Original Article

Implementation of Non-pharmacological Interventions in Dementia Care: Family Caregiver Perspective

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Abstract

Background: Non-pharmacological interventions show promising positive effects on dementia symptoms. Since the majority of dementia care activities are performed by family caregivers, it is important to know how they perceive and implement such approaches. We aimed to investigate the extent to which non-pharmacological interventions are considered by family caregivers in dementia care and the barriers they encounter in implementing them.

Methods: A total of 30 family caregivers (mean age: 63.07 years, female: 70%) living inside (30%) and outside the homes (70%) of people with dementia participated. Descriptive data analysis was used to determine the frequency of non-pharmacological interventions implemented, perceived effects, lacking resources, and barriers, while inferential statistics were used to examine whether funding source varied between interventions with high versus low frequency.

Results: The most frequently implemented non-pharmacological interventions were initiating/maintaining social contact, cognitively stimulating and rehabilitative activities, and time in nature. In general, enjoyment was the most commonly perceived effect of non-pharmacological interventions. Additional effects were reported with respect to well-being, cognitive decline, autobiographical memory, perception of competence, and other symptoms. Major barriers were organizational burden, accessibility, and a lack of funding. Further, lacking resources included a lack of services (e.g., therapies, transport, group activities) and information on possible interventions.

Discussion: This study highlighted that family caregivers frequently implement non-pharmacological interventions in dementia care. Given the perceived positive effects on dementia symptoms, health care interventions are needed that address barriers and provide resources to foster the implementation of non-pharmacological interventions by family caregivers.

Keywords

family caregiver, dementia care, non-pharmacological intervention, dementia symptoms, caregiving challenges

Introduction

Dementias are not only a challenge for those affected and their family environment, it is also a major public health concern.[1,2] The primary cause of this concern is the memory loss; however, the person's thinking, behavior, and ability to perform activities of daily living also deteriorate,[3] resulting in a high financial, emotional, and social burden.[4] About 55 million people worldwide live with dementia and this situation will continue to worsen in the coming years since demographic changes such as decreasing birth rates, paired with increasing life expectancy,[5] result in a substantial increase in the number of people with dementia.[6] In light of this, identifying effective prevention strategies as well as measures to mitigate the progression of dementia has been highlighted as key elements in the public response to dementia.[1] Pharmacological treatments currently have a limited effect on the progression of the underlying disease.[7] Thus, non-pharmacological interventions have moved into the foreground with promising implications for dementia prevention and treatment.[8-10]

Studies have shown that non-pharmacological interventions can have positive effects for people with dementia by improving and maintaining cognitive performance, improving emotional well-being, maintaining functional daily living skills, and alleviating behavioral symptoms.[11] Among the measures that can be used to accomplish this are cognitive stimulation,[12] cognitive training,[13] occupational therapy,[14]

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reminiscence therapy,[15] aromatherapy,[16] and music therapy.[17] This established evidence of non-pharmacological interventions in dementia are well-recognized, so that the guidelines of the World Health Organization,[18] and the "German S3 guidelines on dementia,"[19] an evidence-based action framework for people with dementia in Germany, provide corresponding recommendations for the implementation of non-pharmacological interventions in dementia care. However, the extent to which non-pharmacological interventions are currently being considered in the treatment and care of people with dementia in Germany is unknown.

People with dementia generally require high levels of care, most of which is provided by family caregivers.[20] Most caregiving activities involve personal care,[20,21] although non-pharmacological interventions aim to improve the situation for people with dementia and their environment.[21,22] A systematic review indicated a general lack of funding for non-pharmacological interventions,[23] suggesting they are less likely to be due to the higher financial burden. A study investigating 3 different non-pharmacological interventions, including chair yoga, music intervention, and chair-based exercise, demonstrated how family caregivers reported noticeable changes in cognitive symptoms, physical function, mood, and behavioral symptoms in people with dementia at the end of the 12-week intervention.[22] Although the positive effects of non-pharmacological interventions on dementia symptoms are perceived by family caregivers and described in the literature,[11,21,22] to our knowledge, no study has examined in more detail the extent to which family caregivers incorporate non-pharmacological interventions into the care of people with dementia and the potential barriers they experience in implementing these interventions. Therefore, this study addresses the following research question: How are family caregivers currently dealing with the implementation of such approaches, what is the perceived effect, how are they funded, and what are the barriers to incorporating these approaches.

Methods

Study Design and Materials

A structured interview study was conducted to examine the application of and attitudes toward non-pharmacological interventions in dementia care from different health professional stakeholders as well as from family caregivers and people with dementia. In this work, we focus on family caregivers' experiences and perceptions of (1) personal experiences, including perceived barriers, and knowledge of non-pharmacological interventions, and the (2) effectiveness, applicability, and funding of non-pharmacological interventions. We investigated 2 types of family caregivers: (1) spouse caregivers (at home), and (2) relative caregivers (outside the home). Inclusion criteria were being (1) at least 18 years old, (2) capable of consent (not delirious/no impaired consciousness), (3) having sufficient visual and hearing abilities, and (4) no self-reported physical or mental instability. 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 Germany. A total of 30 family caregivers had participated in the study by July 2022. To gain a better understanding of our sample, we examined the characteristics of participants in terms of caregiver status, gender, age, and education (see Table 1).

Table 1. Characteristics of the Study Participants.

Participant characteristics	Frequency (n, %)/ (Mean, sd)
Status	
Caring spouse (at home)	9 (30%)
Relative caregivers (outside the home)	21 (70%)
Gender	
Female	21 (70%)
Male	9 (30%)
Age	63.07 years, 11.68 years
Min.	31 years
Max.	83 years
Education	
Secondary school	2 (6.67%)
Professional school	13 (43.33%)
College	7 (23.33%)
University	8 (26.67%)

Note. n = number of participants; % = frequency in the sample in per cent; sd = standard deviation; min. = minimum age; max. = maximum age.

Due to the nationwide recruitment approach, designed to obtain a comprehensive overview of non-pharmacological measures in dementia care across the country, interviews were conducted by telephone. If a participant requested an interview in person and this was logistically feasible, this request was complied with. A total of 5 interviews were conducted in person, 25 interviews by telephone.

Interview structure

The interviews lasted approximately 90 minutes, during which, first, the participants' demographic data were requested. Subsequently, structured questions were used to determine the use of non-pharmacological interventions in the following areas: (1) cognitive measures, (2) sensory measures, (3) therapeutic treatments, (4) physical activity programs, (5) measures to promote functional ability in daily life, (6) household activities, (7) educational opportunities, (8) social relationship management, and (9) leisure activities. The non-pharmacological interventions were based on the recommendations in the "German S3 guidelines on dementia."[19] In addition, we inquired regarding the perceived effectiveness and funding of

the reported non-pharmacological interventions as well as which non-pharmacological interventions were considered most useful for common dementia symptoms, what resources concerning the use of non-pharmacological interventions were missing, and what barriers they experienced when implementing non-pharmacological interventions.

Data Analysis

Descriptive data analysis was conducted to examine the differences in the use of non-pharmacological interventions as well as reported helpful non-pharmacological interventions for common dementia symptoms, missing resources, and barriers to implementing non-pharmacological interventions for family caregivers in dementia care. Because a general lack of funding for non-pharmacological interventions has been noted in the literature,[22] we wanted to investigate whether funding source varied between non-pharmacologic interventions with high versus low frequency. To access those differences in the type of funding, we grouped the reported non-pharmacological interventions into interventions mentioned by at least 50% of family caregivers and such that were not mentioned by as many caregivers (<50%). Between group differences were estimated using chi square tests for the type of funding. All analyses were carried out using Stata version 16 and a significance level of $p = .05$.

Ethical Approval

Prior to recruitment and data collection, the study was approved by the University Medicine Greifswald's ethics committee (BB 024/21).

Results

Use of Non-pharmacological Interventions

The most frequently implemented non-pharmacological interventions (over 80%) were, in descending frequency, regular visits from family, friends, and acquaintances, cognitive stimulation, cognitive rehabilitation, and spending time in nature. In contrast, all sensory procedures except massage, all therapy programs, the household activity baking, and leisure activities such as volunteering, drawing, handicrafts, playing musical instruments, learning or using foreign languages etc. were implemented by fewer caregivers (<20%, see Table 2).

Perceived Effects of non-pharmacological Interventions

Enjoyment (86.67%) was the most frequently cited effect of the non-pharmacological interventions used, followed by perceptions of competence (50%) and well-being (46.67%). A total of 37 different effects were mentioned by family caregivers and addressed a wide range of improved domains,

Table 2. Reported Use of Non-pharmacological Interventions in Dementia Care by Family Caregivers.

Non-pharmacological intervention	Application (n, %)
Cognitive measures	
Cognitive stimulation	26 (88.67)
Cognitive training	18 (60)
Sensory measures	
Massages	9 (30)
Aromatherapy	2 (6.67)
Snoezeln	2 (6.67)
Phototherapy	0 (0)
Neurofeedback	0 (0)
Therapeutic treatments	
Animal-assisted therapy	5 (16.67)
Music therapy	2 (6.67)
Dance therapy	1 (3.33)
Art therapy	0 (0)
Drama therapy	0 (0)
Physical activity programs	
Physical activity programs	11 (36.67)
Measures to promote functional ability in daily life	
Cognitive rehabilitation	25 (83.33)
Occupational therapy	12 (40)
Household activities	
Diet	16 (53.33)
Cooking	14 (46.67)
Household cleaning	14 (46.67)
Doing the laundry	7 (23.33)
Baking	5 (16.67)
Repair broken items	2 (6.67)
Educational opportunities	
Visit to counseling centers (information events, if necessary)	18 (60)
Support groups	13 (43.33)
Groups for people with dementia/ and relatives	12 (40)
Participation in psychoeducational patient groups	10 (33.33)
Social relationship management	
Regular visits from family, friends, and acquaintances	28 (93.33)
Regular phone calls with family, friends, and acquaintances	20 (66.67)
Regular trips with family, friends, and acquaintances	20 (66.67)
Accepting neighborly help	14 (46.67)
Use of a visiting service	12 (40)
Meetings in groups or clubs	3 (10)
Volunteering	2 (6.67)
Use of telephone services (e.g., telephone circle, pastoral care)	1 (3.33)
Leisure activities	
Spending time in nature	24 (80)
Watching TV	23 (76.67)
Reading books, newspapers, and magazines	22 (73.33)
Listening to music	20 (66.67)

(continued)

Table 2. (continued)

Non-pharmacological intervention	Application (n, %)
Singing	19 (63.33)
Travel/vacation	17 (56.67)
Parlor games like card games, board games, etc.	17 (56.67)
Gardening	16 (53.33)
Physical activities during free time	16 (53.33)
Puzzles like Sudoku, crossword puzzles	14 (46.67)
Dancing	14 (46.67)
Cultural offers (cinema, museums, theater, art exhibitions, theater)	12 (40)
Pet care	11 (36.67)
Attendance at religious events	10 (33.33)
Needlework (crochet, sew, knit, embroider, etc.)	7 (23.33)
Learning/using a foreign language	5 (16.67)
Drawing	4 (13.33)
Handicrafts	4 (13.33)
Playing musical instrument	4 (13.33)
Others mentioned	7 (23.33)
Summer party, Celebrating the holidays with relatives	1 (3.33)
Creating a cozy atmosphere, cuddling together	1 (3.33)
Treatment of posture and behavior during eating and drinking	1 (3.33)
Computer games	1 (3.33)
Validation	1 (3.33)
Visiting the graves of relatives	1 (3.33)
Application of a tablet-based app with various games	1 (3.33)

Note. n = number of participants mentioned to apply the non-pharmacological intervention; % = frequency in the sample in percent.

including cognitive-related areas as well as relaxation, social contact, effectiveness in daily living, support, health-related, and emotional aspects (see Table 3).

Funding of Non-pharmacological Interventions

Just over 69% of non-pharmacological interventions were reported as not funded. Specifically, either the people with dementia themselves or the caregiver initiated the intervention so that no external costs occurred. This type of funding was reported significantly more frequently for interventions mentioned by at least 50% of caregivers than for interventions that were mentioned by less than 50 % of caregivers (X^2 [15, N = 30] = 33.3, $p > .004$). No significant difference was found for any other funding source (see Table 4).

The second most common source of funding was the nursing home or day care center (53.85%), where complete care is financed by nursing care insurance and personal contributions, but family caregivers and people with dementia do not have to pay separately for non-pharmacological interventions, followed by self-funding (26.92%), other funding sources (23.08%) such as association funds, donations and voluntary work, and health or nursing care insurance (19.23%). Rarely implemented interventions (mentioned by less than 50% of the caregivers) were significantly more often paid for by the person with dementia or the caregiver themselves or funded from other sources than frequently implemented interventions (see Table 3). In comparison, frequently implemented interventions (mentioned by at least 50% of the caregivers) were funded by the nursing home or day care center (see Table 4).

Effective Non-pharmacological Interventions for Common Dementia Symptoms

On the questions around family caregiver perceptions as most effective for dementia symptoms, social inclusion was reported by most participants (see Table 5), particularly visits and shared activities. Family caregivers perceived social inclusion to have a positive effect on people with dementia, promoting well-being, delaying cognitive decline, helping with depression, and help with disorientation.

For behavioral problems, time in nature was perceived as the best mean to manage this problem. For aggression, physical activity, communication, and behavioral training for family caregivers were reported as effective measures. For sleeping problems, routines were the most frequently cited intervention. Other frequently mentioned effective interventions reported by over 20% of the sample were leisure activities, cognitive training, and a stable structure of daily routines and environmental surrounding that help people with dementia navigate their surroundings and reduce confusion or disorientation. Further details can be found in Table 5.

Lacking Resources for Implementing Non-pharmacological Interventions

Family caregivers desire for the person with dementia to access on-site services, however, there is a shortage of resources available. These include general care services such as visiting services, day care, animal-assisted therapy, art and occupational therapy, and recreational activities such as senior sports and group activities. Further, family caregivers would like to see additional services for people with dementia such as transport services to the respective interventions. Another missing resource is knowledge and support for dealing with behavioral symptoms (such as the reversed day-night rhythm).

Barriers to the Use of Non-pharmacological Interventions

Caregivers cited difficulties in organizing the (participation in the) intervention as the major barrier (46.7%), followed by poor local accessibility, lack of funding, and no discernible

Table 3. Most Common Perceived Effects of Non-pharmacological Interventions in Dementia Care by Family Caregivers.

Non-pharmacological intervention	Effects
Cognitive measures	
Cognitive stimulation	Enjoyment (95.65%), improved well-being (91.3%), awakening of old memories (86.96%)
Cognitive training	Enjoyment (72.73%), improved well-being (54.55%), perception of competence (45.45%)
Sensory measures	
Massages	Relaxation (100%), calming (66.67%), well-being (55.56%)
Aromatherapy	No effects reported
Snoezeln	Relaxing (100%), calming (100%)
Phototherapy	No effects reported
Neurofeedback	No effects reported
Therapeutic treatments	
Animal-assisted therapy	Calming (100%), fine motor skills (60%)
Music therapy	Enjoyment (100%), well-being (100%), address emotions (100%)
Dance therapy	Physical activity (100%), awakening of old memories (100%)
Art therapy	No effects reported
Drama therapy	No effects reported
Physical activity programs	
Physical activity programs	Enjoyment (72.73%), mobility (72.73%)
Measures to promote functional ability in daily life	
Cognitive rehabilitation	Orientation (89.47%), security (57.89%)
Occupational therapy	Enjoyment (75%), cognition (75%), independence (50%)
Household activities	
Diet	Preservation of health (81.82%), well-being (45.45%)
Cooking	Enjoyment (76.92%), perception of competence (61.54%), independence (46.15%)
Household cleaning	Perception of competence (80%), independence (60%)
Doing the laundry	Perception of competence (80%), independence (60%)
Baking	Perception of competence (80%), independence (60%)
Repair broken items	Perception of competence (100%)
Educational opportunities	
Visit to counseling centers (information events, if necessary)	Help (90%), support (80%), information (70%)
Support groups	Exchange (83.33%), help (72.22%)
Groups for people with dementia/and relatives	Exchange (83.33%), enjoyment (66.67%), help (58.33%)
Participation in psychoeducational patient groups	Help (92.31%), support (84.62%), information (69.23%)
Social relationship management	
Regular visits from family, friends, and acquaintances	Enjoyment (88.24%), social contact (76.47%)
Regular phone calls with family, friends, and acquaintances	Enjoyment (76%), well-being (68%), social contact (60%)
Regular trips with family, friends, and acquaintances	Enjoyment (88.24%), pleasant experiences (82.35%), movement (70.59%)
Accepting neighborly help	Relief (90.91%), support (81.82%), social participation (63.64%)
Use of a visiting service	Enjoyment (83.33%), relief (66.67%), activation (58.33%)
Meetings in groups or clubs	Social participation (83.33%)
Volunteering	Orientation (100%)
Use of telephone services (e.g., telephone circle, pastoral care)	Feel understood (100%)
Leisure activities	
Spending time in nature	Relaxing (100%), well-being (90.48%), enjoyment (85.71%)
Watching TV	Enjoyment (91.67%), pursuing interests (91.67%), routine (83.33%)
Reading books, newspapers and magazines	Enjoyment (91.67%), conversation stimulating (83.33%)
Listening to music	Enjoyment (100%), awakening of old memories (91.67%), address emotions (83.33%)

(continued)

Table 3. (continued)

Non-pharmacological intervention	Effects
Singing	Enjoyment (94.12%), awakening of old memories (88.24%), activation (88.24%)
Travel/vacation	Enjoyment (92.31%), well-being (84.62%), pleasant experiences (76.92%)
Parlor games like card games, board games, etc.	Enjoyment (91.67%), well-being (83.33%), perception of competence (83.33%)
Gardening	Enjoyment (88.89%), well-being (77.78%), perception of competence (77.78%)
Physical activities during free time	Enjoyment (85.71%), movement (78.57%), well-being (78.57%)
Puzzles like Sudoku, crossword puzzles	Cognition (87.5%), enjoyment (75%)
Dancing	Enjoyment (100%), movement (85.72%), social participation (86.72%)
Cultural offers (cinema, museums, theater, art exhibitions, theater)	Enjoyment (100%), activation (80%)
Pet care	Routine (100%), relaxing (100%), activation (90.01%)
Attendance at religious events	Enjoyment (83.33%), social participation (83.33%), calming (66.67%)
Needlework (crochet, sew, knit, embroider, etc.)	Enjoyment (100%), well-being (75%), perception of competence (75%)
Learning/using a foreign language	Cognition (100%), enjoyment (66.67%), perception of competence (66.67%)
Drawing	Enjoyment (100%), fine motor skills (66.67%), well-being (66.67%)
Handicrafts	Enjoyment (100%), fine motor skills (66.67%), well-being (66.67%)
Playing musical instrument	Enjoyment (100%), perception of competence (75%)
Others mentioned	
Summer party, Celebrating the holidays with relatives	Social participation (100%), enjoyment (100%)
Creating a cozy atmosphere, cuddling together	Calming (100%), relaxing (100%)
Treatment of posture and behavior during eating and drinking	Mindful eating (100%), prevention of swallowing (100%)
Computer games	Perception of competence (100%), cognition (100%), enjoyment (100%)
Validation	Improvement of social relationship management (100%)
Visiting the graves of relatives	Routine (100%)
Application of a tablet-based app with various games	Concentration (100%), attention (100%), cognition (100%)

Note. % = frequency of the perceived effect for the respective intervention.

benefit of the intervention (see Figure 1). In contrast, insecurity regarding contact with strangers, fear of stigmatization, and lack of knowledge about the content of the offer do not seem to be major barriers to the use of non-pharmacological interventions (see Figure 1).

Discussion

The aim of our study was to investigate what kind of non-pharmacological interventions are implemented into dementia care by family caregivers, how they are funded and what effects, lack of resources, and barriers they perceive when implementing these interventions. Family caregivers mentioned that maintaining/initiating social contact, cognitively stimulating and rehabilitative activities, and time spent in nature were frequently implemented. Non-pharmacological interventions such as sensory or therapeutic approaches were least frequently implemented.

The fact that sensory or therapeutic approaches were used least frequently is probably not due to lower efficacy. Indeed, literature reviews show positive effects for sensory and therapeutic approaches[24,25] of which the effectiveness to improve behavioral and psychological symptoms of dementia and to increase well-being and quality of life is perceived by both, people with dementia and their caregivers.[24,25] Rather, the relatively low frequency of use could be related to the fact that these therapies usually have to be self-financed. Our study finds evidence that rarely used interventions were more likely to be self-paid or funded from other sources. In contrast, interventions that can be implemented at little or no financial cost by the person with dementia themselves or by the caregiver are implemented significantly more often. In the literature, this observation is supported by studies indicating a high financial burden for dementia care activities,[20] suggesting that non-pharmacological interventions that need to be self-funded have little to no implementation. On the other hand, we observe a high frequency of self-initiated interventions indicating that caregivers show a great interest in using non-pharmacological interventions in dementia care but try to avoid costs. In addition, the use of fee-based

Table 4. Reported Funding for Non-pharmacological Interventions.

Funding	Total (n = 52) (%)	Frequently implemented non-pharmacological interventions (n = 17)		Rarely implemented non-pharmacological interventions (n = 35)		X^2	*p*	Mean (sd)	Min.	Max.
Initiated by relatives/ self (no external cost)	36 (69.23)	16 (94.12%)	Cognitive measures (cognitive stimulation, cognitive training), Measures to promote functional ability in daily life (cognitive rehabilitation), Leisure activities (e.g., reading, gardening, parlor games), Social relationship management (visits and trips with family, friends and acquaintances)	20 (57.14%)	Leisure activities (e.g., playing musical instrument, puzzles, cultural offers, dancing, needlework etc.), Social relationship management (e.g., attendance at religious event, use of a visiting service, accepting neighbourly help) Household activities (doing the laundry, household cleaning, cooking, baking), Sensory measures (aromatherapy, massages), physical activity programs	33.3	.004	11.57 (4.85)	1	20
Nursing home/day care center	28 (53.85)	11 (64.71%)	Cognitive measures (cognitive stimulation, cognitive training), Measures to promote functional ability in daily life (cognitive rehabilitation),Leisure activities (e.g., reading, gardening, parlor games, singing)	17 (48.57%)	Leisure activities (e.g., playing musical instrument, puzzles, dancing, drawing, handicrafts etc.), Social relationship management (e.g., attendance at religious event, groups for people with dementia/ and relatives, support groups), Household activities (household cleaning, cooking, baking), Sensory measures (snoezeln, massages), Therapeutic treatments (dance therapy, animal-assisted therapy)	4.44	.349	1.8 (4.03)	0	19
Relatives/self	14 (26.92)	3 (17.65%)	Leisure activities (Parlor games, Vacation, spending time in nature, playing musical instrument)	11 (31.43%)	Leisure activities (e.g., puzzles, handicrafts, dancing), Social relationship management (meeting in groups or clubs, groups for people with dementia/and relatives, support groups), Therapeutic treatments (animal-assisted therapy), Physical activity programs,	1.63	.804	1.07 (1.31)	0	5
Others	12 (23.08)	2 (11.76%)	Leisure activities (reading), Educational opportunities (visit to counseling centers),	10 (28.57%)	Leisure activities (cultural offers, dancing), Social relationship management (attendance at religious event, groups for people with dementia/and relatives, support groups, volunteering, use of telephone service, participation in psychoeducational patient groups, accepting neighborly help)	6.6	.359	2.27 (1.31)	0	5
Health /nursing care insurance	10 (19.23)	3 (17.65%)	Cognitive measures (cognitive training), Leisure activities (vacation, physical activity during free time)	7 (20%)	Measures to promote functional ability in daily life (occupational therapy), Leisure activities (drawing, accepting), Social relationship management (support groups, accepting neighborly help), Sensory measures (massages), Therapeutic treatments (music therapy), Physical activity programs	4.29	.509	1.2 (0.97)	0	3

Note. n = number of queried non-pharmacological measures mentioned either >50 %,<50% or in total in the sample; % = frequency of funding source cited by family caregivers for queried non-pharmacological interventions either >50%, <50%, or in total the sample, in per cent; *p* = *p* – value; X^2 = Pearson chi-squared; sd = standard deviation; Min. = minimum number of family caregivers who indicated this type of funding; Max. = maximum number of family caregivers who indicated this type of funding.

Table 5. Reports of Effective Measures for Various Dementia Symptoms.

	In general	Promotion of well-being	Delay of cognitive decline	Helpful with behavioral problems	Avoidance of sleep problems	Helpful with urge to move	Helpful with depression	Against orientation uncertainties
Effective measures	Frequency (n, %)							
Social inclusion	19 (63.33)	13 (43.33)	15 (50)	2 (6.67)	—	—	10 (33.33)	11 (36.67)
Household activities	4 (13.33)	5 (16.67)	2 (6.67)	—	—	—	—	—
Individual activities	7 (23.33)	4 (13.33)	3 (10)	—	6 (20)	4 (13.33)	—	1 (3.33)
Routines	7 (23.33)	4 (13.33)	4 (13.33)	—	8 (26.67)	—	2 (6.67)	4 (13.33)
Promote independence	2 (6.67)	2 (6.67)	2 (6.67)	—	—	—	—	—
Leisure activities	6 (20)	7 (23.33)	4 (13.33)	—	—	—	2 (6.67)	—
Solid external structures	—	1 (3.33)	—	—	—	2 (6.67)	—	10 (33.33)
Relaxation/Calmness	2 (6.67)	5 (16.67)	3 (10)	3 (10)	2 (6.67)	1 (3.33)	1 (3.33)	1 (3.33)
Physical activity	10 (33.33)	6 (20)	7 (23.33)	—	4 (13.33)	8 (26.67)	2 (6.67)	—
Appreciation	2 (6.67)	1 (3.33)	1 (3.33)	—	—	—	1 (3.33)	—
Distraction	—	1 (3.33)	—	3 (10)	—	1 (3.33)	2 (6.67)	—
Physical contact	3 (10)	2 (6.67)	—	4 (13.33)	—	1 (3.33)	1 (3.33)	1 (3.33)
Animals	1 (3.33)	1 (3.33)	—	—	—	—	—	—
Reminiscence work	2 (6.67)	—	2 (6.67)	1 (3.33)	—	—	—	3 (10)
Therapy concepts	4 (13.33)	—	1 (3.33)	—	1 (3.33)	—	3 (10)	—
Spend time in nature	3 (10)	—	—	8 (26.67)	—	—	2 (6.67)	—
Communication and behavioral training for family caregivers	4 (13.33)	—	1 (3.33)	—	1 (3.33)	8 (26.67)	1 (3.33)	—
Cognitive training	—	—	2 (6.67)	—	—	—	—	7 (23.33)

Note. n = number of participants reported the effectiveness of the cited measure; % = frequency in the sample in percent.

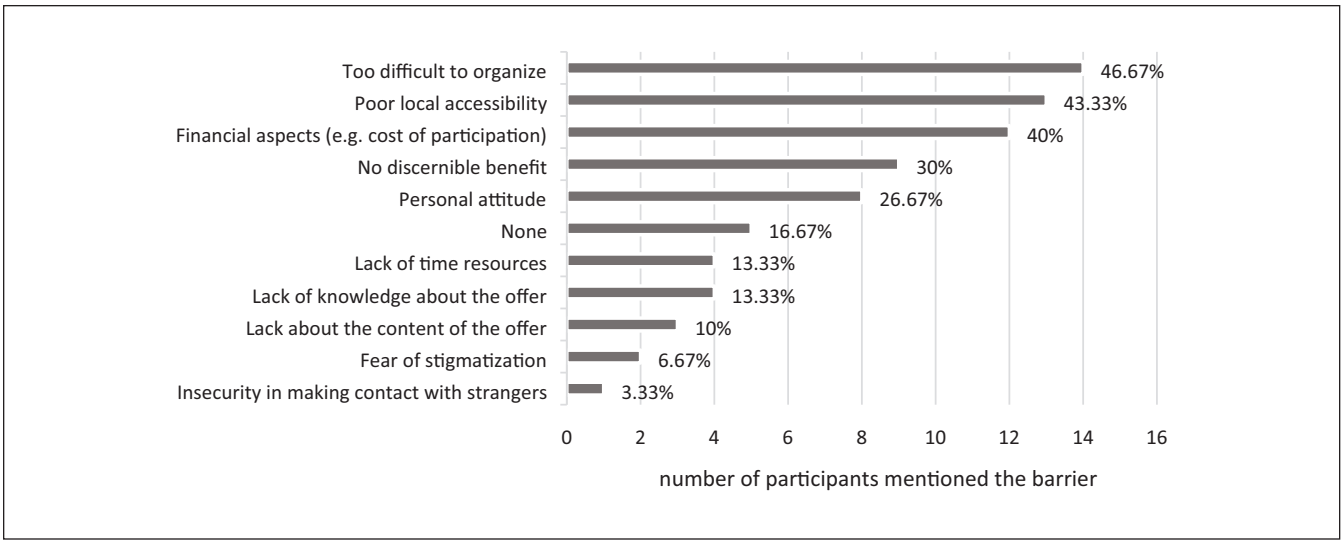

Figure 1. Family caregivers' barriers to implementing non-pharmacological interventions in dementia care.

services often involves more organizational effort, a lack of knowledge or information about the possibility of these services, and a lack of availability close to home.

Among the implemented non-pharmacological interventions, family caregivers frequently perceived enjoyment, sense of competence, and well-being as the effects. This observation is consistent with a previously conducted systematic review that examined the efficacy of non-pharmacological interventions in dementia patients, showing that activities perceived as enjoyable by the person with dementia have a positive effect on well-being, self-perception, and self-esteem.[26] An important aspect for experiencing positive effects is the consideration of the interests of people with dementia.[27]

The greatest impact on dementia symptoms is the result of social inclusion, as our participating family caregivers reported. Indeed, regular visits are the most commonly mentioned non-pharmacological intervention by our caregivers. Previous research has shown that being socially active can be protective against cognitive decline,[28] enhance quality of life for people with dementia,[29,30] and have also beneficial effects on behavioral symptoms.[31] This is particularly true when a social activity is combined with other non-pharmacological interventions, such as musical activities as singing or listening to music together.[32] It is therefore of great importance to involve people with dementia in social activities in order to improve both dementia symptoms and the quality of life of those affected.

Family caregivers indicated that they need effective support services for the implementation of non-pharmacological interventions in dementia care, such as transportation services or appropriate services in rural areas. The need also reflects caregivers' perceived barriers to implementing non-pharmacologic interventions: difficulties in organizing and lack of local offers. Funding and no discernible benefit of the intervention were also cited as barriers. Several studies report that caring for a person with dementia results in psychological distress, physical illness, and high financial expenses for family caregivers.[33,34] It is therefore particularly important to relieve the burden on family caregivers with appropriate support. The need to allocate more resources to non-pharmacological interventions and to increase education about their beneficial effects was identified not only in our study in the German context, but also in a systematic review that included several studies within and outside Europe.[35] Findings from an intervention study highlight that referral and support of family caregivers through appropriate strategies such as communication techniques, environmental adaptations, task simplification, or use of meaningful activities can help manage the behavioral symptoms of dementia and also result in reduced financial expenditures.[36] This underscores the importance of supporting family caregivers more by teaching everyday techniques in dementia care.

There are some limitations to this research. One aspect is that the current study was conducted in Germany. Nonetheless, we believe that many of the points raised are relevant to other countries facing similar challenges for family caregivers, as our results broadly line up with previous findings in the literature. It should be noted that the results provide only an initial, descriptive overview of family caregivers' views and differentiation regarding the type of dementia and the characteristics of the caregiving situation must be evaluated in further research. Moreover, caregivers can report only their individual experiences that are based on access to information. These represent not an objective but a subjective view on the situation.

Conclusion

Findings from our study suggest that non-pharmacological interventions are frequently implemented by family caregivers who notice positive effects on dementia symptoms. Social

contact, in particular, is perceived to promote well-being, delay cognitive decline, help with depression, and eliminate orientation uncertainties. However, the implementation of non-pharmacologic interventions depends on organizational effort, funding, local access to offers, and whether benefit of the intervention is discernable. Therefore, education about non-pharmacological interventions in dementia care should be part of the counseling provided to people with dementia and their family caregivers and to support them in their implementation. In home care, informal caregivers can engage the person with dementia in daily activities with as little assistance as possible, allow them to participate in social life, create memory books to relive memories, and find meaningful activities based on the current interests and abilities of the person with dementia. Future investigations should develop programs that support caregivers in implementing simple and cost-effective non-pharmacological interventions. Only in this way, the full potential of non-pharmacological interventions can be realized in order to maintain a good quality of life for as long as possible. Effective implementation of non-pharmacological measures might also alleviate caregiver burden as well as nursing care costs and therefore be considered as critical components of home health care management and practice.

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Previous Publications

None.

Declaration of Conflicting Interests

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Ethics Approval and Consent to Participate

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.

Availability of Data and Materials

Data available only for proof of scientific validity. Due to privacy/ethical requirements data cannot be made accessible to external persons.

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References

1. Livingston G, Sommerlad A, Orgeta V, et al. The lancet international commission on dementia prevention and care. *Lancet*. 2017;390(10113):2673-2734.
2. The Lancet Public H. Reinvigorating the public health response to dementia. *Lancet Public Health*. 2021;6(10):e696. doi:10.1016/s2468-2667(21)00215-2
3. Kumar A, Sidhu J, Goyal A, Tsao JW. *Alzheimer Disease*. StatPearls Publishing; 2021.
4. Gaugler J, James B, Johnson T, et al. 2022 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18(4):700-789.
5. Council NR, Population Co. *Aging and the Macroeconomy: Long-term Implications of An Older Population*. National Academies Press; 2013.
6. Shin J-H. Dementia epidemiology fact sheet 2022. *Ann Rehabil Med*. 2022;46(2):53-59. doi:10.5535/arm.22027
7. Madhusoodanan S, Ting MB. Pharmacological management of behavioral symptoms associated with dementia. *World J Psychiatry*. 2014;4(4):72.
8. Arora D, Gayatri Devi R, Jothi Priya A. Knowledge and awareness about the connection between lifestyle and dementia among adolescents. *J Pharm Sci*. 2021;33:313-321.
9. Magierski R, Sobow T, Schwertner E, Religa D. Pharmacotherapy of behavioral and psychological symptoms of dementia: state of the art and future progress. *Front Pharmacol*. 2020;11:1168.
10. Zucchella C, Sinforiani E, Tamburin S, et al. The multidisciplinary approach to Alzheimer's disease and dementia. A narrative review of non-pharmacological treatment. *Front Neurol*. 2018;9:1058.
11. McDermott O, Charlesworth G, Hogervorst E, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Mental Health*. 2019;23(4):393-403.
12. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev*. 2012;2:CD005562.
13. Gates NJ, Rutjes AW, Di Nisio M, et al. Computerised cognitive training for 12 or more weeks for maintaining cognitive function in cognitively healthy people in late life. *Cochrane Database Syst Rev*. 2020;2:CD012277.
14. Bennett S, Laver K, Voigt-Radloff S, et al. Occupational therapy for people with dementia and their family carers provided at home: a systematic review and meta-analysis. *BMJ Open*. 2019;9(11):e026308.
15. Woods B, O'Philbin L, Farrell EM, Spector AE, Orrell M. Reminiscence therapy for dementia. *Cochrane Database Syst Rev*. 2018;3:CD001120.
16. Ball EL, Owen-Booth B, Gray A, Shenkin SD, Hewitt J, McCleery J. Aromatherapy for dementia. *Cochrane Database Syst Rev*. 2020;8:CD003150.
17. Moreno-Morales C, Calero R, Moreno-Morales P, Pintado C. Music therapy in the treatment of dementia: a systematic review and meta-analysis. *Front Med*. 2020;7:160.
18. Chowdhary N, Barbui C, Anstey KJ, et al. Reducing the risk of cognitive decline and Dementia: WHO recommendations. *Front Neurol*. 2021;12:765584. doi:10.3389/fneur.2021.765584
19. Jessen F, Spottke A, Deuschl G, Jansen S, Maier W. *S3-Leitlinie Demenzen*. Springer Berlin Heidelberg; 2017.

20. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2022;11:217-228.
21. Neubauer S, Holle R, Menn P, Grossfeld-Schmitz M, Graesel E. Measurement of informal care time in a study of patients with dementia. *Int Psychogeriatr*. 2008;20(6):1160-1176.
22. Park J, Howard H, Tolea MI, Galvin JE. Perceived benefits of using nonpharmacological interventions in older adults with Alzheimer's disease or dementia with Lewy bodies. *J Gerontol Nurs*. 2020;46(1):37-46.
23. Connors MH, Quinto L, McKeith I, et al. Non-pharmacological interventions for Lewy body dementia: a systematic review. *Psychol Med*. 2018;48(11):1749-1758. doi:10.1017/s0033291717003257
24. Patel B, Perera M, Pendleton J, Richman A, Majumdar B. Psychosocial interventions for dementia: from evidence to practice. *Adv Psychiatric Treat*. 2014;20(5):340-349. doi:10.1192/apt.bp.113.011957
25. Hulme C, Wright J, Crocker T, Oluboyede Y, House A. Non-pharmacological approaches for dementia that informal carers might try or access: a systematic review. *Int J Geriatr Psychiatry*. 2010;25(7):756-763.
26. Lin RSY, Yu DSF, Li PWC, Masika GM. *The Effectiveness of Non-pharmacological Interventions Targeting Neuropsychiatric Symptoms Among Persons With Preclinical and Mild Dementia: A Systematic Review and Network Meta-analysis*. Wiley Online Library; 2021.
27. Cohen-Mansfield J. Nonpharmacologic treatment of behavioral disorders in Dementia. *Curr Treat Options Neurol*. 2013;15(6):765-785. doi:10.1007/s11940-013-0257-2
28. Sachdev PS. Social health, social reserve and dementia. *Curr Opin Psychiatry*. 2022;35(2):111-117.
29. Moyle W, Fetherstonhaugh D, Greben M, Beattie E. Influencers on quality of life as reported by people living with dementia in long-term care: a descriptive exploratory approach. *BMC Geriatrics*. 2015;15(1):50. doi:10.1186/s12877-015-0050-z
30. Birt L, Poland F, Csipke E, Charlesworth G. Shifting dementia discourses from deficit to active citizenship. *Sociol Health Illn*. 2017;39(2):199-211.
31. Arai A, Khaltar A, Ozaki T, Katsumata Y. Influence of social interaction on behavioral and psychological symptoms of dementia over 1 year among long-term care facility residents. *Geriatr Nurs*. 2021;42(2):509-516. doi:10.1016/j.gerinurse.2020.09.008
32. Scales K, Zimmerman S, Miller SJ. Evidence-based nonpharmacological practices to address behavioral and psychological symptoms of Dementia. *Gerontologist*. 2018;58(suppl_1):S88-S102. doi:10.1093/geront/gnx167
33. Campbell P, Wright J, Oyebode J, et al. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry*. 2008;23(10):1078-1085.
34. Ringer T, Hazzan AA, Agarwal A, Mutsaers A, Papaioannou A. Relationship between family caregiver burden and physical frailty in older adults without dementia: a systematic review. *Syst Rev*. 2017;6(1):1-12.
35. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev*. 2015;62(3):340-350.
36. Rose KC, Gitlin LN. Background characteristics and treatment-related factors associated with treatment success or failure in a non-pharmacological intervention for dementia caregivers. *Int Psychogeriatr*. 2017;29(6):1005-1014. doi:10.1017/s1041610217000205