

# How Volunteers Contribute to Persons with Dementia Coping in Everyday Life

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Wenche Malmedal<sup>1,2</sup>  
Gunn Steinsheim<sup>1,3</sup>  
Bente Nordtug<sup>4</sup>  
Kari Blindheim<sup>2,5</sup>  
Rigmor Einang Alnes<sup>5</sup>  
Aud Moe<sup>2,4</sup>

<sup>1</sup>Department of Public Health and Nursing, Norwegian University of Science and Technology (NTNU), Trondheim, Norway; <sup>2</sup>Centre of Care Research, Steinkjer, Norway; <sup>3</sup>Centre for Development of Institutional and Home Care Services Trøndelag County, Åfjord, Norway; <sup>4</sup>Faculty of Health Science, Nord University, Bodø, Norway; <sup>5</sup>Department of Health Sciences Ålesund, Norwegian University of Science and Technology (NTNU), Ålesund, Norway

**Introduction:** The society needs volunteers to fulfill its duty to ensure that people with dementia have active and meaningful everyday lives. Volunteers seem to experience their work as positive and meaningful for their own part, but we know less about what motivates volunteers to start working in home-dwelling dementia care and what motivates them to continue their engagement. This study seeks to close some of the knowledge gaps that exist regarding volunteers' engagement in activities for persons with dementia.

**Aim:** The aim of this study was to explore what motivates volunteers to start engaging in volunteer work in home-dwelling dementia care and what motivates them to continue their engagement.

**Methods:** The study design was qualitative, using focus group interviews. Three focus group interviews (n=16) took place between May and June 2018. The text was analyzed using content analysis.

**Results:** Findings in this study indicate that the volunteers were motivated by the feeling of doing an important job for the persons with dementia and their relatives, and that they contribute to their coping with everyday life. Other motivating factors included feeling important to someone, gaining friendship, and sharing common interests. They also believed that they do an important job for the community to fulfill society's goal that people with dementia should stay home longer. However, the volunteers were confused about their role and ask for knowledge, peer support, and clarification of roles.

**Conclusion:** To maintain motivation volunteers need to know what his/her role is. A volunteer can and shall not act as a substitute for a professional, only as a supplement, and the expectations must be addressed to all stakeholders: the health care service, the volunteer, the person with dementia, and their relatives, as we believe that this will contribute to diminishing misunderstandings.

**Keywords:** voluntary work, mild and moderate dementia, coping everyday life, motivation, qualitative study

## Introduction

With the growth in the population of older adults, an increasing number of persons with dementia can be expected, which will challenge primary health care systems. One strategic approach is to increase volunteer involvement, as volunteers and the voluntary sector have been identified as both a cost-effective and good solution to providing care for an aging population.<sup>1</sup> In 2015, the Norwegian government launched a national strategy for voluntary work in the health and care sector.<sup>2</sup> The strategy contributes to recruiting and retaining volunteers, and to form the basis for local volunteering strategies. One of the specific goals in the Norwegian Dementia Care Plan is that cooperation between the municipality and the volunteer

Correspondence: Wenche Malmedal  
Department of Public Health and Nursing,  
Norwegian University of Science and  
Technology (NTNU), Trondheim 7491,  
Norway  
Tel +47 97642156  
Email wenche.k.malmedal@ntnu.no

sector is strengthened in 2020.<sup>2</sup> In contrast to this goal, only 20% of municipalities in Norway have developed a local policy for volunteer work,<sup>3</sup> which could make it difficult to reach this goal. The Dementia Care Plan<sup>2</sup> recognizes that there are unsolved challenges in dementia care regarding activities for those with dementia and provision of relief to family caregivers. The plan states that many are offered activities too late, for too few days per week, and that the activity is not well adjusted and thus, does not provide the best relief to family caregivers. One conclusion in the Dementia Care Plan is that cooperation between public health care and the voluntary sector must be systematized and improved. The importance of volunteers in municipal health care is also highlighted in the quality reform: “A full life – all your life”.<sup>3</sup> We do not know the exact number of those volunteering in dementia care in Norway, and voluntary work within health care services is not very common in Nordic countries,<sup>4</sup> which may be due to well-developed public health care services. This paper aims to shed light on volunteers’ experiences of being a volunteer to persons with dementia.

Research shows that although volunteers perceive their relation with the person with dementia as important and present,<sup>5–8</sup> volunteers can experience the psychological and behavioral problems of the person with dementia as a challenge.<sup>7,8</sup> Guerra et al<sup>6</sup> found that some volunteers experienced that they underestimated the person with dementia, and another study showed that volunteers realized they had been thinking of people with dementia in stereotypes.<sup>5</sup> According to Greenwood et al,<sup>5</sup> volunteers experienced that befriending was a complex and unique phenomenon. Further, volunteers shape the delivery of services in a way that is different from more formal health services and may be different from place to place.<sup>9</sup>

Volunteers may be insecure about their role and taking part in a training program may help them in this matter. In Portugal, volunteers (n = 6) participating in a program designed to support families caring for a person with dementia,<sup>6</sup> reported that taking part in a program enhanced their competence and improved their communication and attitudinal skills, as well as having learned a lot about themselves and how to manage and control their emotions. Other studies have also found that volunteers asked for training and information to feel more secure in their roles.<sup>10</sup>

Engaging in volunteer work has both physical and psychosocial benefits for the volunteers themselves. Findings from a review reveal that volunteering is associated with reduced symptoms of depression, better self-reported health,

fewer functional limitations, and lower mortality, as well as increased social, physical, and cognitive activity.<sup>11</sup>

Volunteers may be motivated by different factors. A review by Hurst et al<sup>12</sup> found that the motivation for volunteers to work in dementia care was only addressed in a few articles. The volunteers’ motivation was influenced by their involvement and how they understood their roles. In a Portuguese study,<sup>6</sup> volunteers reported that their motivation to join the program was related to altruistic values, a desire to learn, personal growth, and the sharing of experiences. A study conducted in Norway among volunteers working in an activity center for home-dwelling people with early-stage dementia<sup>8</sup> showed that volunteers were motivated by being able to influence and participate in the planning of the work, to be part of the social setting, and to learn, though some of the volunteers found it hard to adjust to an adequate role.

Motivation is a reason or reasons for acting or behaving in a particular way. Self-Determination Theory (SDT),<sup>13</sup> is a theory of motivation that describes why a person invest time and energy in an activity. The distinction between intrinsic and extrinsic motivation is based on the different reasons or goals that give rise to an action. Extrinsic motivation generally refers to making choices in order to receive a reward or avoid punishment, whereas intrinsic motivation is a personal engagement or a desire to do something because the work is inherently rewarding, interesting, and/or enjoyable.<sup>13</sup> For intrinsic motivation, the SDT approach is mainly focused on the psychological needs, like needs for competence, autonomy and relatedness, but it also recognizes that engagement in interesting activities can contribute to basic need’s satisfaction. Further, Ryan and Deci<sup>13</sup> state that for a high level of intrinsic motivation people must experience satisfaction of the needs both for competence and autonomy.

Society needs volunteers to fulfill its duty to ensure that people with dementia have an active and meaningful everyday life. Volunteers seem to experience their work as positive and meaningful for their own part, but we know less about what motivates volunteers to start working in dementia care and what motivates them to continue their engagement. This study seeks to close some of the knowledge gaps that exist regarding volunteers’ engagement in activities for home-dwelling persons with dementia.

## Aim

The aim of this study was to explore what motivates volunteers to start engaging in volunteer work in home-dwelling

dementia care and what motivates them to continue their engagement.

## Materials and Methods

### Design

The study design was qualitative. Volunteers from three different municipalities in a region in mid-Norway took part in the study. When the aim is to illuminate attitudes and experiences, focus group interviews are considered a fruitful method.<sup>14</sup> A research topic is explored through interaction between people purposively selected for their experiences with the topic. The data are gained through interaction between participants involving a theme chosen by the researcher. It is of great importance that the researcher has knowledge and understanding of the dynamics between themselves and the informants and how this affects the analysis of the data material and the results of the study.<sup>15</sup>

### Informants

The informants were purposely selected for the focus group interviews. To recruit volunteers engaging in dementia care to reflect on their own experiences, the inclusion criteria for this study were male and female volunteers who had been engaged in organized unpaid voluntary work for persons with dementia. The study population was recruited from three municipalities through the Centers for Development of Institutional and Home Care Services in the counties of Trøndelag, Møre and Romsdal, and the Community Dementia and Memory Teams in the three municipalities. Sixteen participants volunteered for the study, twelve females and four males, all more than 70 years old, except for one female aged 44 years. The informants took part in different types of activities involving persons with dementia, both individual and group activities. Further, the informants mostly volunteered in activities for home-dwelling persons with dementia, such as collect and drive to activities, tour groups, companion to treatment, friend visitor, and going for a walk.

### The Interviews

Informants in each of the three municipalities were contacted and interview appointments arranged. All three focus group interviews took place between May and June 2018, in meeting rooms suitable for the purpose (either at a health care center or at university premises). A semi-structured

interview guide served as a checklist of key questions related to the research questions, which could be used to maintain the thread of the interview. The informants were encouraged to talk freely, and the researcher followed up with questions when clarification or elaboration was needed. The moderator was a researcher in all three interviews, and the co-moderator was either a researcher or a research assistant. The interviews lasted up to two hours and were tape recorded.

### Data Analysis

The recordings were transcribed verbatim. The text was analyzed using content analysis to interpret meanings from the text, inspired by Graneheim and Lundman.<sup>16</sup> The analysis started with all authors reading the text to obtain an overall impression, and then identifying meaning units that were relevant for the study's purpose. Next, the units of meaning were condensed and coded, each interview was coded by two authors. Then, all authors met and worked together and compared the codes for similarities and differences and sorted into subthemes that emerged from the latent content. In meetings, the researchers discussed the analysis of unit meaning and the themes. See [Table 1](#) for an example of the analysis process. Then, the researchers reflected on the latent underlying meaning at an interpretative level until there was agreement on the formulation of four themes, see [Table 2](#).

### Ethical Considerations

The study was approved by The Privacy Issue Unit of the Norwegian Social Science Data Services (Project number 58922). Prior to the study, participants were given thorough information via a letter which described the purpose of the study and a request to participate in the research project. Participants were assured of full anonymity and that information would be de-identified and not recognizable in the results section. It was emphasized that participating in the study was voluntary and the participants were told that they had the opportunity to withdraw from the study at any time without explanation and without consequences. Each participant signed a consent form prior to interview.

### Findings

The main theme "Contributing to a better coping in everyday life for persons with dementia and their relatives", found in this study, indicates that the volunteers are motivated by loving what they do, by feeling committed, and

**Table 1** Example of the Analysis Process

Meaningful Unit	Code	Subtheme	Theme
F1 (I5): I experience that I have contributed to the better for her, eg, when I accompany her to the hospital, the doctor, etc.	Feeling important to someone	The feeling of doing an important job	Motivation for being a volunteer
F1 (I2): In many cases, it is good for those who have dementia to be at home and have these opportunities, and that is perhaps what drives us. I think that it is best for them to be at home anyway.	Contributing, so the person with dementia can live at home		
F1 (I3): She thinks it is very nice when I visit her. [...] We like each other. F1 (I5): Then, I was assigned to a woman and it has worked out very well. We are more like friends, and it turns out that she is a former colleague. She lives alone and does not have any close relatives in Norway. I travel a lot so I cannot visit her regularly once a week, but I call her when I am away if I am not abroad.	Friendship and mutual relations	Joy and connectedness	
F2 (I1): I think that an activity friend (aktivitetsvenn) is a good concept. You do something together, something both want to do. F3 (I5): Many of the participants used to enjoy hiking but cannot go on their own anymore – so I think it is very positive both ways. I think this suits me well.	Common interests		
F1 (I4): When you get that feeling of being important and they say you are doing a great job and that they are looking forward to seeing you, and you get a shoulder clap. I think that is very nice and then I want to continue as a volunteer. F1 (I6): One must desire to keep on and sense that what one does is important. However, I am sure what we do is important. F1 (I4): To be appreciated is good.	Feeling of being important and appreciated	Recognition as a volunteer	
F1 (I5): The relatives also appreciate me, especially the son who lives abroad. I am blessed with good health myself so I must try to give something back as long as I can.	Appreciated by the relatives		
F1 (I6): They should know about us. To be seen by the public authorities, that they think what we do is important.	Appreciated by the relatives		

**Abbreviations:** F, focus Group; I, informant.

that they sincerely mean that they do an important job. We found, however, some factors that are important for maintaining motivation, like good contact with municipality and other volunteers, as well as good relations with relatives.

The analysis resulted in four themes that reflect the informants’ views about what motivates them to become volunteers, as well as what motivates them to remain. The four themes with their connecting subthemes are presented in Table 2.

### Theme 1: Motivation for Being a Volunteer

The main finding in Theme 1 was that the feeling of being of importance to the person with dementia and thus, contributing to a better everyday life was a motivating factor

for volunteers. In addition, they felt that being a volunteer gave them some positive benefits in return, like joy and friendship. Further, it was motivating that their efforts were recognized as valuable by the person with dementia, the relatives, and the municipality.

#### The Feeling of Doing an Important Job

The volunteers felt that they did an important job for both people with dementia, their relatives, and the community. Several stated that through their contribution they helped to fulfill society’s goal that people with dementia should stay home longer. One of the volunteers put it this way:

In many cases, it is good for those who have dementia to be at home and have these opportunities and that is perhaps what drives us. I think that it is best for them to be at home anyway.

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**Table 2** Overview of Main Themes and Subthemes

Themes	Sub Themes	Main Theme
1. Motivation for being a volunteer	The feeling of doing an important job Joy and connectedness Recognition	Contributing to a better coping in everyday life for persons with dementia and their relatives
2. Collaboration between volunteers and the municipality	Contact and relations with municipality and other volunteers Need for training and knowledge Need for exchange of experiences Positive and negative experiences with the municipality	
3. Commitment and concern	Commitment and responsibility Concern and care	
4. Relations with relatives	Positive relations Negative relations	

Another volunteer thought they could, due to their experience, contribute to suggesting measures that could change attitudes in society, and that one important question is: “How can a person with dementia stay at home for as long as possible?” It is motivating for the volunteers to contribute to the person with dementia coping with everyday life, as one volunteer said:

There are many who believe that no, today I will not go for a walk, but suddenly they can have walked one and a half to two kilometers, and then they are so happy afterwards. And I think it is fun, when they cope.

They experienced being supportive and relieving for the relatives when they accompany the person with dementia for a walk: “At the same time, it is safer for the family, and then they have a little free time.”

### Joy and Connectedness

Many of the volunteers described a reciprocity in the relationship between them and the person with dementia. One of the volunteers strongly expressed: “We are more like friends.” A good relationship brings happiness to the person with dementia, but even volunteers have strong experiences of joy and satisfaction in being a volunteer. As one said, when the person she was visiting became so happy when she was invited to go for a walk: “Then you become happy yourself.”

Several of the volunteers used the terms fun, pleasant, or nice when they described how they experienced being with persons with dementia. One said: “It’s a nice group, though. One sees how happy many of them are and for some it is quite huge. Then it’s fun.” The volunteers appreciated being able to contribute to good moments and described several such in the interviews. These good

moments were also perceived as positive for one’s self, and several claimed that they gained a lot themselves by doing voluntary work. They experienced a sense of connectedness. One stated: “It’s really nice to join the activities. One gains a lot for oneself. I think I do.”

Signing up as a volunteer is also a way of avoiding one’s own loneliness and becoming more active and gaining a feeling of belonging. Several said that it had helped them get out and get a new start after becoming a widow/widower and otherwise, they would have stayed mostly at home. It seems important that the activities are something that interests them; they get the most pleasure from it then and look forward to the days they have duties. One of the volunteers talked about the joint satisfaction of being in a tour group: “It is positive both ways. I think this suit me well.”

### Recognition

Several of the volunteers believed that they did an important job and felt that they were appreciated. Being appreciated seems to be an important motivating factor to continue as a volunteer. As one said:

When you get that feeling of being important and they say you are doing a great job and that they are looking forward to seeing you, and you get a shoulder clap. I think that is very nice and then I want to continue as a volunteer.

There is a desire to be seen and recognized by the public authorities: “They should know about us. To be heard and seen by the public authorities, that they think what we do is important.” Several pointed out that their efforts are important for the municipality and that they wanted to be seen by the municipality leaders. Getting feedback that the job they do is important to those with dementia is a motivation for

the volunteers. One of the focus groups pointed out that they felt that people in the community see what they do as valuable. People are aware when something from the activities is posted on social media and this is encouraging for the volunteers. Getting recognition from and being appreciated by relatives was also highlighted as important.

## Theme 2: Collaboration Between Volunteers and the Municipality

The main findings in Theme 2 were that close contact and good relations between volunteers and the municipality, as well as within the group of volunteers, were important to the volunteers in order not to feel alone if they encountered challenges. In addition, they indicated a need for more knowledge about dementia in order to establish a better relationship with those with dementia. Meeting other volunteers and discussing experiences was important in order to clarify their role as volunteers and to thrive as volunteers.

### Contact and Relations with Municipality and Other Volunteers

Most volunteers claimed to have good communication with the municipality health care and felt that they could contact them when needed. It is good to be able to call someone if something occurs. One said: "I have good contact with NN (from dementia care team) if something is wrong, I also have the number for the home care unit, and I can contact them." Several indicated a need to have a permanent contact person in the municipality health care where there is a low threshold for contact. Some said that the dementia care team had been an important support for them; it is like having a safety net knowing that they can call them at any time. They believed that volunteers and municipality health care share common challenges and it is therefore useful to talk together, otherwise, information exchange may fail. Several expressed that it is important that the municipality follows up and coordinates voluntary work.

### Need for Training and Knowledge

Several volunteers indicated a need for training to gain more knowledge about dementia in order to establish a better relationship with those with dementia, and to clarify their role as volunteers. It may be difficult to know when to draw the line and many of them made extensive efforts in order to help the person with dementia in the best possible way. When a volunteer, who was visiting an older woman, was given the key to her apartment, she first found this

difficult: "I really thought I would pass a threshold getting the key, I'm not home care staff, it felt too invading to lock myself in." Eventually, both she and the woman seemed to be fine with it. In one of the groups, a need for knowledge emerged, for instance about available activities in the community suitable for persons with dementia. During the focus group session, the exchange of experience provided useful tips to other group members. Some of the volunteers experienced a dilemma regarding involvement in financial matters. Although they did not really want to, they felt a responsibility to give support in such matters. Regarding medication and possible side effects, some wanted more information about this, while others were aware that this was outside their area of responsibility. When one said that she had wanted a collaboration meeting with the home care staff when the person she visited changed medications, another responds: "You know, for me that is the limit for what I would do. I will not be responsible for any medication or any side effects of medication." Several were concerned that being a volunteer was something other than being a professional; one is a supplement to the health care staff. It seemed that the need for training was not as strong for the volunteers participating in activities involving staff from the municipality health care: "We get the information we need from those who are from the municipality, they are good at informing us," one of the volunteers responded.

### Need for Exchange of Experience

Volunteers from one municipality described that they were invited to meetings with other volunteers and found this very positive. One said:

I am very happy that we are invited to such events, it's nice to be followed up and hear from the other volunteers about their problems and pleasures. It is very useful.

Other volunteers were not invited to such meetings and missed being followed up: "The follow up could be a meeting where we were invited a day yearly, which I would say would be sufficient. I believe that will come. We need it." The volunteers suggested that the municipalities or non-governmental organizations (NGOs) could organize these joint gatherings. Meeting other volunteers and discussing experiences is seen as important.

### Positive and Negative Experiences with the Municipality

The volunteers have mostly positive experiences with the municipality. "I receive good help and support from the

municipality,” one of the volunteers said. Some described how volunteers and staff in the municipality health care work together to facilitate the best possible outcome for the person with dementia. A physiotherapist scheduled the treatment time so it could be combined with a cafeteria visit; according to the volunteer, this was very important for the person with dementia. Most of the volunteers reported having good contact with the staff and that they receive the necessary information. Being valued by the health care staff is a positive factor, as seen by the volunteers. Some of the volunteers had been invited to social meetings/gatherings arranged by the municipality and this was highly appreciated by them.

A few volunteers had negative experiences with the municipality. They described poor communication with staff and sometimes found themselves being a substitute for staff, not a supplement.

### Theme 3: Commitment and Concern

The main findings in Theme 3 were the feelings of commitment, as well as concern. Once the volunteers had signed up for the task, they felt committed to follow up and persevere over time. The volunteers put a lot of time and effort into doing their best for the person with dementia even if it sometimes could be demanding.

#### Commitment and Responsibility

The volunteers felt a great deal of responsibility and commitment. They demonstrated this by always giving notice if they were hindered from showing up, even if they did not always find that they were notified when plans were changed. They may well be away on vacation or get sick, but “then, of course, one must notify.” Some feel extra commitment if the person they are visiting does not have any close family. One said: “I feel you have to commit yourself once you start helping them, and when you have no family around you it is difficult.” When they achieved a relationship with a person, they felt a responsibility to follow up on him/her and that they must persevere over time. One of the volunteers said:

I think that once you get to know and get a relationship with a person, you can't just stay for half a year and then say goodbye. It is a commitment in a relationship.

The volunteers had expectations of themselves that could be difficult to fulfill if something became problematic in the relationship.

### Care and Concern

Some of the volunteers described episodes where they did something extra for the person they visit, either by inviting them to their home, bringing extra good food, or helping with financial matters. One of the volunteers told about when she had a party at home and brought cakes afterwards to the older woman she visited. The volunteers were concerned about the welfare of the persons they visit and felt that they must tell someone when they saw changes in condition, as one said: “Yes, we have a responsibility. Although it is voluntary, we have a responsibility during the time we are there.” The volunteers got involved in the lives of the persons with dementia and their relatives. One of the volunteers told a story where a relative was not listened to by the municipality. The volunteer took the relatives' part against the municipality and stated:

I wish that home care staff or doctors listen to the relatives more often. Some of them fail in this sense, at least in this case. I wish there was better communication.

Some of the volunteers put a lot of time and effort into doing their best for the person with dementia even if it was demanding. “It was very interesting, but also very demanding,” said a volunteer who tried to get the person with dementia to cook.

### Theme 4: Relations with Relatives

The volunteers described both positive and negative relationships with relatives. The main finding in Theme 4 was that they felt that their contribution was of importance to the relatives, although there could be some challenges due to unclarified expectations.

#### Positive Relations

The relationship with relatives can be both positive and negative. On the positive side, the volunteers described that they experience being a relief to relatives and that the relatives appreciate what they do. Volunteers can make a difference to the relatives: “In some people with dementia the loneliness becomes very big and then we will indirectly be a relief for the family. I think one can contribute as a volunteer.” It is important that the chemistry also matches between relatives and volunteers, because as one said:

If that chemistry or feeling of trust is not there, relatives may think that the volunteers interfere too much and suspect that you go far beyond what you should.

Therefore, it is important to clarify the boundaries in advance to avoid misconceptions.

### Negative Relations

On the negative side, volunteers experienced that unclarified expectations from relatives could be challenging. Although they recognized the needs of the relatives, the volunteers could be squeezed between the desires and needs of the relatives on the one hand and the wishes and needs of the person with dementia on the other.

Some experienced that they were not notified by relatives if there were changes in plans. As one said: "What is not good is when they have gone away, and her husband has not told me. When I come to visit her and find the house empty. It is hard."

### Discussion

The aim of this study was to explore what motivates volunteers to start engaging in volunteer work in home-dwelling dementia care and what motivates them to continue their engagement.

The main findings indicate that the volunteers were motivated by the feeling of doing an important job for persons with dementia and their relatives, as well as the society. However, they expressed a strong feeling of experiencing positive benefits themselves by engaging in volunteer work. The volunteers described several factors that could have positive or negative influence on motivation, and they had certain requirements in order to stay motivated.

### What's in It for Me?

Several of the volunteers described that signing up as a volunteer is also a way of avoiding your own loneliness, becoming more active, and gaining a feeling of belonging. This relates to intrinsic motivation, as described in the SDT by Ryan and Deci.<sup>13</sup> Positive benefits for volunteers, such as reduced social isolation, are also reported in other studies.<sup>11,17</sup> We found that a feeling of connectedness was a positive side effect of being together with persons with dementia and other volunteers. Relatedness is recognized as an important intrinsic motivation factor in accordance with SDT.<sup>13</sup> This finding is in line with that of Johannessen et al,<sup>7</sup> where the support persons saw volunteer work as a way back to society, for example, after a period with own illness, and a way of finding meaningful activity.

The findings in this study showed that the volunteers were motivated by the feeling of doing an important job are also supported by other studies,<sup>7,8,18</sup> which show that the

feeling of being useful and filling a need were satisfying to the volunteers. This may affect their identity, and thereby their self-esteem. Self-esteem is a perception of one's own worthiness and self-respect, and a perception that others find one worthy and respectable.<sup>19</sup> Another strong motivation was the reciprocity in the relationship between the volunteers and the person with dementia. A mutual feeling of friendship arose between the person with dementia and the volunteer, and the volunteers used the terms fun, pleasant, or nice when they described how they experience being with persons with dementia. This developing of a close relationship is described in other studies.<sup>6,8</sup> When recruiting volunteers, one should take these intrinsic motivating factors into account. One should strive to find good matches for the volunteers and to fulfil their wishes, both in type of activity and the person with dementia. Doing a thorough job initially will contribute to keeping volunteers motivated.

### A Neglected Volunteer Will Not Come Back

Even though the volunteers experienced positive benefits themselves by engaging in volunteer work, and this was clearly a motivating factor, they also described several factors that could have positive or negative influence on motivation, and they had certain requirements in order to stay motivated.

The volunteers expressed the need to be seen and recognized by the municipality, by the health care system and by the relatives. Volunteers are a crucial part of our community, so they should be given something in return, they should be told that they are making a difference. Some of the volunteers in our study experienced that they were rewarded for their dedication as volunteers, the municipality arranged events for them. Good communication with the municipality health care and having a permanent professional contact person who also knows the person with dementia and their relatives would be helpful, and this could easily be provided by the dementia care services in the municipality. This contact person should also from time to time check-in with the volunteers. Our findings show that regular meetings arranged for the volunteers were regarded as desirable and useful. This is in line with the work of Skinner and Andfossen,<sup>10</sup> where the volunteers expressed their need for a community with other volunteers. Meetings with other volunteers would give them the opportunity to share experiences and to get ideas for activities that were



offered in their region, and most important at the beginning of their work provide them a sense of direction. Support in the form of debriefing sessions where the volunteers can express their thoughts and feelings is found to be important for reducing burnout and meeting unmet needs.<sup>12</sup> One of the focus groups served as such regarding information sharing, and the participants expressed a clear need for this. This finding is in line with the work of Söderhamn et al,<sup>8</sup> where the volunteers participating in their study were invited to meetings arranged for volunteers once a month and found these meetings very useful. Based on our and others' findings we claim that creating a community where the volunteers feel social connected will keep them more motivated.

The volunteers in our study expressed a clear need for more knowledge, in order to be more confident in their role as volunteers and to establish a better relationship with the person with dementia. Need for competence is also regarded as an intrinsic motivating factor,<sup>13</sup> and goes along with the need for autonomy, another intrinsic motivating factor. Most volunteers had received basic training, provided by the municipal health care service or the NGO they were connected to, but they felt that this was not enough. Meeting the volunteers' need for more knowledge regarding persons with dementia would be a way of maintaining their motivation and willingness to engage in activities. We suggest that the volunteers should receive a certificate after training as shown in Guerra et al,<sup>6</sup> this would act as a recognition as well as a proof of their trustworthiness.

## Clarification of Roles

Several volunteers indicated a need for clarification of their role as volunteers. They agreed that being a volunteer was something other than being a professional; one should be a supplement to the health care staff. However, some found themselves put in situations where they felt a responsibility to give support in matters that were beyond their duty, eg, in financial matters. Although they did not really want it, they did what they felt was needed in the situation. The difficulties adjusting to the role were also found in a study by Hoad,<sup>20</sup> where the author describes the boundaries volunteers' experience with professionals and with families. In our study, the boundaries were discussed in the focus groups and some described episodes where they had overstepped common understanding of boundaries, for example, helping in financial matters, bringing food from home to the person they visited. This was something they did off their own bat, and it was justified as care and concern. It may be difficult to know when to draw the line and many of them make

extensive efforts in order to help the person with dementia in the best possible way. Studies show that training and role description of volunteers is vital for reduction of emotional distress, burnout, and volunteer drop out.<sup>12</sup> Intrinsic motivation was clearly an important type of motivation to our informants but acting in accordance with others' expectations is more extrinsic motivated. Getting recognition and approval from others, ie, staff, relatives, persons with dementia, was in our study described as positive motivating factor. This is in line with Ryan and Deci,<sup>13</sup> who claims that people are willing to act in a specific way if they feel that they are valued by significant others to whom they feel connected.

A few of our informants had previous experience as health care workers or were next-of-kin to persons with dementia. This was shown to be a contributing factor to being more confident in the volunteer role.<sup>8,18,20</sup> On the other hand, this can lead to ambiguity when it comes to giving advice, as a former health care worker has the ability and skills to act as a professional but is not supposed to do so in the role as a volunteer befriender. Health care professionals may identify needs that are not met and feel obliged to act. Söderhamn et al<sup>8</sup> found that some volunteers with backgrounds as health care professionals had difficulties in adjusting to the volunteer role in an appropriate way, and this is something that one should be aware of when recruiting and training volunteers.

A clear role description would help the volunteers knowing what is expected from them and what they can expect in return. It should not be too detailed and task-oriented, but more focused on what the volunteer is responsible for achieving. Such an approach will give the volunteer more freedom and flexibility and will ensure autonomy in the role as volunteer. This should go along with guidance and support where needed.

## Methodological Considerations

The purpose of this study was to capture first-hand experiences of volunteers engaging in activities for home-dwelling persons with dementia, and the use of focus group discussions was an appropriate method to gain good insight on the topic. During discussions in a focus group some may feel obliged to share more than they intend, but we had no indication that this was the case in any of the groups. A strength of this study was that we conducted three focus group discussions in different municipalities and even though there were some differences, the commonalities were our overall impression.

## Suggestions

Based on the findings from the focus group discussions and on the authors' reflection upon the results, we have some suggestions that should be noted. We recommend that:

The recruitment and training of volunteers is done in a way that secures the volunteers' need for basic knowledge on dementia care, and that the person with dementia is safeguarded.

The role as a volunteer is clearly stated and addressed to all the involved persons/stakeholders.

The municipalities take responsibility for certifying the volunteers in order to ensure that the volunteer is suitable for the job and has a minimum of knowledge.

The municipalities coordinate all volunteer work in dementia care and provide each volunteer with a contact person, where the threshold for contacting is low.

The municipalities (in cooperation with relevant NGOs) arrange regular meetings for the volunteers where they can share experience with other volunteers and discuss specific problems they meet.

The municipalities acknowledge and recognize the important contribution from the volunteers.

## Conclusions

The current research has identified motivating factors including feeling important to someone, gaining friendship, and sharing common interests. To be recognized by the relatives as well as the community and public authorities are also contributing factors. These related to both intrinsic and extrinsic motivating factors. The essence of volunteering is that it is voluntary rather than an obligation, and although they feel a high degree of responsibility, the flexibility is appreciated by the volunteers. A major motivating factor is the feeling of contributing so the person with dementia can live at home and cope with their everyday life. Important findings in this study are the need for knowledge, peer support, and clarification of roles. A volunteer can and shall not act as a substitute for a professional, only as a supplement, and the expectations must be addressed to all stakeholders: the health care service, the volunteer, the person with dementia, and their relatives, as we believe that this will contribute to diminishing misunderstandings. Additionally, support from the municipality is highlighted in this study, and measures should be taken by municipalities to recruit more volunteers and to ensure that they retain those already recruited.

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