Received: 9 May 2020 | Revised: 17 September 2020 | Accepted: 24 October 2020
DOI: 10.1111/hsc.13238

ORIGINAL ARTICLE

Health and Social Care in the community WILEY

Stakeholder involvement in dementia research: A qualitative approach with healthy senior citizens and providers of dementia care in Germany

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Funding information
Centre for Transdisciplinary Neurosciences Rostock; Bundesministerium für Bildung und Forschung, Grant/Award Number: 01GQ1425B. Open Access funding enabled and organized by Projekt DEAL. WOA Institution: UNIVERSITAET ROSTOCK Blended DEAL : ProjektDEAL

Abstract

Engaging stakeholders in health-related research is becoming commonplace internationally and is increasingly considered best research practice to improve care management services. Many different groups have a stake in dementia care, but the evidence base for stakeholder involvement in dementia research is still small. The aim of this study was to explore views of two major stakeholder groups of dementia care in research priority setting and how they would want to be involved in dementia research. Group discussions were carried out with 47 participants divided into two groups: (a) healthy senior citizens and (b) providers of dementia care. Ensuing responses were analysed using descriptive content analysis. The main research interest of both groups was similar, but senior citizens and providers of dementia care varied in how they perceived the roles of researchers and stakeholders involved. Groups also differed with respect to the amount of time they would be willing to invest into research. The results contribute to our knowledge of group-specific stakeholder priorities and attitudes regarding participatory involvement in dementia research.

KEYWORDS
dementia, participative research, priority setting, public engagement, stakeholder involvement

1 | INTRODUCTION

It is estimated that more than 47 million people are living with dementia worldwide and this number is expected to more than double by 2050 (Livingston et al., 2017). Considering the increasing prevalence of dementia, public involvement in research is imperative to support the development of care management solutions that are in line with the rising demand. Patient and public involvement refers to the process of actively engaging people directly or indirectly affected by a condition like dementia in research and working with them as partners rather than viewing them as participants only (INVOLVE, 2020). Experience-based knowledge generated in such participatory approach provides the opportunity of converging scientific and practical perspectives (Bergold & Thomas, 2012), leads to scientific outcomes and solutions that are not achievable for scientists alone and meets the needs of those affected by the disease (Staley, 2015). Participatory research can avoid wasting public money and resources by exploring issues that are relevant to service users and providers, and enables access to research for people who are normally marginalised (Staley & Minogue, 2006).

In dementia, participatory approaches have been used with different methods in several contexts (Miah et al., 2019; Phillipson & Hammond, 2018), such as identification of dementia research priorities (Bethell et al., 2018; Kelly et al., 2015), analysis of communication and collaboration in dementia care (Karlsson et al., 2015; Risco et al., 2016) and development of assistive technologies for people with dementia (Kerkhof et al., 2019; Meiland et al., 2014; O'Connor et al., 2016). Still, already established methods from participatory research have not yet been widely applied to dementia research (Clarke et al., 2018; Di Lorito et al., 2017; Stevenson & Taylor, 2019).

Patient and public involvement in dementia research is not common practice yet although family, friends and caregivers of people with dementia are strongly affected by the disease (Chiao et al., 2015) and can provide experience-based knowledge. Thus, the involvement of these and other stakeholders in dementia care research would allow a broader understanding of the disease (Staley & Minogue, 2006).

In this study, we aimed to examine research priorities and views on research involvement with two stakeholder groups: (a) healthy senior citizens as potential future users of care for people with dementia and (b) family and professional providers of dementia care experiencing the disease as caregivers and service providers. Given that age is a risk factor for dementia (Chen et al., 2009; Kalaria et al., 2008), the involvement of perspectives of older people as a high-risk group in dementia-related research is important. The participation of care providers enables practical insights into dementia care and the generation of results that can be transferred to service management. Although senior citizens and service providers have been shown to provide valuable knowledge about participatory research (Littlechild et al., 2015; Staley & Minogue, 2006; Velzke & Baumann, 2017), they have hardly been included in research so far. We explored the perspectives on research involvement in dementia with respect to scientific fields that are considered relevant by the two stakeholder groups, requirements for a successful research process, and perceived opportunities and risks of participatory research.

The World Health Organisation (WHO) published a list of research priorities for dementia, taking into account the views of scientists and stakeholders in dementia care, with particular emphasis on prevention, identification and reduction of risks (Shah et al., 2016). Studies on thematic priorities in dementia research with a focus on country-specific structures of care are needed. Based on the guideline for priority setting partnership by the James Lind Alliance (Cowan & Oliver, 2013), important topics for dementia research have been identified in a multi-stage process for the United Kingdom (UK) and Canada (Bethell et al., 2018; Kelly et al., 2015). A similar approach of participatory priority setting in dementia research including country-specific care structures has not yet been adopted for Germany. In the studies mentioned above, views of stakeholders were not analysed separately, although they represent a heterogeneous group. The differences of perspectives on stakeholder involvement in dementia research between senior citizens and dementia care providers need to be identified to develop group-specific recommendations for public involvement.

What is known about this topic:

- The rationale of patient and public involvement is well documented.
- Stakeholder involvement is becoming increasingly important internationally, but is still rarely implemented in dementia research.
- Various actors have a stake in dementia care, including older healthy people as potential future users of the care system, and service providers, who are currently actively involved in the design and implementation of care.

What this paper adds:

- Both groups had similar research interests. However, some research priorities varied depending on the current understanding of roles of the stakeholders.
- The stakeholder groups involved in our study showed relevant differences in their ideas of active participation in dementia research.

2 | METHODS

To examine the research questions, we used a qualitative approach with two groups shown in Figure 1. Sim et al. (2018) recommend to set an approximate and provisional upper limit for the sample size instead of an a priori defined sample size for qualitative studies. In terms of sample size, we followed the design of the final prioritisation workshops of two studies based on the guidelines of the James Lind Alliance, which included between 18 and 28 people (Bethell et al., 2018; Kelly et al., 2015), and tried to recruit a comparable number of people in both groups of our study.

The first group was embedded within a multi-center study (Transfer of cognitive training gains in cognitively healthy ageing: Mechanisms and Modulators-AgeGain) examining a 4-week cognitive training programme to increase cognitive transfer in older people. Cognitively and physically healthy persons aged 60 years and

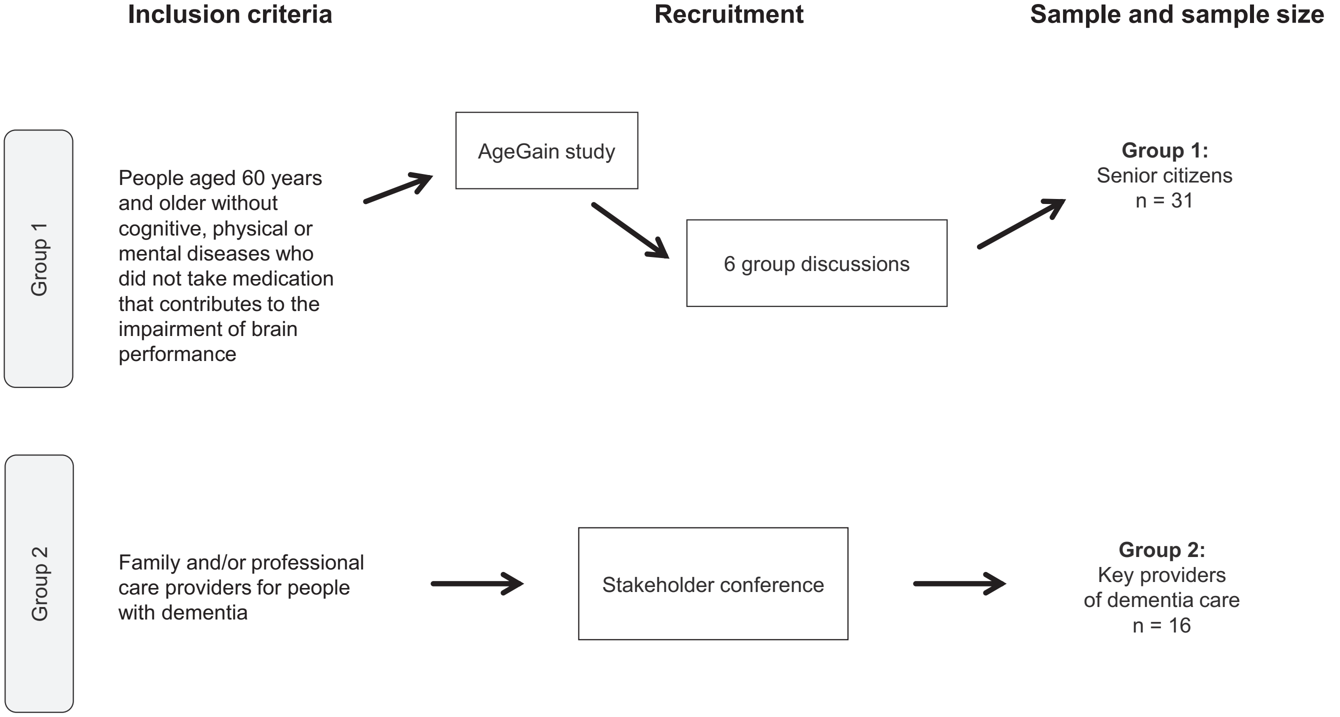

FIGURE 1 Study design with two groups

older who did not take medication with potential cognitive side effects were included in this intervention study. Subsequent to this study, participatory evaluation workshops with four to seven participants each were held where the participants had the opportunity to analyse their own cognitive training data to see if they improved over the four weeks. These workshops were organised because of the pronounced interest of the seniors in the study and its results. As part of these workshops, the 31 participants were asked about their perspectives regarding participatory research on cognitive disorders and these findings are reported for Group 1. We conducted a short questionnaire with closed and open questions. After the participants had filled in the questionnaire, these and additional questions were discussed in the plenum. For the current study, the answers to three of the questions were used, with the participants being able to answer these questions freely without any predetermined answer options:

1. In what kind of research projects would you like to be actively involved?
2. How should participatory collaboration in dementia research look like?
3. What are the opportunities/benefits and the risks of participatory research?

The discussions were documented in writing. For all participants, written informed consent had been obtained before the workshops. The workshops were approved by the ethics committee of Rostock University Medical Center (registration number A 2016-0060). Two researchers implemented and moderated the group discussions and collected the data in Group 1. Six group discussions took place from February to March 2018 in rooms of the Memory Clinic at the Rostock University Medical Center. A total of 31 people participated in the group discussions within Group 1. The participants of Group 1 had an average age of 72 years (range 61–90 years). The majority of participants in this group were women (*n* = 22).

The second group was involved in a stakeholder conference with various providers of dementia care who were invited by e-mail. We identified and recruited appropriate providers of dementia care with the help of dementia experts as gatekeepers (from the German Center for Neurodegenerative Diseases Site Rostock/Greifswald, Rostock University Medical Center, and the regional Alzheimer Association). In addition we used snowball sampling by asking invitees to forward information about the stakeholder conference to other colleagues. The findings of the discussions from the stakeholder conference are reported for Group 2. The stakeholder conference took place on 13/11/2019 in a meeting center in the city center of Rostock. A total of 16 people participated in the stakeholder conference including informal caregivers, representatives of dementia caregivers, coordinators of self-help groups, municipal social counsellors, researchers in dementia care, representatives of the State Seniors Parliament and employees of the regional Alzheimer Association within Group 2. The majority of participants were female (*n* = 15). No further demographic data about the participants in Group 2 were collected.

At the beginning of the stakeholder conference, the participants were divided into two groups of equal size in order to obtain a comparable group size to the discussions in Group 1. All participants of Group 2 were asked about the extent to which they had personal experience with dementia either professional or private and then discussed the same three open questions as was done in Group 1. The data collection in Group 2 was done on flipcharts, where the answers of the three questions were written down by a moderator. The moderators had expert knowledge in the field of participatory dementia research. Starting with the presentation of the research questions, the moderators led the conversation by asking questions about participants' responses. At the end of the discussion, a member from each group presented the answers on the flipchart to the audience. At this stage, the participants could still add and clarify points.

All participants of the stakeholder conference were informed that their participation was voluntary, that no personal data would be collected, and that the data were pseudonymised and stored inaccessibly for third parties. In addition, they were informed that participation did not involve any risk and only included procedures for which written informed consent is not normally sought. Contact details of the study coordinator were provided in case participants had further questions at a later point in time. We decided to dispense with a separate ethical approval for the stakeholder conference, as the same questions were asked as in group discussion with the senior citizens. Two researchers implemented and moderated the group discussion in Group 2.

In both groups, with senior citizens and providers of dementia care, the discussion sessions lasted 3 hr. To analyse the data, a descriptive content analysis was carried out on the basis of the questionnaires and discussion protocols of Group 1 and the flipcharts produced for Group 2 by one researcher. The answers of participants were ranked according to frequency and order of occurrence.

3 | FINDINGS

3.1 | Question: In what kind of research projects would you like to be actively involved?

Participants of both groups would like to be involved in research projects on early detection of dementia. Senior citizens were further interested in prevention of dementia and cognitive training. Providers of dementia care prioritised research on different therapeutic approaches and person-centred care. Senior citizens were interested in scientific studies on gerontology and healthy ageing. Service providers were more interested in care and emphasised the importance of transferring scientific results into practice, while the research interests of the senior citizens were largely theoretical and general with regard to research priorities such as health or environment. Furthermore, senior citizens named age-appropriate housing and independence as well as isolation and loneliness as additional research priorities. Service providers added the role of relatives and training for relatives in dementia care as important research topic with special focus on emergency situations such as acute illnesses of the relative caring for a person with dementia. In addition to the procedure of care assessment by the Health Insurance Medical Service (MDK), the service providers also identified new digital support forms and the associated potential risks as well as changes in the willingness to use technical assistance with regard to users' age as research priorities. Participants of Group 2 highlighted the promotion of acceptance of dementia to improve the public perception of the disease. The topics most frequently mentioned by participants in each group are presented in Table 1.

TABLE 1 Research topics in which the participants prefer to participate actively, by group, $n = 47$

Group 1, $n = 31$ (senior citizens):	Group 2, $n = 16$ (providers of dementia care):
Early detection and prevention of dementia	Early detection of dementia
Cognitive training/functions	Individual and effective therapeutic approaches (drugs and non-drug procedures)
Dementia research in general	Person-centred care
Gerontology	Role of relatives and training for relatives
Healthy ageing	Digitalisation (technical assistance systems, trustworthiness of media, changes in usage behaviour in the next generations)
Isolation and loneliness	Promotion of acceptance of the disease and public perception of dementia
Environment (protection)	Transfer of scientific results into care
Health (other diseases, risk factors)	Emergency situation (e.g. acute illnesses of the relative)
Age-appropriate forms of housing	Procedure of the care assessment by the Health Insurance Medical Service
Natural sciences in general	
Independence	

Note: The statements were arranged according to frequency and order in which they were mentioned by the respondents. *n*, number.

3.2 | Question: How should participatory collaboration in dementia research look like?

Participants discussed access to studies, phases of research in which the public should be involved, how collaboration could look like, the different roles of non-scientists and scientists and the prerequisites for collaboration. The two groups differed in all of the above mentioned areas. Senior citizens wanted to take the initiative themselves to gain access to research, while service providers wanted to be actively approached. The service providers expected that their involvement in research would depend on the disease state of the person concerned, but that it would nevertheless take place across all research phases. In contrast, senior citizens only wanted to be involved in specific phases of the research process and asked for a clearly structured procedure for participatory research. A common recommendation of both groups was training for non-scientists before working with professional researchers. In addition, in the discussion of both groups, the establishment of a lay advisory board for dementia research was favoured after this form of research participation was presented by the moderators. These results are summarised in Table 2.

3.3 | Question: What are the opportunities/benefits and risks of participatory research?

In both groups the expected benefits of participatory research were mentioned as increasing the impact and quality of research. Senior citizens emphasised that they were willing to be involved in research because they were retired and had the time. Service providers described the possibility of translating research results to person-centred dementia care.

Senior citizens saw risks primarily in the quality of research, while providers of dementia care focused on the risk for participants and feared that the data of lay researchers could be misused. The responses to the third question are presented in Table 3.

4 | DISCUSSION

This study examined the priorities concerning stakeholder involvement in dementia research of two public groups: (a) healthy senior citizens and (b) providers of dementia care. The views of the target

TABLE 2 Preferred structure of participatory dementia research, by group, $n = 47$

	Group 1, $n = 31$ (senior citizens):	**Group 2, $n = 16$ (providers of dementia care):**
Access	Information on research projects via local media and information events	Information on research projects via personal contact
Research phase	Participation in parts of the research process	Participation in all research phases
Structure of research	Workshops Preference for highly structured framework of participation	Adaption of study structure on course of disease
Roles of participants and scientists	Setting of priorities by the target group Leadership and decision-making power by scientists Advisory board including non-scientists Role of the participants depends on research topic as well as methodical and content-wise competencies	Collaboration at eye level with researcher People with dementia and their relatives as equal partners in research Advisory board consisting of patients, relatives and possibly service providers
Prerequisites	Training in scientific work for non-scientists before participatory research Participation only in practice-relevant research, not in basic research	Mutual respect, trust and transparency Training in scientific work for non-scientists before participatory research Need for guidelines on participatory dementia research for scientists

Abbreviation: *n*, number.

TABLE 3 Opportunities/benefits and risks of participatory research, by group, *n* = 47

	Group 1, *n* = 31 (senior citizens):	Group 2, *n* = 16 (providers of dementia care):
Opportunities/benefits	Changes in perspective for both sides	Public information about the disease
	Senior citizens have time to participate in research projects	Strengthening of social awareness for dementia
	Planning of studies according to needs and concerns of target group	Contact of different public actors
	Suggestions from citizens can be considered in research	Personal development of non-scientists
	Research topics: bottom-up decision making	Better coping with the disease
		Improvement of service structures
		Creation of sustainable care and management services
		Transfer/Implementation of research results into person-centred care/practice
Risks	Loss of quality in science	Manipulation of participants by researchers
	Lack of research competence of lay persons	Abuse of data
	Science may be too specific and too difficult to understand	Issues with informed consent from people with cognitive impairment
	Too much participation may lead to more complexity in science	Participants may feel overwhelmed, unforeseen problems may arise and need to be handled appropriately
	Equal status may not be possible	

Note: The statements were arranged according to frequency and order in which they were mentioned by the respondents. *n*, number.

groups, the context and process of participatory dementia research were discussed and analysed using descriptive content analysis.

Our results showed that early detection of dementia had a high importance for both groups. The scientists and stakeholders who contributed to the WHO's list of priorities for dementia research highlighted the timely and accurate diagnosis of dementia (Shah et al., 2016). Furthermore, the finding from our group discussions corresponds with written responses to a questionnaire by 514 persons, including respondents from a newsletter, a register and from a website, who also indicated the importance of early dementia detection (Law et al., 2013). In a study in the UK, a total of 18 participants including people with dementia, relatives and professionals identified the impact of early diagnosis as the third most important research priority based on a list previously developed from a survey of 1,563 people with dementia and caregivers (Kelly et al., 2015). In contrast, early detection of dementia was not part of the top 10 priorities for research identified by 28 persons personally or professionally affected by dementia in a Canadian study (Bethell et al., 2018). The different results of UK and Canadian research groups may have resulted from country-specific care structures and methodological differences (Bethell et al., 2018). The majority of the topics prioritised in both groups of our study were also identified as important by participants in other studies: cognitive training (Shah et al., 2016), independence (Kelly et al., 2015), pharmacological and non-pharmacological interventions (Bethell et al., 2018; Kelly et al., 2015; Shah et al., 2016), person-centred care (Bethell et al., 2018), promotion of acceptance of the disease and public perception of dementia (Bethell et al., 2018; Shah et al., 2016), transfer of scientific results into care (Kelly et al., 2015) and digitalisation (Shah et al., 2016). Senior citizens in our study emphasised isolation and loneliness as important research topics that have not been identified in other studies which focused more on well-being and quality of life of people with dementia (Bethell et al., 2018; Shah et al., 2016). The issue of emergency situations was only addressed in Group 2 of our study and was not a research priority in any other study. In previous similar studies (Bethell et al., 2018; Kelly et al., 2015; Shah et al., 2016), dementia-friendly environments were prioritised as a research topic, which was not addressed in our study. The results of our study on research priorities only agree with some of the previous data. This highlights the heterogeneity in the preferences of public groups with regard to the thematic priorities in dementia research. Some of the discrepancies may arise from different methodologies, as we used an open discussion format, whereas some of the previous studies asked participants to prioritise from a list of topics. In addition, in particular in the studies based on the recommendations of the James Lind Alliance, multi-stage procedures for prioritising topics were carried out with different survey methods and target groups. Our study, on the other hand, surveyed two groups, but participants were only included once in the discussion format.

The senior citizens in our study were interested in research on prevention while the providers prioritised healthcare research. This observation suggests that senior citizens perceived themselves in the role of healthy older people who aimed to reduce their personal dementia risk, whereas the caregivers had the perspective of their current position as care providers who identified research gaps on the role of relatives and training for informal caregivers. Thus, the difficulty of taking on a perspective outside of their current role may be a joint feature with professional researchers who may have difficulties to think outside the box as well. According to Bourdieu's concept of habitus, the attitudes and preferences of people are influenced by their environment including their social position (Pinxten & Lievens, 2014). Therefore, public involvement in research aids to overcome the issue of addressing a problem from only one perspective (Kirwan, 2014; Mockford et al., 2011), namely that of the researchers.

With regard to how stakeholder involvement in research should look like, participants from both public groups in our study discussed best ways of recruitment, the research phases in which participatory research could be embedded, the roles and power relations between scientists and public participants and the prerequisites for participation in research. Four recommendations for researchers can be derived from this:

First, recruitment preferences varied between public groups and recruitment strategies should be adapted to the preferences of the target group. In our study, senior citizens preferred information on research projects via local media and information events while care providers wished access to research projects via private contact. Healthy older people preferred to take the initiative themselves in accessing research projects and, in contrast to the service providers, did not want to be addressed directly. In a study comparing three different recruitment strategies including direct mail, advertisement in newspaper and community outreach, direct mailings were identified as the most effective method addressing community-dwelling people with dementia and caregivers (Morrison et al., 2016). In other studies, recruitment via research registries for voluntary participants was a recommended method to reach older people despite the possible lack of representativeness of the study population (Lepore et al., 2017). In previous studies involving different stakeholders in dementia care, a variety of recruitment strategies were used including analogue and digital methods (Bartlett et al., 2019). Some of these methods were also mentioned by the participants of our study but enrolling an adequate number of participants for dementia studies remains a challenge (Chambers et al., 2017; Leach et al., 2016). A combination of different recruitment strategies and a close collaboration of staff involved can promote active participation of hard to reach groups (Field et al., 2019).

Second, both senior citizens and providers of dementia care recommended involvement of the public in dementia research. However, senior citizens preferred involvement only in certain parts of research projects while care providers prioritised participation in all research phases. Senior citizens mentioned that they are at retirement age and therefore do not want to have daily obligations or want to be hired as ‘employees’ for research even if they have enough time to participate. In a qualitative study with 17 participants on participation in palliative care research, the two observed groups of service users and researchers differed in particular in the phases in which non-scientists should participate (Daveson et al., 2015). Only users preferred to be involved in research throughout the entire research process while researchers highlighted the need for flexible service user involvement depending on disease progress and current caregiver's responsibilities (Daveson et al., 2015). Patient and public involvement is possible in all phases of research (Hewlett et al., 2006), from setting research priorities and identifying research questions (Bethell et al., 2018; Kelly et al., 2015) to data collection, data analysis and interpretation (Clarke et al., 2018; Stevenson & Taylor, 2019).

Third, public groups have different perspectives on the roles of academic researchers and the public participating in research. The roles should be communicated and clarified at the beginning of a project to avoid confusion of expectations (Daveson et al., 2015). In our study, senior citizens wanted researchers to have decision-making power. It was noted that research is the job of researchers and that too much involvement of the public could eventually lead to ‘chaos’. Participants in Group 1 criticised the involvement of stakeholders as potentially lowering the quality of scientific results. In contrast, dementia care providers would like to contribute and work with scientists as partners. Respondents of Group 1 had been participants in a research project, AgeGain, which had a traditional hierarchy between researchers and lay persons, before participating in the workshops, different to the members of Group 2. It is likely that this has influenced the different views on researchers' and lay persons’ roles and hierarchies. The notion on participation in research of the senior citizens regarding involvement in our study could be seen as reflecting a very first stage of participation according to the ladder model of citizen participation (Arnstein, 1969). Research has shown that there may be some confusion about the roles and expectations of those involved in participatory research (Cotterell et al., 2011). Although assuming a new role in the participatory process is a particular challenge (Hewlett et al., 2006), development of the role and the perspectives of the research partners are possible (Kirwan, 2014; Mockford et al., 2011). Initial scepticism and fears of those involved in research can be reduced through participation and the associated acquisition of new skills and the feeling of being taken seriously (Bergold & Thomas, 2012).

Fourth, participants need training on research methods. In both groups, participants wished training before involvement in research. The importance of training prior to engagement in participatory research was highlighted by previous studies (Mockford et al., 2016) including methodological training for lay researchers (Bergold & Thomas, 2012; Hewlett et al., 2006) and the teaching of appropriate ways of dealing with those directly concerned by dementia to academic staff (Scottish Dementia Working Group Research Sub-Group, 2014). The necessity of training requires an additional need for time and financial resources (Mockford et al., 2016) which must be taken into account when planning projects with stakeholder involvement. Both groups assessed the opportunities and benefits of participatory research very similarly. Providers of dementia care further emphasised the improvement of social awareness of the disease and the perception of dementia. It is interesting to note that senior citizens feared a reduction in scientific evidence and less valid results through the participation of non-scientists in research. In contrast, providers expected that researchers may have a negative impact on the views of lay researchers. One participant in the discussion of Group 2 highlighted the risk of manipulative approaches by scientists towards public groups. This result underlines the importance of training before public involvement to increase the self-confidence and openness of public groups towards research involvement by imparting knowledge about research methods and procedures.

The following limitations of this study must be taken into account when interpreting the results: One limitation of this investigation was that the sample included seniors who had already participated in a study before. Such a convenient sample may not be representative of the whole population of interest. Methods of data collection differed slightly in our two study groups because data collection was done by different study teams. Furthermore, we decided to use flipcharts and recorded notes by hand for simplicity (Tessier, 2012) and to create an open discussion format. The research questions of our study could be answered with this method of data collection.

We plan to use other formats (face-to-face interviews) to elicit the perspectives of people with dementia on research participation. Recommendations on patient and public involvement in dementia research at the international level (Brooks et al., 2017; Gove et al., 2018; Scottish Dementia Working Group Research Sub-Group, 2014) still need to be adapted to the specific linguistic and cultural context. Other public groups, in addition to those represented here, that are important for dementia research and have a stake in dementia care must be identified and closely defined in future research with regard to their willingness to participate in studies. Focus group discussions and semi-structured interviews are recommended methods for this approach (Reed et al., 2009).

In summary, through group discussions, we were able to set priorities and provide important insights regarding stakeholder involvement in dementia research from the perspectives of healthy senior citizens and dementia care providers. Public involvement in dementia research is a priority, however, as has been shown here, stakeholder groups show relevant differences in their ideas of participation, which must be taken into account for effective public engagement in research.

ACKNOWLEDGEMENTS

The authors thank all participants. The AgeGain study was sponsored by the Federal Ministry of Education and Research (BMBF grant no. 01GQ1425B). The stakeholder conference was financially supported by the Centre for Transdisciplinary Neurosciences Rostock (CTNR).

CONFLICT OF INTEREST

Antonia Kowe is fellow of the program “Freies Wissen” by Wikimedia Deutschland. Stefan Teipel has done the listed works below (all in Germany). MSD Sharp & Dohme GmbH, Lindenplatz 1, 85540 Haar: 11/09/2018 – Quality circle for physicians in Kühlungsborn, Talk: “Dementia and Diabetes – current report”; 14/11/2018 – MSD Expert-forum: NAB Alzheimer in Munich, participator as consultant; 13/08/2019 –Event “Diabetes and Dementia” in Rostock, Talk: “Dementia and Diabetes – current report” ROCHE Pharma AG, Emil-Barell-Str. 1, 79,639 Grenzach-Wyhlen: 12/09/2019 – 3. Nationales Advisory-Board in Frankfurt (Main), participator as consultant; 27/09/2019 – ROCHE Symposium at the DGN Congress in Stuttgart, Talk: “Amyloid as target for diagnosis and treatment in Alzheimer’s disease” Biogen GmbH, Riedenburger Straße 7, 81677 München: 23/04/2020 – Biogen Advisory Board Session; 28/04/2020 – Biogen Advisory Board Session. The other authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTION

A. Kowe collected the data in Group 2, analysed the data of both groups and wrote the paper. S. Köhler collected the data in Group 2 and assisted with writing the paper. O. Klein assisted with writing the paper. C. Lüthje supervised the study design, collected the data in Group 2 and reviewed the paper. S. Weschke designed the study, collected the data in Group 1 and reviewed the paper. J. Kalzendorf designed the study, collected the data in Group 1 and reviewed the paper. S. Teipel supervised the study, collected the data in Group 2 and assisted with writing the paper.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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How to cite this article: Kowe A, Köhler S, Klein OA, et al. Stakeholder involvement in dementia research: A qualitative approach with healthy senior citizens and providers of dementia care in Germany. *Health Soc Care Community*. 2022;30:908–917. https://doi.org/10.1111/hsc.13238