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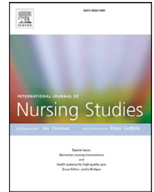

Family involvement in the Namaste care family program for dementia: A qualitative study on experiences of family, nursing home staff, and volunteers

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ABSTRACT

Background: Family caregivers may experience difficulty maintaining meaningful contact with a relative with advanced dementia. Nevertheless, some family caregivers prefer to remain involved in the care of their relative after admission to a nursing home. Family involvement in the care is important but little is known about how this works in practice and what exactly is needed to improve it.

Objectives: To examine experiences of family caregivers, staff and volunteers with family caregiver participation in the Namaste Care Family program, a psychosocial intervention to increase quality of life for people with advanced dementia that may help family caregivers to connect with their relative. Further, we aimed to examine facilitators of and barriers to family participation.

Design: Descriptive exploratory qualitative design using semi-structured interviews.

Setting: Ten nursing homes in the Netherlands.

Participants: Ten family caregivers, 31 staff members and 2 volunteers who participated in the Namaste Care Family Program.

Methods: Qualitative interview study using thematic analysis. Interviews were held with family caregivers, staff members, and volunteers about their experiences with the Namaste Care Family program.

Results: In general, family caregivers experienced their involvement in the Namaste Care Family program as positive, particularly the meaningful connections with their relative. However, putting family involvement into practice was challenging. We identified three themes covering facilitators for and barriers to participation:

(1) *Preferences of family caregivers for activities with their relative (Activities):* practical activities matching one's own interests were seen as facilitating, while perceived lack of knowledge and reluctance to engage with other residents were barriers.

(2) *Communication between family caregivers, staff and volunteers (Communication):* providing clear information about the program to family caregivers facilitated their involvement. Feeling insecure inhibited family involvement.

(3) *Personal context of family caregivers (Personal circumstances):* feeling fulfillment and being appreciated facilitated involvement. Older age, having a family of their own, a job and complex family relations were barriers to family caregiver involvement.

Conclusion: To optimize family involvement, it is important to adopt a family-centered approach and provide training and guidance. Making a personal, comprehensive plan with family caregivers and offering them guidance can help them overcome their uncertainty and remove barriers to being more involved

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with a care program aiming to improve the quality of life of their relative. Also recommended is training for staff to improve communication with family caregivers.
The Namaste study is registered with the Netherlands Trial Register (NTR5692).

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What is already known

- Most family caregivers wish to stay involved in the care for their relative after admission to a nursing home.
- Family caregiver involvement can have positive effects on the wellbeing of both the family caregiver and the care recipient.

What this paper adds

- Despite the willingness of all participants and the positive experiences with involving family caregivers in the Namaste Care Family program, it also turns out to be complicated to actually involve family.
- Involving family caregivers requires careful planning, training and commitment from all involved, and a mutual understanding of interests.
- Some staff members believe that a culture change is necessary to increase family caregiver involvement.

1. Introduction

Dementia is a progressive disease associated with cognitive and physical decline (Prince et al., 2013). Therefore, it has a great impact on the person living with dementia, their family and the community. Half of the family caregivers experience high levels of burden and stress (Meiland et al., 2001; Zwaanswijk et al., 2013). The severity of the dementia, personality changes, and the presence of challenging behavior are related to higher caregiver burden (Chiao et al., 2015). Moderate to advanced dementia in particular demands increasing care and monitoring (Lillo-Crespo et al., 2018; Prince et al., 2013; van der Steen et al., 2006). Caregiver burden is one of the main reasons for admitting the person with dementia to a nursing home (Brodaty and Donkin, 2009; Toot et al., 2017).

After the person with dementia has been admitted to a nursing home, family caregivers often want to stay involved in the care for their relative (Bramble et al., 2009; Davies and Nolan, 2006; Gaugler, 2005; Nolan et al., 2009), but the needs of family caregivers can vary considerably. Some family caregivers wish to stay involved in the care on a practical level, while others prefer a more distant role. Such different preferences should be taken into account (Reid and Chappell, 2017).

Being involved gives family caregivers the opportunity to monitor the situation, which can be important when family is not confident that the best quality of care is being provided (Davies and Nolan, 2006; Grabowski and Mitchell, 2009), and they can check this during their visits (Helgesen et al., 2013). This strengthens their role as spokesperson for their relative and provides opportunities to give immediate feedback to staff. Establishing a good relationship with staff based on trust (Graneheim et al., 2014), and an active role in decision making (Reid, 2017) is important for family caregivers. Making a contribution by helping out at the nursing home makes them feel useful and valued (Milte et al., 2016). However, while active involvement in meaningful activities with the resident is important, it may not always be what family caregivers need most. The opportunity to provide information about their relative and being invited to regular staff meetings can be more important (Reid and Chappell, 2017).

Family involvement benefits the family caregiver, staff and person with dementia (Bramble et al., 2009). It increases the wellbeing of the person living with dementia, and family caregivers may feel more satisfied with the care provided and the nursing home in general (Gaugler, 2005; Maas et al., 2004). Frequent contact with their family caregivers may contribute to feelings of happiness of the person with dementia. Active involvement of the family caregiver enhances the residents' feeling that they are receiving good care and that they have not been abandoned in the nursing home (Milte et al., 2016). Having a close relationship with their relative and satisfying experiences during their visits increases the frequency of family caregiver visits (Bramble et al., 2011).

The family caregivers' unique knowledge about their relatives' life before the dementia can be useful in providing daily person-centered care (Graneheim et al., 2014; Helgesen et al., 2013). Furthermore, a good family-staff relationship has the potential to improve work conditions and decrease negative reactions to family involvement on the part of staff members (Bramble et al., 2009). In short, a good relationship between family caregivers and their relatives, and between staff and family caregivers is of great importance and can support family caregiver involvement.

In addition to known facilitating factors for family caregiver involvement, such as staff supporting family caregivers based on a good relationship (Bramble et al., 2011; Brodaty and Donkin, 2009; Graneheim et al., 2014; Majerovitz et al., 2009), various barriers may challenge achieving family involvement. As the disease progresses, and cognitive impairments therefore increase, people with dementia become more and more dependent and inactive. This makes maintaining meaningful contact with them difficult for family caregivers (World Health Organization, 2015), which may result in family caregiver feelings of grief and loss (Graneheim et al., 2014). It is considered an obstacle to their visiting (Piechniczek-Buczek et al., 2007; Smaling et al., 2018). Moreover, family may limit their involvement when experiencing caregiver burden (Bramble et al., 2009; Gaugler, 2005), when they perceive that nursing staff takes no initiative to invite them to stay involved in caregiving (Davies and Nolan, 2006), and when staff does not welcome their involvement (Davies and Nolan, 2006; Helgesen et al., 2013). Finally, the absence of a calm, recognizable environment that suits the person living with dementia can be a barrier to family involvement. Family caregivers can experience a sense of isolation in an environment that does not offer the care their relative needs. This hampers communication with staff, which is an important facilitating factor to involve family (Bramble et al., 2009).

Research emphasizes that staff must recognize family caregivers as partners and should welcome them to regular meetings (Gaugler, 2005). Family caregivers eventually learn to appreciate forms of interaction with their relative other than just being present (Gaugler, 2005; Graneheim et al., 2014). Two studies (Bramble et al., 2011; Gaugler, 2005) performed pre and post-tests with stress, satisfaction and psychological wellbeing as outcome measures. Only one study (Bramble et al., 2011) concerned an intervention to support the involvement of family caregivers by increasing their knowledge about dementia. This made family caregivers feel more connected to the care of their relative and improved their involvement (Bramble et al., 2011).

To date, many studies have focused on family caregivers' perceptions of their involvement (Davies and Nolan, 2006; Gaugler, 2005; Helgesen et al., 2013; Reid and Chappell, 2017; Specht et al., 2000). In this study, we take the different perspectives of all who are actually involved into account in order to obtain a broader understanding of family involvement. We explore the experiences of family caregivers, staff and volunteers, as well as how family caregivers participated in the Namaste Care Family program, an intervention for nursing home residents with dementia aimed at enhancing their quality of life. A family program benefits the collaboration between staff and family and gives family caregivers the opportunity to be partners in the care for their relative. Our study examines the family caregivers' preferences regarding their involvement and participation in activities, and possible facilitating factors and barriers that influence family caregiver involvement in the Namaste Care Family program.

2. Methods

2.1. The intervention: Namaste Care Family program

Namaste Care is a program based on a palliative and person-centered care approach and aims to increase quality of life of nursing home residents with advanced dementia (Simard, 2013; Stacpoole et al., 2017) at low costs (Bray et al., 2019; El Alili et al., 2020). Loving nursing care is integrated with individual, meaningful activities in two daily group sessions of two hours in which, ideally, 8 to 10 residents per group participate (Smaling et al., 2018; Stacpoole et al., 2017). The sessions are provided in a quiet and homely room with nice smells, soft music, and no outside distractions.

Namaste Care consists of psychological, social, and spiritual components (Simard and Volicer, 2010; Smaling et al., 2018; Stacpoole et al., 2017). It responds to the five most important psychological needs of people with dementia, as identified by Kitwood (1997). These five needs are comfort, attachment, identity, being involved in the process of life (occupation), and feeling part of a group (inclusion). Namaste Care is focused on connecting with the person with dementia, for example through touch or a joint activity. Namaste Care has decreased challenging behavior and improved quality of life (Stacpoole et al., 2015; Simard and Volicer, 2010), and a better connection between family caregivers and staff has also been reported (Stacpoole et al., 2017).

In the Netherlands, Namaste Care was adapted by placing greater emphasis on including family caregivers and volunteers in delivering the sessions in cooperation with the staff. The adapted program was called the Namaste Care Family program (Smaling et al., 2019).

2.2. Study design

This qualitative study had a descriptive exploratory design using data from the Dutch Namaste RCT (Smaling et al., 2018). Exploratory descriptive methodology stems from nursing research and was chosen to reach a fundamental understanding of the concept of family caregiver involvement in an intervention, based on the stories of those involved (Polit and Beck, 2004).

2.3. Recruitment of participants

In the Namaste study, nineteen nursing homes participated in a cluster-randomized controlled trial (RCT) that examined the effects of the Namaste Care Family program on quality of life of nursing home residents with dementia and positive family caregiving experiences. Of the participating nursing homes, ten implemented the Namaste Care Family program, while the other nine continued to provide usual care. Prior to the implementation, information meetings of 30 to 60 min were held in the intervention nursing homes to inform family caregivers and volunteers about the aim and content of the program. The study protocol has been described in detail elsewhere (Smaling et al., 2018). The study has been reviewed and approved by the Medical Ethics Review Committee of the VU University Medical Center (protocol number 2016.399) and is registered with the Netherlands Trial Register (NTR5692).

2.4. Participants

Semi-structured interviews ($N = 40$) were conducted with family caregivers, volunteers, and professional caregivers between December 2017 and October 2018. The interviews were conducted as part of the process evaluation of the Dutch Namaste RCT within a 4-week period, twelve months after implementation of the Namaste Care Family program in the nursing home. A brief description of the Namaste RCT can be found in Appendix 2.

As nursing homes implemented the program at different times, data were collected over a relatively long period. Because two nursing homes discontinued the intervention prematurely, the interviews were there conducted at three ($n = 3$) and six months ($n = 3$) after implementation of the program. Reasons for drop out were ongoing staff shortage, death of participating residents, and organizational problems.

2.5. Data collection

Interviews were conducted with at least one staff member, and one family caregiver and one volunteer, or two family caregivers per nursing home. If the program was organized differently on different wards or locations of the nursing home, participants from all those wards or locations were interviewed. The one-time interviews were conducted by three trained, experienced female psychologists (HS, SD, and a research assistant) at a location of choice of the interviewee, usually at home or the nursing home. The interview comprised a series of open-ended questions based on specific themes relevant for the process evaluation of the Namaste RCT (see interview guide in Appendix 1).

Family caregivers who participated at least two times in the Namaste Care Family program were invited to participate in the interview. Only those staff members and volunteers who regularly took part in the Namaste sessions were invited to participate in the interviews. There were no other inclusion criteria.

Of the 56 people invited, 44 (79%) agreed to participate in the interview. Lack of time ($n = 6$), health issues ($n = 2$), not meeting the inclusion criteria ($n = 2$), death of the person with dementia ($n = 1$), and holiday ($n = 1$) were reasons for not participating. One interview with a family caregiver was lost due to a failing recording device. Three interviews were conducted with two participants at the same time at their request. This resulted in a sample of 40 interviews with 43 participants; 10 family caregivers, 31 staff members, and 2 volunteers about their experiences with the Namaste Care Family program.

Interviews were audio recorded and transcribed verbatim. Transcripts were not made available to the participants. ATLAS.ti software, version 7.5.18 (Atlas.ti Scientific Software Development GmbH, Berlin 2017) was used to support the processing of the transcripts (Friese, 2014).

2.6. Analysis

For this study, a secondary analysis was performed on the interviews conducted for the process evaluation of the Dutch Namaste RCT. The initial coding process of the interviews for the process evaluation is described in Appendix 2. We performed an in-depth

Table 1
Selected codes of the interviews taken from the Namaste RCT process evaluation.

Theme	Code
Family caregiver involvement	Barriers Intensity of participation Manner of participation Suggestions for improvement of family caregiver involvement
Suggestions for improvement of the Namaste Care Family program	Content related factors Practical factors External factors
Effect on family caregiver	Effect on visits Own experiences during Namaste sessions Change in perception of relative Effect on their relationships with all involved

analysis of the codes related to the interview questions about family involvement, about the impact of the program on family caregivers, and recommendations for improvement of the program. The relevant codes are described in Table 1.

An inductive approach with open and axial coding was performed by two researchers (PT and HS), based on the six steps of thematic analysis (Braun and Clarke, 2006). Data from interviews presenting different perspectives was triangulated. In the first step, all content related to our research questions was read by two researchers (PT and HS) to become familiar with the data. In the second step, new codes were added to the coding frame (see Box 1). In step three, the codes were organized in broader themes. Simultaneously, the results were considered per target group (e.g., family caregivers, staff, and volunteers) and re-analyzed separately. During the fourth step, the identified themes were reviewed, modified, and developed.

We examined possible subthemes, overlap, and support of the themes by the data based on the question: "what do they say about family involvement?" During step five, based on a clear overview of each theme that had been developed in the previous steps, themes were identified and the essence of each theme was defined. The result of the analysis process is reflected in Fig. 1, which provides a summary of identified themes and codes. The final step included summarizing and the results and conclusions. In sum, it was an iterative process in which the data was reused multiple times until no more new insights emerged.

To ensure inter-rater agreement, two researchers discussed the coding and analysis. A consensus meeting and discussion about the outcomes was carried out by two researchers (PT and HS). Finally, a researcher who had also been involved in the Dutch Namaste RCT (SD) provided feedback on the results and interpretation. Participants did not provide feedback on the findings.

3. Results

Interviews with 10 family caregivers, 31 staff members, and 2 volunteers were conducted in 10 nursing homes across the Netherlands that implemented the Namaste Care Family program. Family caregivers included a wife, a husband, six daughters, a son, and a son-in-law (see Table 2).

In general, the family caregivers experienced their involvement in the Namaste Care Family program as positive, particularly having meaningful contact with their relative. However, putting family involvement into practice was challenging as family caregivers and staff did not agree on how to involve family caregivers. Where staff preferred firm agreements with family caregivers about their involvement, family caregivers called for more spontaneous participation. Staff often thought they had informed family caregivers appropriately, but family caregivers struggled with unclear expectations, which made their involvement more difficult, as did staff not making them feel welcome. Family caregivers expressed feelings of uncertainty and not feeling supported by staff, whereas staff sometimes had the impression that family caregivers were just relieved that the care task was taken over by the nursing home and they were focused only on their own relatives.

The interviewees from the nursing home that stopped after 6 months had a more positive experience with the program compared to the interviewees that participated only 3 months. Interviewees from the former were actually willing to continue because they were relatively satisfied with the program, reporting only minor points for improvement. By contrast, all interviewees from the nursing home that stopped after 3 months shared several negative experiences and felt that the program was being "imposed top-down".

The complexities of family involvement in practice were evident through a range of facilitating factors and multiple barriers identified from the qualitative analysis. Three themes emerged: 'activities', 'personal circumstances', and 'communication' (see Fig. 1 for an overview of stimulating factors and barriers to family caregiver involvement).

3.1. 'Activities': Preferences of family caregivers for activities with their relative living with dementia

This theme concerns the experiences with activities offered in the Namaste Care Family program; why family caregivers (dis)liked them, when family caregivers enjoyed being involved, what the barriers were to active participation in the activities, and recommendations made by the interviewees for successful family involvement in the Namaste sessions.

Overall, the family caregivers who participated in the Namaste Care Family program were very enthusiastic. There were various activities they enjoyed doing with their relative during Namaste sessions. These activities included walking, painting, reading, reminiscing, cooking together and giving the relative a (hand) massage. Mostly, family caregivers wanted to do practical and clearly defined activities (e.g. cooking, taking a walk or playing a game) with the residents. They preferred to participate in activities that matched their personal interests, things they also like to do in their private life, and activities they felt comfortable with.

> "They also do music [....]. If you don't like this, then you don't go. But if there is table shuffeboard [old Dutch board game] or whatever, and you enjoy that, then you will go there. So I think that is very personal." (family caregiver, daughter)

Family caregivers indicated they were hesitant to engage in activities they were not familiar with. Both family caregivers and staff said that the threshold for family caregivers to join activities such as hand massage and touching is higher because it is perceived as being too intimate. They are not used to that kind of contact with their relative.

> "They (family caregivers) say: "I am not very keen on sitting next to my mother and then giving her that hand massage... It makes people uncomfortable. But if you bring in balloons to shoot those across the table, then they'll join in without a problem. That's not physical....". (manager)

Family caregivers mentioned the joy that activities gave them when they saw a positive response in the resident. The residents seem to light up during the sessions, which made the family caregivers embrace the Namaste program.

> "I thought it was great that my mother connected with that doll. Because for the first time, I saw some expression on her face again. Her eyes lit up again." (family caregiver, daughter)

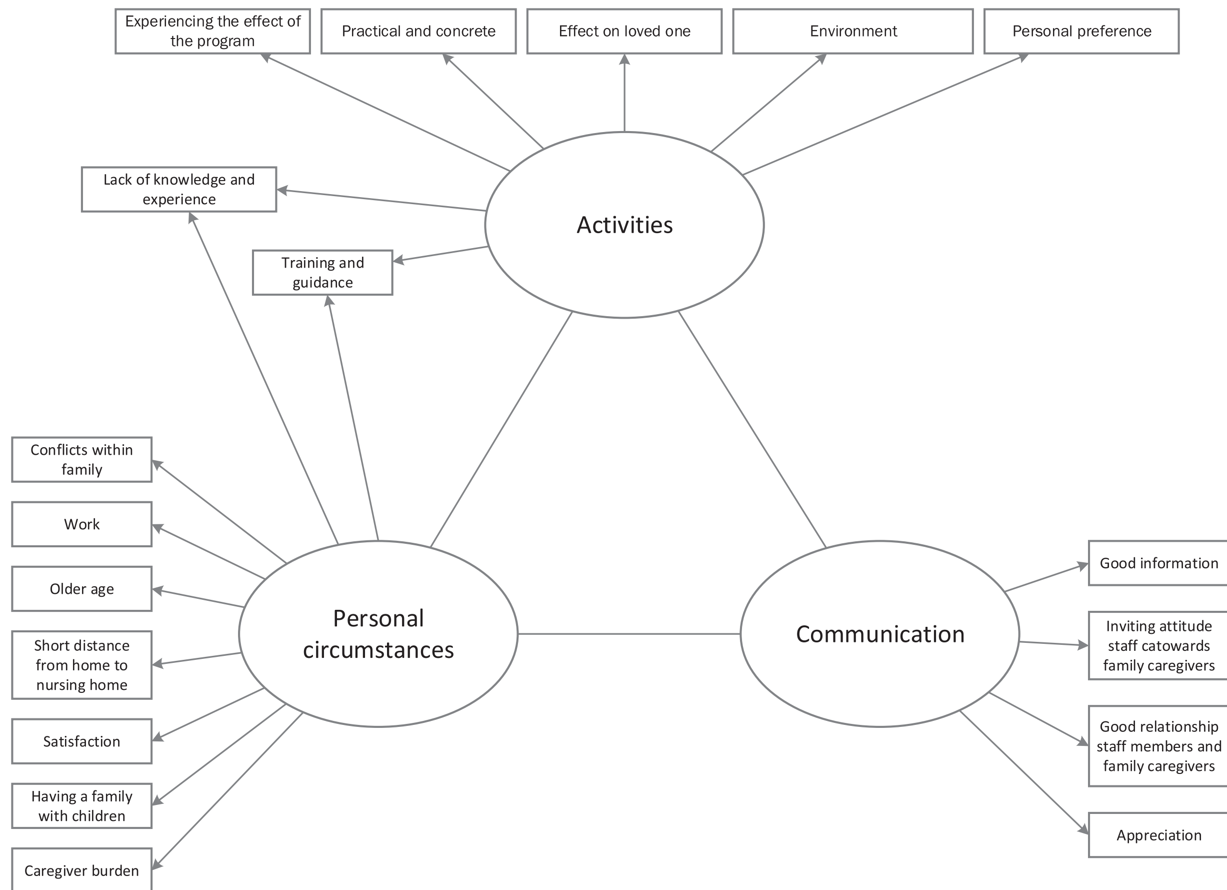

Fig. 1. Overview of stimulating factors and barriers to family caregiver involvement.

Table 2
Description of the interviews ($N = 40$) and interviewees ($N = 43$).

Interviewees, n (%)		
Family caregiver	10 (23)	
Activity coordinator	7 (16)	
Nurse	11 (26)	
Volunteer	2 (5)	
Manager	9 (21)	
Namaste coordinator	4 (9)	
Demographics interviewees		
Female, *n* (%)	40 (93)	
Age, total sample, mean (SD), range	51.6 (12.8)	22–84
Age family caregiver, mean (SD), range	61.4 (11.5)	44–84
Age volunteer, mean (SD), range	51.5 (12.0)	43–60
Age staff, mean (SD), range	48.7 (12.2)	22–64
Gender and family caregivers' relation to resident, *n* (%)		
Female	7 (70)	
Spouse	2 (20)	
Child	7 (70)	
Son-in-law	1 (10)	
Duration of the interviews, mean number of minutes, (SD), range		
Total sample	50.7 (15.3)	27–102
Family caregiver	46.6 (17.6)	27–73
Volunteer	48.5 (16.3)	37–60
Staff member	51.9 (15.0)	34–102

The activities helped family caregivers to better connect with their relative and this resulted in more meaningful interactions. Family caregivers experienced their visits as more meaningful. Seeing and experiencing the effects of the Namaste program firsthand was thus a facilitating factor for family participation. One of the staff members indicated that all involved can only experience the positive effects by doing it themselves:

"A kind of 'seeing is believing'. And that makes it really, really good." (activity coordinator)

According to volunteers, staff paying attention to family caregivers during the activities also contributes to a positive experience and stimulates them to visit more often.

The staff also mentioned several barriers to family involvement in the Namaste Care Family program. They said family caregivers

Box 1
Coding frame of the current qualitative study.

Codes
Communication/information
Lack of knowledge
Confrontation with the disease of relative
Effect on relative
Age of family caregiver
Intrinsic motivation
Positive experience
Feelings of grief/loss
Atmosphere in the group
Time (work)
Appreciation
Structure
Spontaneous participation

were sometimes reluctant to disturb an ongoing session; usually for reasons of modesty or when it was not clear to them whether they could enter the Namaste room. Although most family caregivers also interacted with other residents during the session, family caregivers were generally focused on their relatives and were reluctant to undertake activities with other residents. Staff thought this may be because family caregivers see their regular visits as an activity and that some family caregivers felt strongly that doing activities with (other) residents was part of the nursing staff's tasks. The staff believed a culture change is needed to get those family caregivers more involved. They felt that it is still commonly thought that the nursing home takes care of everything and family caregivers no longer need to do anything. Some staff members felt that their own role must also change to make that culture change happen.

> "Family could do more, but we - as care professionals - should also encourage that. Now we say: you can't continue like this, you need to go to the nursing home and they can take care of everything there. And then we don't have to do anything anymore. That is the shift we need to make. We do tend to take over completely and are very much hospitalized in that sense. In this shift the family would also be allowed more and do more if they want to. This is still too far away. First there is this whole other step that needs to be realized." (manager)

There were also family caregivers who preferred to remain involved in the care for their relative at a distance and were relieved that the nursing home took over the care. According to the nursing staff, these family members generally did not want to take on extra obligations or care by participating in a more structural way in the program.

> "Yes, I have taken advantage of it in the sense of: oh, there is singing here this afternoon and she really enjoys that. She'll be willing to go. And then I can do something else. And I will come in tomorrow." (family caregiver, son)

Some family caregivers also felt they lacked the proper skills to undertake activities during Namaste and did not feel confident enough to deal with people living with dementia and the challenging behavior (e.g., agitation, wandering, calling out repeatedly, anxiety) that often occurs. A lack of knowledge was often mentioned as a barrier and can also be seen as a personal circumstance. It impeded more active involvement. Several family caregivers said that dealing with challenging behavior in a group of people with dementia was also a barrier. However, they indicated that seeing the positive effects of the Namaste Care Family program on the group and just participating in the sessions also gave them the confidence to continue their participation.

A few facilitators and barriers related to the conditions of the program were also mentioned. One family caregiver considered the invitation to participate in the Namaste program as a disguised budget cut, which was reason for her not to actively participate in the sessions.

The interviewees recommended a better exploration of the needs of family caregivers as to how they want to be involved in the Namaste Care Family program, and to personally invite family caregivers to join the sessions to increase family involvement. Family caregivers, staff and volunteers also suggested offering a Namaste training, or developing a manual specifically for family caregivers and volunteers.

3.2. 'Personal circumstances': Personal context of family caregivers

This theme describes which personal circumstances and needs of family caregivers can impact active family caregiver participation. Several facilitating personal factors were mentioned. Participating in Namaste often gave family caregivers a feeling of satisfaction. It made them feel useful, like they were doing something important for the resident(s). This motivated them to continue participating in the sessions. By actively participating in the sessions, family caregivers learned to better deal with challenging behavior. This increased their confidence and facilitated their involvement. Living close to the nursing home was also seen as a facilitating factor.

Lack of time, having a (fulltime) job, and having a family with children were often mentioned as barriers to active participation. Especially during the day, (working) family caregivers reported having limited time to participate. Some interviewees therefore recommended also scheduling Namaste sessions in the evening in order to enable more family caregivers to participate. They reported that family caregivers often visit their relative in the evening.

Some family caregivers believed that participating in a group session would lead to less individual quality time with their relative. Apart from their positive experiences, participating in the Namaste sessions was also difficult for some interviewees. It confronted them with the dementia and the effects of the disease on their relative.

> "You can tell on all sides that it generates feelings of helplessness. People are willing, but they don't really know how. It's only few hours. I manage that pretty well now, although it can be sad sometimes, I can more or less accept how far gone she is. But I have seen a group of family members who attended twice, it is so painful every time to see your wife no longer able to do anything. Then you won't participate in this kind of program." (family caregiver, daughter)

Staff and a volunteer also mentioned the (old) age of the family caregiver, conflicts within the family and caregiver burden as barriers to active family caregiver participation. One husband felt like he was a man in a woman's world and experienced this as a barrier to his participation in the sessions:

> "I was the only man, you know. And then, well, it's different. And then you see how those women interact with the residents. Yes, that is different. Plus, the residents are all different. All different. But, so, on Wednesday there are two male volunteers. That is really good. Makes a change ...." (family caregiver, spouse)

3.3. 'Communication': Communication between family caregiver, staff and volunteer

This theme includes communication between family caregivers, staff, and volunteers, and between the interviewees and the resi-

dents. Communication between staff, volunteers and family caregivers played an important role in the active participation of family caregivers in the Namaste sessions. Both family caregivers and staff expressed a good family-staff relationship as very important for the active involvement of family caregivers in the program.

An important facilitating factor was properly informing family caregivers, before the program is implemented, about the aim and content of the Namaste Care Family program and what is expected of them when they participate in the Namaste sessions. A clear structure for Namaste was also a facilitating factor.

> "Maybe if you do this again, you could say more about what actually happens on these mornings. That's a possibility. Like: we have a fantastic overhead projector and that will be there, and the music and you are welcome to join in. You could give your father and mother a hand massage, or we can do that. Maybe little more like that." (family caregiver, daughter)

While some family caregivers loved the idea of being able to spontaneously join a Namaste session, others preferred a more structured way, with agreements about participation being made in advance. This confirms the different needs family caregivers may have. In one of the nursing homes, family caregivers did not feel welcome during the start-up phase, because at the start of the program staff gave them the impression that spontaneous participation was not possible.

> "I think it would be prudent to say, of course you can visit, but please remember that the Namaste program is underway and please slow down, relax. Yes, exactly. That it works differently. That you don't put up barriers in advance, like, well it's Namaste, so we'd better not visit then." (family caregiver, daughter)

Misconceptions and unclear communication about how family caregivers can participate in the program were barriers to active family caregiver involvement. It should be clear for family caregivers that they can participate in any way they want. Also, feeling welcome and appreciated for helping stimulated family caregivers to participate in the sessions. A few family caregivers felt that their efforts and involvement in the Namaste sessions were not appreciated by the staff and reported this as a barrier to continue participating in the sessions.

Interestingly, some family caregivers in two nursing homes indicated they were insufficiently informed about the program, its potential beneficial effects, and their possible role in it, while the staff of those nursing homes were convinced they had properly informed family caregivers and had asked them repeatedly to participate in the Namaste sessions. The interviewees recommended more contact between staff and family caregivers in order to get them more actively involved in the program. Staff should talk to family caregivers more informally about their experiences with Namaste and help them when they experience difficulties during the sessions. It was also recommended that staff should be more flexible when talking to family caregivers, not only communicate during office hours, but also after office hours (when family caregivers usually do not to work). One staff member also indicated that a motivated and enthusiastic staff with clear vision on the Namaste Care Family program can help lower the threshold experienced by family caregivers to participating in the sessions. So, it is important that the nursing team invests in building a relationship with the family caregivers and to motivate them to join the Namaste sessions.

4. Discussion

The aim of this study was to better understand family caregiver experiences of their involvement in the Namaste Care Family program and to identify the facilitating factors and the barriers to active family involvement. The current study showed that family caregivers are willing to participate in a care program such as the Namaste Care Family program, which is aimed at increasing the quality of life of the residents. The overall experiences with the program were positive. This is in line with other findings (Stacpoole et al., 2017, 2015) that most family caregiver wish to remain actively involved in the care for their relative (Davies and Nolan, 2006; Gaugler, 2005; Nolan et al., 2009; Stacpoole et al., 2017). It was difficult to involve family caregivers and for family caregivers to engage in the program as staff and family held different views as to how families could be involved while taking into account family caregivers' personal preferences. The frequency of their participation and their preferred activities differed. Most family caregivers also interacted with other residents. Three themes covered a range of facilitators and barriers to family involvement, namely activities, communication and personal circumstances.

4.1. Activity

The family caregivers preferred to be involved in practical activities that match their own preferences and interests, such as dining with the resident, small household tasks and going for a drive. This is consistent with findings in other research (Bramble et al., 2011; Graneheim et al., 2014; Milte et al., 2016). The positive response (e.g., smiling, actively participating, touching) that the activities and being in a Namaste session evoked in their relatives was a very important stimulus to stay involved. A good atmosphere is an important precondition for involving family caregivers in an intervention such as the Namaste Care Family program. This environment has sufficient and well-trained staff who are committed to residents and their family caregivers, and where staff work well together in a good atmosphere, supported by management. The study of Bramble et al. (2011) indicates that the right conditions for family caregivers to participate are difficult to realize, and limitations in the organization or setting increase the risk of failure). Currently, the involvement of family caregivers is mostly determined and decided by the nursing home staff, with little room for input from family caregivers regarding their contribution. To improve active family participation, it is therefore important to include family caregivers at an early stage and pay more attention to their possibilities, preferences and needs (Graneheim et al., 2014; Reid and Chappell, 2017).

4.2. Communication

The finding that family caregivers did not always feel welcome or appreciated by staff and experienced a lack of knowledge and experience with people living with dementia is in line with other research. This includes intervention studies with family caregivers and staff, that say that informal caregivers should be recognized as partners in care, and that being welcomed by staff, good guidance and training enhances this partnership (Graneheim et al., 2014; Helgesen et al., 2013; Nolan et al., 2009). Good guidance during the sessions facilitated family caregiver involvement. Lack of knowledge and unclear information and expectations prior to the program, confirmed by earlier research, were barriers to their involvement (Brodaty and Donkin, 2009; Graneheim et al., 2014; McCabe et al., 2017).

Family caregivers in this study did mention having difficulty determining what activity they should do with someone who is increasingly difficult to communicate with. With proper help from the staff, the Namaste Care Family program has the potential to provide family caregivers with the tools to make meaningful connections with their relative, and to therefore be beneficial to

their relationship (Brodaty and Donkin, 2009; Hertzberg and Ekman, 1996; Majerovitz et al., 2009). Maybe staff can benefit from more training prior to the program to become familiar with this role, which is new to some.

Despite family caregivers' willingness to be involved, realizing this in actual practice is complex (Graneheim et al., 2014). This study has provided more insight into how family caregivers want to be involved. Their expectations and needs related to participating in Namaste sessions appeared to be different from what professionals think. Good and clear communication between family caregivers and staff is therefore crucial and it should include an assessment of the needs of family caregivers. A good partnership between staff and family caregivers can grow by paying attention to the ideas of family caregivers (Bluestein and Latham Bach, 2007). Thus listening to family caregivers' ideas for participating in, and their struggles with the Namaste Care Family program, can foster this increase of family caregiver involvement. To transition to a situation with more active family involvement, staff should be more focused on the needs of family caregivers and not see them as informal care professionals who can take over some of their tasks or compete with them (Reese et al., 2016; Robison et al., 2007).

4.3. Personal circumstances

Personal circumstances have a strong impact on family caregivers' possibilities to be or stay involved in the care for their relative. In this study, personal circumstances that stimulated family caregiver involvement included positive experiences that participating in the sessions gave them and feeling welcome to join the Namaste sessions. Older age, living near the nursing home, and having a job were a few of a variety of possible personal circumstances that impeded family caregiver involvement. These findings confirm that, in addition to the general concerns about family involvement, caregivers' individual circumstances should be taken into account (Brodaty and Donkin, 2009).

Limitations of this study include the predominantly female sample and the relatively low number of volunteers that were interviewed. Also, only family caregivers who had actively participated in the program were interviewed. It would have been interesting to interview family caregivers who had not participated in the sessions to learn more about their motives. These limitations may affect the generalizability of the findings. However, as most primary family caregivers are women (Brodaty and Donkin, 2009), the predominantly female participants in our study can be seen as representative of the target group.

Strengths of the current study include the diversity of experiences of the interviewees and the triangulation of the data sources. We also interviewed participants from nursing homes that dropped out prematurely to investigate potential differences in experiences and identify more potential barriers to and facilitators of family involvement.

4.4. Conclusions and recommendations

In general, when trying to involve family caregivers, staff do not always take the individuality of the family caregivers into account. Active, successful family involvement requires good and clear communication about mutual expectations, with emphasis on the benefits for the person with dementia and the family caregiver. Knowledgeable and professional staff is an important prerequisite for successful family involvement.

Family caregiver involvement in a program such as Namaste Care Family, can improve the quality of life of nursing home residents living with dementia, provide positive experiences for family caregivers with the care for their relative, and enable staff to provide person-centered care. To further improve family involvement in the Namaste Care Family program, we recommend developing a brief manual specifically for family caregivers and volunteers. In addition, a person-oriented approach that takes personal circumstances and preferences of family caregivers into account is needed. We also recommend involving family caregivers even prior to implementation of the program. Finally, training staff members to improve communication with family caregivers is advised. Further research on the Namaste program and family caregiver involvement should focus on how reality and wishes of all involved can be better aligned. Exploring the complexity – with the many different ideas and interests of all involved- of family involvement and developing interventions with a stronger focus on the individual needs of family caregivers may help to achieve this.

Credit author statement

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Conceptualization	x		x	x	x
Methodology	x		x	x	x
Formal analysis	x	x	x		
Investigation		x	x		
Data Curation	x	x	x		
Writing - Original Draft	x				
Writing - Review & Editing	x	x	x	x	x
Visualization	x	x	x	x	x
Supervision					
			x	x	x
Project administration					
	x	x	x		x
Funding acquisition	x		x	x	x

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(*Continued on next page*)

Term	Definition
Formal analysis	Application of statistical, mathematical, computational, or other formal techniques to analyze or synthesize study data
Investigation	Conducting a research and investigation process, specifically performing the experiments, or data/evidence collection
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Funding acquisition	Acquisition of the financial support for the project leading to this publication

Declaration of Competing Interest

None declared.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnurstu.2021.103968.

Appendix 1. The interview guide of the Dutch Namaste RCT.

General questions

1. How often have you participated in a Namaste session? Do you register for it? Have you ever 'spontaneously' helped out in a Namaste session?
2. What was it like for you to participate in the Namaste sessions? What effect did it have on you and why? To what extent does the Namaste Family program fit in with your own values, interests, beliefs and preferences?
3. What do you think it is like for the resident(s) to participate in a Namaste session? Why do you think that?
4. Can you describe a situation with regard to Namaste that you remember most clearly (positively or negatively)? What specifically made an impression on you?
5. Have you seen effects of the Namaste Family program?

→ask about effects on residents, staff, family, effects outside the sessions, relationships (between residents, staff-resident, family-resident, within family).

→ ask about positive and negative effects

→ ask about effects on behavior, mood, health, medication, burden

6. Could you describe a moment that you think best reflects the effect of participating in the program for the person with dementia? Why do you choose this moment? What effect did you see?
7. Which parts of the Namaste Family program do you find most valuable and why? What do you feel has the greatest impact?
8. Which elements or activities are you less satisfied with? Why? How could these element/activities be adapted?
9. What are the advantages and disadvantages of the Namaste Family program? What can we do to address the disadvantages?
10. What do you think determines the success of the Namaste Family program?
11. How satisfied or dissatisfied are you with the Namaste Family program? (score 0–10)

Can you elaborate on that?

12. In your opinion, does the Namaste Family program have added value (over the regular care already offered by the nursing home)? Can you elaborate?
13. To what extent would you recommend the program? (score 0–10) Why yes/no?

What recommendations or tips would you give others who wanted to start with the program?

14. To what extent do you think the Namaste Family program would benefit people with dementia who live at home and their relative(s)? Please explain. Do you have any ideas about how this should be designed? What should be different (for family: Would you have liked this when your relative was still living at home? Why yes/no?)

Questions depending on target group

Family/relative

15. How did the nursing home inform you about the Namaste Family program? How did you find out which sessions you could help with? What was this like? What was good about it and what can be improved? How would you have liked to be informed about it?
16. Which activities did you help out with? What made you participate? How did you like it? What was good and what wasn't?

Have there been any activities you did not want to do? What could have been done to ensure that you or other family members participated in the sessions more often?

17. Has the Namaste Family program influenced how you experience visits to the nursing home and your relative? Can you explain? Has it influenced the frequency of your visits?
18. Has the Namaste Family program influenced contact between you and the staff? If so, please elaborate. Have you also noticed an effect on the contact between staff and your relative?
19. To what extent do you think the Namaste Family program suits you and your relative? Can you elaborate? If applicable, why is the program less suitable for your relative?
20. If applicable: Did your relative also receive (elements of) Namaste during the last phase of his/her life? Could you briefly tell us about what happened? What do you think it was like for your relative? What was it like for you?

Management

21. How long have you been working in healthcare? How long with this target group? How long in this nursing home?
22. What was the main reason for joining the Namaste Family program? How did you come to this decision (process)?
23. To what extent does the Namaste Family program fit in with your mission/local culture?
24. Can you tell us about the implementation of the Namaste Family program? Have you implemented or adapted all the elements? How and why?

25. What bottlenecks did you encounter during the implementation? Which factors have hindered the implementation?

How did you tackle these bottlenecks or obstacles? What actions ensured success and what seemed to work less well?

26. What factors do you think were/are essential for effective, successful implementation? Did you miss anything that could have been helpful in the implementation?

27. What do you think of the manual for managers? Did you miss elements, or would you have liked more information or explanations on any topic? Is there anything in the manual that in your opinion needs to be changed? Which sections were most useful? What can be deleted?

28. What is palliative care in your opinion? To what extent is the Namaste Family program, as implemented within your department/organization, compatible with palliative care? How could the contribution made by Namaste be increased or improved?

29. In the context of Namaste, have you also handled things differently compared to ‘normal’ during the dying process? What is different to before Namaste? Can you elaborate with an example? How do you like this ’new’ approach?

30. How many members does the Namaste team consist of (how many staff members on the ward)? How and by whom is the Namaste program coordinated and executed (disciplines, employees per session)? What are your experiences? How would you advise other homes to organize it? *On average, how often do you consult each other about Namaste*?

31. Was Namaste also offered on an individual level? In what situations? How long on average and by whom was it offered? How was this organized?

32. What did you do to involve relatives and volunteers in the program? To what extent did you succeed? What obstacles, if any, did you encounter? What factors or which approach led to success?

33. What are your experiences with involving family and volunteers in the Namaste sessions? What was it like to work with them?

→ continue to probe when was it pleasant, but also when was it *not* pleasant and *why*.

34. Does the Namaste Family program influence how you experience your work? Do you experience your work (or parts of it) differently than before the implementation? If so, what things exactly and why is that?

35. Has the implementation of Namaste caused a shift in tasks on the ward? If so, what does that look like? [If interviewer thinks it would facilitate the interview: did you have to hire extra staff as a result of Namaste?]

36. To what extent do you think the Namaste Family program will continue after the study is completed? What factors would play a major role here? What is needed to include the program in the standard care offered in your nursing home?

Nursing staff

37. How long have you been working in healthcare? How long with this target group? How long in this nursing home?

38. What role have you fulfilled within the Namaste Family program? Did you receive extra compensation for your role in the program or do you see other advantages to your participation in the Namaste Family program (e.g. looks good on CV)?

39. Can you describe what an average Namaste weekly program looks like? How many days of the week are sessions held? How many sessions per day? How long does an average session last?

If not 7 days p/w and 2 sessions per day: Why did you decide to offer fewer sessions? What is required to be able to offer it twice a day?

40. A Namaste session consists of a number of fixed elements (music and scent in the room, personal greeting, screening for pain/provide extra comfort, tasty snacks and drinks and offering these on a regular basis, meaningful activities suitable for the individual, thank participant for attending). Have you added any elements to the program yourself? Were any activities or elements not carried out or carried out differently? Why was this decided?

41. To what extent was (were) Namaste (elements) offered on an individual level? When and how was this done?

42. In the context of Namaste, have you also handled things differently compared to ‘normal’ during the dying process? What is different to before Namaste? Can you elaborate with an example? How do you like this ’new’ approach?

43. To what extent was the implementation of the Namaste Family program supported in the organization (imposed mainly top down or joint decision or by the employees)? To what extent was the implementation supported by management? To what extent did you feel supported by your manager in the implementation of the program?

44. To what extent did you have time and room to experiment with the new way of working? To what extent did you reflect and evaluate together?

45. What problems were you confronted with during the implementation and execution of Namaste? How did you solve them?

46. Has the manual for staff helped you with the implementation and execution of Namaste? Is anything missing from the manual? Are there things in the manual that in your opinion need to be changed (content, shorter, expand)? Which parts were most helpful to you?

47. To what extent do you screen the residents for pain every session and make them as comfortable as possible? Do you also use the PAINAD (Pain Assessment in Advanced Dementia Scale? (Follow-up questions: your experiences with PAINAD? Use of other instruments)?

→ What do you do when you observe pain or changes in behavior in a resident? Is this communicated to the physician? → Has Namaste influenced the frequency of medication reviews?

48. To what extent have family members and volunteers been involved in the execution of Namaste? What have you done to involve family members and volunteers in the program? To what extent was this successful? What were obstacles, if any?

49. Were you happy with the commitment of family members and volunteers in the execution of the program? Was it easy to get them to help with the activities or to demonstrate what was asked of them during the session?

What was it like to work with them? → ask when it was positive but also when it was not positive and why.

50. Does the Namaste Family program influence how you experience your work? Do you experience your work (or parts of it) differently than before the implementation? If so, what exactly and what is the reason?

51. To what extent has the implementation of Namaste influenced your daily tasks and activities (work pressure, shift of activities, division of tasks in team)?

52. To what extent do you apply elements from Namaste outside the sessions/in the regular care moments?

Appendix 2. Additional information about the Dutch Namaste study

In the Dutch Namaste study, three sub-studies were completed: 1) a study set out to explore instruments to measure positive experiences of family caregivers of nursing home residents with dementia; 2) a cluster RCT to explore effects of the Namaste Care Family program on quality of life and family caregiving experi-

ences; and 3) a pilot study to investigate the feasibility of the Namaste program for the home care setting.

Process evaluation

Along the RCT, a process evaluation was conducted. The Consolidated Framework for Implementation Research (Damschroder et al., 2009), a framework in which the successful parts of a number of implementation theories have been merged, was used to inspire development of the interview guide for the process evaluation.

For the process evaluation, the interviews were analyzed independently by two researchers (HS and SD). Coding was done per research question. One of the research questions related to family caregiver involvement. After the first three interviews were coded independently by two researchers, a consensus code framework was developed. This coding framework was then used to recode the first three interviews and to code three new interviews. This led to a further refining of the coding framework and recoding of previous interviews. This process was repeated until all interviews were coded. Inter-rater reliability was ensured by means of independent analysis by two researchers and a consensus meeting to discuss differences. A third researcher was consulted if consensus could not be reached.

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