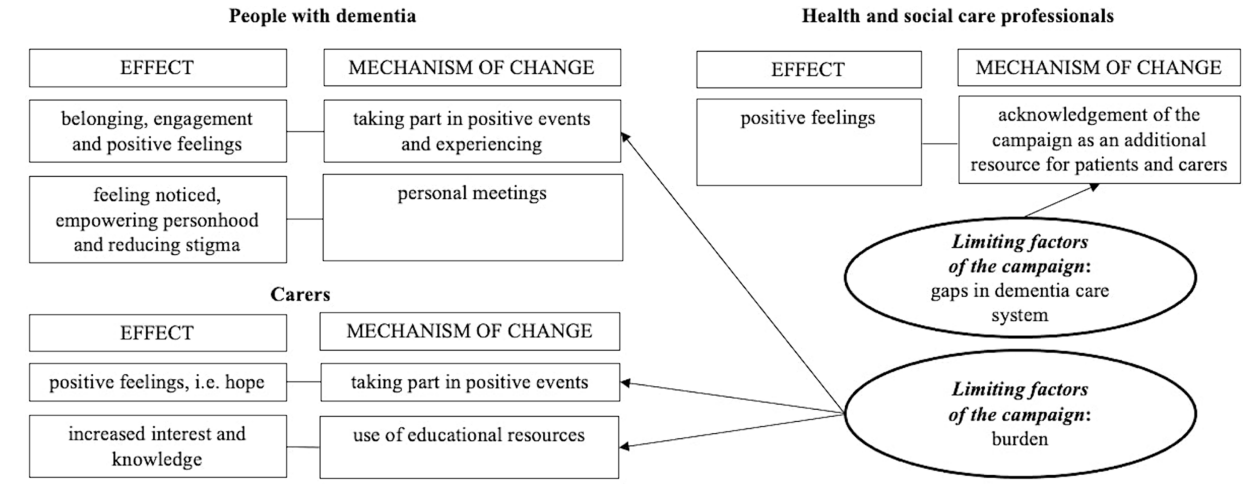

FIGURE 3
Qualitative themes arrangement.

3.3.1 People with dementia

Mechanism of change: taking part in positive events and experiencing.

Effect: belonging, engagement and positive feelings.

The campaign offered many events in which people with dementia took part. These events were often not directly informational, but concerned joint activities, interactions with others or artistic experiences. People with dementia recalled these experiences with enthusiasm and attributed positive emotional meaning to them.

> *"I did not always get the idea but I had a feeling that it* [the campaign] *was something important."* [Female, Person with dementia, 80].
>
> *"I do not remember everything, but it was very interesting. And I was happy to go to such a meeting, because I'm always curious to hear something new."* [Female, Person with dementia, 75].
>
> *"We had a great trip! We saw exposition of the painter living with dementia"* [Person with dementia, Female, 79].

Campaign events enabled people with dementia to become active and meaningful participants in the community. Through joint activities and interactions with other people, especially those sharing similar experiences, they received a sense of social support and belonging to a larger social group.

> *"I have found out that there are many, many of us, yes, who want to hear something, learn something. (…) I thought to myself that it would be good to train the mind a little, train myself and to do this being among other people. To be able to function, to cope."* [Person with dementia, Female, 79].

Mechanism of change: personal meetings.

Effect: feeling noticed, empowering personhood and reducing stigma.

People with dementia emphasized that the campaign's information materials, such as leaflets, posters or the website, had almost no effect on them. Cognitive difficulties and technological barriers prevented people with dementia from using written campaign resources, including the website. However, the most effective communication channel for them was personal meetings with other people who spread the campaign's key messages.

> *"To be honest, I do not read any leaflets. I just listen to the people [at daycare facility], what they say and suggest"* [Person with dementia, Female, 79].
>
> *"It matters what someone says to me. When I read, I forget it right away"* [Person with dementia, Female, 79].
>
> *"Well, you would have to, you would have to have someone else next to you who would bring these brochures and talk to you."* [Person with dementia, Female, 80].
>
> *"I am sorry, I do not use internet. I do not even have it. My granddaughter does."* [Person with dementia, Male, 83].

The campaign made people with dementia feel noticed, supported and understood. Publicizing the topic of dementia gave them the feeling that they were not left out. People with dementia were also pleased that the campaign was being led by younger generation. The personal involvement of the team organizing the campaign in contacts with its recipients inspired trust in the initiative.

> *"I am glad we have you. I feel calmer that you are dealing with this topic"* [Person with dementia, Female, 79].
>
> *"Your project is for people like me. So that other people will start to look at us differently, so that they will not laugh, so that they will understand."* [Person with dementia, Female, 83].

> *"I wasn't always able to get the point, understand it all. This whole initiative. But I always thought it was smart. And you, young people ... those people who sit there* [participants of the day care facility] *need you, consciously or unconsciously. Because I do not know how they perceive it. It's not always possible to do something with our state, but we know we have help."* [Person with dementia, Female, 80].

3.3.2 Carers

Mechanism of change: taking part in positive events. Effect: positive feelings,* i.e., *hope.

Carers took part in campaign events, usually accompanying people with dementia. Carers appreciated the positive emotional influence of these initiatives and were personally connected. The character and tone of the events resonated with their feelings and personal experiences.

> *"We were at an interesting conference where we heard about other events. It gave a lot of hope."* [Carer, female, 55].
>
> *"Definitely, beautiful activities were prepared. We talk to artist* [campaign ambassador – painter with dementia]. *An amazing person! I admire her very much."* [Carer, female, 62].

Carers rejoiced in the positive effect that taking part in the campaign events had on the people with dementia. They also observed the impact of these positive experiences on their own emotional well-being and motivation to act. Carers emphasized that participating in the campaign gave them hope that living with dementia is possible and can still be valuable.

> *"For the next two weeks, my mother was fascinated and often mentioned her experiences from the concert."* [Carer, female, 62].
>
> *"Sometimes I get burned out with care. Then you need a few days of rest. The events of the project motivated me to continue the care."* [Carer, female, 62].
>
> *"When you are a carer, you catch everything regarding the topic* [dementia] *that provide you with any hope for better health and life."* [Carer, female, 55].

Mechanism of change: use of educational resources. Effect: increased interest and knowledge.

The carers expressed a strong interest in the informational materials and content on the website. They declared that they had thoroughly reviewed the information resources. The fact that the campaign was developed by scientists from medical university was valued. Carers wished that the website would be expanded, and the materials would be more widespread and accessible.

> *"The webinar was genuinely interesting. It had an accessible, popular science form. I think it would be of interest even to people who are not struggling with this problem. You can listen to it again on YouTube and you do not need to be there."* [Carer, female, 28].
>
> *"I am interested in new materials on the site. I regularly look there to see if there is something new."* [Carer, female, 62].
>
> *"Those who were not interested might have problems with noticing the campaign. I was hoping that there would be more advertising materials, for example posters."* [Carer, female, 50].
>
> *"Yes, I would recommend the website to others. I believe in competent people. And I consider you and your initiative as such."* [Carer, female, 61].

Carers pointed out the importance of acquiring knowledge about dementia, particularly in managing its symptoms, fostering empathetic understanding of the sick person, and preparing for the future. They observed an increase in their knowledge due to the campaign, perceiving it as a response to the existing gaps in the resources for carers.

> *"Such a project is very necessary, because you hear that more and more people have dementia and the people who care for them have problems of* various kinds. *You have to know how to deal with a sick person and how not to get angry with them… It opened my eyes a lot. There will be more to come, probably, more things that are incomprehensible and tiring and that this disease will simply not retreat, that it will not get better, just the opposite."* [Carer, female, 75].
>
> *"I was very pleased when I heard about the project. A year earlier, I sought help in many places, but there was very little information."* [Carer, female, 62].
>
> *"At first, we got angry or laughed at grandma. We could not cope. I started to understand what dementia is thank to the campaign."* [Carer, female, 28].

Limiting factors of the campaign: carer time and burden.

Carers pointed out also the limitations of the campaign's effectiveness. They referred to the dependence of a person with dementia on their support, their workload and struggling to reconcile time for caring responsibilities and work. As a consequence, the carer's time constraints did not allow them to attend campaign events with the person with dementia. Moreover, caregivers pointed to gaps in the care system and lack of respite care, which the campaign cannot address. The campaign key message about hope for a positive life with dementia was perceived by some as overpromising and, in the face of the shortcomings in the care system, disappointing.

> *"When I was at work, no one could give my mother a lift to an event."* [Carer, female, 62].
>
> *"What would I add to the website content? More information on the forms of institutional assistance. I know how it looks like in Poland. There is little support. Perhaps to website could present incentives to create such places* [support centres for PwD]." [Carer, female, 61].
>
> *"Materials are interesting, and they cared a lot to use words that give hope that you can still live your life. On the other hand, reality hits hard and one could be disappointed."* [Carer, female, 55].

3.3.3 HSCP

Mechanism of change: acknowledgement of the campaign as an additional resource for patients and carers.

Effects: positive feelings.

Professionals found the campaign valuable mainly as an information source for caregivers of their patients. They were pleased that such an initiative existed, enabling them to recommend it to individuals dealing with dementia and their caregivers. However, they perceived limited direct impact on enhancing their skills and practices.

> *"I got acquainted with the website recently. I do not use it to develop my professional skills. But I can offer it as a reliable resource for my patients."* [HSCP, female, 30].
>
> *"Very nice, clearly made. That the people who are struggling with this problem could certainly find something for themselves."* [HSCP, female, 50].
>
> *"I flicked through section for professionals mostly but I strongly recommended news and stories for my patients. I gave them the website's address on the piece of paper so they can search for it."* [HSCP, male, 27].
>
> *"I recommend the website whenever I see the need in my everyday practice. Especially to the carers, because most of patients with dementia are not able to use the internet."* [HSCP, female, 51].

HSCP experienced positive emotions in response to the campaign and website launch. The campaign events were perceived as filled with hope and positivity. Raising the topic of dementia through the *Razem przed siebie* initiative in public sphere was assessed as very needed and valuable.

> *"There has been a break in dementia psychoeducation in the last two years* [pandemic period], *so I enjoyed the campaign all the more."* [HSCP, female, 55].
>
> *"I enjoyed the opening conference as it was interesting fulfilled me with hope."* [HSCP, female, 55].
>
> *"I loved the concert! It would be great to repeat such event and make campaign more visible."* [HSCP, female, 50].

Limiting factors of the campaign: gaps in dementia care system.

HSCP referred to the reality of people with dementia and their caregivers in the Polish care system. They emphasized that the campaign was unable to address the shortcomings in dementia care, i.e., difficulties in obtaining a professional diagnosis, insufficient number of places in care facilities or lack of respite care for carers. Campaign key messages and images may even be overly optimistic, fostering hope that might be broken when confronted with realities.

> *"It all looks so perfect on this website that actually everyone is hugging, and life is good, and in practice, as I observe it, it is very different. Of course, it's not, as I say, it's not like a death sentence right away and something terrible. And in fact, there are a lot of seniors who really enjoy life, despite the diagnosis and the dementia. And they are really great people. However, this is also not so colorful and joyful always. I think that campaigns often show it like that, and, and this ... is not such a black and white image."* [HSCP, female, 24].
>
> *"I did not find a tab with specific addresses of institutions in different regions. Caregivers are not so much willing to read as caring looks like. They need specific information on what they can do, where to go."* [HSCP, female, 30].
>
> *"There is too little institutional help. These outposts are overcrowded. Cafes for seniors could also be created. As a result, caregivers are overburdened."* [HSCP, female, 56].
>
> *"We have a lot of specialists in a large city, but it is important that people in small cities are aware of where they can go."* [HSCP, female, 55].

3.3.4 Mapping campaign effects onto the social health conceptual framework

Post-hoc analysis of the qualitative results allowed for mapping the effects of the *Razem przed siebie* initiative onto the social health framework (Table 3) (21). This analysis reveals its empowerment effects on some of the individual and social environment markers of social health among people with dementia. Taking part in positive events of the campaign and experiencing them reinforced the social participation among individuals with dementia and reaffirmed the idea that they retain their social capabilities, despite

TABLE 3 Mapping *Razem przed siebie* campaign effects onto the social health conceptual framework.

	Level	Domain	Markers examples
The concept of social health	**INDIVIDUAL**	**Capacities**	***Reciprocity***
		Independence	*Autonomy*
		Social participation	***Social Participation, Social Engagement, Social Leisure, Activities, Social Isolation***
	SOCIAL ENVIRONMENT	**Structure**	***Frequency of Contact, Social Network, Living Alone, Martial Status***
		Function	*Inability to help, Exchanging support*
		Appraisal	**Loneliness**

Bold font indicates areas implemented in the *Razem przed siebie* campaign. Adapted from: Vernooij-Dassen et al. (21).

the disease. The presence of ambassadors with first-hand experience of dementia signaled that people with dementia have social rights and can still fulfill social obligations and specific roles (e.g., an artist or wife). Contact with others during the campaign also influenced the social environment of people with dementia by strengthening its structure, reciprocity, and enabling for its more positive appraisal. As a result of the campaign, carers were able to shift their attention toward the more positive facets of their caregiving responsibilities and acquire knowledge that enhanced their ability to support the social health of people with dementia. In turn, HSCP acquired supplementary psychoeducational resources which they can distribute to their patients to offer additional support following diagnosis. However, alterations at the social environment level were restricted and not comprehensive. The campaign did not instigate notable alterations in the structure of the social environment in terms of facilitating access to post-diagnostic care, introducing long-lasting solutions in care system, or providing respite options for carers. In the context of stigma, the campaign addressed only some of its aspects. It did not affect its structural dimension.

4 Discussion

Our research contributes to the limited body of evaluation studies on dementia campaigns by expanding it to a novel cultural setting. To our knowledge, this is the first study evaluating a dementia campaign conducted in Poland. The evaluation outcomes suggest that the campaign and the associated website were very positively received. It effectively impacted several principles of the social health framework. Moreover, the campaign made strides in addressing the stigma associated with dementia, fostering a greater understanding of the social health dimensions essential to improving the well-being of individuals with dementia. Campaign effects, underlying mechanisms of change as well as significant limitations influencing the effectiveness will be discussed.

An integral element of the *Razem przed siebie* initiative was a website that condensed the educational message and disseminated news about the ongoing campaign. The website received very positive feedback across various dimensions from both carers and HSCP, highlighting the widely noticed demand for web-based knowledge resources (29). The majority of visitors commended the user-friendly interface and reported that the content captivated their attention for a considerable duration, prompting them to visit the website again. The most users visited the *Dementia diagnosis* section, potentially influenced by its positioning as the first thematic section. Nevertheless, this trend could also suggest that the key messages of the campaign and website held significant relevance at the onset of the dementia journey. Further, the predominant means of learning about the website was through word-of-mouth recommendations, originating from friends, family, or colleagues. As research indicates (30), this mode of information dissemination is common in healthcare and also in our study turned out to be effective. Therefore, it seems that the lesson for the future is not to rely solely on websites that passively convey health messages to people, but that more active, grassroots campaigns are required with different types of activities that people can engage with and talk about. Disappointingly, very few carers learned about the site from HSCP. However, this pattern should be evaluated over the long term, as during the study period, the promotion of the website among HSCP was still in progress.

Importantly, no person with dementia completed the website evaluation survey. A similar problem was noted by researchers from Australia (8), who struggled to recruit people with dementia to evaluate their campaign, even though, unlike Poland, they have programs supporting patient involvement in research (31). Absence of respondents diagnosed with dementia suggests that despite careful preparations (25), the website may not have been adequately tailored to the needs of people living with dementia (e.g., outlined in the DEEP Guide) (32). Furthermore, it underscores the prevalent challenges faced by older individuals in accessing digital resources, stemming from limited digital literacy and technological proficiency (33). This observation hints at the potential ineffectiveness of Internet sources, particularly conventional ones, targeted toward individuals with dementia.

The conclusions regarding the limited usability of the *Razem przed siebie* website for people with dementia are supported by the findings of our qualitative research. In our study, individuals with dementia indicated a deficiency in Internet usage skills and found written materials from the campaign less useful due to difficulty in assimilating new information. In spite of that, their perception of the campaign was mainly shaped by the emotional experiences they had during the events they attended (such as excitement, joy, pleasure, etc.), as well as the positive appraisal of the contacts with other people (feeling of connection with others). This finding aligns with evidences that emotional cues enhance memory in people with dementia (34), and emphasizes the potential of emotional communication as a foundation for dementia-friendly initiatives (34, 35). Moreover, it indicates that the design of *Razem przed siebie* campaign adhered to recommendations for creating initiatives aimed at mitigating the social exclusion of people with dementia (36, 37), primarily by offering them opportunities for meaningful engagement within a stimulating community environment (36, 38). Interviewees also acknowledged the significance of meetings with campaign ambassadors, which highlights the importance of empowering individuals with firsthand experience of dementia during social campaigns (17, 18, 20). Interestingly, some study participants emphasized the importance of involving young people in the campaign, indicating substantial potential for integration initiatives and multi-generational projects in dementia (36, 39). By mapping the results of our analysis to the social health framework, it can be inferred that the campaign contributed to bolstering the social health of people with dementia, both on an individual and societal level (see Table 3). Thus, contributing to overcoming social stigmatization.

The effectiveness of the campaign among individuals with dementia heavily relied on the capabilities of carers. Commonly, carers were responsible for seeking information about the campaign and accompanying individuals with dementia to the events, offering transportation and necessary support. Carer burden, frequently reported among this group in Poland (15) and globally (40), influenced whether a person with dementia could benefit from the event. This highlights that the campaign did not offer carers a form of respite from caregiving responsibilities, which is often sought in psychosocial interventions in dementia (36). Despite this notable barrier to the campaign's effectiveness,

carers also found *Razem przed siebie* to have a positive impact on their caregiving role. Participating in positively charged events allowed caregivers to witness the enjoyment of their loved ones with dementia, share moments of fun together, and experience positive emotions themselves. This translates into a tangible reinforcement of the positive aspects of caregiving, including sense of competence in providing care, strengthening relationships with a person with dementia, and fostering hope for the future in the journey with dementia. This is particularly important in the light of research results indicating that strengthening the positive aspects of care is necessary to maintain a good quality of life for carers and to protect them from adverse effects of caregiving (41). Unlike people with dementia, carers extensively utilized the educational resources provided by the campaign and benefited from the digital materials (which, especially since the pandemic, have proven to be convenient and time-efficient medium for Polish carers (42)). The need for access to reliable information about the disease highlighted by this study is consistent with the results of other research on the well-being of carers indicating that knowledge of dementia is a basic mean to better undertake the caregiving role and to prevent and manage specific situations (41, 43). Crucially, carers we surveyed highlighted that the information acquired during the campaign broadened their biomedical knowledge about dementia. Most importantly, it also enhanced their understanding of behaviors and approaches to communication with people with dementia. This outcome indicates that the *Razem przed siebie* campaign promoted the principles of person-centered care (44, 45), acknowledged as the highest standard of care for people with dementia (46, 47).

It should be noted, however, that in our study a few carers, along with some of the HSCP raised concerns that while the campaign's key messages may instill hope, they could ultimately prove disappointing when confronted with reality. Consequently, the *Razem przed siebie* campaign may have echoed the trend identified in the literature on the cultural images of dementia (48), wherein there is a tendency to portray life with dementia in an excessively optimistic manner. As indicated by research (49), these overly positive images could result in unintended consequences, such as worsening stigma by not adequately portraying the challenges faced by individuals with dementia, potentially causing those who are not living well to feel like they had failed. Providing positive information about diagnosis (that the campaign encouraged) is insufficient, if there is no benefit through supports and services. Both carers and HSCP highlighted that the campaign materials failed to provide specific information about post-diagnostic care facilities and voiced discontent over the lack of systemic solutions for post-diagnostic support in Poland. Therefore, the campaign failed to address the needs of carers and HSCP in terms of enhancing their perception of availability of post-diagnostic support, a need that is not only important in Poland (15), but also elsewhere (50). Werner et al. reported that the perception of a lack of institutional support (conceptualized as structural stigma) that is associated with an increase in caregiver burden (51). Further, it seems the campaign did not prompt significant changes in the structure of the social environment (interpreted as a dimension of social health) for people living with dementia.

The surveyed HSCP, apart from referring to systemic barriers limiting the impact of the *Razem przed siebie* initiative, expressed their satisfaction that a new, reliable source of knowledge about dementia had been created. Nevertheless, professionals viewed the campaign and the website almost exclusively as resources they could recommend to their patients. Like the web-based initiatives in Australia (8) and Canada (6), the *Razem przed siebie* in Poland had limited effect on altering the professional practices of the surveyed HSCP; this can be understood in different ways. Firstly, the campaign design might have been overly ambitious concerning the intended target groups. With limited resources, a small team, and only local reach, it struggled to develop precisely targeted key messages and tailored promotional strategies. Alternatively, as in the Australian and Canadian cases (6, 8), HSCP may perceive significant systemic shortcomings that make them feel unable to offer proper post-diagnostic support to their patients. They may also lack hope that changes in their approach to dementia could improve the situation for people with dementia and their family carers. This aligns with the common "nothing can be done" mindset seen among HSCP, reflecting therapeutic nihilism, feeling of hopelessness, and a perceived lack of agency in managing dementia in their patients (52–54).

While the research results presented offer multiple perspectives regarding the effectiveness of the *Razem przed siebie* campaign in Poland, its limitations should also be considered. The study's design relied solely on a post-campaign evaluation. Although formative research was conducted prior to the development of the campaign, it cannot be used to directly compare or evaluate behavioral changes resulting from the campaign. Moreover, the study's timeframe did not allow for testing potential long-term outcomes of the campaign and the website use. Additionally, the qualitative approach used in the study has inherent limitations. While it provides in-depth data on the audience's personal experiences, it restricts the representativeness of the findings (55). In turn, in the context of website evaluation, relying solely on a self-report questionnaire may not accurately capture user behavior. Therefore, it is advisable to supplement these data with more comprehensive insights obtained from online tools for analyzing website statistics (56, 57). Another challenge was participation bias (58). The study included individuals who proactively sought dementia information or had received support from dementia-related institutions. They were enthusiastic about and willing to participate in campaign events, as well as interviews or surveys. Moreover, due to the extensive distribution of the campaign across numerous channels, we encountered challenges in estimating the full scope of audiences and surveying a representative sample of them. Since, to our knowledge, this is the first evaluation study of a dementia campaign conducted in Poland, it is not possible to compare the current results with outcomes of other initiatives conducted in similar cultural setting. Our findings provide a reference point for stakeholders and researchers interested in developing and evaluating future dementia-friendly initiatives.

5 Conclusion

In conclusion, the analysis of the results presented enables us to identify areas where the Polish *Razem przed siebie* campaign proved

effective and where it fell short. Firstly, the campaign successfully incorporated specific recommendations for effective anti-stigma campaigns and, moreover, these efforts were noticed and appreciated by target audiences. In terms of social health, on an individual level, involvement in the campaign facilitated the enhancement of social participation among people with dementia and reinforced the notion that they maintain their social capabilities, despite the disease. The campaign can also be viewed as a catalyst for change within the social environment of people with dementia. Thanks to the campaign, carers could focus on more positive aspects of their caregiving role and gain knowledge enabling them to better support the social health of a person with dementia. In turn, HSCP obtained additional psychoeducational resources that they can share with their patients to support them after diagnosis. However, the very positive reception of the campaign by the majority of respondents should not be taken for granted. The inclination toward such favorable evaluations may stem from a dearth of alternative sources and may operate under the principle of *something is better than nothing*. The shortcomings of the campaign must also be acknowledged. The campaign's tone was sometimes perceived as overpromising and not entirely tailored to the realities of the Polish health and social care systems, which may trigger unintended additional frustration and disappointment. Also, the assumptions regarding effectively reaching such diverse target audiences proved to be overly ambitious for a campaign with limited organizational resources. The campaign's key messages had the least influence on HSCP, indicating a need to explore alternative initiatives targeted at this group.

It is evident that the campaign formula was also unable to overcome barriers arising from the existing social welfare system, e.g., alleviating carer burden. The *Razem przed siebie*, albeit local in scope, may attract the attention of local and state authorities to the plight of individuals with dementia and underscore the necessity to establish the long-term systemic solutions that addresses the needs of people with dementia and their carers. Considering the presented findings, it is urgent to develop and implement nationwide, evidence-based social campaigns aimed at impacting the social environment of people living with dementia. Integrating awareness initiatives into dementia health policy should be a permanent fixture. This study may also encourage further research evaluating dementia campaigns, as the insights gleaned from such evaluations facilitate the development of subsequent, more tailored and effective interventions. Equally crucial is the necessity to document unintended consequences of the campaigns, serving as a cautionary note for the creators of future actions.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Bioethics Committee, Wroclaw Medical University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

MB: Conceptualization, Data curation, Investigation, Methodology, Writing – original draft, Writing – review & editing. DS: Conceptualization, Methodology, Supervision, Visualization, Writing – review & editing. MC: Data curation, Investigation, Methodology, Writing – review & editing. JER: Investigation, Visualization, Writing – original draft. L-FL: Supervision, Writing – review & editing. HB: Supervision, Writing – review & editing. JR: Conceptualization, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2024.1418867/full#supplementary-material

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EDITED BY
Wendy Moyle,
Griffith University, Australia

REVIEWED BY
Jan Oyebode,
University of Bradford, United Kingdom
Anthony Scerri,
University of Malta, Malta
Carol Podgorski,
University of Rochester, United States

*CORRESPONDENCE
Damaris Aschwanden
✉ damaris.aschwanden@unige.ch

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The use of audio-biographical cues in dementia care: a four-year evaluation in Swiss hospitals, care, and domestic homes

Heather Edwards[1], Sandra Oppikofer[2] and Damaris Aschwanden[3]*

[1]Hellesdon Hospital, Norfolk and Suffolk NHS Foundation Trust, Norfolk, United Kingdom, [2]Center for Gerontology, University of Zurich, Zürich, Switzerland, [3]Center for the Interdisciplinary Study of Gerontology and Vulnerability, University of Geneva, Geneva, Switzerland

Introduction: In dementia care, the integration of innovative interventions is essential to enhancing the wellbeing and quality of life of people with dementia. Among these interventions, the Music Mirror intervention has emerged as a promising tool to provide personalized audio-biographical cues aimed at soothing, motivating, and engaging people with dementia. This study examined the effects of a Music Mirror intervention on the (a) wellbeing, emotions, and behavioral and psychological symptoms of 155 individuals with dementia, (b) perceived burden, relationship quality, and gains of their informal/formal caregivers, and (c) momentary closeness, wellbeing and stress of caregivers.

Methods: This four-year study employed a quasi-experimental waiting-control group design, utilizing before-after measurements in Swiss hospitals, care homes, and domestic homes. For four 6-week intervention phases, Music Mirrors, i.e., brief written resources of acoustic material, associated with practical activities of daily life, were applied at least twice a week by the caregivers during critical moments such as staff handover. Repeated measures' analysis of variance and other tests were used to analyze the data.

Results: Individuals with dementia had a higher wellbeing after the Music Mirror use across different care situations. While the Music Mirrors were played, individuals with dementia showed more positive than negative emotions at each measurement occasion, but emotion scores did not significantly change over time. After the MM use, caregivers felt better, closer to the person with dementia, and less stressed. Caregivers also reported significant gains at the end of the intervention. However, there were no significant changes in the frequency of the behavioral and psychological symptoms of dementia, care-related burden and relationship quality over time, regardless of the treatment condition.

Discussion: By incorporating personalized audio-biographical cues into their care routines, the wellbeing of people with dementia was improved as well as it had positive momentary effects on their caregivers. The Music Mirror intervention addresses the preferences and needs of people with dementia and helps build bonds between care-recipients and caregivers. Therefore, Music Mirrors can be seen as a highly adaptive and individualized instrument to improve momentary wellbeing of people with dementia in various care situations during daily life.

KEYWORDS

dementia, biography, music, memory, emotion, relationship, person-centered care

1 Introduction

With an estimated 50 million people currently living with dementia worldwide and approximately 10 million more diagnosed each year, dementia care—in particular person-centered care—is an issue of growing importance (World Health Organization, 2021). Dementia commonly causes difficulties in navigating activities of daily life, and increasing frailty may lead to a move to residential living or hospital stays, bringing with it added stress and anxiety of changes of routine and care personnel (Aaltonen et al., 2012). The need to be understood, seen, and treated as an individual affects not just the person living with memory loss but has an impact on the quality of relationships with those involved in care and support (Nowell et al., 2013; Røsvik and Rokstad, 2020). The burden of caring may lead to exhaustion or burnout for both formal and informal carers (Costello et al., 2019). It thus is important to have strategies and/or tools that support both care-recipients and caregivers in different care environments during times of transition and uncertainty (e.g., during the move from one's own home to a care home). For example, there is an acknowledged need for information supporting personal identity to follow people through the transitions of their care as part of health and social service records (Fortinsky and Downs, 2014; Hampson and Morris, 2016). In the United Kingdom, documents of individual wishes and preferences such as *Advance Care Plans* and *This is Me* leaflets are widely used to address this issue (Petty et al., 2020). However, in countries where no such aid is available, the need remains to support the identity of people with dementia. Familiar words, sounds, or music can be powerful reminders of past experiences, both positive and negative (Jäncke, 2008). Memories and feelings associated with sound are in general retained longer than those without, even in dementia (Schaefer, 2017). If they have positive associations, they may be of practical help in supporting identity, sustaining relationships in care environments, and providing reassurance at times of transition and uncertainty (Baird and Thompson, 2018; Särkämö and Sihvonen, 2018). In terms of dementia care, the social positioning of the person with dementia is important: some researchers highlight that if the person with dementia is positively positioned and supported, the self can be maintained (Hampson and Morris, 2016). If negatively positioned, the self of the person is deconstructed to the point of being lost. Music Mirrors (MMs); i.e., brief written resources of acoustic material, associated with practical activities of daily life, are an established extension of care plans in the United Kingdom (Craig, 2020; Edwards, 2018, 2020).

MMs are positive life story memories involving sounds or music, written down briefly in someone's own words and linked to acoustic cues to reinforce their emotional significance (Edwards, 2018). MMs are based on the concept of music-evoked autobiographical memories—i.e., personal memories that are triggered by hearing music (Janata et al., 2007)—and the established evidence that music effectively evokes autobiographical memories and associated emotions in people with dementia (Baird and Samson, 2015). While music interventions have been widely adopted as a potential non-pharmacological therapy for people with dementia (Koger et al., 1999), MMs expand on such interventions due to the addition of individually important memories. Through these memories, the activated brain network is extended and may even lead to more emotional stimulation than music alone. In contrast to playlists with favorite songs, MMs are written and acoustic resources (i.e., a collection of autobiographical sequences) that also aim to facilitate the building of relationships between caregivers and care-recipients. Specifically, as resources of uniquely personal memories (e.g., the sound of rain on a caravan roof, a melody one's father whistled out of tune the bark of one's favorite dog), MMs can be used to ease the stresses of daily life, give comfort and orientation, reflect identity, and add quality to care relationships. Audio-biographical cues are collected via conversations with the person concerned and written as emails or stored as part of a care plan, with links embedded via YouTube to recorded sound. The completed MMs can be accessed on a smartphone, tablet or as information on paper without any special or personalized equipment. As such, MMs can be relatively easily integrated into daily routines of caregiving and are a low-cost intervention and can be provided when needed, not when planned (Hämäläinen et al., 2023). However, up to date, research on the MM intervention is scarce. To our best knowledge, this is the first study aiming to investigate the effects of MMs on different variables in people with dementia and their caregivers. The Center for Gerontology at the University of Zurich conducted a four-year randomized control study of the implementation of MMs in the cantons of Aargau and Basel in Switzerland. The goal of the study was to examine the effects of MMs on people with dementia and their caregivers. Specifically, we examined the effects of MMs on (a) the wellbeing, emotions, and behavioral and psychological symptoms of dementia (BPSD) of participants with dementia, (b) the perceived burden, relationship quality and gains of their caregivers, and (c) the perceived closeness between the care-recipients and informal and formal caregivers (rated by the latter) as well as the momentary wellbeing and stress of caregivers.

2 Materials and methods

The study was approved by the Swiss Ethics Committee on Research Involving Humans. The study was conducted according to the Swiss legal requirements, the World Medical Association Declaration of Helsinki, and the principles of Good Clinical Practice. The study was designed to gather information in real time in participants' natural environments in residential dementia care, acute hospitals, and family homes. This quasi-experimental waiting-control group study was structured in four six-week intervention phases from 2016 to 2020.

2.1 Procedure

The study included a baseline assessment (during 2 weeks before the start of the MM intervention), a mid-evaluation assessment (during week three and four of the MM intervention) and a post-test assessment (during the 2 weeks after the MM intervention). The MM intervention lasted 6 weeks. Over the study period, four intervention phases were conducted to respect the difficulties of participant acquisition when working with people

with dementia (Sung et al., 2006). Participants were divided into a waiting-control and an intervention group for each phase according to their registration. Participants of the control group were automatically assigned to the intervention group in the next phase, so that all participants ultimately received the MMs. During the intervention phases, a MM was used by the caregivers of the intervention group at critical moments—such as staff handover, when night personnel needed to make a bond with the person with dementia, or when a patient was anxious about a change of dressing—or at minimum twice a week for at least 10 min. During the intervention phase, the control group received normal care with no MM. Measures that were assessed at baseline, mid-evaluation and post-test were completed in both the intervention and control groups (with a few exceptions, see Section 2.3).

2.2 Participants

For the project, three different groups of individuals were recruited, that is, (a) individuals with dementia, (b) caregivers that applied the MMs, and (c) volunteers that made the MMs.

2.2.1 Individuals with dementia

People with dementia were recruited from eight research partners: care and residential homes, a specialist hospital, and an umbrella dementia organization (see Table 1). A diagnosis by a clinician was required, but etiology, duration and severity of disease were not considered as a criterion of exclusion. Potential participants were included if a screening conducted via the Mini Mental Status Examination (0–30 points) revealed 24 points or less, which is a generally accepted cutoff score indicating the presence of cognitive impairment (Folstein et al., 1975; Mitchell, 2009), with scores >19 = mild, 10–18 = moderate, <9 = severe. Exclusion criteria were schizophrenic symptoms or the need for a hearing aid. Participants were assigned to the intervention group and control group at random, but those in the control group also received the intervention eventually. Altogether, 199 individuals with dementia were recruited. Thereof, 54 individuals dropped out before or during their participation in the intervention because of moving to a different care setting, development of insuperable hearing problems or death. Participants recruited were living in nursing homes or at home alone or with their partner. The sociodemographic survey of the baseline assessment was completed for $N = 155$ individuals with dementia. However, numbers completing each measure varied across measures and measurement occasions; we report the sample sizes in brackets in the results section. The mean age of the participants was 82.54 years (SD = 9.97, Range = 55–104), and 38.5% had an Alzheimer's disease (AD) diagnosis. The sample characteristics of the persons with dementia are shown in Table 2.

2.2.2 Informal and formal caregivers

Ninety-nine caregivers were recruited (87.90% female, 24.20% college degree or higher). Caregivers were family members or friends (if people with dementia lived at home) and professional care staff (if people with dementia lived in nursing homes or were in the hospital). Inclusion criteria were being able to use the MM at least twice per week with at least one person with dementia and to fill in questionnaires. No sociodemographic information was collected on caregivers.

2.2.3 Volunteers

Twenty-three volunteers were recruited. Inclusion criteria were: They should be interested in music, in people with dementia and be motivated to have a conversation with them. Furthermore, they should be empathic, open minded, engaged, patient, flexible to visit the people in the canton of Aargau or Basel, understand Swiss German, and have knowledge in word processing. Finally, they should also have internet access and an e-mail address. No sociodemographic information was collected on volunteers.

2.2.3.1 Making of music mirrors

Volunteers attended two workshops (one on MMs and one on how to communicate with people with dementia). Then, they conducted interviews with the individuals with dementia and if necessary, with their relatives or carers, to collect biographical information. The interviews lasted a maximum of 60 min. Volunteers were instructed to take notes during the interview and importantly, to write down the exact words or quotations when important positive memories were mentioned. Based on this information, the volunteers created the MMs for the people with dementia together with the research team. The MMs consisted of four to five quotations about positive memories and their corresponding acoustic cues (e.g., spending lots of time outdoors in nature during childhood and the sound of a stream). Examples and vignettes of MMs are shown in Supplementary material. The acoustic cues serve as a connection point for memories and emotions, were downloaded from iTunes, and stored on the iPads. Volunteers revisited the people with dementia and played the MMs to confirm the content. If necessary, the MMs were adjusted. The iPads with the final MMs were handed over to the caregivers to use during the 6 weeks of intervention.

2.2.3.2 Application of music mirrors

For the intervention phase, caregivers received a laminated manual with instructions on how to use the MMs. Caregivers were instructed to use the MMs at critical moments—such as staff handover, when night personnel needed to make a bond with the person with dementia, or when a patient was anxious about a change of dressing—or at minimum twice a week for at least 10 min if no critical moments occurred. Caregivers were provided with the study iPads that contained the MMs as well as an instruction video and further videos with different examples of how the MMs can be used. As one MM contains four to five memories, caregivers could choose any memory depending on the situation. For example, sometimes the memory fits the situation very well, such as when a person with dementia has a memory of hiking with their father combined with a hiking song, then the MM could be used to motivate the person for a walk. The goal of using the MM was to evoke positive emotions, distract from stress and deepen the relationship with the caregiver.

TABLE 1 Recruitment.

Care setting	Ambulant care		Long-term care		Acute hospital	
	CG	IG	CG	IG	CG	IG
Intervention Phase 1 ($n = 20$)	4	6	5	5	0	0
Intervention Phase 2 ($n = 45$)	10	10	9	10	0	6
Intervention Phase 3 ($n = 50$)	0	5	23	22	0	0
Intervention Phase 4 ($n = 84$)	0	3	0	80	0	1
Sum (N =199)	14	24	37	117	0	7

CG, Control Group; IG, Intervention Group. A total of $N = 199$ individuals with dementia were recruited for the study. Thereof, $n = 54$ dropped out before or during the intervention phases 1–4. For a total of $N = 155$ individuals with dementia, the sociodemographic part of the baseline assessment was completed.

TABLE 2 Descriptive statistics of people with dementia at baseline.

Variables	People with dementia
Age (M, SD, range)	82.54 (9.97), 55–104
Female	70.30%
College degree or higher	17.50%
German (mother tongue)*	76.70%
Alzheimer's disease	38.50%
Vascular dementia	9.70%
Mixed dementia	19.40%
Other diagnosis	7.10%
Type of dementia unknown	25.20%
Antidepressants	34.80%
Neuroleptics	32.90%
Pain killers	24.50%

N = 155. *Of the participants with dementia, 1.9% had French, 0.6% had Italian, and 0.6% had English as their mother tongue. Further, 7.3% reported "other" as their mother tongue and 12.9% did not report their mother tongue at all.

2.3 Measures

The outcome measures are summarized in Table 3 and briefly described below. At baseline, caregivers filled out a sociodemographic survey for people with dementia to obtain information on age, gender, mother tongue, education, musicality. living status, care setting, and medication. In general, measures that were assessed at baseline, mid-evaluation and post-test were completed in both the intervention and control groups (except the measurement of emotions and MM-related gains, see corresponding sections below). Measures that were assessed before and after each use of the MMs were completed in the intervention group only. Internal consistency (Cronbach alpha) is reported for measures that were assessed at baseline. Table 4 provides an overview of the descriptive statistics of the outcome measures at baseline and post-test depending on group membership.

2.3.1 Behavioral and psychological symptoms of dementia (BPSD)

At baseline, mid-evaluation and post-test, caregivers in both the intervention and control groups were asked whether there are any phases during which the person with dementia refuses to cooperate or to be taken care of. If so, caregivers subsequently rated five symptoms (i.e., restless, apathetic, irritated, depressed mood, aggressive) from the neuropsychiatric inventory (NPI) (Reuther et al., 2016). Caregivers rated if the symptom was present (yes/no) and if yes, how frequent it occurred (on a scale from 1 = seldom to 4 = very often), how severe it was (on a scale from 1 = mild to 3 = severe) and how stressful it was for the caregiver (on a scale from 0 = not at all to 5 = extreme). Cronbach's alphas ranged from 0.60 (severity) to 0.71 (stress) at baseline, indicating acceptable internal consistency.

2.3.2 Emotions

At baseline, mid-evaluation and post-test, student assistants and researchers applied the Observed Emotion Rating Scale (OERS; Lawton et al., 1999) while caregivers played the MMs for the people with dementia in the intervention group. The OERS was used to observe five emotions in people with dementia, three negative (anger, anxiety, sadness) and two positive (pleasure, interest), which are derived from Ekman's universal basic emotions theory (Ekman and Friesen, 1971). The appearance of these emotions was rated for approximately five minutes on a five-point Likert scale, ranging from "never" to "more than three minutes". To calculate a sum score, the points of positive and negative emotions were added separately, then weighted, and finally, the negative emotion score was deducted from the positive emotion score. A positive sum score indicates that the person with dementia exhibits more positive emotions relative to negative emotions. Cronbach's alpha was 0.73 at baseline, indicating acceptable internal consistency.

2.3.3 Wellbeing

Before and after each use of the MMs, the well-being of people with dementia in the intervention group was assessed using an alteration of the Dementia Mood Picture Test (Tappen and Barry, 1995) by the person with dementia him-or herself or the caregiver. People with dementia were shown six different pictures in six simple line drawings of a face (see Supplementary Figure 1) by the caregivers. The faces depicted expressions on a six-point Likert scale, ranging from happy (1) to sad (6). Lower scores reflect higher well-being. People with dementia were asked to point on the face that currently reflects their mood best. The caregiver noted the answer accordingly. If people with dementia could not rate

TABLE 3 Outcome measures.

Outcome	Measurement	Reference	Rated by	Rated when
BPSD	Neuropsychiatric inventory (NPI)	Reuther et al., 2016	Caregivers (IG, CG)	Baseline, mid-evaluation, post-test
Emotions	Observed emotion rating scale (OERS)	Lawton et al., 1999	Student assistants, researchers (IG)	Five-minute observations while applying the music mirrors at baseline, mid-evaluation, post-test
Wellbeing	Diary	Visual Scale, Supplementary Figure 1	People with dementia or caregivers (IG)	Before and after each use of music mirrors
Caregiver-related burden and gains	Caregiver distress scale (CDS)	Cousins et al., 2002	Caregivers (IG, CG)	Baseline, mid-evaluation, post-test
	Gain in Alzheimer care instrument (GAIN)	Yap et al., 2010	Caregivers (IG)	Post-test
Acute stress	Diary	Single item	Caregivers (IG)	Before and after each use of music mirrors
Closeness	Diary	Single item	Caregivers (IG)	Before and after each use of music mirrors
Relationship quality	Six self-generated items	Authors	Caregivers (IG, CG)	Baseline, mid-evaluation, post-test

BPSD, Behavioral and psychological symptoms of dementia. IG, intervention group, CG, control group. IG and CG refers to in which group the measure was conducted.

TABLE 4 Descriptive statistics of measures.

Variables	Baseline IG	Baseline CG	Mid-evaluation IG	Mid-evaluation CG	Post-test IG	Post-test CG	Range
Aggression (BPSD, measured with the NPI)	1.59 (1.55)	2.10 (2.15)	1.48 (1.40)	1.52 (1.66)	1.39 (1.42)	1.71 (1.56)	1–4
Depressive mood (BPSD, measured with the NPI)	1.54 (1.59)	1.76 (1.75)	1.25 (1.33)	1.44 (1.69)	1.08 (1.26)	1.82 (1.56)	1–4
Apathy (BPSD, measured with the NPI)	1.48 (1.62)	1.45 (1.68)	1.20 (1.45)	1.20 (1.58)	1.30 (1.53)	1.32 (1.52)	1–4
Irritability (BPSD, measured with the NPI)	1.68 (1.57)	2.09 (1.49)	1.40 (1.54)	1.64 (1.66)	1.37 (1.69)	1.86 (1.56)	1–4
Aberrant motor behavior (BPSD, measured with the NPI)	1.35 (1.66)	2.21 (1.80)	1.39 (1.74)	1.68 (1.84)	1.17 (1.59)	1.93 (1.74)	1–4
Emotions (measured with the OERS)	11.86 (10.49)	NA	8.09 (6.70)	NA	7.83 (6.66)	NA	−24–24
Caregiver burden (measured with the CDS)	1.15 (0.88)	1.74 (0.87)	1.24 (0.78)	1.92 (0.85)	1.04 (0.86)	1.74 (0.89)	0–4
MM-related gains (measured with the adapted GAIN)	NA	NA	NA	NA	2.57	NA	0 to 4
Relationship quality (measured with self-generated items)	8.16 (1.42)	7.84 (1.55)	7.85 (1.72)	7.26 (2.23)	8.08 (1.37)	8.32 (1.38)	1–10
Diary	**Before MM**	**After MM**	**Range**				
Wellbeing of people with dementia (visual scale)	3.00 (0.72)	2.15 (0.55)	1 to 6				
Wellbeing of caregivers (visual scale)	1.77 (0.77)	1.46 (0.58)	1 to 6				
Closeness (one item)	2.41 (0.89)	2.88 (0.87)	1 to 5				
Stress (one item)	1.30 (0.66)	1.09 (0.48)	1 to 6				

The numbers reported in the table refer to the mean with standard deviations in brackets. BPSD, behavioral and psychological symptoms of dementia (frequency); NPI, neuropsychiatric inventory; OERS, observed emotion rating scale; CDS, caregiver distress scale; MM, music mirrors; GAIN, gain in Alzheimer care inventory; IG, intervention group; CG, control group; NA, not applicable as the variable was not assessed; MM, Music Mirror. Note that for wellbeing, lower scores reflect better wellbeing.

the pictures themselves due to severe cognitive impairment, the caregivers rated the current well-being of people with dementia.

2.3.4 Caregiver burden and gains

At baseline, mid-evaluation and post-test, the Caregiver Distress Scale (CDS; Cousins et al., 2002) was used to assess potential caregiver burden in both the intervention and control groups. The scale contains 17 items that were rated on a five-point Likert scale ranging from 0 (strongly disagree) to 4 (strongly agree). Cronbach's alpha was 0.94 at baseline, indicating high internal consistency.

Likewise, an adapted version of the Gain in Alzheimer Care Inventory (GAIN; Yap et al., 2010) was used to measure MM-related gains at post-test in the intervention group only. The GAIN was adapted such that the items referred to the MM intervention. Specifically, each item started with "The use of the music mirror in people with dementia…" and was continued by the original GAIN items (e.g., "… increased my patience and made me to a more understanding person"). Caregivers reported on all 10 adjusted GAIN items on a five-point Likert scale ranging from 0 (strongly disagree) to 4 (strongly agree). Cronbach's alpha was 0.94 at baseline, indicating high internal consistency.

2.3.5 Relationship quality

At baseline, mid-evaluation and post-test, caregivers reported on their relationship satisfaction with the person with dementia in both the intervention and control groups. The six items were designed by the researchers (e.g., "I am satisfied with the contact to the care-recipient") and answered on a scale from 1 (total agreement) to 10 (total rejection). The items are listed in Supplemental material. Cronbach's alpha was 0.89 at baseline, indicating high internal consistency.

2.3.6 Diary

During the intervention phase, a diary consisting of a short questionnaire was filled out by the caregivers each time after they had used the MM. Over the four intervention phases, 1,406 diary entries were collected. The goal of the diary was to collect information on various variables in real time in the participants' natural environment (Mehl et al., 2014). In the diary, caregivers reported first on the state (i.e., depressive, apathetic, aggressive, irritated, restless) in which the person with dementia was immediately before the MM application. Second, caregivers reported in which situation the MM was applied (i.e., medication, meals, doctor's appointment, transfer, nursing care, change of caregivers, evening rest, and something else). Third, caregivers rated (or helped to rate) the wellbeing of the person with dementia and for themselves before and after the MM application on the visual analog scale described above Tappen and Barry (1995). Fourth, caregivers rated their stress levels (one item) before and after the MM application on a scale from 1 ("not stressed at all") to 6 ("very highly stressed"). Fifth, caregivers reported which emotions (i.e., anger, fear, sadness, joy, alertness) were evoked how strongly (1 = not at all, 5 = very strongly) through the MM application in the person with dementia. Finally, caregivers rated their perceived closeness (one item) with the person with dementia before and after the MM application on a scale from 1 ("not close at all") to 5 ("very close"). In addition, caregivers had the opportunity to write down any comments (e.g., reason for early demolition, observations made during the application).

2.4 Statistical analyses

2.4.1 Power analysis

A power analysis using G*Power (Faul et al., 2007) was conducted to determine the sample size. The effect sizes used for the power analysis are based on a meta-analysis of music therapy for dementia with dependent variables such as agitation/relaxation, cooperation, positive/negative affect, social interaction and cognitive/dementia-related measures (Koger et al., 1999). The mean effect size of Koger et al.'s meta-analysis was $d = 0.788$, corresponding to a f-value of 0.349. Depending on the statistical analysis (e.g., generalized linear model, one-sample t-test), the sample should comprise at least 15 (one-sample t-test) to 31 (generalized linear model) individuals. The power analysis indicated that a total sample size of 31 participants would be necessary to detect a moderate-to-large effect size with 80% power at the 5% significance level.

2.4.2 Tests used for analyses

Normal distribution was tested, and parametric methods of analysis were used if applicable. For ordinally scaled items, scale and subscale median scores were used in place of missing item values. A repeated-measures' t-test was used to examine whether there is a significant difference in the momentary wellbeing (diary data) of individuals with dementia before and after the use of MMs. Using a generalized linear model, we explored whether the effect of the MM intervention on momentary wellbeing varied depending on seven care situations (medication, meal, doctor's visit, nursing care action, change of caregivers, evening rest, another situation). One-sample t-tests were used to examine whether people with dementia showed more positive relative to negative emotions while listening to the MMs at baseline, mid-evaluation, and post-test. Using the t-tests, we tested whether the mean differences in the emotion scores (OERS) at different time points (baseline, mid-evaluation, post-test) were significantly different from zero. If the mean differences differ positively (vs. negatively) from zero, people with dementia show more positive (vs. negative) emotions while listening to the MMs. In addition, we used a one-way repeated measures' analysis of variance (ANOVA) to test whether the emotion scores significantly changed over time in the intervention group. A two-way repeated measures ANOVA was used to examine the effects of treatment (intervention, control) and time (baseline, mid-evaluation, post-test) on each of the BPSD (NPI). For the data of caregivers, repeated-measures' t-tests were used to examine whether there were significant differences in the momentary wellbeing, closeness and stress (all diary data) of caregivers before and after the use of MMs. Two-way repeated measures ANOVAs were run to examine the effects of treatment

(intervention, control) and time (baseline, mid-evaluation, post-test) on care-related burden and relationship quality. One-sample *t*-tests were used to examine whether caregivers in the intervention group reported any gains (GAIN) from the use of MMs at post-test. All analyses controlled for education. We did not control for etiology of observed cognitive impairment nor gender as there is no evidence suggesting a meaningful influence on results. Unstandardized coefficients and *p*-values are reported.

3 Results

3.1 Effects of the MM intervention on people with dementia

The repeated-measures *t*-test showed a significant positive effect of the MM application on the momentary wellbeing (measured using the visual scale in the diary) of people with dementia. After the MM use, people with dementia ($n = 125$) reported a 0.9-point better wellbeing (measured on the 6-point visual scale in the diary) than before the MM use ($t = 7.69$, $p < 0.001$; before: $M = 3.00$, $SD = 0.72$ vs. after: $M = 2.15$, $SD = 0.55$; lower scores reflect better wellbeing). The effect size was $d = 0.65$, referring to a moderate effect (Cohen, 1992). Our exploration analysis (using a generalized linear model) showed that the effect of the MM intervention remained significant across different care situations (medication, meal, doctor's visit, nursing care action, change of caregiver, evening rest, another situation; $n = 125$, B = 1.07, SE = 0.6, t = 19.39, $p < 0.001$). This means, the wellbeing of people with dementia was higher after (vs. before) the MM use irrespective of different care situations.

Moreover, the mean differences in the emotion scores (measured using the OERS) were significantly different from zero at baseline ($n = 31$, $t = 3.99$, mean difference: 0.72, $p < 0.001$), mid-evaluation ($n = 29$, $t = 4.56$, mean difference: 0.53, $p < 0.001$), and post-test ($n = 28$, $t = 5.10$, mean difference: 0.59, $p < 0.001$). This means, student assistants and researchers observed more positive (vs. negative) emotions in the individuals with dementia while the caregivers played their MMs for them. The analysis was repeated with a subgroup of people with severe cognitive impairment (MMSE<5; $n = 20$ at baseline, $n = 19$ at mid-evaluation, $n = 18$ at post-test), and results remained the same (all $p < 0.004$). This means, the MM contributed to positive emotions regardless of the severity of cognitive impairment. However, the emotion scores did not significantly change over the three measurement occasions (one-way repeated measures ANOVA: $n = 28$, $F_{(1.37,27.45)} = 0.031$, $p = 0.922$, $\eta^2 = 0.002$). Likewise, there were no significant changes in the frequency of any of the five BPSD (measured using the NPI) over time, regardless of the treatment condition. Additionally, there was no interaction effect, indicating that the MM intervention did not differentially affect changes in the BPSD over time. Specifically, for aggression, the two-way repeated measures ANOVA revealed no significant main effects of neither treatment [$F_{(1,12)} = 1.240$, $p = 0.287$, $\eta^2 = 0.094$] nor time [$F_{(2,24)} = 1.044$, $p = 0.368$, $\eta^2 = 0.080$], and no significant time x treatment interaction [$F_{(2,24)} = 0.915$, $p = 0.414$, $\eta^2 = 0.071$]. For depressive mood, the two-way repeated measures ANOVA showed no significant main effects of neither treatment [$F_{(1,6)} = 0.140$, $p = 0.721$, $\eta^2 = 0.023$] nor time [$F_{(2,12)} = 0.329$, $p = 0.726$, $\eta^2 = 0.052$], and no significant time x treatment interaction [$F_{(2,12)} = 2.183$, $p = 0.155$, $\eta^2 = 0.267$]. For apathy, the two-way repeated measures ANOVA showed no significant main effects of neither treatment [$F_{(1,7)} = 0.488$, $p = 0.507$, $\eta^2 = 0.065$] nor time [$F_{(2,14)} = 0.116$, $p = 0.891$, $\eta^2 = 0.016$], and no significant time x treatment interaction [$F_{(2,14)} = 0.685$, $p = 0.520$, $\eta^2 = 0.089$]. For irritability, the two-way repeated measures ANOVA revealed no significant main effects of neither treatment [$F_{(1,7)} = 0.733$, $p = 0.420$, $\eta^2 = 0.095$] nor time [$F_{(2,14)} = 0.167$, $p = 0.848$, $\eta^2 = 0.023$], and no significant time x treatment interaction [$F_{(2,14)} = 0.607$, $p = 0.559$, $\eta^2 = 0.080$]. Finally, for aberrant motor behavior (such as restlessness, repeatedly opening drawers, and pulling at clothing), the two-way repeated measures ANOVA showed no significant main effects of neither treatment [$F_{(1,7)} = 0.799$, $p = 0.401$, $\eta^2 = 0.102$] nor time [$F_{(2,14)} = 0.773$, $p = 0.480$, $\eta^2 = 0.099$], and no significant time x treatment interaction [$F_{(2,14)} = 0.407$, $p = 0.673$, $\eta^2 = 0.055$].

3.2 Effects of the MM intervention on caregivers

There were no significant changes in care-related burden (assessed using the CDS) and relationship quality (assessed using the six self-generated items) over time, regardless of the treatment condition. There were neither any interaction effects, indicating that the MM intervention did not differentially affect changes in care-related burden and relationship quality over time. For care-related burden, the two-way repeated measures ANOVA revealed no significant main effects of neither treatment [$F_{(1,102)} = 1.562$, $p = 0.214$, $\eta^2 = 0.015$] nor time [$F_{(2,204)} = 0.695$, $p = 0.500$, $\eta^2 = 0.007$], and no significant time x treatment interaction [$F_{(2,204)} = 2.133$, $p = 0.121$, $\eta^2 = 0.020$]. For relationship quality, the two-way repeated measures ANOVA showed no significant main effects of neither treatment [$F_{(1,102)} = 3.044$, $p = 0.084$, $\eta^2 = 0.029$] nor time [$F_{(2,204)} = 0.045$, $p = 0.888$, $\eta^2 = 0.000$], and no significant time x treatment interaction [$F_{(2,204)} = 1.205$, $p = 0.288$, $\eta^2 = 0.012$]. Of note, the relationship quality was already relatively high at baseline in both groups (see Table 4). Nevertheless, caregivers reported MM-related gains at post-test (assessed using the adapted GAIN; $n = 67$, t = 19.96, mean difference: 2.29, $p < 0.001$). Moreover, the use of MMs had positive momentary effects on the caregivers: caregivers ($N = 99$) felt closer to the person with dementia (almost +0.5-point on a 5-point-scale, assessed using one item in the diary) after the MM use ($t = -4.26$, $p < 0.001$; before: $M = 2.41$, $SD = 0.89$ vs. after: $M = 2.88$, $SD = 0.87$). The effect size was moderate ($d = 0.49$). Caregivers also reported a 0.3-point better wellbeing (measured on the 6-point visual scale in the diary) after the MM use ($t = 6.58$, $p < 0.001$; before: $M = 1.77$, $SD = 0.77$ vs. after: $M = 1.46$, $SD = 0.58$; lower scores reflect better wellbeing). The effect size was $d = 0.46$, referring to a moderate effect. Likewise, caregiver felt less stressed (-0.2-point on a 6-point-scale, assessed using one item in the diary) after the MM use ($t = 6.41$, $p < 0.001$; before: $M = 1.30$, $SD = 0.66$ vs. after: $M = 1.09$, $SD = 0.48$). The effect size was small to moderate ($d = 0.33$).

Finally, researchers reached out to caregivers after the study again for a short follow-up survey. Of 29% of caregivers who

participated, 62% have used the MM at least once a month after study completion. Although 64% said that they lacked the technical resources to use the MM fully, only 6% of those questioned would not recommend MMs to others. In two cases, MMs had aroused negative emotions in the individuals with dementia, or the person with dementia had lost interest.

4 Discussion

The goal of the study was to examine the effects of MM on the (a) wellbeing, emotions, and behavioral and psychological symptoms of dementia (BPSD) of participants with dementia, (b) perceived burden, relationship quality and gains of their caregivers, and (c) momentary closeness, wellbeing and stress of caregivers. The findings showed that, on average, people with dementia had a better wellbeing after the MM use, across different care situations. Individuals with dementia also showed more positive than negative emotions while the MMs were played at each measurement occasion. However, the emotions did not significantly change over the intervention period. Although the MMs evoked more positive than negative emotions at each measurement occasion, these effects seemed to be rather short-term (i.e., in the moment) as they did not lead to any longer-term change such as significantly more positive emotions at the end vs. at the beginning of the intervention. Likewise, there were no significant changes in the frequency of any of the five BPSD over time, regardless of the treatment condition. Additionally, there was no interaction effect, indicating that the MM intervention did not differentially affect changes in the BPSD over time. However, the use of MMs had positive momentary effects on the caregivers, such that they felt (a) better, (b) closer to the person with dementia, and (c) less stressed after the MM use. Caregivers also reported significant MM-related gains at post-test, but there were no significant changes in care-related burden and relationship quality over time, regardless of the treatment condition. As such, the effects of the MM seem to be rather short-term (i.e., in the moment) than long-term on both people with dementia and their caregivers, but with moderate effect sizes. The use of MMs can be seen as a highly adaptive and individualized way to improve momentary wellbeing in people with dementia, when different behavioral and psychological symptoms of dementia occur and in various situations of daily life.

The findings of the present study are in line with other research, showing that music can evoke biographical memory and associated emotions in people with dementia (Baird and Thompson, 2018; Ridder et al., 2023). Moreover, it has been found that brain regions which are active when musical memory is encoded correspond to areas with minimal cortical degeneration and minimal disruption of glucose-metabolism in AD patients (Jacobsen et al., 2015). Another group of researchers showed that musical evoked audio-biographic memories were not only significantly more specific than memories retrieved in silence, but also retrieved significantly faster in people with AD (El Haj et al., 2012). The present work adds to the existing literature that audio-biographical cues (i.e., MMs) in various contexts of care led to positive outcomes in both people with dementia and their caregivers. MMs offered ways to ease and defuse difficult moments of care and further granted insights into behaviors and motivations. This encouraged enhanced social interactions and better understanding between people with dementia and their caregivers. Caregivers themselves experienced temporary benefits in increased wellbeing and reduced sense of acute stress. This suggests that the use of MMs strengthens the momentary connection of the person with dementia and their caregiver. However, the MM intervention did not reduce the care-related burden of caregivers. This may be because caring situations can be inherently challenging and difficult. Nevertheless, MMs seem to promote resilience, such that caregivers reported MM-related gains, suggesting that the MM intervention has the potential to support personal growth of caregivers. Caregivers may benefit in terms of personal development, which may help them to deal with acute stress situations. Of note, the majority of participants intended to use MMs beyond the duration of the study. The MMs concept of personal resources of audio-biographical cues was found to be a valuable practical tool in enhancing the quality of relationships in dementia care, and relevant and transferable to Swiss care contexts.

Limitations of the study are the difficulty of recruiting people living at home as well as in hospitals (cf. Table 1). There are several reasons why recruitment and the implementation of MMs may be more challenging in these settings compared to acute and long-term care: Domestic caregivers that live together with the person with dementia may be under significant stress and may not feel open to trying new or unfamiliar interventions. Likewise, hospitals are often fast paced with a focus on immediate medical treatment. The urgent nature of care can make it difficult to prioritize or integrate complementary interventions like MMs. Moreover, hospitalized patients often have severe or critical health conditions, which may limit their ability to participate or engage in MMs. Hospitals may also face staffing shortages, and allocating time for MMs may be seen as less critical compared to essential medical care. In addition, limited space within hospitals may contribute to the difficulty of implementing MMs, especially if patients share rooms. Further studies could work with music therapists and other (external) healthcare professionals to integrate MMs into holistic care of hospital patients. Furthermore, we did not use individualized measurements. In future work, it is recommended to explore individual goals as outcome measures (Clare et al., 2019). An additional possibility would be to monitor target complaints: change of severity or degree of improvement as methods for scoring (Donnelly and Carswell, 2002). Likewise, physical measures for an objective just-in-time adaptation and outcome measure could be of interest. In addition, internal validity could be increased by conducting a randomized controlled trial, whereas our sampling was non-random. We aimed to evaluate the effectiveness of a specific intervention, which we believed to be effective, and ensured that this information was not withheld from individuals with dementia. The main question was therefore on how to find an appropriate balance between scientific ambition, ethics, and feasibility. Additionally, the research question required testing in a natural setting for higher external validity. We thus chose a quasi-experimental design and refrained from conducting a randomized control trial. Moreover, if participants were assigned to the control group, they were assigned to the intervention group during the next phase; however, this means that those participants

had to wait several months (up to 12) until they could participate in the intervention. Future studies may adapt their study design, such that the participation in the intervention is possible directly upon completion of the control group phase, and the wait gets reduced to 6 weeks only.

In future studies, it would be interesting to investigate how individualized MMs change over time and whether there are specific situations, characteristics, and contexts in which they are particularly effective. Furthermore, it would be interesting to find out for which other groups of people MMs could help to build and stabilize relationships and wellbeing (e.g., in the disability sector).

To conclude, MMs are just-in-time adaptive interventions as they offer support at the right time (i.e., when needed) and in the right quantities (i.e., as long as requested) (Nahum-Shani et al., 2015). The use of MMs is a form of a highly individualized intervention, which has the potential to enable people to do what they have reason to value (World Health Organization, 2015). It addresses preferences and needs of people with dementia, enhances their identity and social participation and helps to build bonds between carers and care-recipients. For individuals with late-stage dementia, such non-verbal communication is crucial for person-centered care to succeed in meeting their psychological needs (Ridder et al., 2023). MMs are therefore in line toward a more person-centered and innovative approach of long-term care for people with dementia.

Data availability statement

The datasets presented in this article are not readily available because the data cannot be made publicly available for legal and ethical reasons. Unfortunately, the disclosure to third parties was not included in the declaration of consent during the data collection process. Requests to access the datasets should be directed to sandra.oppikofer@zfg.uzh.ch.

Ethics statement

The studies involving humans were approved by Swiss Ethics Committee on Research Involving Humans. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

HE: Resources, Writing – original draft. SO: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Supervision, Writing – review & editing. DA: Methodology, Visualization, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frdem.2024.1429290/full#supplementary-material

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EDITED BY
Anthea Innes,
McMaster University, Canada

REVIEWED BY
Rosalie Ashworth,
NHS Tayside, United Kingdom
Margaret Calkins,
IDEAS Institute, United States

*CORRESPONDENCE
Susanne de Wolf-Linder
✉ susanne.dewolf-linder@zhaw.ch

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Meaningful patient and public engagement in dissemination—embedding co-production in dementia research

Susanne de Wolf-Linder[1,2]*, Iris Kramer[1], Martina Hersperger[3,4], Maria Schubert[1], Sonja Bächi[1,4], Monika Stolz[4,5], Emma Wolverson[2,6] and Christina Ramsenthaler[1,2] on behalf of SENIORS-Involve

[1]School of Health Sciences, Institute of Nursing, ZHAW Zurich University of Applied Sciences, Winterthur, Zürich, Switzerland, [2]Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Kingston upon Hull, United Kingdom, [3]"Plattform Mäander" Foundation, Zürich, Switzerland, [4]Department of Health Sciences, PPIE Stakeholder Group for People With Dementia, Institute of Nursing, Winterthur, Switzerland, [5]Person Living With Dementia, Winterthur, Switzerland, [6]Dementia UK, London, United Kingdom

Background: Patient and Public Involvement and Engagement (PPIE) is still underutilised in both dementia research and corresponding dissemination activities.

Aim: To describe the methods, format, and lessons learned in co-creating and co-producing a dissemination strategy for a research project focused on establishing patient-centred outcome measures into routine palliative community care for persons living with dementia (PLWD) and their informal carers.

Materials and methods: A participatory, hybrid-format workshop was conducted to co-create the dissemination strategy with a PPIE group. A video presentation of findings and a list of prompts shared prior to the workshop were used to elicit views on dissemination strategies and knowledge translation. The workshop was followed up with a survey to consolidate the dissemination strategy. Workshop minutes and survey responses were analysed using qualitative thematic analysis.

Results: 22 participants from our diverse PPIE group attended the workshop. Two major themes emerged: (a) Knowledge translation: building bridges between research and practise, and (b) Collaboration and dissemination: everyone's voice is needed. Participants suggested critical changes to dissemination methods and materials. Successful knowledge translation depends on a strong evidence base. For this, materials need to be tailored to specific audiences. Everyone's voice needs to be integrated through co-production in dissemination activities by PPIE members to influence societal change. Tailored dissemination activities within a dissemination strategy were co-created spanning all phases of the research cycle.

Discussion: Informing and educating the public and policymakers about the needs of PLWD relies on disseminating and fostering knowledge translation throughout all phases of the research cycle.

KEYWORDS

participatory research, dementia, palliative care, person-centred care, person-centred outcome measures, dissemination

1 Introduction

Patient and public involvement and engagement (PPIE) is defined as conducting research and developing policies with or by patients and members of the public rather than on their behalf (NIHR INVOLVE, 2012). Involving members of the public in this way has been mandated by the UK Government since the late 1990s as both a core democratic principle and for pragmatic reasons (Jackson et al., 2020). Recognising the voice of those being affected by research findings and policies constitutes the moral and political principle of equity and ownership in having a say how public resources are spent (NIHR INVOLVE, 2021). It also can enhance the quality and relevance of research by including a unique perspective "from the inside" (Gove et al., 2018).

Over the past 10 years, the discourse around PPIE has changed from one of passive consultation to active involvement of people in all phases of the research cycle, ranging from conceiving relevant research questions to disseminating research findings, onto participatory research paradigms with co-production of research (Bethell et al., 2018; Burton et al., 2019; Hickey et al., 2018). As can be seen in the acronym, in its current conception PPIE focuses on three pillars: public involvement, public engagement, and participation. What must be avoided is a tokenism of involvement (Jackson et al., 2020; Hilton et al., 2024). This is partly reflected in who should be involved as members of the public. PPIE members nowadays include (potential) patients, their carers, health care professionals, but also voluntary sector workers or policy makers (NIHR INVOLVE, 2012). The aim is for researchers and the community to co-produce research that is scientifically robust, yet follows community wishes.

The incidence of dementia is increasing, affecting a substantial number of people worldwide and in European countries (World Health Organization, 2015). This has led to the European Union (EU) declaring it a priority with a view to support a rights-based approach to dementia research. However, due to its disease course of cognitive decline, people living with dementia (PLWD) have been those to whom the "right to voice" has most often been denied (Georges et al., 2022). Several national and international or European organisations and funders have tried to shift this underrepresentation by releasing position statements and standards of PPIE in dementia research (Georges et al., 2022; Gove et al., 2018). This has resulted in a growing number of research studies delivering and evaluating co-production of dementia research, potential barriers to involvement, and effective strategies to enable meaningful involvement of PPIE representatives (Bethell et al., 2018; Burton et al., 2019; Di Lorito et al., 2020; Iliffe et al., 2013; Kirby et al., 2024; Lord et al., 2022; Miah et al., 2019; Molinari-Ulate et al., 2022; Morbey et al., 2019; Poland et al., 2019; Smith et al., 2024). Meaningful involvement of PPIE representatives is of equal high value regardless the size or the focus of the study (Kirby et al., 2024; Smith et al., 2024). Involvement of PLWD and members of the public in research has been shown to support and promote a person-centred model of health care (Beresford, 2013; Collins et al., 2022; Gerlach and Kales, 2022). Three scoping reviews of PPIE involvement in dementia research conclude a tentative positive effect of such involvement (Burton et al., 2019; Miah et al., 2019; Kirby et al., 2024). However, barriers in how research is funded and organised, or barriers around researchers' and organizations' attitudes and unconscious biases have been reflected upon in qualitative and case study evaluations of PPIE in dementia research as resulting in a potentially negative effect (Bethell et al., 2018; Biddle et al., 2021; Di Lorito et al., 2020; Lord et al., 2022; Mathie et al., 2018; Mockford et al., 2016; Poland et al., 2019; Waite et al., 2019). The recruitment and long-term retention of PLWD (and not only their informal carers) in PPIE activities as well as establishing a true collaborative model of involvement and engagement are further challenges (Bartlett et al., 2019).

In dementia research, studies have developed models of co-producing research to address these challenges (e.g., the CO-research INvolvement and Engagement in Dementia (COINED) model) (Di Lorito et al., 2020; Lord et al., 2022; Mockford et al., 2016; Swarbrick et al., 2019). In these models, strategies for meaningful involvement are usually centred around the phases of a research project. These models also acknowledge the Standards of Involvement as proposed by the National Institute of Health Research (NIHR) in the United Kingdom (NIHR INVOLVE, 2012). Dissemination is defined as the active approach of spreading evidence-based findings to the target audience via determined channels using planned strategies (Tabak et al., 2012; Minogue et al., 2022). Unanimously, all studies reporting on PPIE activities in dementia research relegated these dissemination activities to the last phase of their study (Di Lorito et al., 2020; Lord et al., 2022; Mockford et al., 2016; Swarbrick et al., 2019). Some were fortunate to find some additional funds to pay for dissemination (Mockford et al., 2016) but approaches are rarely published. The only dissemination approaches identified in the literature have targeted either an academic or at least an informed audience (by PPIE members co-authoring scientific publications or co-presenting at scientific or patient organisation conferences) (Brooks et al., 2017; Utengen et al., 2017;). Direct feedback from researchers to PPIE members, particularly at the end of the study when funding might have run out (Jackson et al., 2020), is also often missing (Bagley et al., 2016; Mathie et al., 2018; Popay and Collins, 2014); and the lack of a formal evaluation of PPIE activities and their benefit to PLWD and the wider public remains an important gap in the current discourse (Mathie et al., 2018). To date, no dissemination strategy is available in dementia research that has been co-produced with PPIE and focuses on knowledge translation to the wider public.

Therefore, in this short research report we describe the methods, format, and lessons learned in co-designing and co-producing a dissemination strategy for a research project focused on establishing patient-centred outcome measures into routine palliative community care for PLWD and their informal carers. We illustrate the development of a dissemination strategy that works across all phases of the research project. Together with our diverse PPIE group involving stakeholders from different public areas, we explore novel and meaningful dissemination activities that address a wider public than is currently the case in dementia research. See Box 1 for a summary of this brief research report for the wider audience.

BOX 1 Involving people from the public, people living with dementia and people supporting a person with dementia meaningfully in research: Summary for the wider audience.

Dementia often is not recognised enough in society. One reason for the limited recognition is that professionals often act without asking those affected by dementia. This is also true for research. Not enough people from the public, people with dementia and those supporting a person with dementia are involved or engaged in research. We wanted to address this by working together with a group of people from the community and then create a plan to share the research's findings.

Our research is about making sure people with dementia and people supporting a person with dementia get good companionship and/or care by asking them regularly about how they are feeling (e.g., are they feeling sad or are they in pain).

First, we all got together for a workshop. Some of us met in person, and some joined online. Before the workshop, we sent out a video with the findings from the research and some questions. We wanted to know how best to share these findings with a wider audience. After the workshop, we asked everyone their opinions in a survey. Then, the research team and members of the PPIE group looked at all the ideas and talked about them.

We found two big ideas: one is about making sure our research results get used in real life. The other is about making sure everyone's voice is heard when we share our findings. We learned that it is important to have good evidence when sharing our research. And we saw that it is best when everyone works together to ensure the information reaches different groups of people in easy-to-understand language.

Our plan now includes ways to share our research at every step. We believe that if we inform politicians and healthcare workers about what people with dementia need, it will make a big difference. We also believe letting people affected by dementia take the lead in disseminating this information will enhance the quality of our research. It further contributes to the inclusion/participation of people with dementia in our society.

2 Methods

Our research program in dementia focuses on developing, validating, and implementing person-centred outcome measures (PCOMs) into routine community care in Switzerland (de Wolf-Linder et al., 2021, 2022). Existing measures in dementia may not include outcomes important to PLWD as their perspectives are often poorly represented in the development of such measures (Morbey et al., 2019). Moreover, most measures focus on nursing home populations only, thereby inadequately reflecting the symptoms and concerns of PLWD living at home across mild to severe stages of dementia (Morbey et al., 2019; Murphy et al., 2015). Despite the inclusion of PLWD of all stages, in our research studies we conceptualise measurement of person-centred symptoms and concerns under a holistic palliative care viewpoint (Radbruch et al., 2020). Both these angles—developing a community-based and person-centred outcome measure for PLWD—have not been explored in Switzerland before. After the multi-methods development and validation of the Integrated Palliative Care Outcome Scale—Dementia for the community care setting, the research team is now co-producing a digital version of this outcome measure. The idea for this follow-on research project, the "Electronic PerSon-cENtred care and Specialised Palliative Care for people with dementIa: Improving the quality of life with Outcome guided Recognition and assessment of relevant Symptoms, neeDs and care issues" (eSENIORS) study, was voiced directly from PPIE and nurses from community/district nursing services.

Our PPIE group is embedded in the ongoing eSENIORS study (2023-2024). Participants for the group were recruited through various channels in 2023. Recruitment to this group is ongoing. We aim for a diverse range of people, including PLWD, informal carers, members of community care services, health insurance companies, public health, ethics, or health policy representatives, non-profit organisation (NPO) representatives, media experts and members of patient or dementia-related organisations e.g., Alzheimer's Society. PPIE members can represent more than one group or organisation. Most members were recruited through snowball sampling. We also promote the group, among the first of its kind in Switzerland, at public events and conferences. Individual consent for participation is negotiated via email or phone calls and re-established at the beginning of the PPIE group's activities.

2.1 The workshop

As part of the PPIE activities, we ran a two-hour workshop to co-design and co-produce the dissemination strategy for our research program. The workshop in December 2023 used a hybrid format of in-person attendance at our university and online attendance via a Webex board (big screen with camera). The hybrid format was agreed with the PPIE members prior to the workshop to enable inclusive opportunities according to the NIHR's standards (NIHR INVOLVE, 2012). Hybrid or online formats have been successfully employed with PPIE groups in dementia research (Brighton et al., 2018; Molinari-Ulate et al., 2022). We have followed their lessons learned to enable life conversations and interactions with all workshop participants. Three facilitators were involved in the study, the project lead (CR) and the two research associates (SdW, IK). We refrained from appointing a co-facilitator from the PPIE group due to the fact that the level of familiarity between researchers and PPIE members was not sufficiently developed at that particular moment.

All PPIE workshop participants received materials for preparation two weeks before the workshop. These included a video presentation of the study results created by the project lead and the research associate, as well as a set of questions about the presentation of results (understandability, design, style) and further avenues of knowledge translation to the public (see Table 1). We followed guidance on question prompts in communications according to the NIHR's guidance (Hickey et al., 2018).

In the workshop, we began with a round of introductions and clarifying expectations and setting ground rules for collaboration and co-production. Co-production of the dissemination strategy involved discussing the question prompts in small groups of four participants per table/breakout room from mixed backgrounds/groups, using first the think-pair-share method and then a world café approach (Keogh et al., 2021). Online participants were allocated in groups of four and mixed backgrounds in

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TABLE 1 Question prompts for building the dissemination strategy.

Prompts for considering project results:
- Which results are particularly important to you? Why? - Who do you think needs to know about the results? - Can you think of a person who – knowing the result – would change how they act or care for PLWD?
Prompts for considering the dissemination strategy:
- Where should we publish the results? - Which media could we use to disseminate the results? - How could we use informal channels to distribute the findings? - Who in the group is in contact with diverse stakeholder groups? - Who would like to collaborate to make the results more accessible for everyone? - Whom, do you think, could you present the results? Who should listen to us?

online breakout rooms. Both activities, think-pair-share method and the world café approach, were facilitated by the researchers. Spontaneously, one PPIE member co-facilitated the discussion at the in-person table seating the PPIE member with early-onset dementia. At the end of two rounds of discussion per table/breakout room, results were shared in the larger group and recorded on flipchart paper and—simultaneously—on a Padlet page for online attendees. The final round of discussion was followed by a casual exchange that blended formal and informal elements and concluded the workshop. We reimbursed our participants for their time per hour to prepare and attend the workshop in line with the INVOLVE guidance (Hickey et al., 2018).

After the workshop, all PPIE group members ($n = 40$), including those not able to attend the workshop ($n = 18$), were sent a survey. The survey's aim was two-fold; first, conducting a short evaluation of the first workshop and further eliciting preferences around attendance for future workshops and PPIE activities; second, confirming proposed tactics and extending ideas regarding the dissemination strategy and knowledge sharing/translation with the public. The survey link was sent out via Redcap® (Harris et al., 2009). Participants could choose whether to complete the survey online or in a print-out format.

TABLE 2 Profile of PPIE group members ($n = 40$; 4 double roles*), attendees at the workshop (n=22; 1 double role**), and participants providing answers to the survey ($n = 24$; 3 double roles***).

Roles (*n*)	PPIE group ($n = 40^{*}$)	Workshop ($n = 22^{**}$)	Survey ($n = 24^{***}$)
Person living with dementia	2	1	1
Family member	10	6	7
Nurses			
Community care	10	6	5
Acute care (geriatrics)	5	2	3
Geriatric/dementia counselling	3	2	3
District nurse union	1	1	1
Support group manager	2	-	-
Social counselling	1	-	-
NPOs for dementia, geriatric associations			
Managing director NPO	1	1	1
Senior citizens organisation	1	-	1
Church community	1	1	1
Public relations (journalist)	1	1	-
Alzheimers Association	1	-	1
Cultural club	1	1	1
Gerontological association	1	1	1
Politician	1	-	-
Community administration	1	1	1

2.2 Analysis

A qualitative, thematic analysis and synthesis (Braun and Clarke, 2006) of both the workshop minutes and discussion notes and survey answers was undertaken by the researchers (SdW, IK). The thematic analysis focused on responses regarding the development of the dissemination strategy. We used member checking with three PPIE workshop participants (one PLWD, one managing director of an NPO, and one nurse) to validate and extend results.

3 Results

Twenty two participants attended the workshop, 15 in person and 7 online. See Table 2 for the profile of participating PPIE group members. Comments in the survey were received from 24 participants. Five survey participants were unable to attend the previous workshop and therefore responded only to strategical questions with regards to the dissemination strategy. Overall, the workshop was evaluated as a positive activity for those attending. Several adjustments for making PPIE contribution an inclusive opportunity were described by survey respondents.

Two major themes emerged regarding how best to achieve a collaborative model of involvement and engagement in disseminating research: (a) Knowledge translation: Building bridges between research and practise, (b) Collaboration and dissemination: Everyone's voice is needed. We lastly present a dissemination strategy that integrates into all phases of the research cycle.

3.1 Knowledge translation: building bridges between research and practise

PPIE participants needed encouragement to voice critical views on the materials received. Participants suggested small

changes to the prepared dissemination materials which can be summarised under the heading "less is more". For instance, they felt we needed to tailor information materials to the intended audience by focusing on one message per slide in presentations and choosing a simpler colour scheme. For a successful knowledge translation reaching a diverse range of audiences, participants suggested a different use of language and alerted to the use of technical terms and jargon that might be differently understood by different audiences. However, participants were adamant about the need to be evidence-based in their dissemination:

> *"Research is part of everyday life"* (Advanced nurse practitioner, Geriatric/dementia counselling)

To achieve knowledge translation into everyday life, they suggested support from non-academic writers to avoid jargon in dissemination materials like newspaper articles or flyers. Once trust was built among members of the workshop, participants felt comfortable to take control of the dissemination. They suggested developing larger communication programs (e.g., a series in newsletter format) to disseminate implications for practise and research.

3.2 Collaboration and dissemination: everyone's voice is needed

Participants voiced concerns about the power imbalance when researchers communicated to non-academic audiences. Several ideas around co-presenting or sole facilitation/dissemination by a lay member were brought forward to reach diverse audiences. Several of our group members (particularly informal carers) stepped up during the worldcafé to spontaneously co-facilitate the discussion at their table. Some PPIE members also helped each other while preparing for the workshop. With the facilitation of a community nurse familiar to her, our PLWD member was able to contribute important insights for both designing dissemination materials tailored to PLWD and the importance of

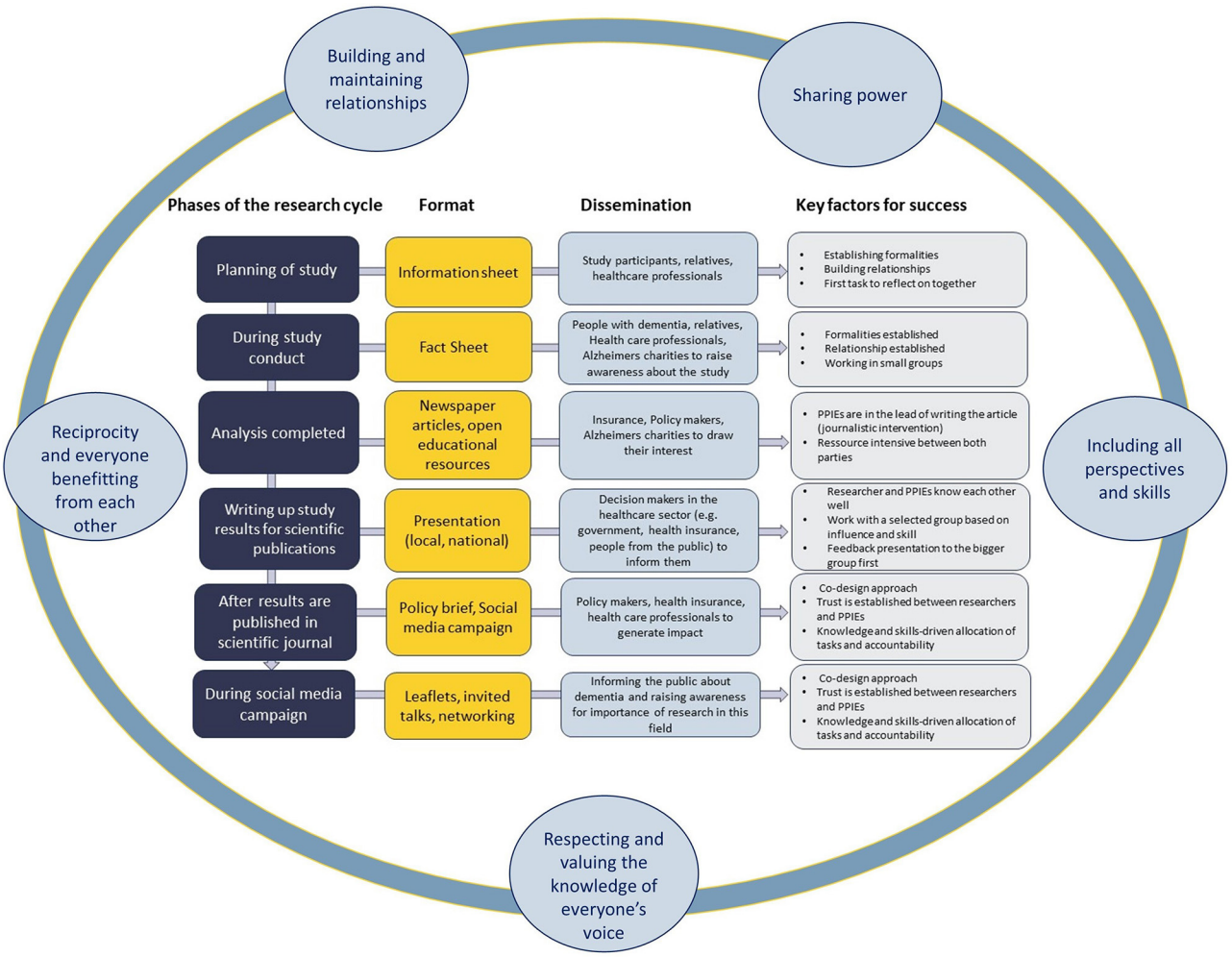

FIGURE 1
Dissemination strategy integrated into all phases of the research cycle embedded in the key principles of the NIHR guidance on co-producing research (NIHR, 2019).

a joint dissemination/communication strategy uniting all voices. The group felt that given dementia is often perceived as a Cinderella disease, isolating, and rendering those affected by it almost invisible, everyone is needed to contribute to research findings to be heard:

> *"From backyard thinking to network thinking—that's the mission!"* (PR for dementia and geriatric association)

3.3 Dissemination strategy to communicate results in dementia research

At the end of the workshop and with the help of consolidation via the online survey, we agreed on a dissemination strategy traversing the whole research cycle. In order to reach different audiences and for everyone to be able to contribute, participants suggested to integrate dissemination strategies and knowledge translation throughout all phases of a research project. Figure 1 summarises a range of strategies to reach academic and non-academic audiences and the general public, the target of the dissemination activities, and key factors for success.

4 Discussion

Using a co-production workshop with members of our PPIE group, we have developed a dissemination strategy that transcends all phases of the research cycle. Unlike common models of integrating PPIE activities into a study, we propose for dissemination to become an integral part of the research lifecycle, not just at the end of the study when it might be difficult due to time and funding constraints to reach meaningful involvement and engagement of PPIE (Bate and Robert, 2006; Greenhalgh et al., 2019; Kirby et al., 2024). Based on our findings, we propose for dissemination and knowledge translation to be considered activities of co-production rather than mere person or user-centred traditional approaches of consultation (Jackson et al., 2020). Collaborating as equal partners while recognising and valuing diverse knowledge, experiences, social networks, and cultural methods, are essential moral principles that should guide individuals engaged in co-productive activities (Jackson et al., 2020). Ideally, these dissemination activities are organised according to the key principles of the NIHR guidance on co-producing research (NIHR, 2019)—(a) sharing power, (b) including all perspectives and skills, (c) respecting and valuing the knowledge of all those working together with equal importance of everyone's voice, (d) reciprocity and everyone benefitting from each other, and (e) building and maintaining relationships as a means to share power. Embedding such a dissemination strategy (Figure 1) into the overall PPIE strategy can directly benefit the research project, e.g., representing the project as a lay member at the ethics committee review meeting, reviewing and adapting patient information leaflets or writing a lay summary. Such dissemination strategies can draw on and benefit from the unique inside perspective of PPIE participants, and their diverse skill set, experiences, and social networks. For this to be successful, the NIHR's (2019) principles need to be followed. This can then build the collective confidence of the PPIE group. PPIE members in our workshop group were cognizant of both the power of their voice and the right to express that voice as a political means to confirm the personhood of PLWD in society.

Through the feedback in our workshop, we have also realised that a view of framing PPIE as co-production in both research and dissemination may be too high a demand in a PPIE-naïve country without funding infrastructure such as Switzerland (Biddle et al., 2021; Miah et al., 2019), an aspiration and goal rather than a reality. Similar to what is concluded in existing scoping reviews of PPIE co-production in dementia research, there also remains a need for the thorough evaluation of PPIE activities, also capturing less positive or overwhelming experiences with PPIE reported from all perspectives (Hendriks et al., 2017; Russell et al., 2020). The members of our PPIE group were eager to transform less positive experiences from the workshop (e.g., feeling overwhelmed by too much material, researchers talking to long about research findings, reacting spontaneously to new material, public speaking) into valuable learning opportunities for future workshops by assuming responsibility for driving positive change within the group. While our PPIE group members also remained very keen on contributing to the study and the dissemination of its findings, barriers to meaningful, sustainable contribution were also voiced. Many of the issues around time constraints, conflicting care obligations, money and reimbursement issues, and worries about committing long-term to the group may also reflect the socioeconomic disadvantage of belonging to a group often marginalised in Western societies (Biddle et al., 2021; Miah et al., 2019). As part of the workshop and its evaluation, participants have also suggested ways to address these barriers (see Table 3). We have categorised the suggestions around the six NIHR standards of involvement (NIHR INVOLVE, 2019). In addition, we have embedded suggestions from the literature on how to achieve meaningful engagement and co-production via PPIE in dementia research (Bagley et al., 2016; Burton et al., 2019; Ferra et al., 2023; Georges et al., 2022; Gove et al., 2018; Hilton et al., 2024; Jackson et al., 2020; Kirby et al., 2024; Lord et al., 2022; Masoud et al., 2021; Mathie et al., 2018; Miah et al., 2019; Morbey et al., 2019; Poland et al., 2019; Popay and Collins, 2014; Smith et al., 2024; Staniszewska et al., 2017). Many of these suggestions are novel in the sense that they focus on how to engage PPI members in dissemination activities, rather than focusing on how to engage them in dementia research. However, these more general recommendations also apply to engaging them in dissemination activities.

We acknowledge that in the workshop, we only had one PLWD attending. In our PPIE group, we currently have two PLWD participants. It has been acknowledged that recruitment and retention of PLWD to PPIE activities remains a challenge (Masoud et al., 2021; Moreno et al., 2023). Our workshop did not include co-facilitation by PPIE members as our primary focus was on exploring the expectations and visions of the group regarding their involvement and establishing a basis for our work. As dementia-aware facilitators, we appreciated that the group was diverse in their needs (Masoud et al., 2021). By using group work techniques that facilitated peer support and hearing diverse voices we hoped to develop a co-created code of conduct with shared values, beliefs, and attitudes. However, with the group now being

TABLE 3 Addressing the NIHR's six standards of involvement around PPIE in dissemination with lessons learned.

NIHR's standards of involvement (NIHR INVOLVE, 2019)	Explanation	Identified risk factors for achieving meaningful PPIE involvement in dissemination	Lessons learned for meaningful engagement in dissemination activities
Inclusive opportunities	Offer public involvement opportunities that are accessible and that reach people and groups according to their needs	- Risk of information overload, feeling overwhelmed by too much information - Cost barriers - Tokenism and using PPIE involvement as an afterthought - Venue selection and accessibility - Meeting schedules and manners of involvement not meeting the needs of various stakeholder groups - Communication challenges - Overprotection and limitation of engagement - Time constraints	- Integrating PPIE-led and co-produced dissemination activities throughout the research project and not confining it to the last phase of the project. - Co-developing meaningful activities around sharing research findings as well as engaging the wider community. - Involving everybody in a manner that they find meaningful. - Members of the PPIE group working in pairs, peer support as key. - Sending study-related questions and information ahead of the workshop and involving members of the PPIE group - Flexibility around meeting times and manner of involvement, following a person-centred approach - Planning additional costs, also around co-facilitation and running meetings in an inclusive way - Pragmatism and compromise - Ongoing engagement and recruitment - Open format engagement - Accessibility and dementia-friendly formats, short communication
Working together	Work together to value all contributors, and that builds and sustains mutually respectful and productive relationships	- Lack of person-centred approach - Limited choices and adaptability - Insufficient group building - Neglecting multiple viewpoints - Inadequate support and training - Power imbalance and role ambiguity	- Researchers and members of the PPIE group openly discuss the duration of their commitment. Various forms of commitment, such as those that incorporate breaks, may emerge and require consideration and integration - Prioritising well-being and choice - Build rapport and equality, establish a buddy system and peer support in the group - Include diverse viewpoints and diverse smaller groups to engage with certain dissemination activities - Provide support and training to all members, use co-facilitation in training sessions - Encourage mutual understanding and learning - Establish clear roles and responsibilities, but keep them short term and tailored to the individual dissemination activity - Promote cooperative management structures - Engage the community and with the wider societal views of dementia to combat the cinderella status of dementia
Support and learning	Offer and promote support and learning opportunities that build confidence and skills for public involvement	- Lack of informal environment - Neglecting carer support and guidance - Lack of communication training for researchers - Uncertainty and anxiety around contributing to research - Emotional toll on researchers and PPIE	- Substantial time should be allocated to identify support and learning needs from everyone in the PPIE group - Using informal meeting components to address anxieties, create an informal environment - Researchers and PPIE members to co-plan meetings and learn about needs, facilitate pre-meetings - Offer specific communication training for different groups and use PPIE members to co-facilitate training - Making sure to plan meetings and engagement with carer support in mind, also supporting carers to support the PLWD - Engage PPIE members to create resources (e.g., short videos) what PPIE work is about - Prioritise knowledge assimilation and cultural understanding

(Continued)

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TABLE 3 (Continued)

NIHR's standards of involvement (NIHR INVOLVE, 2019)	Explanation	Identified risk factors for achieving meaningful PPIE involvement in dissemination	Lessons learned for meaningful engagement in dissemination activities
Governance	Involve the public in research management, regulation, leadership and decision making	- Lack of clarification and documentation of how PPIE input is used in the dissemination strategy - Insufficient monitoring of activities - Lack of formal governance structure leading to inconsistencies in decision-making, and potential biases	- Researchers ought to allocate time and resources to draft clear and concise codes of conduct using accessible language, involving PPIE members - Document involvement processes - Lobby and co-design the governance structure, build in monitoring activities and frequent feedback to make sure that all processes align with the standards
Communications	Use plain language for well-timed and relevant communications, as part of involvement plans and activities	- Excluding relevant stakeholders - Misunderstandings and tensions in PPIE activity, unmet expectations and failure to recognise that - Inconsistencies in seeking input from PPIE contributors - Lack of training around appropriate communication for researchers	- Researchers transfer the lead for communications to members of the PPIE group to ensure that the message is conveyed in a manner that is easily comprehensible to the intended audience - Provide consistent and supportive guidance for PPIE contribution - Check on mutual understanding of tasks and involvement/engagement, recognise PPIE activities as a site of multiple understandings - Invest in training - Understanding the audience and produce targeted resources for the intended audience
Impact	Seek improvement by identifying and sharing the difference that public involvement makes to research	- Lack of formal evaluation making it difficult to assess the benefits and the effectiveness - Lack of frequent feedback loops, lack of focusing on learning from negative experiences, lack of assessing potential negative experiences among PPIE members - Inadequate resources for monitoring and evaluation - Limited reporting of PPIE impact in dissemination - Absence of standards for evaluating PPIE quality	- Formally evaluate the effectiveness and impact of PPIE involvement in dissemination - Frequent evaluations and feedback loops engaging all members in a format and to an extent that is appropriate and meeting needs - Plan and allocate sufficient resources for evaluation - Systematically reporting PPIE impact in all activities - Co-creating standards of involvement and how to best evaluate them

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initiated, and with the ongoing recruitment of new members, we are planning to explore avenues for co-facilitation to better consider the needs of PPIE group members, particularly around avoiding information-heavy meetings. Lastly, as academic researchers we also acknowledge the need for further training around effective communication and facilitation strategies of workshops with a diverse range of people from different backgrounds attending.

Limitations to this work apply. Although we analysed our study using principles of qualitative thematic analysis, the manner of sampling, data collection, and analysis cannot be considered representative of a qualitative study. We share anecdotal evidence of what worked in our project. The representativeness of our findings is limited.

5 Conclusion

We have developed a dissemination strategy with a diverse PPIE group, including PLWD and informal carers. In every dissemination activity, we advise to tailor the illustration, language format, and overall message to a specific target audience and working with PPIE group members to co-produce disseminiation materials. By sharing or even handing over the lead in dissemination activities, we believe that knowledge translation can be fostered and that research findings can reach those audiences that can bring about a change in public health and societal views around the stigma associated with dementia (Low and Purwaningrum, 2020). Our results provide new avenues of how and when to disseminate research findings to maximise their impact.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the corresponding author upon reasonable request.

Author contributions

SW-L: Conceptualization, Formal analysis, Project administration, Writing – original draft, Writing – review & editing. IK: Formal analysis, Writing – review & editing. MH: Writing – review & editing. MSc: Funding acquisition, Writing – review & editing. SB: Writing – review & editing. MSt: Writing – review & editing. EW: Conceptualization, Writing – review & editing. CR: Conceptualization, Funding acquisition, Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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W. George Kernohan,
Ulster University, United Kingdom

REVIEWED BY
Aoife Conway,
Ulster University, United Kingdom

*CORRESPONDENCE
Maud Graff
✉ Maud.Graff@radboudumc.nl

†These authors have contributed equally to this work

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Discussing methodological gaps in psychosocial intervention research for dementia: an opinion article from the INTERDEM Methodology Taskforce guided by the MRC framework

Sara Laureen Bartels[1†], Nathan Stephens[2†], Federica D'Andrea[3†], Melanie Handley[4], Marine Markaryan[1], Andrea Nakakawa Bernal[5], Lieve Van den Block[6], Simone R. de Bruin[7], Karen Windle[8], Martina Roes[9,10], Niels Janssen[1], Hannah Christie[1,11], Lesley Garcia[12], Gwen Teesing[13], Esme Moniz-Cook[14] and Maud Graff[15,16]*

[1]Department of Psychiatry and Neuropsychology and Alzheimer Centrum Limburg, Mental Health and Neuroscience Research Institute, Maastricht University, Maastricht, Netherlands, [2]The Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Worcester, United Kingdom, [3]The Geller Institute of Ageing and Memory, School of Medicine and Biosciences, University of West London, London, United Kingdom, [4]Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, United Kingdom, [5]Design Department, Politecnico di Milano, Milan, Italy, [6]VUB-UGent End-of-Life Care Research Group, Department of Family Medicine and Chronic Care, Vrije Universiteit Brussel, Brussels, Belgium, [7]Research Group Living Well with Dementia, Division Health and Social Care, Windesheim University of Applied Sciences, Zwolle, Netherlands, [8]Centre for Applied Dementia Studies, University of Bradford, Bradford, United Kingdom, [9]German Center for Neurodegenerative Diseases (DZNE), Witten, Germany, [10]Faculty of Health, Department of Nursing Science, University of Witten/Herdecke, Witten, Germany, [11]School of Population Health, Royal College of Surgeons in Ireland, Dublin, Ireland, [12]School of Sociology and Social Policy, University of Nottingham, Nottingham, United Kingdom, [13]Alzheimer Nederland, Amersfoort, Netherlands, [14]Faculty of Health Sciences, University of Hull, Hull, United Kingdom, [15]Department of Rehabilitation, Radboudumc, Radboud University Medical Centre Nijmegen, Nijmegen, Netherlands, [16]Department of IQ Health, Radboudumc Alzheimer Center, Radboud University Medical Center Nijmegen, Nijmegen, Netherlands

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Introduction

> "*Whilst research on psychosocial interventions in [...] dementia is already showing signs of increased rigor and robustness [...], there is a need to allow a variety of types and sources of evidence to influence practice, and not simply be driven by results from randomized controlled trials*" (Woods, 2003, p. 6).

This statement is over 20 years old. Yet, it remains pertinent today as dementia research still shows an over-reliance on Randomized Controlled Trials (RCTs) for testing intervention efficacy within "ideal world" or optimum conditions (Hui et al., 2021; Oyebode and Parveen, 2019). Furthermore, over 20 years ago, a hierarchical framework

for ranking intervention evidence noted that the human subjective experiences of the recipient can be devalued, unless appropriate research designs are used (Evans, 2003). Despite increasing research commitment to involve people living with dementia and unpaid carers, meaningful involvement often remains superficial in many studies (Miah et al., 2019; Kirby et al., 2024). Consequently, there is a risk of research waste due to an "implementation error" where costly and time-consuming outcome evaluations including RCTs may (i) not demonstrate effectiveness but interventions themselves reported positive effect on peoples' experiences; (ii) demonstrate effectiveness but are unfeasible, unacceptable, ineffective in practice or viable only under limited circumstances (Vernooij-Dassen and Moniz-Cook, 2014). In contrast, diverse forms of evidence through the appropriate use of approaches to develop, implement, and evaluate interventions lead to more efficient, practical, and impactful research and practice (Skivington et al., 2021). Based on observations in the literature and the author's scientific views, this article draws attention to three methodological concerns: (1) people living with dementia, unpaid carers, and other stakeholders are not always *meaningfully involved*, (2) many current methods are not ideal in understanding *what works for whom, how, and why* and, (3) key features of *context and intervention complexity* are sometimes neglected.

Psychosocial interventions in dementia are considered as complex because of the intervention characteristics as well as how these characteristics interact with the inner and outer intervention context, as also described by the Medical Research Council (MRC) framework (Skivington et al., 2024). Characteristics of the intervention include, for instance, number and flexibility of components, the range of target behaviors, expertise, skills, and attitudes of health and social care professionals required, as well as people living with dementia and unpaid carers expected to receive the intervention. The context can refer to the setting in which the intervention is intended to be used, such as the country, to its policies and culture, and to the person's living situation (e.g., home-based, dementia day care, hospital, care home). The interaction between interventions and contexts is of relevance as this link is part of the mechanism of change, where causality between the intervention characteristics and outcomes can be determined (Skivington et al., 2021). Understanding causality is important so that appropriate evidence can be developed on outcomes at multiple levels [e.g., individual, service, and implementation (Proctor et al., 2011, 2023: Damschroder et al., 2022; McDermott et al., 2019; Moniz-Cook et al., 2011)]. Various frameworks can be used to develop, implement, and evaluate complex interventions (e.g., Damschroder et al., 2022; Bartholomew et al., 1998; Guise et al., 2017). The updated UK MRC aims to *"help researchers [. . .] to design and conduct research with a diversity of perspectives and appropriate choice of methods"* (Skivington et al., 2021, p. 1). It has been cited over 5,000 times (Status: WoS May 2024), where at least 300 are connected to "dementia". Therefore, it appears timely to reflect on its application in psychosocial dementia research.

The MRC framework outlines six core elements (i.e., consider context; develop, refine, (re)test program theory; engage stakeholders; identify key uncertainties; refine intervention; economic considerations) interacting with four phases (i.e., develop/identify intervention; feasibility; evaluation; implementation) (see Figure via link). We welcome Skivington et al. (2021, p. 1) acknowledgment that trade-offs exist for researchers between answering "*questions that are useful to decision makers rather than those that can be answered with greater certainty*". For example, RCTs can provide evidence on the effectiveness of psychosocial interventions in dementia (Aguirre et al., 2013) but literature in medical and social sciences may overestimate the accuracy of aggregated statistical estimates (Fisher et al., 2018). The issue is also linked to the "*overconfident belief in replicability*" of statistically significant effects (Vasishth et al., 2018) and a limited generalizability from the group to the individual level (Molenaar, 2004). Unraveling intra- and inter-individual differences is especially important given the substantial heterogeneity in dementia manifestations. Although promising approaches, such as item response theory (Murray et al., 2021) or single-case experimental designs (e.g., Lagerlund et al., 2022; Yorozuya et al., 2022), have emerged to address these short-comings of RCTs, the aspect listed above are rarely considered in interpretation of psychosocial data.

Moreover, the MRC framework documents the need to consider intervention context (e.g., circumstances surrounding the intervention's development, evaluation, and/or implementation) and complexity (e.g., emergent costs and effects, multiple and interacting components and systems). These features of psychosocial dementia interventions are not always considered (Christie et al., 2018). Often, limited attention is paid to the underlying mechanisms for *how* and *why interventions work or not*, thereby reinforcing reductionist approaches of merely reporting *what* changed (Moore et al., 2019).

Overall, the MRC framework emphasizes the importance of developing, evaluating, and implementing interventions based on theory (e.g., implementation science), practice knowledge (e.g., what works or not), and lived experience involvement (e.g., preferences, values, co-approaches) (Skivington et al., 2021, 2024). In some research studies, novel methodological approaches are emerging that better acknowledge real-world contexts and recognize the importance of involving people living with dementia, unpaid carers, and other stakeholders (Phillipson and Hammond, 2018). The MRC framework has scope to guide approaches and advance psychosocial dementia research. However, it is currently unclear which designs and methodologies frequently used in psychosocial dementia research address which questions, core elements, or relate to particular phases.

In this opinion paper, we discuss methodological gaps in psychosocial intervention research for dementia as identified by members of the Methodology Taskforce of INTERDEM. We reflect on and outline approaches that align with several of the MRC framework's core elements useful for research questions related to the development, evaluation, and implementation of psychosocial interventions in dementia. Specifically, we focus on stakeholder-informed and co-approaches with people living with dementia and unpaid carers, as well as theory-driven evaluation. The overarching aim of this opinion article is to stimulate a debate and to promote best research practice in the field.

Stakeholder-informed and co-approaches in psychosocial dementia research

All phases of the MRC framework recognize stakeholder engagement as a core element (Skivington et al., 2021). Stakeholders are defined as: individuals, groups of individuals, and organizations who affect intervention development, implementation, or evaluation (Social Value International, 2019). Within dementia research, key stakeholders include people living with dementia (defined as Public Involvement by Alzheimer Europe), unpaid carers, health and care professionals, insurers/commissioners, and decision/policy-makers.

Conducting complex interventions research alongside or with people living with dementia is essential (Gove et al., 2018), especially due to the multifaceted nature of the condition (Warran et al., 2023). Ensuring wider representation, including under-represented groups (Low et al., 2019; Vyas et al., 2018), and achieving "true" or meaningful engagement remains a challenge (Roberts et al., 2020). Empowering people living with dementia and unpair carers to participate actively in decision-making processes requires specific considerations to minimize power imbalances and avoid tokenism (Swarbrick et al., 2019; Marjanovic et al., 2015). While the MRC framework highlights the importance of stakeholder engagement, to the authors knowledge, designs and methodologies that can specifically engage and empower people living with dementia and unpaid carers are not yet utilized optimally, also neglecting underrepresented populations (e.g., ethnic minorities, immigrants, socio-economically disadvantages individuals). This issue may also be due to researchers finding it challenging to reach these populations and/or to engage people living with dementia in a meaningful way.

Participatory research, defined as an approach where researchers work in partnership with people living with dementia and unpaid carers throughout the research process, is slowly increasing in the field (Reyes et al., 2023). In practice, participatory research ranges from stakeholder involvement in an advisory role, such as reviewing research proposals, to collaborative co-approaches where power and responsibility are shared (Farr, 2018; Moll et al., 2020). Co-production, co-design, and co-creation are often used interchangeably due to limited consensus on definitions of co-approaches (Cowdell et al., 2022; Grindell et al., 2022). The MRC framework suggests that early stakeholder involvement can contribute to identifying and prioritizing ideas for research to answer "real world" questions, defining topics, gaining insight into problems, and optimizing study design/evaluation and implementation (O'Cathain et al., 2019; Skivington et al., 2021). Nonetheless, active involvement of people living with dementia and unpaid carers in designing, planning, and dissemination may be rarer due to stigmatizing narratives (Cowdell et al., 2022), top-down research, policy prioritization of epidemiological perspectives, and methodologies focusing on effectiveness, generalizability, and replicability (Warran et al., 2023). It is therefore crucial to emphasize the value of different types of data and equal collaboration with people living with dementia and unpaid carers "*to identify what ways of knowing are important*" (Warran et al., 2023, p. 5).

The most used co-approach methods with people living with dementia, unpaid carers, and stakeholders appear to be interviews or focus groups (Cowdell et al., 2022), often involving family or professional caregivers which can hinder fully capturing the voices of people living with dementia due to gate keeping (Novek and Wilkinson, 2019). Additionally, these methods usually rely on abstraction, recall, and verbal communication, which may be difficult for some people (Phillipson and Hammond, 2018). In response to these limitations, novel methods have been used (Campbell et al., 2023; Hogger et al., 2023), including visual (Chen et al., 2022), creative methods (Murphy and Oliver, 2013; Phillipson and Hammond, 2018), and sensory techniques (Buse and Twigg, 2016; Fleetwood-Smith et al., 2022) also capturing non-verbal communication. In the CONNECT study, experience-based co-design (Bate and Robert, 2006) and visual methods were used to develop an intervention that facilitates person-centered approaches to "constant observation", a model of care allocating staff for one-to-one support or close supervision of a small group of patients in hospital. Informed by literature (Handley et al., 2023) and mapping of the practices in three hospitals, vignettes and visual illustrations in the form of storyboards represented common, reoccurring scenarios of the delivery and experience of constant observation. The "touchpoints" depicted in the vignettes and storyboards enabled people living with dementia, unpaid, and carers to react to and empathize with situations, directly influencing priorities, values, appearance, and ways to use the intervention. Similarly, in the HOMEDEM network, several projects use participatory, user-centered design, and co-design approaches to support home-based people living with dementia and unpaid carers, including iterative procedures where feedback from people targeted by an intervention is integrated repeatedly, thus, increasing the likelihood of success (Lord et al., 2022). HOMEDEM offers early-career researchers interdisciplinary training including secondments to industry partners and combines methodological knowledge of design researchers with expertise in psychology, healthcare sciences, and health economics.

These examples demonstrate the value of co-designing with diverse stakeholders, using novel approaches. Engaging co-designers at an emotional level, integrating creative materials, collaborating across disciplines, and employing iterative procedures facilitates shared understanding. Thus, people living with dementia, unpaid carers, and other stakeholders are placed at the heart of the design and research process.

Theory-driven evaluation approaches in psychosocial dementia research

Evaluation of psychosocial interventions varies depending on the research question, targeting implementation (van Mierlo et al., 2018), effectiveness/cost-effectiveness (Brooker et al., 2018; Henderson et al., 2021), involvement (Buckner et al., 2022), sustainability (Morton et al., 2024), and scalability (Knapp et al., 2022). While evaluative studies should focus on the most proximal research question [World Health Organization (WHO, 2009)], controlled trials dominate, quantifying the effectiveness of an intervention based on "clinically meaningful" results (i.e., significance and/or effects sizes) (Skivington et al., 2021).

Psychosocial dementia research is no exception (Chow et al., 2021; Teahan et al., 2020). In many ways, striving for clinical effectiveness has little moral and methodological compass as firstly, outcomes measured may not be relevant to people living with dementia and unpaid carers (Harding et al., 2019); secondly, research methods do not always detect change accurately due to power issues (Stoner et al., 2019); thirdly, effect sizes may lack comparability as results can be "*seriously inflated*"; and finally, longitudinal pragmatic RCTs are often unpracticable (Schäfer and Schwarz, 2019). Therefore, few studies can replicate effectiveness (Aarts et al., 2015) or clinically meaningful outcomes (Schulz et al., 2002), when people living with dementia or unpaid carers may experience meaningful change. Expectations of funding bodies, decision makers, and researchers regarding which evaluation approaches and evidence are appropriate have started to shift recently. Notably, questions of context and complexity are fundamental to questions of efficacy and effectiveness, for which theory-driven approaches are widely advocated (Chen, 2012; Crane et al., 2019; De Silva et al., 2014). The MRC framework (Skivington et al., 2021) could therefore signal change for the evaluation of psychosocial dementia interventions.

Theory-driven evaluation is an umbrella term for various approaches including Programme Theory (Chen, 2012), Theory of Change (De Silva et al., 2014), and realist evaluation (Pawson and Tilley, 1997). These evaluations focus on *how and why* interventions work (or not) by investigating underlying theory of change, and/or mechanisms that produce outcomes in specific contexts (Funnell and Rogers, 2011). Grounding the evaluation of psychosocial interventions in a theoretical framework that can be refined supports intervention effectiveness, sustainability, and scalability (De Silva et al., 2014) and is starting to gain traction in the field of dementia care [e.g., using Theory of Change to guide the development and evaluation of a whole-setting nursing home intervention (Gilissen et al., 2018, 2019)]. Theory-driven approaches involve stakeholders to uncover and include meaningful outcomes (Øksnebjerg et al., 2018), and open the "black box" of interventions by identifying interactive components within multi-level contexts/systems leading to change (De Silva et al., 2014; Gilissen et al., 2018). For example, realist evaluation questions "*what works, for whom, under what circumstances and how*" to generate context-mechanism-outcome configurations (CMOs) (Pawson and Tilley, 1997). As such, a realist-informed process evaluation refined a theory of collaborative improvement with diverse stakeholders to explore and quantify implementation (e.g., fidelity), process (e.g., changes in practice), and individual outcomes (e.g., knowledge) (de la Perrelle et al., 2021). Another example is the realist rapid review and realist multiple case study design as part of the MENTALITY project which were used to define underlying mechanisms for successful dementia friendly communities and initiatives (Thijssen et al., 2022, 2023).

Despite burgeoning use of realist evaluation, it is not without its criticisms. Interpreting context when forming CMOs is not straightforward. What defines a context in one example may be used as a mechanism in another, and vice versa (Shaw et al., 2018). Those using RE should be aware of and accommodate for the instability of context in the design (Greenhalgh and Manzano, 2022). For instance, realist evaluation and Soft Systems Methodology was applied to evaluate the sustainability of Meeting Centers in rural UK areas (Morton et al., 2024). Combining these approaches appears to be an effective way to model complexity, leading to a transparent programme theory (Dalkin et al., 2018). Furthermore, realist evaluation has been suggested to enhance RCT design (Bonell et al., 2012). To the authors' knowledge, examples to critique in psychosocial dementia research are scant (Jeon et al., 2019), although combining RCT and realist evaluation as a pragmatic trial has been questioned from a philosophical perspective (see Van Belle et al., 2016).

Theory-driven evaluation approaches adhere to most MRC core elements, can be applied in any phase, and have methodological and reporting standards (Wong et al., 2017). Importantly, these approaches do not claim to offer silver bullets for success. Rather, theory-driven evaluation acknowledges that nothing works everywhere, for everyone, all the time, and according to pragmatic principles (epistemological, methodological, and operational practicality) to develop, test, and refine context-sensitive evidence for more accountable decision-making.

Toward advancing the field: the METHODEM project

To advance the field of psychosocial dementia research, it is essential to not just discuss exemplary approaches but aim to:

(i) provide a comprehensive overview of which (novel) designs and methodologies are being used;
(ii) reach a consensus on which designs and methodologies (a) integrate the core elements of the MRC framework and (b) suit the objectives of each phase in this area best (i.e., which design/methodology is suitable when, how, and why).

These aims will be targeted in the METHODEM project through a systematic review of the literature covering the past 25 years, and a Delphi study integrating input from researchers, health and social care professionals, policy makers, people living with dementia, and unpaid carers. Gathering, discussing, and disseminating evidence on current research practices and future directions for methodology in psychosocial intervention dementia research has global relevance (WHO, 2017) and may inform further iterations of the MRC framework.

Conclusions

This article has argued against waste in research endeavors so funding bodies, decision makers, and researchers can consider appropriate designs and methodologies for psychosocial intervention in dementia. We highlight important methodological concerns which should be addressed. To reduce the gap between research and practice and ultimately improve the lives of people living with dementia and unpaid carers, researchers are urged to continue to critically reflect on limitations of currently used methodologies and designs. Guided by the MRC framework, research should consider context and complexity to achieve sustainable impact on the real world and relevance through engagement of people living with dementia, unpaid carers, and other stakeholders.

Author contributions

SLB: Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Funding acquisition. NS: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. FD'A: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. MH: Methodology, Writing – original draft, Writing – review & editing. MM: Methodology, Writing – original draft, Writing – review & editing. AN: Methodology, Writing – review & editing. LV: Conceptualization, Writing – review & editing. SB: Conceptualization, Writing – review & editing. KW: Conceptualization, Writing – review & editing. MR: Conceptualization, Methodology, Writing – review & editing. NJ: Writing – review & editing. HC: Methodology, Writing – review & editing. LG: Writing – review & editing. GT: Writing – review & editing. EM-C: Conceptualization, Methodology, Supervision, Writing – original draft, Writing – review & editing. MG: Conceptualization, Funding acquisition, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
W. George Kernohan,
Ulster University, United Kingdom

REVIEWED BY
Faranak Ebrahimian Sadabad,
Yale Medicine, United States

*CORRESPONDENCE
Ana Diaz
✉ ana.diaz@alzheimer-europe.org

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Informed consent in dementia research: how Public Involvement can contribute to addressing "old" and "new" challenges

Ana Diaz*, Cindy Birck, Angela Bradshaw, Jean Georges, Daphne Lamirel, Soraya Moradi-Bachiller and Dianne Gove

Alzheimer Europe, Senningerberg, Luxembourg

Informed consent is a critical ethical requirement in research, ensuring the protection of participants' rights and promoting their wellbeing and autonomy. In dementia research, this process becomes particularly complex due to cognitive impairments and fluctuating capacity. While substantial work has been done to address these challenges, much of the literature on informed consent in dementia research has been shaped by the perspectives of researchers and healthcare professionals, with less focus on those with lived experience. This paper provides an overview of the perspectives of people with dementia and their carers resulting from Public Involvement activities organized by Alzheimer Europe. It builds on Alzheimer Europe's previous work with the European Working Group of People with Dementia and draws on discussions held during a face-to-face meeting about Participant Informed Consent forms and processes used in two specific European projects. We highlight views and key concerns raised by people with lived experience regarding the informed consent process, including barriers and facilitators. In addition to ensuring understandability, the discussions emphasized the importance of promoting respect and autonomy, ensuring that the values and interests of people with lived experience remain central throughout the research process. This paper contributes to the ongoing dialogue on improving informed consent practices in dementia research, highlighting the need for continuous involvement and the inclusion of people with lived experience in shaping consent practices to address both old and emerging challenges (i.e., new types of research such as artificial intelligence and data sharing/re-use) in dementia research.

KEYWORDS

Public Involvement, informed consent, research, dementia, lived experience

1 Introduction

Informed consent is one of the most fundamental conditions for the ethical conduct of research, ensuring that participants' rights, wellbeing, and autonomy are promoted. It is not only an ethical necessity but, in some instances, also a medico-legal obligation to prevent exploitation and provide information about potential harm (i.e., linked to preventing abuse, deception, illegal experimentation, and the charge of physical assault).

Informed consent must be obtained before the participant enters the research study and should provide full information so that potential participants understand what the research is, what they are consenting to and the voluntary nature of their participation and possible withdrawal. The process typically involves three stages: (1) disclosing the information needed to make an informed decision about participation, (2) a discussion to address any questions or concerns that may arise, and (3) obtaining formal consent from the person (or a proxy), voluntarily confirming their willingness to participate.

Due to the nature of dementia and associated symptoms and impairments, informed consent for dementia research can present significant challenges. Issues surrounding capacity are a common concern for dementia researchers and have been an important focus of research work and legislation over past decades. Over the years, a very important and relevant amount of work has been conducted to address the complex nature of consent for people with dementia, understand the practical and ethical challenges, and provide guidelines on how to assess and address capacity during this process (e.g., Hubbard et al., 2003; Hellström et al., 2007; Dewing, 2008; Nuffield Council on Bioethics, 2009; Beattie, 2009; Howe, 2012; Alzheimer Europe, 2019; O'Connor et al., 2022; Tauzer et al., 2023; Pyer and Ward, 2023).

Alzheimer Europe (2019, 2020, 2023) and other organizations have highlighted that decision-making and capacity should not be considered as an "all or nothing" or "one-off" event but as an ongoing process, taking into consideration that decision-making is task-specific i.e., related to performing "a particular decision-making task at a particular time and under specified conditions" (Buchanan and Brock, 1990, p. 18) and that capacity can fluctuate. Such considerations are therefore central to informed consent and the inherent imperative to promote autonomy. Recent studies looking at the views, perspectives and concerns of people with dementia in relation to consent have shown that people with dementia and carers describe the consent process as a journey. This work also highlights the value and importance of taking a flexible approach to consent (Pyer and Ward, 2023). As suggested by Hellström et al. (2007), the question therefore should no longer be whether people with dementia should be included in research, but rather how we can best achieve this.

The progressive nature of dementia calls for continuous engagement with research participants, including regular monitoring of their capacity and willingness to continue participating, as well as considering different possible levels of support for decision making when and if needed. Concepts such as "adapted consent" (Alzheimer Europe, 2019), "person-centered/process consent" (Dewing, 2008) and "supported decision making" (Alzheimer Europe, 2019; Griffiths et al., 2022) have all been developed as part of this work and efforts made by researchers to address this complex issue.

There are also broader considerations related to capacity and consent. People with dementia should have an equal right to accept risks in the context of research and in so doing, to contribute toward scientific progress. However, it is important to protect potential participants from therapeutic misconceptions and from exaggerated claims about the benefits of the research. Altruism is a frequently cited motive for taking part in research but having a terminal condition puts people in a vulnerable position with regard to accepting risk. The informed consent process should help ensure that any unrealistic expectations, fears or misguided beliefs about the nature of research do not interfere with making truly informed decisions that are in keeping with people's values and personal interests.

While there is quite a lot of research and literature on informed consent in dementia research, most of this work has been shaped by the perspectives of researchers and healthcare professionals. In this article, we would like to contribute to these discussions surrounding informed consent in dementia research by summarizing the views and concerns expressed by people with lived experience in the context of Public Involvement (PI) activities, conducted by Alzheimer Europe (AE), in different European projects.

In addition, the field of dementia research is rapidly evolving with the emergence of new types of research and study designs (e.g., involving people at risk of dementia with no symptoms, artificial intelligence, and data sharing/re-use). These changes have exacerbated some of the existing challenges in obtaining informed consent and introduced new concerns. In this article, we therefore explore how PI work can contribute toward the understanding and conceptualization of consent in the light of existing and new challenges.

2 Approach

Although PI is not the same thing as qualitative research, a qualitative approach/methods can be used. PI is about involving people with dementia in the research process, but not as participants. It is about creating a partnership between researchers and members of the public, whereby all contribute collaboratively in varying degrees toward the research process or the research output. AE has promoted PI in dementia research for over a decade (Gove et al., 2018). Examples of PI activities conducted in the context of European-funded research projects include, among other activities, the review of research protocols and participant-facing materials, participation in the process of selecting devices to be used in the study, discussions related to recruitment and retention strategies planned for the study, as well as discussions related to ethical issues linked to the study or future use of the project-related outcomes (Owens et al., 2020; Diaz et al., 2021; Brem et al., 2023; Muurling et al., 2023).

Through the active involvement of members of the European Working Group of People with Dementia (EWGPWD, https://www.alzheimer-europe.org/about-us/european-working-group-people-dementia) and various project-specific Advisory Boards, AE has facilitated meaningful involvement of people with dementia and carers in European research projects.

- The EWGPWD is composed of 14 people with dementia from different European countries and with different types of dementia. Members are nominated by a national Alzheimer Association for a term of office of 3 years. The group

meets regularly including face-to-face and online meetings. Members can be supported for travel and at meetings by a person of their choice, usually a relative, friend or member of an Alzheimer organization. In this article, we refer to the person providing support to the person with dementia as carer/supporter.

- The Advisory Boards are composed of people with Mild Cognitive Impairment (MCI) due to Alzheimer's disease (AD), people with dementia and carers, and are set up to provide feedback and advice to a specific project. The number of members of the Advisory Board can vary, typically ranging from 7 to 15 members.

This article draws on the discussions at a face-to-face meeting held on 15 and 16 November 2023 in Luxembourg, on the topic of informed consent in dementia research, in the context of two ongoing European research projects: EPND and ADIS. ADIS is a European Union Joint Programme—Neurodegenerative Disease Research (JPND)-funded project aiming at characterizing the role of peripheral blood cytotoxic lymphocytes as potential biomarkers for the early prediction of AD, and to investigate the influence of sleep disturbances on these biomarkers. EPND is an Innovative Medicines Initiative (IMI) project that is developing a platform for researchers to share data and biosamples from neurodegenerative disease studies so that these can be (re)used for further research. AE has led PI activities in both projects addressing in this work a broad number of topics such as, for example, ethical challenges linked to the early diagnosis of Alzheimer's disease in ADIS and to data sharing/re-use in EPND.

The meetings in Luxembourg were facilitated by AE staff, and involved a total of 29 people including people with dementia (members of the EWGPWD), people with MCI due to AD and the supporters/carers of the people with dementia/MCI due to AD.

This paper summarizes some of the discussions that took place during this meeting, highlighting how informed consent was perceived by these people with lived experience and what they felt were the more relevant current and future challenges related to this topic. The discussions were based on issues linked to the Informed Consent forms used in the ADIS and EPND projects. In the case of EPND, this referred to consent to secondary use of data and data sharing. In addition, there was a broader question about how they perceived informed consent and the main concerns and issues that need to be addressed, including barriers and facilitators for involving people with cognitive problems/dementia in this process. The paper also builds on AE's previous PI work in the context of several research projects (https://www.alzheimer-europe.org/our-work/current-work) with members of the EWGPWD over the years for which the topic of consent, whilst not the key topic, was also discussed and therefore reflects an ongoing dialogue on the topic (see for example Muurling et al., 2023 in the context of the Innovative Medicines Initiative (IMI)-funded project RADAR-AD, https://www.radar-ad.org/).

In this paper, we use the term "people affected by dementia" to refer collectively to the views and concerns of people with dementia, MCI due to AD and carers/supporters involved in this work.

3 Key issues related to informed consent raised by people affected by dementia

Discussions with people affected by dementia emphasize the great relevance of the topics of research and informed consent. Access to research can be hindered not only by practical factors (e.g., lack of research opportunities) but also, by misconceptions about dementia and about the capacity, abilities, and willingness of people with dementia to contribute to research. Unfortunately, dementia is still often portrayed and perceived by many people as the moderate and especially the late stages of the disease. An important message that emerged from the discussions was that, without denying or neglecting the challenges that people with dementia may experience, the focus should be on how to promote and enable participation in research for those who are interested and willing to participate. Enablers can include, for example, advance directives where the person could indicate in advance their wishes about research participation in the future when the condition progresses, but also reflections on how to promote and support autonomy and meaningful decision-making processes. The following sections summarize four important topics related to informed consent raised by people affected by dementia:

1. Broadening the understanding of informed consent.
2. Supporting the "informed" part of the informed consent process.
3. Beyond the provision of information: Promoting respect, recognition and wellbeing.
4. New research approaches will affect the consent process in dementia.

3.1 Broadening the understanding of informed consent

Consent has usually been conceptualized as a process starting just before a participant enters a research study, focused solely on that particular study. However, other broader elements, not specifically related to the study, such as awareness of the general public about research, opportunities to access research and "normalizing research" can all play an important role and should also be considered when planning informed consent materials and procedures. Many members of the public, including people affected by dementia, have limited awareness of research, lack understanding about its value, and sometimes, have misconceptions or fears about research and research participation. Being "research-aware" and understanding what it entails and its value, could influence trust and make people more open and better prepared to make informed decisions about participating in research. In addition to this, people affected by dementia should be involved in developing research materials (e.g.,

informed consent forms). This could help "normalize" research, thereby making it more inclusive and appropriate for people with dementia.

> *"I'm part of a Dementia Research Advisory Team, so if researchers want to do a new piece of research, they talk to us. This normalizes research."*
>
> *"Often doctors don't know much about research. It needs to be normalized, and Public Involvement needs to happen early. We can help develop consent forms."*

3.2 Supporting the "informed" part of the informed consent process

An essential aspect of consent is that it is "truly" informed. The specific needs and preferences of people affected by dementia should be considered and the process should be flexible and adapted to such needs and wishes.

> *"Informed" is the crucial part of the term informed consent."*
>
> *"Everyone has to be on an equal footing."*
>
> *"There is no one size fits all. The process (for informed consent) needs to take this into account and be flexible and adaptable."*

In line with this, a key priority for people affected by dementia relates to how to facilitate and support comprehension and understanding in a respectful and meaningful manner. Aspects that can facilitate understanding and accessibility include the terminology used and the length and layout of the document, but also more subtle elements such as the complexity of the content and the tone/style used.

3.2.1 Language and jargon

All participant-facing documents should be clearly worded, in lay language, avoiding technical terms and jargon, and phrased in a way that does not assume any prior knowledge. At the same time, it is also important not to assume that everyone lacks knowledge, as some people may be familiar with some of the technical or medical terms used. Glossaries and lay summaries were suggested as possible ways to support potential participants in the consent process whilst recognizing their different abilities, skills and needs.

> *"If instead of CSF, "lumbar puncture" was in there, I would have caught this."*
>
> *"I think the glossary is a good idea and it helps with having a balance because some people might already know some of the more technical terms."*

3.2.2 Length

Another important issue is that informed consent forms are often excessively long and this may put people off reading the whole text or make it difficult to read. This is particularly relevant for people with cognitive problems but it can also be an issue for carers and other potential participants who do not have any cognitive issues. The issue of length was also related to the amount and type of detail included. It was acknowledged that researchers may need to include certain information or details as these may be required by Research Ethics Committees, but, at the same time, there was a concern that the information that is emphasized may not necessarily correspond with participants' needs, priorities or what is meaningful and relevant for them. Finally, it is important to consider the complexity of the topics addressed as certain topics, such as risk, privacy, artificial intelligence, or data protection, can be very technical, and some people may find it difficult to make sense of them or understand their potential implications.

> *"For me, just in general, the whole thing's too long. If I got that as a carer, I just wouldn't. Honestly, I wouldn't read it all, because I just wouldn't have the time to do it. (…) I just think there's a lot in the beginning that I probably want to just quickly flash through, and then I would have signed."*
>
> *"The medical part is ok… but you are more interested in what concerns you, what affects you directly."*
>
> *"Regarding information about how people's data is stored, I don't know if people will have any know-how in technical issues and data security."*

3.2.3 Tone of the document

The tone of the document (e.g., friendly, formal or academic) and the layout were perceived to be as important as the issues linked to terminology and length. An academic, medical or formal style of writing (even if jargon is not used) can make the text much more complex, difficult to read and potentially daunting, and make people more uncomfortable or ill at ease, whereas a more informal writing style can help the person to read faster and more confidently.

> *"The way the document (the ICF) is written is very medical, 'legalistic.' It would be easier to read if it was written in a friendlier and warmer manner."*

3.2.4 Presentation: layout and visuals

The layout of the text is also important. Highlighting the most important sections, breaking down the document in smaller chunks of information, using visuals and colors to help the person understand when one topic ends and a new one begins, and using different strategies or methods for providing information, were all described as ways of facilitating understanding. The use of visuals can be particularly helpful when discussing the topic of risk in different contexts. For example, visuals which use a traffic-light inspired approach using the colors red (high risk), amber (moderate risk), and green (lower risk) to visually indicate different levels of risk could be helpful to explain risk to participants in a simple manner. This may not be the best approach for people with color blindness, so alternatively other visual approaches such as pie charts, use of different shapes or percentages

should also be considered to explain risk or other complex topics (e.g., side effects). It should also be born in mind that preferences regarding graphics and visuals can vary considerably between individuals.

> *"It is not about wording - it is about format and layout. One way of making the information provided easier is by adding a box with bullet points at the end of each section. These bullet points would act as natural pauses between sections of the participant information sheet and would also act as a reminder for the participants of the information just read."*
>
> *"Information about risks is very important and it should be communicated in different ways, not only with words, but using visuals too, e.g., traffic lights, pie charts…"*

3.3 Beyond the provision of information: promoting respect, recognition, and wellbeing

Not only the physical materials but also the relationship with the researchers can play a key role in the consent process. Researchers are trusted and expected to have empathy and the skills to communicate the relevant information and ensure that the person is able to understand it and feels comfortable in the process. Empathy and communication skills are particularly important during face-to-face informed consent processes, as potential participants often rely on researchers to explain and provide additional information during these interactions. Having enough time to take the decision and, if appropriate, to discuss this with other people was also identified as an important issue.

> *"It is necessary that the doctors put themselves in our place, sometimes they explain 50 things to you and when you leave you don't know what they have told you, empathy and clearer things are very important aspects."*
>
> *"Although all this information is well written, the most important thing is that they (the researchers) tell you, that they explain it well to you."*
>
> *"The problem is the time, you give this document to me to sign and I can talk to my children and they say, dad did you understand this? Maybe someone in the family who is a doctor can help. The problem is that there is no time. Either you sign or you are out of the study, and sometimes you sign out of desperation."*

Easy-to-read and accessible materials can also have an important impact on the person's wellbeing and on existing misconceptions about dementia. Excessively long, technical or complicated documents may cause avoidable distress to the person, or place them in a situation of having to ask for or rely on support from others. Researchers should be able to present complex information in a lay and accessible way, rather than relying on the capacity of people to understand technical terminology and jargon.

The language used in participant-facing documents such as Informed Consent Forms should be appropriate and respectful. For example, in some consent forms whilst the participants who do not have the condition under study (the "healthy volunteers") are referred simply as participants, the participants who have cognitive impairment are referred to as "patients." This was perceived as an unnecessary distinction as in the context of research all groups are equally contributing to the research and are not necessarily patients. Moreover, it reflects the processes of labeling, stereotyping, and, potentially, devaluation, which are key components of stigma.

Research participation may often be about benefit to society, future generations, and one's family, rather than direct benefit. This benefit and the value of participating in research is not usually reflected in participant information sheets or informed consent forms. Recognizing and appreciating the value of the participation of people affected by dementia in research is important and fair as research would not be possible without them. It could also help to promote further participation of other people and help address some of the stigma and misconceptions linked to dementia. On the other hand, this can also be a challenge as it could affect free will and decision making.

> *"Even with the disease, in a research study I am a participant and should be treated the same way as the participants without the disease."*
>
> *"An acknowledgment means that researchers recognize the importance of research participants as an active agent of the research itself. Whatever the findings are from the research, these are because of both the work of the researchers and of the participants. The participants' role is extremely important to help future generations with the disease."*
>
> *"Referring to the benefit to other people with similar conditions might make people feel bad or guilty about not consenting to it, so it could be like a subtle form of pressure."*

3.4 New research approaches will affect the consent process in dementia

The field of dementia research is rapidly evolving with the emergence of new types of research and study designs. Among many other aspects, the use of Artificial Intelligence (AI) and data sharing/secondary use of data have become very relevant.

AI is increasingly being used in different aspects of health care and research. Many research projects use AI at some point and for different purposes. An important issue is how to explain the precise nature and extent of its use, including any potential risks, limitations or future consequences to participants during the consent process. This is further complicated by the fact that AI might not be directly related to their participation in the study (e.g., if data provided by the participant—e.g., blood sample or a brain scan—is used later on to develop a tool or a model using AI). Topics such as bias and possible discrimination, accountability and regulation, and the possible impact of AI-based tools on the patient-doctor relationship are all relevant to people affected by dementia. Further work is needed to develop information about AI and its impact in lay terms and understand the amount of information and detail that is appropriate for different scenarios.

Many people affected by dementia may be quite open and feel positive about the potential secondary use of their data for future research. However, the potential secondary use of data should be outlined when participants consent to join a study. This is complex information that must be understood by the participant in addition to the details of the actual study that they are about to join, and there is often, at that time, uncertainty about whether, how, with whom and for what purpose the data may be shared. This can result in relatively vague clauses in informed consent forms, as it may not be practical or possible to provide further details about the way their data will (or not) be shared in the future. Key concerns raised during our consultations related to the individual(s) or entity receiving the shared data, in particular whether the data will be shared with for-profit companies and the location of the researchers with whom the data would be shared e.g., particularly if this is outside of Europe. People affected by dementia were also concerned about data privacy, explaining that terms relating to anonymization of data (e.g., pseudonymization, "coded sample") may not be widely understood. These terms are sometimes used inconsistently in the consent forms, thereby contributing to uncertainty and confusion, which is not conducive to promoting informed consent. On the other hand, people may be reassured by the need for ethical approval and the existence of clear regulations and standards for data protection in Europe, identifying these parameters as enablers of trust in data sharing. However, the challenge remains of how to add this additional information at the time of consent when, often, other more time-critical information tends to take precedence.

4 Conclusion

Over the last decade, AE has actively promoted and conducted Public Involvement (PI) activities in dementia research, involving people with dementia, carers/supporters and other members of the public (e.g., people with MCI). The work described in this article was conducted under the framework of PI using a qualitative approach. This is not qualitative research, but a systematic and rigorous methodology was nevertheless used (Gove et al., 2018).

The issue of informed consent in research has been an important topic in the work of AE, with discussions taking place as part of PI activities across several EU-funded projects. Based on this work and in one recent face-to-face meeting dedicated to this topic, we can argue that key aspects of consent relate to how participants are involved, informed and supported before, during and after their participation in research. This goes beyond the specific time where the formal process of consent takes places and encompasses issues related to comprehension but also emotions, feelings and the portrayal of dementia. It includes understanding consent in a broad context and including issues related to research awareness and access to research opportunities.

Ensuring that potential participants with cognitive problems and dementia fully understand the information provided to them is a key concern which echoes other previous work in relation to consent in dementia. This includes how the information is provided and presented to the person and a relationship of trust and respect. However, it goes beyond the mere wording and length of the text. For instance, it includes other factors that can support the person whilst promoting independence and wellbeing (e.g., tone of the document and relationship with researchers). Beyond the issue of understandability, a final key factor is linked to promoting respect, autonomy, and acknowledging the contribution and the value of participation.

Consent in dementia research is complex and it is becoming even more challenging in the context of new approaches to dementia research. Involving people affected by dementia in discussions about consent and its process can help to address these old and new challenges.

The PI work described in this article is valuable in identifying important issues about consent from the perspective of people affected by dementia and could form the basis for and contribute toward qualitative research on this topic to develop a guiding framework for informed consent in European research with people affected by dementia.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AD: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. CB: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. AB: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. JG: Conceptualization, Methodology, Writing – review & editing. DL: Conceptualization, Investigation, Methodology, Writing – review & editing. SM-B: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. DG: Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Investigation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Gen AI was used in the creation of this manuscript.

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EDITED BY
Wendy Moyle,
Griffith University, Australia

REVIEWED BY
Shirley Barbara Evans,
University of Worcester, United Kingdom

*CORRESPONDENCE
Emma O'Shea
✉ emma.oshea@ucc.ie

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Meaningful inclusion of people with dementia in interview research: adopting the "intentional stance"

Emma O'Shea[1]*, Suzanne Timmons[1] and Kate Irving[2]

[1]Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork, Cork, Ireland, [2]School of Nursing, Psychotherapy and Community Health, Dublin City University, Dublin, Ireland

Engaging people living with dementia in interview research presents unique ethical, methodological, and practical challenges. In recent years there is an increased recognition of the importance and value of meaningfully including people with dementia in research, and of the epistemic injustice of systematic exclusion. While there are a growing number of research papers suggesting strategies for fostering ethical and meaningful inclusion, this area is still very much in development, theoretically and methodologically. This paper outlines how a theoretical perspective on selfhood in dementia, which incorporates the concept of the "Intentional Stance" (as per Sabat), may be a useful means of reaching people with dementia in a meaningful way via open, curious and personhood-supporting interactions. Embodying the "intentional stance" refers to operating under the assumption that all behavior and interactions do have meaning(s), even if it is not immediately or intuitively evident to the researcher what the meaning(s) are. Here, we draw on excerpts from an interview I conducted with a person living with dementia about his experiences of and perspectives on respite and day services, using the intentional stance, in conjunction with a range of other strategies for maximizing reciprocal communication. The analysis highlights instances where the intentional stance was central to connecting with the person, and temporarily entering their lifeworld. Adopting this stance is a means of reducing the epistemic injustice that people with dementia have faced, through longstanding omission and exclusion from research, and from social spheres more broadly.

KEYWORDS

dementia, interview research, semiotic status, person-centered, intentional stance

Introduction

Dementia is considered a worldwide public health challenge, affecting approximately 55 million people globally, with prevalence projected to rise further in coming decades (World Health Organization, 2023). Historically, research in dementia has been conducted through a biomedical lens. Given the deficit-focus of the biomedical model, the perspectives of healthcare professionals and/or family carers of people with dementia were prioritized as holding more validity than the perspectives of those living with dementia (Niner et al., 2023; O'Shea et al., 2017). This has limited scopes of research inquiry, potentially leading to the proliferation of practices and policies that have failed to reflect the priorities and needs of people with dementia (Rivett, 2017). It constitutes what Halonen et al. (2024) and others (Price and Hill, 2021; Spencer, 2023; Fricker, 2007) refer to as "epistemic injustice," i.e., mistreating people in their capacity as "knowers," based on prejudices or stigmatizing attitudes.

In recent years, there has been growing recognition of the value of inclusive research approaches that actively involve people with dementia as research participants and co-researchers, rather than as "subjects" (McConnell et al., 2019; Shannon et al., 2021). However, engaging people living with dementia in research presents unique ethical, methodological, and practical challenges. Cognitive impairments associated with dementia can confound communication, but they do not necessarily preclude participation; rather, they underscore the need for innovative, flexible, and ethically-sound strategies to support inclusion.

There is a growing body of research exploring how we can include people with dementia in interview-based research, focusing on overcoming barriers, and maximizing their ability to contribute meaningfully (Hellström et al., 2007; Murphy et al., 2015; Clarke and Keady, 2002). Many of the strategies noted in these studies have been useful for me, as an early career researcher, who has endeavored to foster inclusive practices. Additionally, guidance from advocacy groups (e.g., Dementia Engagement and Empowerment Project (DEEP)) offers practical tips for researchers on how to foster an ethical and meaningful research relationship/encounter. Some of the common research and advocacy insights mentioned in these works include speaking with family about the person in advance, simplifying language and syntax, asking one question at a time, ensuring "dementia-friendly" environments and privacy, using formal communication aids (e.g., Talking Mats; Murphy and Oliver, 2013), paying attention to non-verbal communication, actively listening, and leading with empathy. Such strategies are sensible and vital elements in any qualitative researcher's "toolkit." However, such a toolkit, while necessary, is not always sufficient for facilitating meaningful engagement.

Below, I will outline how a theoretical perspective on selfhood, which can be supported by adopting what Professor Steven Sabat has referred to as the "Intentional Stance" (Sabat and Harré, 1994, p. 147), can create an internal shift in the researcher that can transform the research interaction into something both parties experience as meaningful, while also producing relevant data.

Selfhood and the intentional stance

A headlining point within Sabat's philosophy of dementia care is the notion that the effects of dementia can be either aggravated or ameliorated to various degrees, by the way that the person with dementia is positioned by others. This is an uncontroversial take, and is in line with the principles of person-centered care (Kitwood, 1997). However, it was Sabat's teachings on the "how to" of supporting personhood and selfhood that has had the biggest hand in shaping my research approach. This refers to interrogating your own assumptions about the "semiotic status" of people with dementia.

In order to support personhood, Sabat indicates the value of adopting the "intentional stance" when engaging with people with dementia (Sabat and Harré, 1994). The "intentional stance" is a concept that Sabat adapted from the writings of Dennett (1987). In Sabat's use, he is referring to the criticality of the assumption that the behavior of people with dementia is *meaning-driven*. He suggests that positionings of people with dementia, underpinned by the core assumption that they are "semiotic beings," ultimately serves to scaffold their sense of self (Sabat and Harré, 1992; Sabat, 2001).

Sabat critiques the widespread, but often unconscious, tendency to view individuals with dementia as lacking intentionality, particularly when they present with recall and/or communication difficulties. What is really happening, he contends, is that these issues create challenges for the researcher in interpreting meaning; not that there is no coherent meaning to be made. Thus, the key point here, in the context of interview research, is that researchers should conduct interviews under the assumption that all behavior and interactions do have meaning, even if the meaning is not immediately evident to the researcher, i.e., taking an intentional stance.

Sabat and Harré (1994), p.147) elaborate on their concept of "semiotic beings," defining them as:

> "People who can act intentionally in the light of their interpretations of the situations in which they find themselves, and who are capable of evaluating their actions, and those of others, according to public standards of propriety and rationality"

The authors added the following clarification:

> "It does not follow that the capabilities will always be realized in speech and action."

However, they argue that *"creating an appropriate conversational context can make possible the discursive recovery of the power to present oneself as a semiotic subject."* This is something that I have found to have validity. I will elaborate on this below.

The intentional stance in interview research

In a research context, we necessarily enter into interview sessions with an agenda guiding how we interact with participants. However, in adopting an intentional stance, you must be able to hold space for the person, and at times that means suspending your research agenda and topic guide.

Finding the meaning, means intending to enter the person's lifeworld, in as much as you can, and finding creative and natural ways to relate their experiences and narratives to aspects of your research question. Slowing down the pace, and being comfortable with silence are also necessary techniques. Sabat and Harré (1994) encourage embracing silence; specifically, not jumping in to fill silences when the interviewee pauses or appears to need "communication support."

In 2019, we published a study with six people living with dementia, exploring their perspectives on respite services (O'Shea et al., 2020). The "approach" outlined indicated the adoption of an "empathetic" approach to interviewing (as per Fontana and Prokos, 2016), with the cited theoretical basis being that of Kitwood (1997) person-centred care. However, this description was simply an indicator of the style of interviewing, from my perspective, and the values that I was trying to embody during data collection. In terms of guiding other researchers on how to meaningfully include people with dementia, that description was accurate, but not particularly instructive.

Here, I will elaborate on how the adoption of the "intentional stance" contributed to meaningful inclusion in research, ultimately yielding valuable insights about the perspectives of the participants with dementia on the research topic (i.e., experiences of day and respite services).

Of course, despite adopting the intentional stance, there were still instances where I failed to find meaning during interviews. Sometimes, after these interviews, in particular during the transcription process, I heard something the interviewee had said differently, and hypothesized

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(albeit too late) other potential meanings and connections. Here however, I want to make the case for the power of adopting the intentional stance, and the potential breakthroughs that can be made in reciprocal communication, which would not otherwise have been possible.

Case study: "Professor John"

Below is an excerpt from an interview with a man "John" [pseudonym] that I will describe as a case study. John was a University Professor, which his wife indicated had been a core aspect of his identity. At the time of data collection, John was attending day services twice weekly. According to his wife, he was diagnosed with Alzheimer's disease 6 years prior to the below encounter.

I had a lengthy discussion with John's wife about his career, their relationship and family life, his interests/hobbies, some of his behavioral and communication "quirks," and what was on his (and her) mind currently. I also spoke with day service staff about John, and during the recruitment process, one staff member had indicated to me that while John wanted to participate, she did not believe it would benefit my research. She said he often did not make sense, was demanding, and that he sometimes believed he was still working as a Professor. She also noted that he could get quite agitated, and on occasion, physically aggressive.

I proceeded with the interview, since John was eager, and his wife was supportive.

Interview excerpt 1

I focused the initial stages of the interview on his career. He echoed some of the career highlights his wife had disclosed, and more. At one point, he mentioned how '*not all students can be taught marketing methods here*'. I asked him what he meant. The following is the interaction that followed, with some explanatory notes.

> John: *"I've met some good girls here… Upstanding people, first-class qualifications, MBAs, but they have not a clue what marketing is all about. And the worst thing, they did not seem capable of learning…. [Extended silence] There was no reason given for why we had no choices."*

I wasn't sure yet what this meant, if it had relevance to my research question, or where the discussion was going, but I did not need to formulate at this time. I decided to just listen and reflect back my understanding:

> "It sounds like they weren't interested in learning what your needs were?" I asked, tentatively.
>
> John responded: "*No they were not at all interested in learning, in my learning, of my making suggestions… They came to the table with a card and a list of things. Normally they would do 4–5 objectives and my first impressions after 5 or 6 weeks was, 'is this all that's on offer?' There was no meat, no fish, just crisps and potatoes—things I never asked for.*"

I began to suspect that this may be related to the issues with the day service food described by his wife, but I still did not understand this enough from his perspective. I needed to hear more:

> I probed: "*This is pretty fresh in your mind?*"
>
> John: "*Very fresh. I began to say at home last night… I asked myself questions… how do I feel about this experience… do I feel rejected? The answer is yes… Do I feel that I did not… that my opinion was not worth taking? The answer is yes… And I did not find it easy to get over it. I'm still suffering inwardly a bit.*"

It was clear that this experience had deeply impacted John. I offered some more space:

> EOS: "*From feeling rejected?*"
>
> John: "*Yeah, they raised expectations… I do not know how they did this, but they did not check me out and see what did I want… And yet I knew the girls well and I hated marking them down so much….*"

Here the "*marking them down*" was referenced earlier in another context, and it referred to grading students. In this context, I believed he might be referring to his dissatisfaction regarding staff not enquiring about his food preferences.

I wanted to know if we could anchor his narrative more firmly in relation to the day service. As we were physically in the day service, I asked:

> "Would you say that that is typical here [pointing down to the floor]?"
>
> John: "*Yes, I would. In a sense it wasn't a once-off… The very fact that we had to intervene from Geneva and create a course and a method… What do they like? How do you know they like it? When did you last ask them?*"

The Geneva reference may seem out of place, but it is important and relevant, for John. His wife had disclosed that John had advised international leaders about "economics." I could never have inferred this otherwise. I reflected this back to him, using his own terminology:

> EOS: "*Right – you have to ask the consumers, to get to know the market?*"

It seems he felt seen:

> John: "*Oh yes [long pause]… My wife must have known how disappointed I was, if she told you all about this.*"

I tried to both validate this and steer us back to the issue at hand, from my perspective, i.e., lack of choice.

> EOS: "*She had mentioned you were not impressed with the food situation here.*"

He elaborated and provided even greater insight into his experience of the power dynamics at play in the service, i.e., the "*hierarchy*." In particular, he pointed to his feelings of disempowerment, which perhaps were far removed from what his normal was, as a working Professor.

> John: "*No… and in fact yesterday, if I had any way of making a decision in that hierarchy, I felt like calling a meeting of everybody,*

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> *all the teachers and students, and having a general department meeting and asking… Why did they do it*?"

There was a lot within this statement to deconstruct, and so I stayed with this to give more space for him to get his perspective across.

> EOS: "*That's what you felt like doing*?" [long pause].
>
> John: "*Well… Mixed feelings… I am not as satisfied as I was… I was a reasonably satisfied customer 2–3 weeks ago, but since this has happened, I'm not. And if this happens once more, I'm finished… You can be certain there'll be something signed by me and signed by at least half a dozen others, to say why we are not attending…*."

Acknowledging his desire to take power back, I asked:

> "You want to take action?"

He confirmed, nodding, but indicated that trying to foster collective action might be a challenge for him in this context:

> John: "*Yes! but the man next to me had the same five chips [that] I had. He did not seem to object! I tried to suss him out, asking 'are you satisfied?' I could not draw it out of him.*"
>
> EOS: "*He wasn't saying either way?*"
>
> John: "*He wasn't feeling like me, maybe*."
>
> EOS: "*Hmmm… Maybe… Maybe he wasn't as vocal about it*?"

John quickly quipped:

> "*Maybe I would not be either if I had not been in marketing*."

We both laughed.

This was a striking display of self-awareness and humor from John, related back to how he had framed much of this discussion, and hit me as an example of how conducting an interview with the intentional stance can bolster selfhood, in a way that allows to you to reach into the person's lifeworld, and sit in it with them, momentarily.

Of course, the above interaction could have gone entirely differently. I could have pressed on with my interview schedule and hit all the topic points, as I had done many times before.

Instead, I downed tools, listened, and assumed there was meaning in what John was communicating to me. The language at times appeared "irrelevant," in that the references to "students," "teachers," "Geneva," "departmental meetings," "creating a course," and "marking down" could have been interpreted, as the service staff had indicated, as him not always being coherent. In my view, John was simply circumventing word-finding problems he was experiencing, by employing terminology that had been central to his lived experience of complex systems and hierarchical power dynamics. Understanding this, the workaround seemed not only logical, but sophisticated.

Interview excerpt 2

During the interview, I was curious about John's thoughts on the activities within the day service. He offered a story, which shone a light on what staff had deemed "aggressive" behavior. While it did not lead to a discussion on activities in the sense that I had envisioned, the resulting conversation was extremely valuable and relevant to my research question.

> Me: *Can you tell me about the activities you do here?*
>
> John: *I had some [laughs nervously]… angry activities [Extended silence…] There were two staff one day, who decided to teach me a lesson. I was asking too many questions. And ehm…I could move my seat, they were movable, so I could move it, but not a certain distance because they threatened to block me…*
>
> Me: *Right.*
>
> John: *And that in a sense is threatening to block my ideas…and ehm… and that turned out nasty… I got so annoyed with her…. Do you see this stick here? I used this with both of them [staff members]… I turned it on one of them. I mean I did not ever think it would come to that.*

In this moment, it was clear to me that John was somewhat shocked by his own behavioral reaction. However, he also was also strong in his conviction that his grievances were valid. I leaned into that:

> Me: *You were frustrated?*
>
> John: *I was very frustrated… and it was all because of the movement of seats. They wanted to inch me and keep me away from the Headquarters.*

The "Headquarters" reference to me indicated that this was an issue of feeling controlled, in very minor behaviors. John was acutely aware that he was not treated with the same respect he once was. He also understood that his reaction was not acceptable and, in this moment, he chose to gently reassure me that he wasn't a risk:

> John: *And in case you think I'm like that…I would never use it.*
>
> EOS: *I know you will not…*

He continued, describing how jarring the experience was for him:

> "I was disappointed in one aspect because there was a girl here that I expected would be on my side and would be open to hearing my views and ehm…strangely enough she didn't seem to think there was anything wrong with them doing it… They [staff] are mostly nice, but it needs to be sincere."

Perhaps at the core of his frustration, was that he felt staff *did not* take an intentional stance in this situation, i.e., they did not try to understand why he wanted to move his chair. He felt he had a rapport with one staff member and was thus particularly hurt by her perceived unwillingness to hear his "ideas." Of course, this interpretation is based on John's perspective, which while valid, is not a complete

account. We say this not because he is living with dementia, but because every person involved in the scenarios he described will have their own perspectives on what occurred, how and why.

Discussion

The above interaction demonstrates how holding space, learning as much about the person as possible ahead of interactions, and assuming that there is meaning to be made (i.e., adopting the "intentional stance"), will lead to more meaningful engagement, and may lead to fruitful data for answering research questions. These lessons are not just relevant to meaningfully including people with dementia in interview-based research; they are transferrable and apply to communication more generally. They also apply in the context of providing person-centered dementia care. Indeed, we assert that adopting the intentional stance, to support personhood, is a pre-requisite for person-centered dementia care.

While the "intentional stance" might read like a purely academic concept, in practice, it is an internal shift that calls for you to remain open and curious about the person's experiences and viewpoints. It is a commitment to uphold personhood by trying to understand, regardless of whether you are acquiring the data you set out to collect. Adopting this stance is a means of reducing the epistemic injustice that people with dementia have faced, through longstanding omission and exclusion from research, and from social spheres more broadly.

The use of the "intentional stance" necessitates a level of comfort with making inferences in a way that triangulates various perspectives (in this case, i.e., John's wife, John, staff members) in real time. A key challenge therein is the question—how much of my interpretation is based upon an appropriate translation of John's account? Valuable steps toward creating a reflexive space in the research process included: (i) checking my understanding of the interviewee's experience with them frequently during the interview process, and (ii) interrogating my interview approach and discussing my interpretations of the resulting data with my co-authors. Any use of the intentional stance is fortified by putting in place these safeguards, which helped me to unearth biases and blindspots that one might not otherwise arrive at.

Earlier, I noted how in our 2019 paper (O'Shea et al., 2020), we declared an "empathetic" approach to the interviews with people with dementia, but that this was not particularly methodologically instructive. This is largely because "empathy" as a concept is multidimensional, interpersonal and context-bound and difficult to define (Cuff et al., 2016; De Vignemont and Singer, 2006; Decety, 2020). One way that empathy is commonly understood, is as having both cognitive and affective domains (Cuff et al., 2016), where "cognitive empathy" is the ability to accurately recognize and understand others' emotional states, while affective empathy refers to the ability to "feel with" others.

In the context of dementia, these cognitive and affective "abilities" relating to empathy are underpinned by assumptions relating to the semiotic status of people with dementia. You must believe that there is intent, and meaning to be made, in order to activate and access genuine empathy, either cognitive or affective for the person you are including in your research.

Thus, purposefully adopting the intentional stance, as was done here with John, can help to bridge the perceived personhood gap that has been created through historical biomedical constructions of dementia. If inclusion in research is to be meaningful, the intentional stance may indeed be a fundamental prerequisite, underpinning interactions with people with dementia. We posit that this stance may be a key means of fostering the type of internal shift needed, to overcome the biomedical construction of dementia that guides many of our unconscious assumptions about the semiotic status of people with dementia. We encourage future research to formally consider the role of the intentional stance when interrogating person-centeredness in the context of research, care, and everyday interactions. Similarly, we encourage health and social care professionals, and the general public, to adopt the intentional stance in their observations of, and interactions with, people living with dementia, and to reflect on the outcomes and implications of those interactions.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Dublin City University Research Ethics Committee (DCUREC/2017/018). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants, where possible, and/or participants' legal guardians/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

EO'S: Writing – original draft, Formal analysis, Project administration, Methodology, Conceptualization, Data curation, Investigation, Writing – review & editing. ST: Writing – original draft, Conceptualization, Supervision, Writing – review & editing, Methodology. KI: Supervision, Validation, Conceptualization, Writing – review & editing, Methodology, Writing – original draft, Data curation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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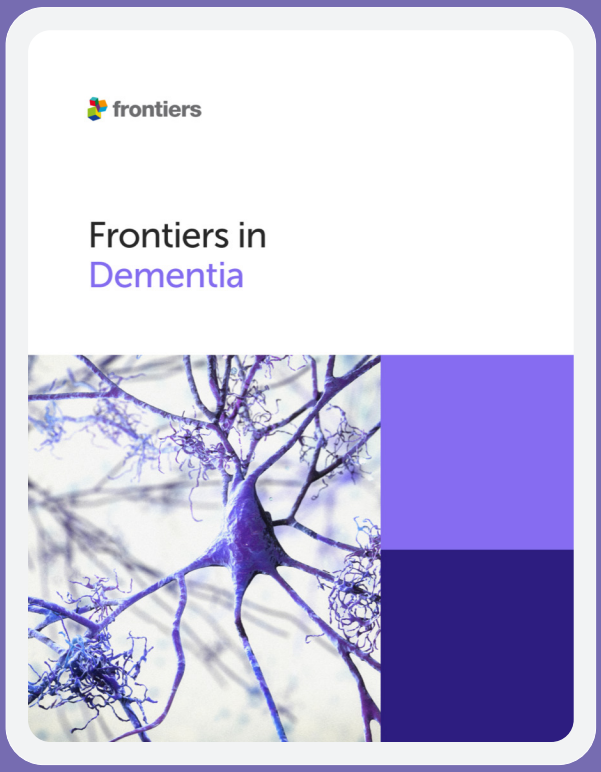

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