



Identifying relevant psychosocial factors in the care of people with dementia: findings of a focus group study with health professionals and informal caregivers

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Abstract

Aim The extent to which psychosocial factors are considered in the treatment and care of people with dementia is unknown, despite their promising treatment effects. Therefore, the aim of this study was to explore the relevance, implementation, and the challenges of integrating psychosocial factors in dementia care.

Subject and methods A qualitative design, in adherence to the COREQ checklist, was used with three expert focus groups in the treatment and care of people with dementia (10 health professionals and 6 informal caregivers). The focus group discussions were transcribed verbatim and analyzed using qualitative content analysis.

Results It emerged that psychosocial factors, particularly social contact, seem to come with a beneficial effect on daily life performance and general well-being. Psychosocial interventions also seem to aid people with dementia in experiencing competency. Findings also indicate that needs, interests, and preserved abilities should be the focus when deciding on the integration of psychosocial factors into care. Perceived barriers to the implementation of psychosocial factors in daily life were bureaucracy, inadequate staffing, cost, societal challenges, and limited offers of appropriate psychosocial services.

Conclusion Psychosocial factors were consistently perceived as beneficial. Programs should be developed to address the barriers and implement model projects within the respective medical health care system to serve the dementia patients in the community as a whole.

Keywords Caregiving issues · Qualitative methods · Quality of life · Dementia care

List of abbreviations

BPSDs behavioral and psychological symptoms

Introduction

The challenges of caring for people with dementia is a well-reported phenomenon for both informal caregivers (Allen et al. 2020) and health professionals (Chang et al. 2009; Larson and Stroud 2021). Not only does the main symptom of dementia, progressive cognitive decline, pose a challenge, but so do behavioral and psychological symptoms (BPSDs). Those include, but are not limited to, agitation,

aggression, apathy, anxiety, and depression, and other problematic behaviors that do not conform to social conventions (Bessey and Walaszek 2019; Cerejeira et al. 2012; Kales et al. 2015). Concurrently, these symptoms deteriorate the individuals' independence, resulting in higher care costs (Tible et al. 2017). Given the expected dramatic increase in dementia prevalence, it is even more important to maintain the independence of people with dementia in order to reduce the burden on healthcare systems (World Health Organization 2021). Since pharmacological treatments have shown limited effectiveness (Madhusoodanan and Ting 2014), the focus on non-pharmacological interventions including psychosocial factors has increased.

Psychosocial factors in the context of dementia encompass a range of psychological and social aspects, including physical, cognitive, and social activities that have the potential to preserve or enhance daily functioning, interpersonal relationships, and overall well-being among individuals with dementia (McDermott et al. 2019; Moniz-Cook et al. 2011). A number of psychosocial factors have been identified that

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have promising implications for the treatment and care of people with dementia, including various lifestyle interventions. One factor, for instance, is physical activity, which – as reviews report – has been found to have beneficial effects on cognition, independent functioning, and psychological health (Nuzum et al. 2020; Cardona et al. 2021). Combining physical and cognitive interventions in a group-based setting seems to bring additional effects such as maintaining social activity, which is also a risk factor (Marioni et al. 2015), and quality of life (Tanaka et al. 2021; McDermott et al. 2019). Redesigning the environment, such as in a milieu therapeutic design, can improve cognitive status (Pedrinolla et al. 2019), aimless wandering, and aggressive and agitated behavior (Bautrant et al. 2019). Other examples found to have beneficial effects on dementia symptoms include cognitive stimulation (Chan et al. 2020; Bahar-Fuchs et al. 2019), music therapy (Elliott and Gardner 2018; Van der Steen et al. 2018), reminiscence therapy (Cuevas et al. 2020; Elfrink et al. 2018), and art (Hsiao et al. 2020; D’Cunha et al. 2019). A synthesis conducted by McDermott et al. (2019) evaluating 22 reviews on psychosocial factors provides evidence from 197 studies supporting the efficacy of multi-component exercise, including physical activity combined with cognitive stimulation, showing positive outcomes in improving physical, cognitive, and daily functioning, while also highlighting the potential importance of social integration. Although the positive effects of psychosocial factors on dementia are described in the literature, little is known about how and which psychosocial factors are already implemented in dementia care.

The aim of the study was to explore experiences of health professionals and informal caregivers regarding the use of psychosocial factors in the care and treatment of people with dementia as well as their perceived barriers and challenges.

Methods

We considered expert focus groups as a suitable method to explore health professionals’ and informal caregivers’ experiences of psychosocial factors in dementia care. Including participants from various health professions and informal caregivers in different care situations and of people with varying dementia types allowed the participants to exchange thoughts and ideas, thus extending the understanding of the research question (Krueger 2014). In this way, we increased the possibility of shedding light on the research questions from various perspectives. The expert groups were qualitative exploratory in nature.

Participants

Participants were recruited nationwide by telephone or email from a diversity of network partners known to the study team

as well as from interest groups in XX. Three focus groups were conducted, involving a total of 16 participants. Specifically, there were two focus groups with health professionals, with a group size of ten participants (five participants in each group), and one focus group with informal caregivers, consisting of six participants. We separated groups in this way to prevent a power imbalance between professionals and informal caregivers and to ensure that all participants could speak freely without shame and fear. The variety of participants is illustrated in Table 1. The two focus groups with health professionals consisted of professionals from different health services and services in the municipality. The other focus group with informal caregivers consisted of participants who care for people with dementia (the majority of care recipients had probable Alzheimer’s disease, one frontotemporal dementia) either at home or in geriatric care facilities.

Structure of the focus group interviews

The focus groups were conducted using a semi-structured interview guide. The interview guide was developed based on a previously conducted literature review and identified knowledge gaps. The guide focused on questions relating to (1) Which psychosocial factors respondents used in everyday life? (2) What positive effects can be observed when psychosocial factors are used? (3) How much effort is required to implement psychosocial factors?

The focus groups were conducted by the main moderator (XX) who asked the questions based on the interview guide. A co-moderator (YY) assisted the main moderator by time-keeping, taking notes, and ensuring that the discussion has covered all the topics to be discussed. Further, the co-moderator assisted the moderator in making sure that all participants were encouraged to make their voices heard and equally engage in the discussion. Due to Covid-19

Table 1 Participants in the focus group

Professions/Care situations	N
Self-employed occupational therapist	1
Occupational therapist in hospital	1
Neurologist	1
Employee of an inpatient geriatric care facility	1
Manager of an inpatient geriatric care facility	1
Leader of a day care service	1
Manager of a day care service	1
Volunteer with the Alzheimer Association	3
Informal caregivers of people with dementia who live in a geriatric care facility	2
Informal caregivers of people with dementia who live at home	4
Total	16

pandemic restrictions, all three focus groups were held in an online meeting room. This also enabled participants from all across XX to participate. The focus groups lasted about 90 min each and were audio recorded and transcribed verbatim before analysis using a transcription service. Transcribed files were manually checked for accuracy against recordings and clarified where needed. Audio files and transcripts were then anonymized. The interview was conducted, in adherence to the COREQ checklist (Tong et al. 2007) (Supplementary material, Table 1).

Preunderstanding

The main moderator (XX) is a registered nurse specialized in geriatric care. The co-moderator (YY) is a PhD student with a cognitive psychology background. Both carried out the data analysis, drawing on expertise in qualitative data analysis and in the field of dementia. Neither of them had any (prior) relationship with the participants.

Data analysis

A qualitative content analysis was found to be suited best for analyzing the focus group discussion given the limited pre-existing research on the topic of the actual inclusion of psychosocial factors in dementia care (Elo and Kyngäs 2008). Qualitative content analysis systematically guides subjective categorization of text-based data and as such can be used to identify themes without a large theoretical foundation (Hsieh and Shannon 2005).

In a first step, text files were loaded into NVivo12 qualitative software. Qualitative content analysis was based on Graneheim and Lundman (2004) and Hsieh and Shannon (2005) using a manifest and latent analysis approach (Graneheim et al. 2017). The manifest analysis was used to identify the content of the focus group discussions while the latent analysis was employed to identify the meaning of the health professionals' and informal caregivers' experiences in relation to psychosocial factors in dementia care. The two authors (YY, XX) read through all transcripts independently and repeatedly to get a sense of their content. Further, they identified categories and subcategories relating to the research questions in each focus group transcript. Through word by word reading, key thoughts or concepts for each underlying meaning unit of identified categories were generated independently and labeled with descriptive and low-interference codes (Graneheim and Lundman 2004). By comparing and discussing these codes, the initial coding scheme was developed (Hsieh and Shannon 2005). This coding scheme was used by YY and XX to independently code the first transcript. Data that did not fit any existing code were assigned a new code. Following this, the authors met to compare coded transcripts as well as to discuss and agree

upon the emerging new codes. The resultant final coding scheme containing initial as well as newly emerged codes was used to reanalyze the first transcript conjointly and to independently analyze the remaining two transcripts. Strong coder congruence was established for the latter (83.28 %). Finally, an overall synthesis of the reviewed categories was established to identify the latent themes (Graneheim and Lundman 2004). Credibility of the findings was supported by including direct quotations from the transcribed text to categories (Graneheim and Lundman 2004). Similarities and differences in the reports from health professionals and informal caregivers were identified. Examples from the analysis process are illustrated in Table 2.

Ethical approval

Prior to recruitment and data collection, the study was approved by the XXX ethics committee (XXX). Informed consent was obtained from all participants via mail prior to the focus group discussion.

Results

Six categories emerged from qualitative analysis, (1) Integration in everyday (professional) life, (2) Effects on dementia symptoms, (3) Preservation of a positive self-image, (4) Organizational aspects in everyday (professional) life, (5) Societal challenges, and (6) Role of informal caregivers. Key findings from the interviews are presented in Fig. 1 and provide a framework to illustrate the interplay of components that contribute to the inclusion of psychosocial factors in the care and treatment of people with dementia.

Integration in everyday (professional) life

Both groups, health care professionals and informal caregivers, recognize the value of integrating psychosocial factors in care, especially when they are aligned with the biography of the person with dementia. Health professionals emphasize using current interests and resources to enhance autonomy. A volunteer highlighted this by saying that *"just because someone used to be in the church choir doesn't mean they want to sing in the church choir now, or any other choir."* The importance of resource adaptation, as well as exploring the sudden decline of skills, was highlighted by an employee in a care facility who shared an example: *"We have a resident who has been doing crossword puzzles, solving them, all her life. All of a sudden she did not do it anymore. (...) Okay, hmm until a week ago she had this resource and what has changed now? (...) In the end it was that the eyesight just deteriorated. Yes then she got the questions read to her and lo and behold she could do the crossword puzzle again."*

Table 2 Example of analysis steps from quotation to category

Quotations	Codes	Subcategories	Categories
<i>"So I think it is very important not only to look at the past in terms of interests, but also to perceive the present and the current resources."</i>	Adaptation to current interests, biography and current resources	Adjustment of psychosocial factors	Integration in everyday (professional) life
<i>"I think that the better the patient is equipped with relatives who take care of him, the better he feels and I would say that this has an absolutely positive effect on the course of the disease."</i>	Social inclusion has a positive impact on dementia progression	Importance of social inclusion	Effects on the course of dementia
<i>"He used to be in the garden a lot and if you clarify this self-efficacy again with certain tasks, you can already see many positive changes in him."</i>	Meaningful activity promotes sense of competence	Experience of competence	Preservation of self-image
<i>"The fact that someone always has to go along represents the greatest expense and, of course, the small financial resources."</i>	Lack of funding and appropriate services prevents use of psychosocial services	Expenditure of psychosocial factors	Organizational aspects in everyday (professional) life
<i>"But there is just a very, very big fear. You don't want to have dementia because you can't control it, because you don't know what's going to happen, and that creates an aversion to the person with dementia."</i>	Social fear of dementia generates aversion to people with dementia	Dementia from the perspective of a meritocracy	Societal challenges

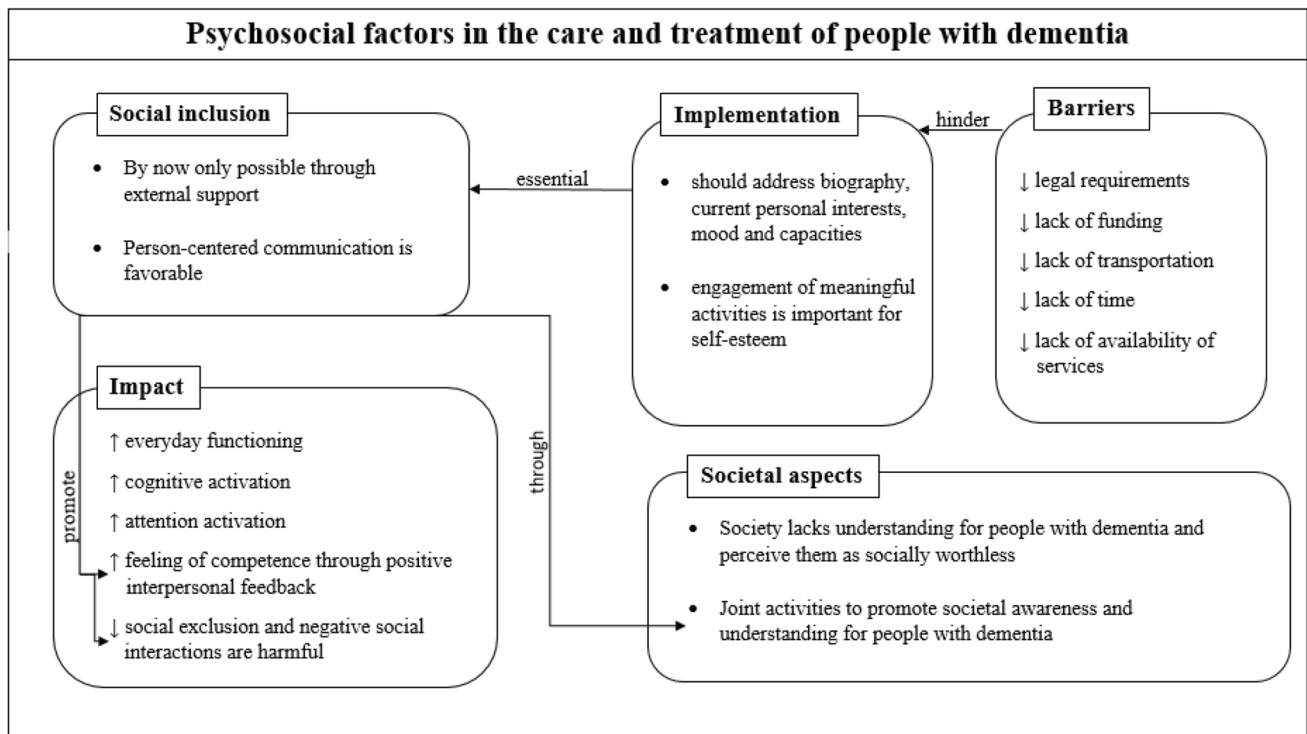


Fig. 1 Interplay of key components when investigating psychosocial factors in dementia care structures

Conversely, informal caregivers tend to emphasize that it is important to use psychosocial factors flexibly to respond to the current mood and situation of the person with dementia. For instance, an informal caregiver described adapting to her father's claim that he was too busy for the everyday companion by engaging in an activity that matched his interests: "(...) the everyday companion went out with him and raked the leaves and disposed of them. So always adapted to the situation, they [everyday companion] look very sensitively how they just find access to him [person with dementia], because otherwise he sends them away."

Occupational therapy was widely mentioned and used by both groups. Health professionals specifically mentioned other forms of therapy, such as music and cuddle therapy. However, health care professionals stressed the importance of recognizing therapists' professional competence and "the widespread denial of this therapeutic competence when dealing with dementia patients," especially from the perspective of family members.

Although both groups reported incorporating psychosocial factors into dementia care, different interventions are applied by both groups. Health professionals cited implementing singing, sports and cultural activities, creating routines, adapting living space, and training informal caregivers in their everyday professional practice. In contrast, informal caregivers reported more individualized approaches such as utilizing the support of an everyday companion and creating

personalized photo books. One informal caregiver reports that "it has become a ritual to go through the photo album with him [person with dementia] at least once a week, and it has been a completely new experience for him each time."

Effects on dementia symptoms

In general, the effects of psychosocial factors on the course of dementia are perceived as exclusively positive. The positive impact on everyday functioning, the activation of cognition and attention as well as on BPSDs was emphasized. A care facility manager reported that family members called her because of her psychosocial support services and said, "Wow, he's [person with dementia] become much calmer. Or he [person with dementia] has the will to write short sentences. He [person with dementia] can get in the shower by himself again."

Both groups perceive social inclusion as the most important psychosocial factor for a positive effect on the course of dementia. As a result, the loss of social relationships can promote worsening of dementia symptoms leading to loneliness and depressive symptoms. "Interpersonal loss is traumatizing for everyone. If we no longer have interpersonal relationships, then the negative curve rises and the dementia will in any case be noticeably progressive," as a care facility manager stated. The reversed effect was emphasized from an informal caregiver who observed that

“especially the little grandchildren (...) actually manage to make him [person with dementia] more cognitively fit, active and agile as well.”

Preservation of a positive self-image

Both health professionals and informal caregivers stressed the importance of promoting an environment in which a positive self-image can be preserved. One way of doing so is through engaging in meaningful activities. The participants emphasized that while doing so it is important to adapt these activities to the capacities of the person with dementia and to provide external encouragement. It should be noted that feelings of success can be quite different. An employee in a care facility noted that *“my sense of accomplishment is different from that of my partner or my friends. And I think that the affirmation of those little moments makes a lot of difference, even if I’m only successful with little things.”*

In contrast, regimentation and the denial of competence seems to lead to minimizing the expression of the self. For instance, an occupational therapist reported that when people with dementia are *“limited in their ability to make decisions, they simply shut down or do nothing out of frustration and lack of self-motivation.”*

While social inclusion was identified by both groups as an important psychosocial factor in dementia care, the quality of social relationships should not be ignored. These negative effects were also noted by an informal caregiver who had observed people with dementia in the nursing home during the pandemic who *“flourished due to limited contact with family members because no one was nagging at them [person with dementia] anymore saying, oh you can’t do that anymore, why can’t you do that anymore? You used to love to play pinball, why don’t you play pinball anymore? ”* The absence of negative social interaction created an environment in which people with dementia could maintain a more positive self-image.

Organizational aspects in everyday (professional) life

Lack of funding, inflexible frameworks, bureaucracy, and lack of transportation prevented health professionals and informal caregivers from incorporating psychosocial factors into dementia care. Health professionals mainly cited legal requirements, including staffing requirements, as well as inflexible service conditions and lack of funding as barriers to integrating effective psychosocial factors in care. A care facility manager reported the difficulty of integrating psychosocial measures because, for example, *“he cannot bring to life the situation of buying groceries and then boiling down applesauce from the purchased apples because there are simply too high hygienic and safety hurdles.”* The

inclusion of psychosocial factors for informal caregivers depended mostly on funding. Further, challenges are seen regarding transportation options, time, and the availability of the services/therapies in the area. One informal caregiver pointed out that *“what is absolutely underestimated is the time it takes to get the person with dementia in the chair and get them dressed. (...) It can take an hour for them to even leave the house (...) and all the stress of picking them up for an hour of music therapy is sometimes just too much. Especially since you cannot afford such services until you reach a certain level of care.”*

The suggestions for improvements varied between the two groups. While health care professionals would like to see less bureaucracy and more financial options, informal caregivers would like to see more inclusion of the interests and biographies of people with dementia in care and a change in medical service structures. For instance, one informal caregiver complained about a *“lack of services/funding for accompaniment to doctor’s visits’ and about inadequate accommodation of people with dementia in hospitals and wish “that one had the possibility to accompany dementia patients to the hospital and that extra rooms were created for this purpose.”*

Societal challenges

Even when the moderators directed the discussion toward the experience of psychosocial factors in dementia care, the participating health professionals and informal caregivers frequently returned to the societal challenges of integrating people with dementia. They identified two main barriers to the participation of people with dementia in society: One, that people with dementia can only experience social participation through external support, and two, that society lacks understanding of people with dementia. Health professionals highlight the social fear dementia creates in others leading to avoidance of people with dementia. Participants also indicated that having dementia leads to perceived social worthlessness, as *“performance in society is associated with cognition.”* In addition, informal caregivers complain that the BPSDs, such as aggression, wandering, and behavioral challenges, are not accepted in society and that the self of people with dementia is disrespected because people talk about them instead of with them. As an informal caregiver reported, people came up to her and complained that her mother was *“doing things that were out of convention instead of talking to her even though she was standing next to me.”*

The groups also identify ways of removing barriers to participation. Specifically, they advise promoting awareness and participation through joint activities between people with and without dementia. A care facility manager

reported to organize senior parties because in this way “*everyone comes together and everyone has the same feeling of accomplishment because such a party is the same for everyone.*”

Role of informal caregiver

Generally, it emerges that it is important that informal caregivers choose a positive way of communicating with people with dementia. While health professionals advise informal caregivers to use person-centered communication that focuses on the needs of the person with dementia, informal caregivers report communication styles that they have adopted individually and that always prove the person with dementia right in order to avoid conflict situations. An informal caregiver mentioned that it is only important that “*the answer satisfies him [person with dementia], so by no means make an objection (...) and always answer in the same casual tone.*” Only one informal caregiver reports having sought professional help and has since used “*a change of perspective in order to be able to put myself [informal caregiver] in the shoes of the person with dementia and to communicate with him at this level.*”

Beyond communication styles, health professionals advise to involve informal caregivers more and to inform about dementia. This is the only way to “*increase a greater understanding of the disease and has further a positive influence on the person with dementia in terms of preservation of independence, stability of the home situation and the inclusion of psychosocial factors in everyday life,*” as pointed out by a volunteer.

Overall interpretation

Despite differences in the care and treatment setting of people with dementia, the importance of psychosocial factors in dementia care was always emphasized. An overall synthesis of the categories generated from the data material reveals a comprehensive understanding expressed as the latent theme: A desire to do the best for people with dementia to enhance their everyday functionality and quality of life. It represents a conflict, in which health professionals and informal caregivers wanted to do as much as they can but are prevented by many factors.

Discussion

The core objective of this study was to investigate how health professionals and informal caregivers perceive psychosocial factors in the care and treatment of people with

dementia, including relevance, implementation, barriers, and challenges. Participants value the positive impact of psychosocial factors in dementia care, such as autonomy enhancement, cognitive activation, and most importantly, enjoyment and perception of competence. Yet, they emphasized that in order to achieve these effects, psychosocial factors must also be designed accordingly and individualized to the person with dementia. In essence, it is not primarily about which psychosocial factors are used, but that the biography as well as the current actual state with interests, mood, and capacity are included. In addition, the activities chosen should be meaningful to the person with dementia so that they can perceive themselves as competent. This observation is consistent with a previously conducted synthesis in which people with dementia indicated that they want to participate in personally meaningful activities in order to be connected to themselves, to others, and to the environment (Han et al. 2016). Providing meaningful activities that are specific to each person is also an important component of person-centered care that supports psychosocial well-being, meets psychological needs, and maintains the self (Edvardsson et al. 2014; Dementia Action Alliance 2013; Kelly 2010). Therefore, a person-centered approach to dementia care is highly conducive to effectively integrate psychosocial factors.

Participants reported that positive effects of psychosocial factors can be enhanced by social integration and that social experiences can serve as beneficial psychosocial treatments. Social isolation, on the other hand, exacerbates the progression of dementia. This is also consistent with previous findings showing that social isolation and loneliness impair cognitive function (Sachdev 2022). Recent studies have also found a neuropsychological link between social isolation and a decrease in gray and white matter volume, while social support was associated with better brain structure over time (van der Velpen et al. 2021; Felix et al. 2021) which may also reduce the risk of dementia later in life (Salinas et al. 2017). Therefore, social integration is important to prevent the development of dementia and to slow down its progression. It should be noted that the quality of the social contact was perceived of great importance: People with dementia should be supported and accepted by their environment without their competence being doubted or confronted with reproaches, because the personal attitude of the environment is of central importance for their well-being and the success of psychosocial factors. Findings also support the notion that disrespect and negative interactions can lead to self-withdrawal or even the worsening of symptoms. An appropriate form of communication with people with dementia must also be established. In a pilot study, the “talking sense programme,” an individualized, one to one, cognitive behavioral approach for developing knowledge,

skills, thinking, and behavior of dementia friendly carers in managing communication difficulties, revealed promising implications to reduce communication difficulties (Barnes and Markham 2018). This underscores the importance of such a program.

In general, people with dementia should be perceived as worthy individuals. Therefore, psychosocial factors should be individually tailored to the person with dementia to unfold their full impact. More time, less bureaucracy, competent staff, funding, and revision of medical service structures are needed to implement psychosocial factors on an individual basis. Model projects for the implementation in public medical systems are urgently needed. The required measures would amortize in the long run, by enabling people with dementia to remain independent for longer, which would reduce the burden on the health care system (Kindermann et al. 2012). In addition, there is promising evidence that psychosocial factors can alleviate BPSDs, which can pose a risk for secondary complications such as falls and hip fractures leading to emergency room admission and eventual institutionalization (Tible et al. 2017). This leads to higher costs for therapy and care.

However, even more change seems necessary. In our study, a recurring topic was the societal challenge of destigmatizing dementia and the integration of people with dementia into society. Recommended were more education as well as joint events between people with dementia and the general public to promote social understanding and dementia-friendly communities. The demand for dementia-friendly communities is gaining societal attention. In 2012, the German *Alliance for People with Dementia* laid the foundation for awareness and the importance of dementia-friendly communities, on the basis of which the National Dementia Strategy was developed and launched in 2020 (BMFSFJ & BMG 2020). Alongside XX, other countries such as the United Kingdom (Alzheimer's Society 2013) and Australia (Alzheimer's Australia Inc 2014) are promoting dementia-friendly communities to integrate people with dementia by creating supportive social and physical environments. While these efforts for inclusion and participation are a good first step, as the results of the study suggest, there is still much to be done.

A limitation of the current study is that the study was conducted in XXX. We believe that many of the points raised are relevant to other countries facing similar challenges to participation for people with dementia. It should be noted that the results can only serve as an orientation framework for care practice and cannot be generalized, as they are purely descriptive in nature and reflect the subjective perceptions of the participants. Consistent with the exploratory nature of this study and the associated small sample size, it was not possible to differentiate and contextualize the results with regard to various sociodemographic and socioeconomic

aspects, the type of dementia, and the severity. Given this, only a limited range of experiences could be considered, although a consistent overall picture nevertheless emerged.

Conclusion

The study reveals health professionals' and informal caregivers' perspective on psychosocial factors in dementia care. In concordance with the literature, health professionals and informal caregivers experience and notice the beneficial effect of psychosocial factors on cognitive functioning as well as on BPSDs. Psychosocial factors should be implemented within the current capacities, mood, and interests as well as the biography of the person with dementia for their full effect to unfold. Among psychosocial factors, social integration, social events, respect despite loss of abilities, and positive communication are considered very important. However, participants report a lack of time, inadequately qualified staff, bureaucracy, financial resources, flexible frameworks, and inadequate transportation as barriers to integrating psychosocial factors into dementia care. These barriers need to be overcome to more effectively integrate clinical research results into dementia care structures. Model projects overcoming these barriers should be implemented within a public medical health care system in order to maintain the independence and quality of life of people with dementia for as long as possible and thus reduce the burden on the health care system.

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Declarations

Ethics approval The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the

Helsinki Declaration of 1975, as revised in 2008. Prior to recruitment and data collection, the study was approved by the University Medicine Greifswald's ethics committee (BB 177/21).

Consent to participate Informed consent was obtained from all participants via mail prior to the focus group discussion.

Consent for publication Informed consent for publication was obtained prior to the focus group discussion.

Conflicts of interests The authors declare that they have no conflict of interests.

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