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What are best practices for involving family caregivers in interventions aimed at responsive behaviour stemming from unmet needs of people with dementia in nursing homes: a scoping review

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ABSTRACT

Objectives This study aimed to determine best practices for involving family caregivers in interventions aimed at preventing and reducing responsive behaviour stemming from unmet needs, including pain.

Design Scoping review, reported according to the Preferred Reporting Items for Systematic Reviews, Meta-Analyses extension for Scoping Reviews reporting guideline.

Data sources PubMed, Embase, Emcare, Web of Science, COCHRANE Library, PsycINFO, Academic Search Premier and Cinahl searched up to 23 July 2023.

Eligibility criteria Studies reporting on family involvement in interventions for nursing home residents with dementia were included.

Data extraction and synthesis Two researchers independently extracted the data, followed by a content analysis.

Results Of the 1486 records screened, 20 studies were included. Family caregivers were involved in interventions aimed at planning care, life review (eg, documentation of life experiences of their relative), and selecting activities for their relative. Family caregivers preferred an active role in developing optimal care for their relative. Drivers of success and barriers to family involvement centred around three themes: (1) communication between all involved; (2) prerequisites (organisational and other conditions) and (3) personal circumstances (family's coping and skills).

Conclusion Best practices for involving family caregivers in interventions aimed at addressing responsive behaviour in residents with dementia concerned those interventions in which family caregivers were given an important role in managing responsive behaviour. This means that, in order to achieve an active role of family caregivers in the whole care process, their needs must be taken into account.

Trial registration number The protocol of the review was regisered at OSF; https://osf.io/twcfq

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review used experiences with family involvement in interventions specifically aimed at reducing responsive behaviour and pain in nursing residents with dementia. As pain and behaviour are closely related to quality of life, any improvement may potentially result in rewarding gains for residents, family and staff.
- ⇒ Identification of barriers and drivers of success was not always straightforward and subject to interpretation.
- ⇒ This scoping review included a thorough search guided by search terms used in other relevant reviews, and the broad scope in which facilitators and barriers were identified resulted in studies with a richness of data.

INTRODUCTION

Family caregivers often take a step back in the care for their relatives with dementia after they have been admitted to a nursing home,[1–3] although family caregivers are often willing to remain actively involved. Several contributing factors to this sudden decline in care involvement have been described in literature: it is common that care is taken over by the nursing staff and family caregivers are not seen as partners in care.[4 5] Also, lack of regular contact between family and staff, and family caregivers not feeling welcome play an important role.[6–8] This is unfortunate, as family involvement can have positive effects on both resident and family caregiver, for example, increased well-being of the person living with dementia by making them feel they are receiving good care and are not being abandoned in the nursing home, and increased family caregivers' satisfaction with dementia care.[7 9–11] Not taking advantage of the willingness of family to be involved in their relative's care may therefore represent a missed opportunity.

The impairments resulting from the progression of dementia make it increasingly difficult to express wishes, needs and problems. This can lead to 'responsive behaviour' such as aggression, anxiety, apathy or screaming.[12–14] Such behaviour is common in people living with dementia.[13–15] It can make caring for them stressful and burdensome, while it also negatively impacts other residents[13 16] and reduces the quality of life of the person expressing the behaviour.[14 17 18] Preventing and decreasing these behaviours that are challenging to all involved, is therefore of paramount importance.[17 19 20]

Such responsive behaviour often stems from unmet needs, which can be viewed as unfulfilled primary needs of the person living with dementia that accumulate if not recognised by their caregivers.[12 21] Unmet needs comprise psychological, social, spiritual and physical needs.[12] Examples of psychological and social needs are comfort, attachment, identity, companionship and intimacy.[21 22] Pain is a common, highly prevalent physical unmet need that can lead to responsive behaviour in nursing home residents.[12 23 24] Family caregivers have unique knowledge about their relatives and can play an important role in identifying and finding solutions for (unmet) needs.[25 26] This information could be useful for providing daily person-centred care, an important approach to address responsive behaviour.[3 25 27] However, it is important to consider that not all unmet needs are manifested in responsive behaviour and it is not always possible to identify which need relates to the behaviour.

To date, studies on family involvement in nursing home dementia care have primarily focused on family participation in daily care or care in general, and the factors influencing their involvement.[2 3 7 8 28 29] For example, a good relationship with and support from the staff stimulate family involvement,[30 31] while the increasing difficulty in communicating with their relatives and staff not making them feel welcomed by staff are barriers to family caregiver involvement in caregiving.[32] Less is known about how to involve family caregivers in the treatment of responsive behaviour in general and pain specifically. Although numerous interventions aimed at reducing responsive behaviour in nursing homes are available,[27 29 33] few actually involve family caregivers.[34]

The aim of this review is to determine best practices for involving family caregivers in preventing and reducing responsive behaviour stemming from unmet needs including pain in nursing home residents living with dementia. We examine drivers of success, such as activities in which family caregivers have been successfully involved and how their involvement is given shape, and main barriers to family involvement in those interventions aimed at reducing responsive behaviour stemming from unmet needs. In this review, a best practice is defined as a practice that successfully involved family caregivers, potentially inspiring healthcare professionals and family caregivers to optimise joint caregiving.

METHODS

Research design and methodology

A scoping review was chosen to explore and map the literature for our broad research question on family involvement in addressing responsive behaviour stemming from unmet needs.[35] This review followed the Preferred Reporting Items for Systematic Reviews, Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) reporting guideline.[36] A completed PRISMA-ScR checklist is available in online supplemental file 1.

The scoping review was guided by the framework of Levac *et al*,[35] and we used five of the six stages: defining the review question, searching for relevant studies, selecting the studies, mapping the data and comparing, summarising, and reporting the results. Stage 6, consultation of stakeholders, was not addressed in this review, as this is part of a next step, that is, preparing for the future implementation of an intervention based on the results of this review. This approach allowed us to incorporate a range of study designs and address questions beyond those related to treatment efficacy. While a scoping review shares a number of similarities with a systematic review, it does not typically involve quality assessment and findings are reported in a narrative format.[35]

Defining the review question

The main review question for this scoping review was: What are best practices for family caregiver involvement in interventions aimed at responsive behaviour stemming from unmet needs of nursing home residents with dementia?

We were particularly interested in interventions addressing unmet needs through preventing and reducing responsive behaviour, including pain; we, therefore, also address the following review questions:

- Which interventions are family caregivers being involved in and what shape does their involvement take?
- Which activities that are part of interventions do family caregivers prefer to be involved in?
- Which key barriers to family involvement in interventions can be identified?
- What are the main drivers of successful family involvement in interventions and how are they best incorporated to arrive at best practices?

The protocol for this scoping review was published on OSF https://osf.io/twcfq in 17 December 2020.

Searching for relevant studies

Search strategy and extraction of data

A literature search was conducted by a librarian in the following databases: PubMed, Embase, Emcare, Web of Science, COCHRANE Library, PsycINFO and Academic Search Premier on 20 August 2020 and repeated on 22 October 2021. Additional searches, which included Cinahl, were performed on 23 November 2021 and 23 July 2023. Box 1 provides an outline of the search strategy and MESH terms and keywords used.

Box 1 Outline of the search strategy: MESH terms and keywords

Family:
((“family”(mesh] OR family(tw] OR families(tw] OR Spouse(tw] OR spouses(tw] OR husband*(tw] OR wife(tw] OR wives(tw] OR partner(tw] OR partners(tw] OR child(tw] OR children(tw] OR grandchild*(tw] OR granddaughter*(tw] OR grandson*(tw] OR son(tw] OR sons(tw] OR daughter*(tw] OR sibling*(tw] OR brother*(tw] OR sister*(tw] OR relative(tw] OR relatives(tw] OR “in-home care”(tw)) AND
Involvement:
(Involv*(tw] OR “Stakeholder Participation”(Mesh] OR participat*(tw] OR engag*(tw] OR cooperat*(tw)) AND
Dementia:
(“Dementia”(Mesh] OR dementia*(tw] OR Alzheimer*(tw] OR “Mental Disorders”(mesh:noexp)) AND
Caregivers: (“Caregivers”(Mesh] OR caregiver*(tw] OR “care giver*“(tw] OR caring(tw] OR care(ti] OR “carer”(tw] OR “carers”(tw)) AND
Nursing home:
(“Residential Facilities”(Mesh] OR “nursing home*“(tw] OR “nursing-home*“(tw] OR “long-term care setting*“(tw] OR “residential long-term care”(tw] OR “residential care”(tw] OR “Residential Treatment”(mesh)))

The full search strategy is available via https://osf.io/h4ru2.

Selecting the studies

Articles were screened on abstract and title by two researchers (PT-D, HJAS or MN) independently to identify whether they met the inclusion criteria. EndNote V.20 was used to organise the references.[37] We included:

- Studies referring to family caregiver involvement.
- Reports on family involvement in non-pharmacological or pharmacological interventions aimed at unmet needs of nursing home residents with dementia.
- Studies concerning the perspective and experiences of family caregivers or healthcare professionals regarding family caregiver involvement.
- Studies with a population of professional or family caregivers of older people living with dementia in a nursing home.
- Empirical studies such as qualitative studies, randomised controlled trials, case reports, mixed-methods, quasi-experimental, observational studies that include people living with dementia in a nursing home.

Exclusion criteria were as follows:

- No empirical data reported (eg, discussion papers or commentaries, editorials, protocols, manuals, guidelines, reviews).
- Studies concerning people with young-onset dementia.
- Studies in long-term care in mixed populations without an identifiable subgroup of persons with dementia living in a nursing home.

Articles that potentially met the inclusion criteria were retrieved and screened by the same researchers. In both rounds, disagreements were resolved by consensus or by discussion with a third researcher. Studies that were authored by PT-D and HJAS were screened by MN and a second independent researcher.

Mapping the data

A data extraction form was developed to extract the following data from the included papers: first author, country, study aims, barriers, drivers of success, participants, setting, design, intervention outcomes, instruments and major findings. Data extraction forms were completed by two researchers independently (PT-D, HJAS or MN), followed by multiple consensus meetings.

Quality assessment

Subsequently, the methodological rigour of the included research was evaluated independently by two researchers (pairs of PT-D, HJAS and MN) using the Mixed Methods Appraisal Tool (MMAT).[38] The outcomes were compared and discussed. In situations of disagreement a third researcher was consulted. Authors did not rate their own studies; the authors’ own studies were evaluated by colleagues. MMAT was used to assess the methodological soundness of various study types. It distinguishes five study designs, that is, qualitative studies, randomised controlled trials (RCTs), non-randomised studies, quantitative descriptive studies and mixed-methods studies. The MMAT defines five criteria tailored to each design. Ratings can range between 0% (no quality criteria are met) and 100% (all five quality criteria fulfilled). A comprehensive rationale for assessment can be viewed in online supplemental file 2.

Comparing, summarising and reporting the results

To facilitate the analysis, all data were categorised per review question by PT-D and discussed with HJAS. A narrative analysis was conducted by PT-D and HJAS. A content analysis[39] was conducted by two researchers (PT-D and HJAS) to identify barriers to and drivers of success for family involvement in interventions. Findings were then discussed within the research team to further ensure analytical rigour.

Patient and public involvement

No patients or members of the public were involved in this study.

RESULTS

A summary of the included articles is shown in table 1. An elaborate overview of the included articles is presented in online supplemental file 3. Of the 20 included articles, 7 were from the USA, 3 from the UK, 3 from Australia, 3 from Canada, 3 from the Netherlands and 1 from New Zealand. Seven articles were published before 2016, the first in 1992, and 13 more recently. Ten used a qualitative design, two used a quasi-experimental design, four used mixed methods, three were RCTs and one had a cluster randomised cross-over design. The process of selecting the studies is shown in the flow chart (figure 1).

Table 1 Summary of the characteristics of the included articles

Authors	Country	Participants*	Setting	Design	MMAT
Akram *et al*, 2021[41]	USA	People with dementia (n=16), family caregivers (n=8) and staff (n=14)	Veteran affairs nursing home	Qualitative study	80%
Anderson *et al*, 1992[42]	USA	Residents (n=12), family caregivers intervention group (n=6) and control group (n=6), registered nurses (n=2)	Nursing home care unit in Veterans Care Medical Centre	RCT	60%
Bird *et al*, 2009[43]	Australia	Residents (n=33) and community-dwelling persons with dementia (n=11)	Dementia special care unit in a long-term care (LTC) facility and a community setting	Quasi-experimental	80%
Brannelly *et al*, 2019[44]	New Zealand	Family caregivers (n=11), healthcare professionals (n=9)	Dementia special care unit in an LTC facility	Qualitative study	100%
Foley *et al*, 2003[40]	UK	People with dementia (n=70), staff (n=36)	Dementia special care unit in an LTC facility	Qualitative study	80%
Garlinghouse *et al*, 2018[45]	USA	People with memory loss (n=15), of whom 8 had a dementia diagnosis, family caregivers (n=13), healthcare professionals (n=6)	Residential LTC facilities	Mixed-methods	60%
Johnson, 1998[46]	USA	Residents (n=4) family caregivers (n=4)	Private care facility	Qualitative study	20%
Kontos *et al*, 2021[47]	Canada	Residents (n=67), family caregivers (n=15)	Residential LTC facility and community setting†	Qualitative study	60%
Lignos *et al*, 2022[48]	Canada	Residents with dementia (n=55), family caregivers (n=11), nursing staff (n=16)	Private nursing home	Mixed methods	20%
Mbakile-Mahlanza *et al*, 2020[49]	Australia	Residents with dementia (n=40), family caregivers (n=40)	General and psychogeriatric nursing homes	Cluster randomised cross-over design	60%
McAllister *et al*, 2020[50]	Australia	People with dementia (n=3), family caregivers (n=6), healthcare professionals (n=1)	Residential LTC facility	Qualitative study	40%
McCallion *et al*, 1999[51]	USA	Residents and their primary family caregiver: intervention group (n=32), control group (n=34) No data reported on nursing staff	Nursing homes, including short stay rehabilitation ward	RCT	60%
Nijsten *et al*, 2023[52]	Netherlands	Family caregivers (n=7), professional caregivers (n=15)	Nursing homes	Qualitative study‡	40%
Schneider *et al*, 2003[53]	USA	Residents (n=9), family caregivers (n=8)	Care units at a centre for senior lving	Quasi-experimental study	60%
Smaling *et al*, 2023[54]	Netherlands	Family caregivers (n=12),staff (n=31)	Nursing homes	Descriptive qualitative study	100%
Subramaniam and Woods, 2016[55]	UK	Residents (n=6), family caregivers (n=9)	Care homes	Mixed methods	60%
Subramaniam *et al*, 2014[56]	UK	Family caregivers (n=23), residents with dementia (n=23), staff (n=68)	Care homes	RCT	60%
Tasseron-Dries *et al*, 2021[57]	Netherlands	Family caregivers (n=10), nursing staff (n=31), volunteers (n=2)	Nursing homes	Qualitative study	80%
Tjia *et al*, 2017[58]	USA	Family caregivers (n=41)	Nursing homes	Mixed methods	20%
Yous *et al*, 2023[59]	Canada	Family caregivers (n=10), (nursing) staff (n=58)	Nursing homes	Qualitative descriptive study	80%

A comprehensive overview of the included articles can be accessed in online supplemental file 3.
*Not all studies describe a population with only people with dementia or living in an LTC facility. Half of the population in the study by Kontos *et al*,[47] and two thirds of the participants in the study of Bird *et al*[43] include our target population. The subgroups were identified during the data extraction phase.
†The focus in this study was on nursing home residents.
‡We assessed this study as qualitative, although quantitative measurements were also conducted. The authors did not analyse the quantitative data due to too much missing data. The qualitative data were collected, analysed and properly interpreted, so we considered it unreasonable to rate it as mixed methods given that the researchers were transparent and described it as a qualitative study.
MMAT, Mixed Methods Appraisal Tool; RCT, randomised controlled trial.

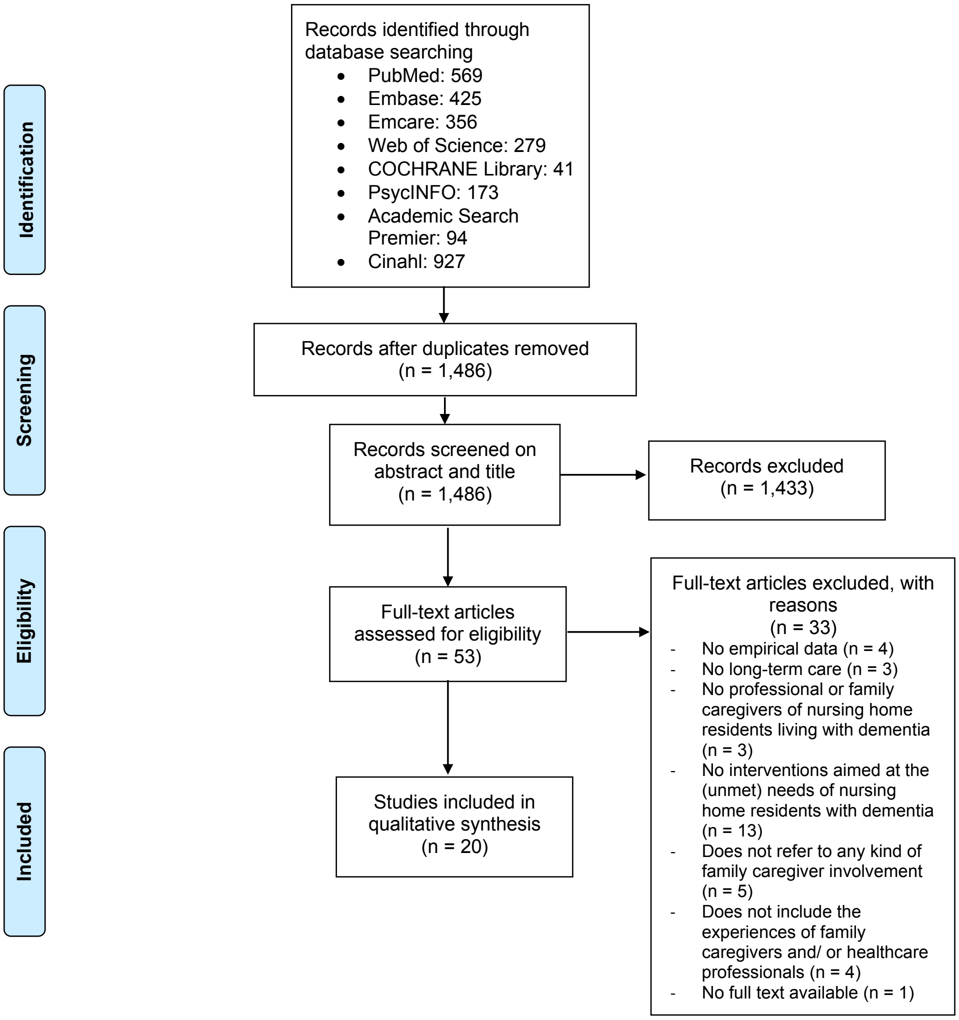

Figure 1. Flowchart of search process

Figure 1 Flow chart of search process.

Table 1 shows the MMAT score for included studies. The qualitative studies had an average score of 68% of criteria met, and the quantitative studies met a mean of 70% of criteria. RCTs scored a mean of 60%. Mixed-method studies had lower quality (40% on average). Important issues of the mixed-method studies were incomplete data, poor methodology, small samples and lack of rationale for choosing a mixed-method design.

Which interventions are family caregivers being involved in and what shape does their involvement take?

We identified a total of 19 interventions in the 20 included articles. One article did not describe a specific intervention, but the family was involved in the management of responsive behaviour by means of collaborative problem solving with staff, checking case management and interaction with their relative. Various techniques for managing the behaviour were used, for example, educating family or family participating in one-on-one activities with the resident.[40] The interventions all aimed at collaboration and creating a partnership between family caregivers and staff,[41–59] such as ongoing monitoring of case management, interaction and socialisation.[40 45 46 48 50 52–56 59] Twelve of these studies involved interventions of family participation in preventing or reducing responsive behaviour.[43 45 46 48 50 52 54–56 58 59] In 13 studies, the intervention was designed to support meaningful activities.[41 45–49 51–57 59]

Of the interventions aimed at solving and preventing responsive behaviour, one focused on shared decision-making regarding medication use, involving family caregivers to provide information about their relatives, helping staff to develop the care plan.[58] In this particular intervention, informing family caregivers about benefits and risks of medication was also an important part of their involvement. Furthermore, one intervention included a training for family to improve communication with their relative.[51] Two interventions aimed at optimisation of nursing care, for example conducting an activity plan, together with family.[42 52]

Two of the 13 interventions in the form of meaningful activities were movement programmes,[41 47] three related to conducting a (digital) life story book.[46 55 56] Two interventions were based on the Montessori method, in which activities are tailored to the needs and capabilities of the individual.[49 53] One of these offered family caregivers the opportunity to engage in activities they had chosen for their relatives during a visit.[49] Three studies explored the Namaste Care Family programme that invited family to participate in a psychosocial intervention to increase the quality of life for people with advanced dementia.[54 58 59] Another intervention included facilitating reminiscence by using three-dimensional printed objects.[45] Finally, an interactive ambient activity technology device ('ABBY') provided tangible and pleasurable experiences by means of a touchscreen, such as stroking a cat or visualising individualised media content (eg, photographs and videos).[48]

The involvement of family caregivers mainly took the form of giving family caregivers an active role in conceptualising, creating and implementing person-centred activities for their relatives in cocreation with staff.[42 44 49 50 52 53] Family caregivers were often asked to provide information about the relative, for example, about their hobbies, interests, occupations or the kind of music they like.[42 44 52–54 59] Items brought in by family caregivers (ie, pictures and memorabilia) were then often used to develop activities for the residents or in creating a draft life story book.[45 50 52 53 55 56] Regarding their involvement, family caregivers expressed a need for more communication and exchange of ideas about the care of their relatives with staff,[52 54 57 58] as well as a need for guidance and education about dementia and its effect on their relative.[42 54]

Looking at specific aspects or activities from the intervention in which family were involved, these were mainly prearranged by staff or focused on their relative's preferences[44–46 48–50 52–55 57 59] and intended to benefit their relative's quality of life,[41 47 48 52 54 57 59] leaving little opportunity for family caregivers to shape their own involvement.[41 45–50 52–56 59] Family caregivers also participated in activities, but they participated only occasionally in activities suggested by themselves and motivated by their own needs. In one study, family caregivers were asked to interact with their relatives in a different way by carefully following their relative's reaction and adapting their own behaviour accordingly.[49] Some activities involved the use of technology[45 48 50] aimed at facilitating reminiscence, and an initial meeting was arranged with residents and family caregivers.[45] Participating in activities together with their relatives allowed family members to make meaningful connections with their relative. In the study by Kontos *et al*,[47] family caregivers and volunteers were encouraged to participate in a dance session rather than just observe or only support the participation of persons living with dementia.[47]

Which activities that are part of interventions do family caregivers prefer to be involved in?

Although limited data were provided on the specific family caregiver preferences that were taken into account prior to implementation of the intervention, most studies did mention general preferences of family caregivers regarding the activities they preferred to be involved in. These included clearly defined practical activities and activities they enjoyed doing themselves, that matched their own interests and that they felt comfortable with.[52 57] Examples of practical activities family caregivers preferred were cooking, watering plants, sending a postcard together, painting, going for a walk or playing a game. Family caregivers also specifically mentioned attending church or attending community gatherings, such as playing Bingo,[42] reading the newspaper together, having dinner outside the facility, reminiscing or listening to music as enjoyable activities.[42 49 52 53 57 59] Furthermore, sharing memories with their relative, for example, while watching photos or a video of the resident's life, was enjoyable for both family caregiver and resident.[48 55 56]

Drivers of success and barriers to family caregiver involvement

Of the 20 included articles, 2 did not mention any barriers to or drivers of success for family caregiver involvement.[42 53] From the perspectives of family caregivers, organisation, staff and to lesser extent the residents, three themes were identified (ie, communication, table 2; prerequisites table 3 and personal circumstances, table 4) with multiple barriers to and drivers of success for family involvement in interventions aimed at responsive behaviour stemming from unmet needs (tables 2–4).

Communication

The theme communication included factors related to communication between all involved and increased preparedness to launch interventions. Receiving a positive response from the resident during meaningful contact was a frequently mentioned facilitating factor for both family and staff.[40 41 45 55 57] Additionally, good and frequent communication between staff and family caregiver in which family caregivers feel appreciated, and staff offering family caregivers guidance and support to shape their involvement were identified as factors promoting success.[40 44 50–52 54 57–59] Resident and family sharing memories was also a facilitating factor.[45 52 55 56]

Lack of good communication and regular contact between staff and family, sometimes resulting in inadequate collaboration, was often a barrier to family caregiver involvement.[40 52 54 57 58] Also, the presence of family caregivers may be perceived negatively by staff, making communication difficult and limiting family involvement.[57 58]

Prerequisites

This theme involved prerequisites that contribute to the successful implementation of an intervention. Categories

Table 2 An overview of the theme communication including categories, and codes of the drivers of success and barriers to family involvement in interventions aimed at unmet needs of nursing home residents with dementia

Theme	Categories	Facilitator codes	Barrier codes
Communication	Between family caregiver and staff	▶ Managing expectations[57] ▶ Using aids to facilitate communication between staff and family caregivers[45] ▶ Staff being available to talk to family caregivers and having regular (informal) contact[40,52,57–59] ▶ Family feeling welcome and supported by staff during stressful visits[44,57] ▶ Staff's knowledge about how individual family caregivers want to be informed[44] ▶ Staff paying attention to family caregivers during the activities[57] ▶ Good family–staff relationship[57]	▶ Insufficient opportunities for family caregivers to communicate with staff[58] ▶ Family caregivers are insufficiently informed about the care for their relative[58] ▶ Staff not involving family caregivers in the complete care process or in non-pharmacological management[58,59] ▶ Staff not making family caregivers feel welcome[52,57] ▶ Staff perceive communication of involved family caregivers as negative[40] ▶ Inadequate collaboration between family caregiver and professional caregiver because of staff not considering individual preferences of family caregivers[52] ▶ Absence of regular family-staff consultation[52]
	Between family caregiver and resident	▶ Supporting family caregivers by training them in how to communicate with their relative[51] ▶ Reminiscing together[45,55,56] ▶ Family caregivers receiving a positive response from the resident[45,55,57] ▶ Effective and meaningful interaction[45,54] ▶ Family caregivers undertake activities with other residents[57] ▶ Family caregivers feel they are doing something important for the resident[57] ▶ General involvement and regular visits of family caregivers[44,45]	▶ Communication difficulties due to cognitive decline[51] ▶ Family caregivers focusing only on their own relative[57] ▶ Family caregivers not knowing the resident(s)[40] ▶ Severity and unpredictability of the challenging aggressive behaviour of their relative[40,48] ▶ Unhappy relationship with the institutionalised relative[40]
	Between resident and staff	▶ Staff experiencing a positive response from residents as appreciation for their work[44] ▶ Residents having mild or limited communication difficulties[51]	
	Increased preparedness to launch interventions	▶ Sufficient information[40,57,58] ▶ Offering peer support to family caregivers[40,49] ▶ Informing family caregivers about the advantages of involvement in an intervention[51] ▶ Offering family guidance and support[40,50,54,57] ▶ Encouraging participation in care planning or caregiving (eg, by conference call or evening meetings)[40] ▶ An inviting attitude of staff towards family caregivers[57] ▶ Staff feeling appreciated by family caregivers[44] ▶ Considering family history and relationships in shaping family involvement[40] ▶ Good coordination between family caregivers and staff[45] ▶ Staff personally inviting family caregivers to participate in the intervention[57]	▶ Family caregivers' feelings of uncertainty and not feeling supported by staff[57] ▶ Not involving family caregivers prior to implementation of intervention[58] ▶ Misconceptions and unclear communication about how family caregivers can participate in an intervention[52,57] ▶ Family caregivers and staff disagree on how to involve family caregivers[57] ▶ Unable to reach family caregivers in time for consultation[58]

Table 3 An overview of the theme prerequisites including categories, and codes of the drivers of success and barriers to family involvement in interventions aimed at unmet needs of nursing home residents with dementia

Theme	Categories	Facilitator codes	Barrier codes
Prerequisites	Organisational conditions	▶ Taking into account the limitations and capacities of the care environment[43] ▶ Group training for family caregivers and staff to become familiar with the intervention[50] ▶ Prioritise becoming familiar with activity/intervention[50] ▶ Activity planning for resident together with family caregivers[40] ▶ Commitment from leaders is essential to encourage care staff to use technology[50]	▶ Lack of available professionals to engage with family in a timely manner[54,58] ▶ Lack of time[45,46,50,57,58] ▶ High staff turnover[52,58] ▶ Staff stress[43] ▶ The pressure on nursing staff to 'tick something off' according to protocol[58] ▶ Little opportunity for family caregivers to spontaneously engage in the intervention[52] ▶ Lack of priority for the intervention goals to be achieved[52] ▶ COVID-19 restrictive measures[52]
	Family involvement is recognised in the organisation's mission	▶ Recognition by staff and organisation of family caregivers' legal right to represent a resident's interests in nursing homes[58] ▶ Recognition by staff that families are a central element of the care for institutionalised persons with dementia[40,59] ▶ Motivated and enthusiastic staff with clear vision[54,57] ▶ Embedding the intervention in person-centred care and daily routine[50,80]	
	Feasibility of intervention in daily practices	▶ Family caregivers living close to the nursing home and being able to visit their relatives often[57] ▶ Easy to use (digital) tools in the intervention[45,48,50,52,54] ▶ Limited staff needed to implement the intervention[51] ▶ Interests of resident are identifiable[50] ▶ Giving staff the opportunity to perform a specific role focused on the intervention including family involvement while not assigned other duties[44] ▶ Facilitating staff to carry out an intervention that includes family caregiver involvement[51] ▶ Staff who are interested in an intervention in which involving family is an important element[51]	▶ Unclear what the short-term effort to implement an intervention will achieve and whether it is proportional[58] ▶ Absence or limited family caregivers[40,45,51]
	Nursing skills	▶ Competent staff[44] ▶ Effective leadership capabilities[44] ▶ Qualified staff[51] ▶ Open to receiving feedback about their caring abilities and about improvements[44] ▶ Having a sense of responsibility[44] ▶ Being at ease in their role[44] ▶ Ensuring that family caregivers are actually involved[44] ▶ Understanding the needs of family caregivers in how and to what extent they want to be involved[45,52,57]	▶ Limited experience with technology[48,50] ▶ Limited experience with the intervention[54] ▶ Staff not using family caregiver as a resource in the care for the resident[59]

Continued

Table 3 Continued

Theme	Categories	Facilitator codes	Barrier codes
	Activities and attributes of the intervention	▸ Family caregivers and resident enjoying reminiscence[45 55 56] ▸ Recording and creating the resident's life story[55 56] ▸ Activity/intervention provides enjoyable and meaningful engagement[48 50 54] ▸ Activity/intervention supports the relationship between resident and family caregiver[50 54] ▸ Emphasis on creative self-expression[47] ▸ Failure-free experience[47] ▸ Family caregivers providing information about their relatives to staff[40 81] ▸ Matching activities with family caregivers' interests[45 57] ▸ Clear structure with clearly defined scheduled activities clearly defined[57] ▸ Participants seeing the positive effects of the activity/intervention and their actions[41 52 57] ▸ Practical and clearly defined activities[52 57] ▸ A manual with clear instruction for the intervention[45 50 57] ▸ Intervention providing a tangible way for family caregivers to help their relatives while supporting their own reminiscence and reflection[50] ▸ Being in a homelike environment[54] ▸ Correct form, quality and content of the intervention materials. Availability of clear instruction materials for the intervention and activities[52]	▸ Specifically for men: no other men present[57] ▸ Activities family caregivers are not familiar with; physically intimate activities[57] ▸ Unavailability of the intervention[48] ▸ Possible lack of residents' interest in the materials of the intervention[81] ▸ Residents concentrating on interacting with the device detracts from connecting with other residents[48] ▸ Little opportunity for family caregivers to spontaneously engage in the intervention[52]

in this theme included organisational conditions, nursing skills and activities in which family was involved. Furthermore, categories in this theme are the organisation's recognition of family involvement, feasibility of the intervention and family supporting the intervention.

The most frequently mentioned drivers of success included supporting family by providing training about dementia, communication with their relative, responsive behaviour and the circumstances, for example, being in a homelike environment, that influence the behaviour.[43 46 51 54] These trainings ranged from a one-time meeting to biweekly 1-hour training sessions,[45 49 50 56] which made family involvement easier for family caregivers.[45 50 57]

Recognition by staff that families are a central element of the care for persons with dementia is also essential.[40 44 58 59] Motivated and driven staff with strong leadership who can evaluate and reflect on their actions feel empowered to contribute to a successful intervention.[44 50 51] Lack of time, high staff turnover and experienced level of stress were often barriers to family involvement.[43 45 46 50 57–59] Nijsten *et al*[52] specifically mentioned the COVID-19 restrictive measures.

Personal circumstances

Finally, family caregivers' personal circumstances influenced their level of involvement. Circumstances related to family caregivers' burden, coping, motivation and care skills. Psychoeducation and gaining more experience over time were identified as an important facilitator for family caregivers,[49–51 57] while confrontation with their relatives' limitations and sometimes difficult behaviour was often mentioned as a potential barrier to family involvement.[40 48 49 54 57]

DISCUSSION

The aim of this study was to identify best practices for involving family caregivers in preventing and reducing responsive behaviour stemming from unmet needs in nursing home residents with dementia, and to map drivers of success and barriers to family caregiver involvement. Facilitators and barriers were categorised into three themes: (1) communication between those involved in the intervention; (2) prerequisites (eg, organisational and other conditions required for the intervention) and (3) personal circumstances of those involved. Best practices include good collaboration between family and staff, with an active role for family caregivers in the care process of their relatives that, takes into account the family caregivers' needs and preferences.

Which interventions are family caregivers being involved in and what shape does their involvement take?

In general, family caregivers are being involved in interventions that include codesigning the care for their relatives and choosing appropriate activities for their relatives to enjoy. Their involvement is mainly shaped by giving

Table 4 An overview of the theme personal circumstances including categories, and codes of the drivers of success and barriers to family involvement in interventions aimed at unmet needs of nursing home residents with dementia

Theme	Categories	Facilitator codes	Barrier codes
Personal circumstances	Coping and caregiver burden	▶ Having support in place[40] ▶ Family caregivers having more energy due to handing over care after admission of their relatives to a nursing home[40] ▶ Efficient/good coping of family caregivers with situation[40] ▶ Awareness that people with dementia have greater abilities than anticipated[54]	▶ Confrontation of family caregivers with their relative's limitations and behaviour caused by dementia[40,49,54,57] ▶ Caregivers' stress[40,43,57] ▶ Participating in an activity/intervention can be burdensome for family caregivers[49] ▶ Additional personal circumstances that can also have a negative impact on caregiver burden, such as older age and memory, work, own family, social welfare, low income, unstable social and living environment, long caregiver burden, having a family with children, (fulltime) job, health problems or move to a more distant location[40,49,50,57] ▶ Family caregivers' lacking social support network[50]
	Family caregivers' motivation and skills	▶ Family caregivers' knowledge and understanding of the resident's challenging behaviour[51] ▶ Offering family caregivers psychoeducation (eg, information or training about dementia and challenging behaviour)[49–51,57] ▶ Family caregivers being enthusiastic and willing to contribute[50] ▶ Incorporating small-scale activities in regular care routines matching the skills of the (family) caregiver and preferences of the resident[52] ▶ Family caregiver gaining more experience over time[54]	▶ Lack of knowledge or education about dementia[40,52,54] ▶ Family caregivers' lack of experience with dementia[40,52,54,57] ▶ Severity and unpredictability of the challenging aggressive behaviour of their relative[40] ▶ Belief that the nursing home takes over and family caregivers no longer need to do anything[57] ▶ Family caregivers feeling they do not have the proper skills to undertake activities[41,57] ▶ Finding it difficult to engage in meaningful activities because of the dementia-related limitations[44] ▶ Factors that make coming to the nursing home difficult (eg, having no means of transportation or living far away)[40,51] ▶ Family caregivers relying on the idea that the professional knows best[58] ▶ Family caregivers not involved in the care for their relative[52] ▶ Family caregivers not in a position to provide information[52]

them an important active role in providing care, planning and tailoring activities to the needs of their relative. Family feels comfortable in this role. These findings are in line with the findings of other studies on how to involve family in similar populations.[30,60,61]

Being part of activities in interventions can be helpful for family being more involved and having more meaningful contact with their relative. Interventions are often created by the professionals and family can then participate in them.[30,61,62] Family caregivers generally appear not to have a say in the choice of intervention. Involving family in developing or choosing an intervention can, therefore, potentially increase their involvement.

Which activities that are part of interventions do family caregivers prefer to be involved in?

We found family caregivers enjoyed activities they had chosen for their relatives and which their relatives also used to love doing during life before the diagnosis of dementia. Reminiscing was an important element in these activities. Other research confirms that reminiscence-related activities, such as recording their relative's life story and engaging in tangible memories, have a positive effect on both resident and family caregiver.[63–65]

Even though family caregivers are actively involved in creating and participating in activities for their relative, their own needs and preferences are not taken into account to the same degree.[4,60,61] In line with other research concerning family involvement in nursing home dementia care,[7,62] several studies in this review indicated that having a say in shaping the care of their relatives gives family a more active role and encourages them to participate in the intervention.[40,42,45,48,49,52,54–56,59] It could, therefore, be argued that family not being seen as important is a barrier. To recognise family caregivers' needs and preferences, a more family-centred approach is needed.[57,66] In this approach, the question 'what kind of activities do you like and want to be involved in?' should be discussed with the family caregivers.[3,4,30,61]

Drivers of success and barriers to family involvement

We identified a number of drivers of success and barriers to family involvement, showing the complexity and sensitivities of joint caregiving by family and staff. Organisational conditions are important for the success of family caregiver involvement as also shown in other studies.[2,4,7,67] Despite a motivated workforce, interventions may still fail if the organisation does not facilitate and support them.[68]

Therefore, it is very important to identify these conditions before involving family caregivers in an intervention, and for the organisation to facilitate staff to support implementation.

Specific family caregiver personal circumstances, such as living far away, are well known as limiting family involvement.[7 61] This study confirms these findings.[49–51 57] Staff and the nursing home organisation can support family caregivers to overcome some of these barriers. For example, the nursing home can arrange transportation or accommodation to stay with their relatives to facilitate visits to the person with dementia.

Demanding family caregivers can be an issue for staff and may negatively impact staff's attitude, thereby posing a barrier to further active family involvement.[40 44 57] Other studies confirm that staff can perceive family as demanding and sometimes difficult to deal with.[1 61 69] It is important to create awareness among staff that building a trusting relationship, a partnership with family caregivers can benefit them. It may lead to family caregivers being more involved in the care for their relative, which can also save staff time.[1 60 69] Furthermore, it may—in time—result in family caregivers being 'less demanding': as they begin to feel they can let go, their need to monitor the care for their relative is reduced.[8 70]

Family caregivers may be uncertain as to how to engage with the person with dementia showing responsive behaviour out of lack of knowledge and experience with that particular behaviour. Numerous studies have consistently highlighted this issue as a significant impediment to the caregiver's relationship with a relative living with dementia.[71–75] This issue has long been recognised but continues to pose a challenge. Studies included in our review confirm this is a barrier to family caregivers' involvement in the care of their relatives in the nursing homes.[40 52 54 57] Nursing staff, and other healthcare professionals in the nursing home, can play a pivotal role in actively guiding and encouraging family members to acquire knowledge and information that supports them in better understanding the resident and coping with the challenges arising from cognitive decline. Staff who are aware of their role in this and of the fact that more (informal) contact with the family to provide personal support and information about their relatives situation is an important condition to facilitate families in their involvement in the care for their relative.

Best practices for family caregiver involvement

Increasing family involvement may be difficult and family caregivers' needs differ.[3 7 61] Considering their needs and preferences is therefore important. Best practices for involving family are based on a good relationship and sound communication between family and staff, including out-of-office contact options. This includes working towards an active role for the family in their relative's care process. Providing them with a level of authority may be a powerful way to support their feeling like a partner in the care for their relative.[4 61 62] For example, inviting them to join multidisciplinary team meetings and emphasising the family caregivers' role as a partner in care for the resident. The finding that most of the studies and thus best practices included small samples sizes may suggest that starting a pilot to implement an intervention to involve family caregivers may be preferred over implementing an intervention on all wards. A small setting may be logistically more convenient and get better support from all stakeholders. And it may function as a 'test case', resulting in learnt lessons and intervention 'champions' to facilitate larger-scale implementation.

Although not a primary aim in this study, several studies presented positive effects of family involvement on resident outcomes, such as an improved quality of life,[49 55 56] an improved relationship between resident and family caregiver[49 55 56] and a reduction in psychotropic medication use[43 51] and responsive behaviour.[42 43 48 51 53 55] Apparently interventions in which family is actively involved may reduce responsive behaviours in people living with dementia. There is already considerable evidence on the positive effects of family involvement on family, staff, and residents,[76–79] but more research is needed with a specific focus on how to involve family caregivers.[60] Furthermore, the findings in this scoping review support the importance of involving family in interventions aimed at management of responsive behaviour and pain.

Limitations

Most included studies had relatively small sample sizes, highlighting the need for future research using bigger samples. Although barriers and drivers of success could be identified in most articles, analyses were not straightforward but based on reading 'between the lines'. By reaching clear agreement on these barriers and facilitators in the consensus meeting and consulting a third colleague in case of doubt, we have tried to ensure reliability.

CONCLUSION

This scoping review clarifies how family can be involved in interventions aimed at responsive behaviour stemming from unmet needs of nursing home residents with dementia. Furthermore, this review highlights the importance of involving family in the approach to responsive behaviour, as this improves quality of life and reduces responsive behaviour. Best practices of family involvement are those interventions focused on cocreation, based on a good partnership between family and staff, and staff supporting the family caregivers in their efforts to become more involved. The adoption of a family-centred approach, which focuses on family caregivers' personal needs, helps family caregivers to overcome their personal barriers to participating in their relative's care. Moreover, it is important that family caregivers are seen as equal partners by staff and given an active role with some authority to emphasise this partnership. Family caregivers should be involved early in the implementation process of an intervention to give them a stronger say in the content of the intervention and what their involvement should look like.

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