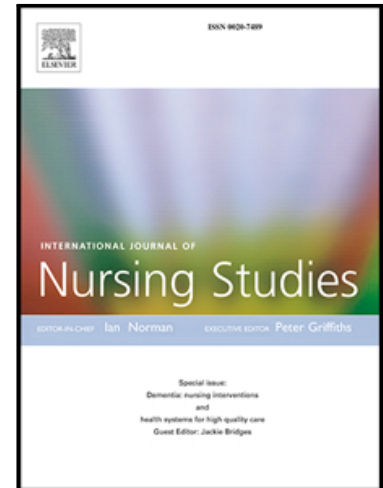


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Family involvement in the Namaste Care Family program for dementia: A qualitative study on experiences of family, nursing home staff, and volunteers

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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 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).

Keywords: dementia, experiences, family caregivers, nursing home, quality of life, family involvement, qualitative research

What is already known about this topic

- ◁ 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.

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.

Methods

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).

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).

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 minutes 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).

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.

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).

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 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.

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

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.

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

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 Figure 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.

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?
Æcontinue 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 staff37. 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)?

ÆWhat do you do when you observe pain or changes in behavior in a resident? Is this communicated to the physician? Æ 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? Æask 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 experiences; 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.

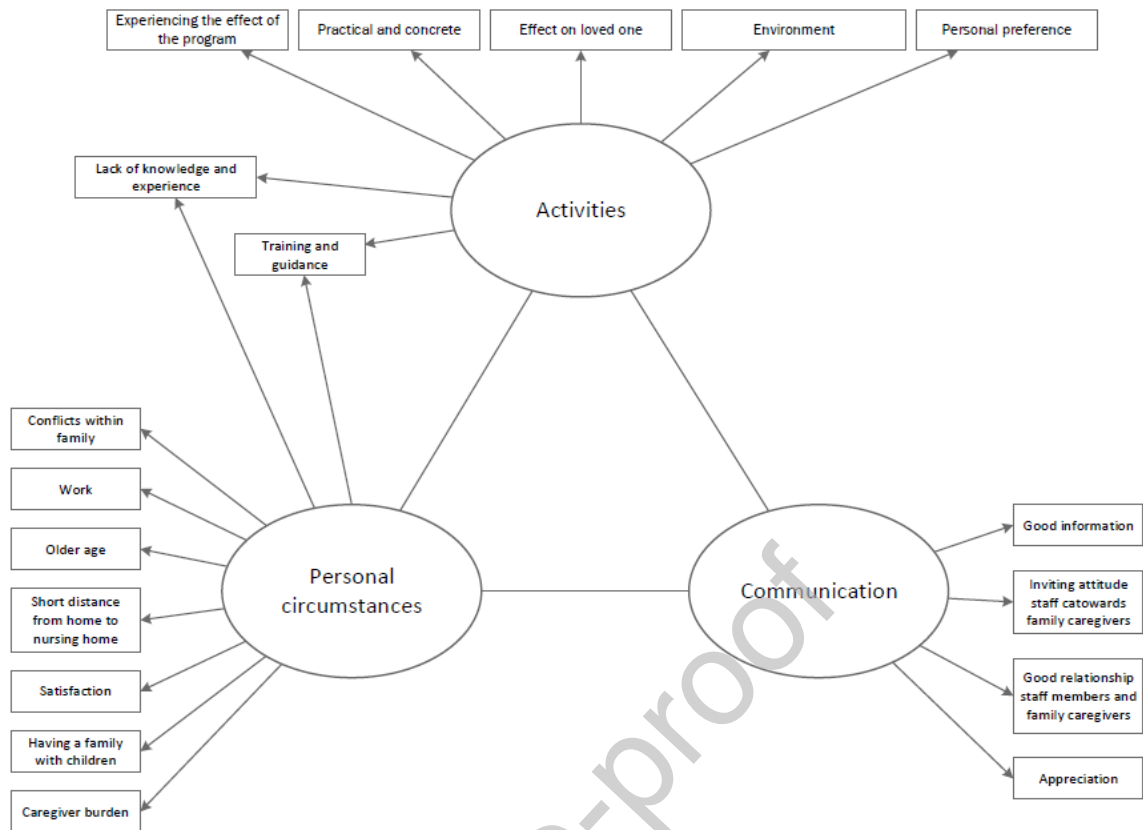


Figure 1: Overview of stimulating factors and barriers to family caregiver involvement