

Family carers' experiences of attending a multicomponent psychosocial intervention program for carers and persons with dementia

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Background: Psychosocial interventions for persons with dementia and their primary family carers are promising approaches to reducing the challenges associated with care, but, obtaining significant outcomes may be difficult. Even though carers in general are satisfied with such interventions, few studies have evaluated the interventions by means of qualitative methods.

Aim: The objective of the study reported here was to investigate family carers' experiences of a multicomponent psychosocial intervention program, and also to offer advice on how to develop the intervention program.

Methods: Content analyses were taken from individual qualitative interviews conducted in 2012 with 20 carers (aged 50–82 years) who participated in a psychosocial intervention program that included education, individual and family counseling, and parallel group sessions for carers and persons with dementia.

Results: Two main categories emerged: 1) benefits of the intervention program, which sets out the informants' experiences for the benefits of participation, described in the subcategories "importance of content and group organization" and "importance of social support"; and 2) missing content in the intervention program, which details the informants' suggestions for future interventions, contained in the subcategories "need for extended content" and "need for new group organization".

Conclusion: The carers found the interventions useful. The importance of even earlier and more flexible interventions for the family carers, the extended family, and the persons with dementia was underscored.

Keywords: carers, dementia, evaluation, intervention, qualitative method, subjective experiences

Introduction

Dementia is a syndrome caused by a variety of brain disorders. The condition is often of progressive nature and leads to increased need for assistance from family carers as well as from society; the prevalence of dementia will increase dramatically in the decades to come.¹ Most people with dementia live in their own homes and are assisted by close family members for several years until the later stages of the disorder.² The carers are, according to research reports, at heightened risk of developing stress-related health problems caused by the burden of care and managing the symptoms related to dementia.^{3,4} Also, both the carer and the person with dementia are at risk of social isolation and a reduced quality of life.⁵ Aiming to reduce the carers high risk of developing stress-related health problems, many psychosocial interventions (PSIs) for carers have been developed – to educate them about dementia, enhance their communication skills, and provide them with training in problem solving – and are considered to be a promising approach in this respect by many researchers in the field.^{6–8}

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Later reviews have confirmed the positive effect of PSIs on stress-related health problems and the well-being of carers⁹ as well as the delay in nursing-home admissions for the persons with dementia.¹⁰ However, the continued efficacy of PSI after the programs have been completed diverges and shows sparse-to-moderate effects on quantitative self-rating outcome measurements like burden of care among the carers.⁷ The sparse-to-moderate effects of a PSI have also been confirmed in other studies, such as the Danish Alzheimer Intervention Study (DAISY) by Waldorff et al¹¹ and in a randomized controlled trial (RCT) by Bruvik.¹² There have been questions raised as to whether a quantitative approach is sufficient to grasp the experiences of burden of care due to methodological challenges to categorizing interventions and defining health problems and burdens.⁷ The evaluation of DAISY¹¹ also included a qualitative approach, which showed that the carers benefited from the PSI.¹³ This is also in line with other studies.^{14,15}

As part of the evaluation of the PSI reported here conducted in a Norwegian setting,¹² we planned a qualitative approach focusing on the experiences of the participating family carers, because quantitative methods do not necessarily catch valuable dimensions of the caring process such as relationships, intentions, contexts, and “own experiences”.^{16,17} These complex and interpersonal aspects of care are often overlooked in the process and search for benefits, and they are also not covered by quantitative self-administration questionnaires,¹⁸ thus obtaining significant outcomes may be difficult. Therefore, the study reported here was performed by means of qualitative methods in order to evaluate the PSI under study from the perspective of the carers who participated. Our ultimate goal here is also to offer advice on how to develop the study program further.

The intervention program

The “PSI Program for Home-Dwelling Persons with Dementia and Their Carers” – a Norwegian initiative by Bruvik devised to strengthen and support families with dementia – was conducted in Norwegian municipalities between 2009 and 2012.¹² The PSI was a multicomponent RCT program, lasting for 18 months (Table 1). The program encompassed education, counseling, and group meetings. Furthermore, the carers were introduced to cognitive techniques such as structured problem solving (Table 2).

Study aim

The objectives of the study reported here were to investigate family carers’ experiences of the study intervention

Table 1 The content of the intervention program

Education	<ul style="list-style-type: none"> • The carers received education about dementia either in a community-based educational program (“school for carers”) or in two half-day seminars • They received a booklet about dementia and relevant brochures
Counseling	<ul style="list-style-type: none"> • There were five counseling sessions, each of 1 hour’s duration, to identify the needs and resources of the family and to find ways of dealing with challenges by using structured problem solving • The primary carer participated in all the sessions • The person with dementia participated in two of the five sessions, in which the focus was on how to maintain performance of daily tasks and involve him/her in pleasant activities • One session was used for the whole family network
Group meetings	<ul style="list-style-type: none"> • The main approach in the six carer groups was to use structured problem solving to develop ways of coping • In the six group meetings for people with dementia, the focus was on information about dementia and pleasant activities • Two follow-up group meetings took place after 12 and 15 months

and also to offer advice on how to develop the intervention program.

Methods

Qualitative research methods are helpful in providing knowledge of phenomena in areas where little is known.¹⁹ To obtain a deeper understanding of the family carers’ experiences of the study PSI, we therefore used a qualitative approach requiring the use of individual interviews.

Participants

A total of 20 family carers selected from among the 115 carers who participated in the PSI were interviewed. The informants were selected purposively by the first author. In order to strive for variation the participants were included from seven of

Table 2 Problem-solving method in six steps

Step number	Step
1	Define a problem as concretely as possible
2	Brainstorm; all proposals to be recorded
3	Discuss the proposed solutions: pros and cons
4	Choose a solution or a combination of solutions
5	Detail a description of how to carry out the chosen solution
6	Evaluate at the next meeting

the 17 intervention groups, and represented seven different municipalities in southern Norway. Moreover, they were also selected to strive for extended variation in carers and family members with dementia in terms of age, sex, relationship with the person with dementia, and living circumstances in relation to the person with dementia – 14 spouses, one daughter, and one son lived together with the person with dementia when the intervention started, and eight persons with dementia were still home-dwelling when the interviews were performed (Table 3). The carers were contacted by phone and asked if they would participate by the first author. None of them declined.

Data collection

The carers were interviewed in 2012 after they had completed the intervention program. The interviews were conducted by the first author. The interview guide was based on thematic questions focusing on the carers' experiences when participating in the intervention. Questions such as: "How has it been to participate?" "What kinds of experiences did you have after participating?" and "How did you experience the content of the intervention?" were asked. Depending on their replies and reflections, new ideas brought up by the participants raised further questions that were asked to obtain

additional information. In this process, inspired by Corbin and Strauss,²⁰ each question was considered completed when no additional information emerged. The interviews were carried out in a conversation-based format, lasting 20 to 45 minutes, and taking place in the participants' homes, according to their preferences for time and date. A professional writer transcribed the tape-recorded interviews shortly after each interview. The first author performed a quality control check on the transcribed interviews.

Analysis

Manifest qualitative content analysis was used to study the transcripts.²¹ Initially, the transcribed texts were read carefully several times to establish an overall impression. Then "meaning units" – that is, words and sentences expressing a central meaning – were identified and later on systematically condensed without changing the original meaning. At the second stage, the condensed units were labeled with a code stating their content. In the third and final stage, categories and subcategories were created. The subcategories represent an abstraction of groups of codes developed at stage two. The final categories represent an interpretation of benefits, and recommendations for program improvement, as described by the participants.

Table 3 Characteristics of the persons with dementia and their carers

Person with dementia		Carer		
Number	Sex	Age, ^a years	Relationship	Age, ^b years
1	M	76	Wife	72
2	M	78	Wife*	74
3	F	77	Husband	81
4	F	83	Daughter	54
5	F	64	Son	52
6	M	88	Wife	67
7	F	77	Son	52
8	M	77	Wife*	65
9	M	85	Wife*	62
10	F	76	Daughter	50
11	M	69	Wife*	67
12	M	65	Wife*	66
13	M	68	Wife*	68
14	M	72	Wife	71
15	F	75	Husband*	82
16	F	86	Daughter	50
17	F	84	Son*	56
18	F	67	Daughter	55
19	M	81	Wife	70
20	M	76	Wife	76

Notes: ^aAge at inclusion; ^bage when the interviews were performed; *the persons with dementia were home-dwelling when the interviews were performed.

Abbreviations: F, female; M, male.

Ethics

This study followed the ethical principles outlined in the revised Declaration of Helsinki²² and those of the Regional Committee for Ethics in Medical Research, Southern Norway. The Norwegian Data Protection Authority also approved the study. The participants received oral and written information about the study and gave written consent before they were interviewed.

Results

The informants' experiences from the intervention are presented in two thematic categories. Each category includes a number of subcategories presenting different aspects of the categories (Table 4). Quotations from some interviews

Table 4 Categories and subcategories related to the carers' experiences of participating in the intervention

Category	Subcategory
Benefit of the intervention program	Importance of content and group organization
	Importance of social support
Missing content in the intervention program	Need for extended content
	Need for new group organizations

are presented to help the reader evaluate the credibility of the findings.

Category I: benefit of the intervention program

Importance of content and group organization

In this subcategory, the informants talked about the “importance of content and group organization”. The counseling sessions prior to the education and group meetings were expressed as being useful by the informants. However, some found it difficult to talk freely when the person with dementia participated. Other carers said that these meetings had been stressful for the person with dementia because the disorder had increased, making the meeting more stressful and of less benefit for the person with dementia, as one wife of a person with dementia expressed: “It was very good to participate in the sessions. I have made progress myself and it has been very helpful, though stressful.”

The informants pointed out that the counseling session with the whole family network was beneficial. This session contributed to a better common understanding of the situation and better collaboration within the family.

The informants saw the intervention as valuable, resulting in a more appropriate way of coping in everyday life. It gave them knowledge about dementia, which led to a broader understanding of the symptoms of the disease. The intervention helped them to accept the situation in another way, and also contributed to a better understanding of the symptoms they had to deal with. As a result, some informants said problems at home had been reduced. It was easier to stay calm, not to be irritated or angry. They had somehow managed to link disruptive behavior to the disorder in a better way. As one daughter of a person with dementia expressed it: “I manage to tell myself that this is an illness when she repeats herself. I could not have managed to do that in the same way if I hadn’t attended this course.”

To learn more about dementia made them feel safer. It was also good to learn about different symptoms and gain a better understanding of the progression of the disease, because this made them feel more prepared for the future. For some carers it was frightening getting to know about symptoms that may occur among people with dementia, such as aggression. However, they stated that it was useful to hear about other types of dementia and stories from other carers. All the themes in the different parts of the intervention were useful. Structured problem solving helped them to manage challenging situations in a more appropriate way, and they found sharing experiences useful, knowing that their

disclosures would stay within the group. One son of a person with dementia expressed:

I do not know how it will be when the winter comes, but she might stay at home one more year than she probably would have done if we had not participated in that course.

Furthermore, carers reported that it had been important to have a clear structure and agenda in the group sessions; otherwise, it would have been difficult to learn from the other participants’ experiences or carry out the problem-solving method (Table 2). Using the problem-solving method was helpful for finding solutions to problems they were facing in everyday life, and it was inspiring to contribute to the solution of other participants’ problems.

Importance of social support

The subcategory “importance of social support” describes the need for social support and the different ways participants experienced the social support they had received through the intervention. The informants needed someone to talk to and to be supported in a life situation in which they felt isolated and alone on account of the problems linked to the carer tasks. The intervention contributed to giving them easier access to information about where to go or whom to phone for support in the municipality; this was seen as useful knowledge. To be given the opportunity to spend time with other carers and hear about others’ situations contributed to reducing their feelings of being alone; it contributed to making them feel safer in everyday life. In general, it was valuable to meet others who knew about the challenges of living with a person with dementia, which was difficult for neighbors and friends to understand.

The intervention contributed to a broader understanding of the situation among other family members also, and they explained that it felt good to involve other family members. Furthermore, adult children who participated in the family counseling session received a better understanding of the situation of the primary carer and were given the opportunity to express what they felt themselves. Overall, it was easier to collaborate and receive support from other family members. As one husband of a person with dementia said: “I have been depressed, but now I often meet with my son, and he supports me, which helps.”

The group discussions also contributed to encouraging carers to continue with their own activities and jobs, and also reduced their feeling of guilt when asking for help of different kinds from the municipality. The family carers’ feelings of guilt were also reduced when deciding to apply for, or after, short-term or permanent placement in a nursing home. As one

wife of a person with dementia expressed it: "I do not need to feel guilty anymore because the health care personnel and other carers in the group supported me and said that applying for nursing-home placement was the right thing to do."

Moreover, they reported that the intervention had made them more open about the disorder. It had contributed to giving them the chance to see some humor in difficult situations and everyday experiences, situations that are difficult to share with someone without these experiences.

Category 2: missing content in the intervention program

Need for extended content

In this subcategory, "need for extended content", the informants described their suggestions for improving the program. In general, the informants reported a large degree of satisfaction with the intervention. Still, they proposed some adjustments. One of their central suggestions was that there should be more focus on how to reduce the feeling of guilt, a feeling that was often linked to making decisions that would lead to nursing-home placement. As expressed by one wife of a person with dementia:

I constantly have guilt feelings, but I just have to put that behind me. It is not my fault that he is ill, but I should visit him more often [in the nursing home].

Furthermore, they suggested spending more time focusing on how to cope with the institutionalization process of the family member with dementia, along with the grief that may occur after nursing-home placement. Also, the loneliness in everyday life experienced by the carer, as well as by the person with dementia, could be focused on more. Some also expressed a need for more information about whom to contact if needs should arise after the intervention has ended – as one husband of a person with dementia expressed:

I do not know whether I have anyone to contact now, something that perhaps many of us might miss, because the contact in the municipality is not there anymore.

Further suggestions were that more information be given about financial matters and rights related to public services, topics that were covered in the educational program but probably should be repeated in the intervention. Uncertainty associated with their new economic situation, as well as future costs related to caring, made the informants worried. Some wanted a focus on how to handle the practical details of their own work situations.

In general, they felt that the structure of the group meetings was necessary to be able to complete the problem

solving. However, some informants felt that it could sometimes be a bit tough to be the one in focus. They added that they would have liked a little less group structure and more time for open discussion and other themes at the end of the group meetings.

Need for new group organization

In the subcategory, "need for new group organization", the informants said that it was important for participants in such groups to be more or less in the same situation when it comes to the person with dementia's age and the stage of the disorder that they are experiencing. Those who had their family members in an institution were sorry that the intervention had come too late and wanted their own groups. These groups could revolve around themes such as everyday life in an institution, loneliness, and grief among carers. Also, how to cope with feelings of guilt should be a central theme in such groups.

Moreover, in this category participants clearly expressed that it was important for both carers and persons with dementia to be offered this type of intervention as early as possible. The fact that the intervention for some participants came so late in the dementia trajectory resulted in little benefit for the person with dementia. Therefore, they proposed that the municipality should set up some sort of list when receiving information about families with a person with dementia early after diagnosis. In line with this, they mentioned their exhaustion, and that caring had led to poorer health. As one husband of a person with dementia expressed it:

I believe the intervention would have been more beneficial for me if I had participated earlier. I was just walking around in a daze until I ended up in a hospital. I did not recognize that I was so tired and burdened.

Furthermore, the informants found it beneficial to invite more than one family member to participate, especially in the counseling meetings. They stressed the importance of giving other family members the chance to learn about dementia in general – for example, by motivating them to attend educational programs such as "the school for carers". One informant had participated in the counseling sessions and group for carers together with another close family member, and said: "It was beneficial to participate in the groups together, because then we could talk about it later."

Some said it was difficult to get support from other family members and that these family members also refused to participate in the counseling sessions. They seemed to imply that health care personnel should make more effort

in persuading other family members to participate in order to get more support from other family members.

Learning about different symptoms and diagnoses of dementia and meeting others with different familial relationships to the person with dementia were reported to be positive experiences in the group sessions. The size of the groups was important; in smaller municipalities where everyone knows each other, it is perhaps better to offer individual sessions. Furthermore, the informants said that carers of people with young-onset dementia (below 65 years old) should, if possible, be offered their own groups, because they were in another life situation and were facing other kinds of challenges. As a wife of one person with young-onset dementia mentioned: "The only thing I felt was that I was quite young compared with the other ones."

Discussion

The main finding of the study reported here is that the carers generally evaluated the intervention positively and reported receiving benefits from the content, even though they had some proposals for how to improve the program. This finding stands, perhaps to some extent, in contrast to the quantitative evaluation of this PSI study, for which no intervention effects were reported due to no differences in depressive symptoms between the intervention and control group at 12 months follow-up.¹² On the other hand, there is not necessarily a contrast in this, since a person can feel having benefit without the feeling alleviating depression. This stresses the shortcomings of evaluating such interventions with quantitative methods only, using self-reported questionnaires or interviews with previously defined outcomes. In line with the positive outcome of the present study, there is a consensus that this type of intervention is important and necessary for the carers as well as the persons with dementia.⁷ This has also been underlined in other studies.^{13,15} This study points out that there is a risk that effective interventions could be rejected due to inappropriate outcome measures. In accordance with this, we thought it would be important to use a qualitative approach when evaluating this PSI, as has also been reported in other qualitative studies.¹³⁻¹⁵

Furthermore, the findings show that the intervention contributed to making the carers feeling safer, giving them a better understanding of the disorder. Also, the intervention helped them to be more open about their situation and more prepared for the future. The responses from the informants indicated that this intervention contributed to reducing the burden and loneliness caused by the disorder, as well as preventing social isolation. As also stated by the World Health Organization,¹

dementia puts a heavy burden on carers and is still a stigmatizing disorder. The positive effects of the intervention are, thus, factors that in the long run may counteract the negative effects of the disorder and promote health.²³

In the findings feelings of guilt and grief were described. These feelings were mainly linked to getting help in everyday life and during the institutionalization of the person with dementia. In order to reduce these feelings, future interventions and support initiatives must focus on normalizing these burdensome feelings, something that health care personnel often do not acknowledge.²⁴ As these feelings are associated with depression, ignoring these feelings may lead to poorer psychological health for the carer and earlier institutionalization of the person with dementia.²⁵

Moreover, the intervention gave carers information about how, where, and who to contact in the municipality to ask for support; however, not all informants were satisfied with this information. Therefore, this theme must be highlighted in future programs, in accordance with the findings of Ducharme and coworkers.²⁶ Other themes that need more focus are the carers' rights and costs linked to services, and the next of kin's opportunities to keep on working when this is relevant.

The structure of the group meetings was also found to be beneficial, primarily because the structured problem-solving method made it easier for everyone to get a word in, to find solutions to problems, and learn from the other participants, a finding that contradicts the meta-analysis of Li and colleagues,²⁷ who have reported increased dysfunctional coping associated with the use of structured problem solving.

To summarize, the findings show that the carers learned a lot, and that all themes were beneficial, although some could have been elaborated on in greater detail. Other positive findings included the benefit of receiving support from other group members and the group leaders, and also that of giving support to other carers. This finding is inline with Buber's²⁸ illustration of how human life finds meaning in relationships when people support each other and receive confirmation through others.

Although some informants found the information about symptoms that could occur over the course of the disease (such as aggression) scary, the majority did acknowledge it. They could distinguish their own relative's situation from those of others, but emphasized that the information about what could possibly occur in the future made them more prepared, which was in contrast to Proctor and coworkers,²⁹ who found that information could lead to more anxiety among carers. However, health care personnel still need to be aware of how they present information. They must distinguish

between different types of dementia and point out that not everyone with dementia will become aggressive or show other kinds of disruptive behavior.

The findings also show that it would be beneficial for carer groups to be more homogeneous, as those who had had their family members in an institution should be offered their own groups focusing on themes more adjusted to their situation, like everyday life in the institution and feelings of grief and loneliness. In particular, younger carers of people with young-onset dementia pointed out the need for separate groups. This suggestion is in line with other studies showing that people with young-onset dementia are in need of other services and are more aware of their situation.^{15,30} However, the wish for more homogeneous groups would be easier to achieve if the intervention were to be implemented as an ordinary service in the municipality. Still, in smaller municipalities, it might be difficult to organize homogeneous groups. To counteract this, group leaders must actively point out similarities as well as differences between the participants. In all groups, some similarities will always exist, according to Yalom.³¹

Another important finding reported was that the intervention came too late in terms of the progression of the disease and, therefore, was of little benefit for the person with dementia. Other later studies also point out that the persons with dementia are in need of their own interventions, interventions that can give them the chance to talk about their lives with dementia.^{26,32} This accords well with one of the major points in Minghella and Schneider's^{33,34} new model of care for dementia. Such interventions should come very early, because the level of stress and the burdens are relatively low in the pre-dementia stage, so there is time to empower the resources of the person with dementia as well as the caregivers.^{26,31,33,34} The informants' proposal that local health authorities responsible for dementia care should be told when a person is diagnosed with dementia could allow for this. This suggestion is in line with Minghella and Schneider's^{33,34} model of care.

Moreover, another important finding was how carers benefited from the inclusion of other family members at one of the counseling meetings, as well as their participation in the educational program, "the school for carers", because it led to better collaboration within the family. This meeting reduced primary carers' feelings of being left alone with the care tasks, which is in line with the positive findings of Mittelman and colleagues.³⁵

Methodological considerations

The choice of methods was inspired by a few previous studies on the outcomes of an RCT from the perspective of

the carers.¹³⁻¹⁵ The present study used a purposive sample of 20 carers who had participated in the PSI study. The carers were of different ages and sexes, and had different relationships to, and experiences of living together with, the persons with dementia (Table 3). In addition, they came from different groups and various smaller and bigger municipalities. In the data-collection process, inspired by Corbin and Strauss,²⁰ in order to capture variation in experiences, we tried to select a heterogeneous group in an open sampling until no additional information emerged. We hold the opinion that this variation helped to validate the findings.¹⁹ To contribute to trustworthiness, quotations are presented in the text. In addition, the data were analyzed and discussed between all of the authors, as recommended by Patton.¹⁹ Even though findings of qualitative research designs cannot be generalized in a statistical sense, we argue that our findings represent the carers who participated and that they can be transferred to other contexts such as other groups of families in other municipalities in Norway and elsewhere. The findings may contribute to the development of interventions and organization of services for families with dementia, thereby promoting health in a more holistic way. A clear weakness of the study is that people with dementia were not included in the evaluation of the PSI, as suggested and done in other studies.^{13,15,36}

Conclusion

By conducting this qualitative study, we aimed to identify both the strengths, and recommendations for program improvement of a psychosocial intervention to carers and persons with dementia. In general, the carers found the PSI under consideration useful, but the importance of even earlier, as well as flexible, interventions for the carers, the extended family, and the persons with dementia was underscored. Moreover, the study points out a need to include the theme of feelings of guilt and grief in an extended way.

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