

## Motivating and discouraging factors with being a support contact in the dementia care sector: a grounded theory study

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(Received 29 March 2011; accepted 3 February 2012)

**Background:** People with dementia need different forms of assistance as the disorder progresses. In Norway, support contacts work as ‘paid friends’ and their role can be compared with respite carers or voluntary workers’ in other Western countries. Support contacts may be helpful within the dementia sector, especially in the early stages of the disorder, though they are rarely used.

**Aim:** The aim of this study was to find out how the support contacts perceive their work.

**Method:** Grounded theory, a qualitative method, with interviews of 19 participants (14 women and five men aged 40–75 years) during 2009–2010, from 12 local authorities.

**Findings:** This study describes the participants’ motives for becoming a support contact and their encouraging and discouraging experiences while being a support contact, expressed as four sets of opposites; flexibility vs rigidity; being compensated vs feeling used; affiliation vs abandonment; and satisfaction vs lack of satisfaction.

**Conclusion:** Greater flexibility, adequate compensation, a sense of affiliation and satisfaction, together with potential for building relationship with families, are factors that will encourage dementia care supporters to continue with their work.

**Keywords:** dementia; health promotion; respite care; voluntary workers’ experiences

### Introduction

Improved health among the general population has resulted in longer life expectancy. Since the incidence of dementia increases with age, the prevalence of dementia is increasing. However, dementia can also occur before the age of 65 (Ott et al. 1998; Launer et al. 1999; Harvey, Skelton-Robinson, and Rossor 2003). Dementia is a progressive syndrome; symptoms include a deterioration of memory and cognitive abilities, such as judgement, executive function and general information processing. Increasing behavioural and psychological symptoms of dementia (BPSD), such as sleep disturbances, anxiety, depression, confusion and hallucinations, are a common part of the disorder and increase challenges for carers (Mittelman et al. 2006; Riedijk et al. 2006). Available drug treatments seem to have little effect on behavioural and

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psychological symptoms for persons with dementia (Courtney et al. 2004; Birks 2006; Selbæk, Kirkevold, and Engedal 2007).

The majority of people with dementia in Scandinavia live in their own homes with assistance from close family members and some additional formal help from the social services until the later stages of the disorder (Edhag and Norlund 2006). Caring for a family member with dementia is associated with a well-documented risk of developing health problems of one's own (Schulz et al. 1995; Ulstein, Bruun Wyller, and Engedal 2007; Brodaty and Donkin 2009), but a review study also shows that such giving of care can be a positive experience, valuable for the relationship between family members (Schulz and Sherwood 2008). From a public health perspective it is important to provide a variety of formal help and assistance initiatives to these families during the entire progress of the disorder, so as to maintain personal activities, prevent social isolation and to promote health (Holley 2007). Formal help can reduce stress among family carers and assist the person with dementia (Schulz and Sherwood 2008; Westius, Andersson and Kallenberg 2009).

As a consequence of having a family member with dementia, the primary family carer as well as the person with dementia, and in some cases the whole family, may become socially isolated. This isolation will weigh upon the carers as well as the person with dementia as the disorder progresses (Engedal and Haugen 2009; Brodaty and Donkin 2009). Researchers have demonstrated that families of people with dementia require more formal help of various kinds from local authorities as the disorder becomes more severe (Engedal and Haugen 2009; Brodaty and Donkin 2009). Day care, short-term residential care for the person with dementia, and a range of home care services can be helpful for families to prevent social isolation and to promote health (Holley 2007). Different services may influence the ability of the carers as well as the persons with dementia to cope with and participate in everyday life and maintain a reasonable level of participation in society. From a public health perspective it is, therefore, important to provide families with a flexible variety of services that correspond to the stage and symptoms of the disorder, as well as the individual's functioning in daily life. A study by Blackman et al. (2003) also shows that accessibility to public space and physical environments is often reduced for those with dementia who are experiencing difficulties with spatial recognition. Behavioural symptoms may also effectively reduce access to public space for people with dementia, whose carers – responsible for managing the stigma associated with dementia – may avoid encounters in public places (Blum 1991).

According to the recommendations of the Norwegian Directorate for Health and Social Affairs (HOD 2005–2006) and the Government's Dementia Plan (HOD 2008), a strategy has been developed in order to make society more inclusive for people with dementia. This can be done via activities, adopted by the municipal community, either in their homes, in nursing homes or at day care centres. Another way of supporting people with dementia and their carers is by so called support contacts, they are people who can be a supporter in everyday life. These ideas are in accordance with those expressed in universal design to promote health by Story, Mueller, and Mace (2001). These sources argue that anyone in need of practical or personal help in their daily life due to disability, disorder, age, or for other reasons, has a right to receive support from the local authority when that individual is no longer able to take care of themselves. The local authorities may choose the best way to help these people and a support contact can be one such service, alone or in combination with other measures listed in the Social Service Act (HOD 2006). In this

article, the term ‘supporter’ will be used to identify someone fulfilling this role. According to a survey by Westerberg (2009), supporters are rarely used in Norwegian dementia care, with only one third of 430 Norwegian local authorities offering this service. Legislation grants people mentioned above the right to be assigned a supporter within allotted time frames, across the Scandinavian countries. In Norway and Denmark there is no age limit on the receiver of this service but in Sweden there is a maximum age limit of 65 years (Svensson, Ekvall and Storfält 2007). In Norway, support contacts work as ‘paid friends’ and their work tasks can be compared with befrienders, respite carers or voluntary workers in Norway and other Western countries.

In Norway, supporters do not provide treatment and are not required to have any formal education or training; they are usually hired on a part-time basis by the local authorities in a self-employed capacity. The supporters sign a confidentiality agreement, as do other professionals. Their role in Norway is deemed to have the following functions: helping the supported person to participate in social, cultural and physical activities, to be a social contact or someone to talk to, or to go shopping with the supported person and also to contribute to relief for carers. In this study, the focus is on supporters in the dementia care sector and how they can help people with dementia and their carers maintain a link to society, thereby reducing the incidence of health problems associated with isolation of families with people suffering from dementia.

A review of research (Johannessen 2009) shows that supporters, befrienders or voluntary workers in dementia care are mostly women, but they are difficult to recruit and tend to quit after a short period of time. Furthermore, the review suggests that more information about dementia along with more frequent counselling from health personnel is needed to enable supporters to sustain their involvement (Johannessen 2009). Beyond this, little is known about why they become supporters, why this service is rarely used in Norwegian dementia care and what it is like to work as a supporter in this field of care (Westerberg 2009).

### **The study**

In order to address this gap in the knowledge a qualitative study was undertaken to find out how dementia care supporters perceive their work.

A purposive sample of 19 dementia supporters aged 40–75 was drawn from 12 local authorities covering urban and rural areas in southern Norway. Recruited by administrators of the services, the sample offered a wide range in terms of gender, age, experience of dementia and dementia support as shown in Table 1. Participants had become involved in this work after responding to advertisements in the local press (6), through their place of work (6) or through friends and personal contacts (7) and they were all still supporters. Five had previous experience as supporters for other patient groups.

Following ethical approval by the Regional Committee for Ethics in Medical Research, southern Norway, semi-structured interviews were undertaken by one of the authors in the participants’ own homes at times of their choosing. Focusing on experiences of being a dementia care supporter, a conversational approach encouraged participants to offer reflections on their experiences. Interviews were audio recorded, transcribed verbatim and checked for accuracy by the interviewer

Table 1. Backgrounds characteristics of the 19 participants.

Participant	Gender		Weekly hours	Experience of being a supporter	Experience of dementia	Working experience
	M/F	Age				
1	F	60–65	8	5 years	Work	Nurse assistant
2	F	60–65	3	2 years	Close family	Mercantile
3	F	65–70	3	2 years	Friends	Health care worker
4	F	70–75	4	4 years	Close family	Health care worker
5	F	50–55	16	10 years	Close family	Nurse assistant
6	F	40–45	7	1 years	Work	Nurse assistant
7	M	60–65	3	1 years	Work	Nurse assistant
8	F	70–75	4	8 years	No	Teacher
9	M	55–60	4	2 years	No	Finance
10	F	60–65	5	2 years	Work	Nurse assistant
11	F	45–50	4	9 years	No	Mercantile
12	F	40–45	4	2 years	Work	Nurse assistant
13	M	70–75	4	4 years	No	Economic
14	F	70–75	4	2 years	Close family	Mercantile
15	F	60–65	5	6 years	Close family	Health care worker
16	M	70–75	4	2 years	None	Health care worker
17	F	55–60	4	1/2 years	Work	Nurse assistant
18	F	45–50	12	1 years	Work	Nurse assistant
19	M	55–60	12	1 years	Close family	Health care worker

Note: M = Male; F = Female.

within one week. Corbin and Strauss’ (2008) reformulated grounded theory was used to analyse the data using open, axial and selective coding.

### Findings

The findings in this study describe the supporters’ motives for becoming a supporter, and their experiences of encouraging and discouraging factors in the process of being a supporter in the dementia sector, experiences which covered sets of dimensional experiences, expressed as opposite pairs of words showing dimensions representing a continuum where experiences can vary.

In this study, the participants described two dimensions of motivating factors to becoming a supporter. All of them wanted to be of help to others while at the same time doing it for personal benefit, and they wanted to assist the person with dementia

to cope and fulfil his or her activities and to reduce the carers' burden of care. Furthermore, all of the participants wanted to try to give the person with dementia a good time with humour and joy. To provide something to other people also means a personal feeling of satisfaction and personal development. Being a supporter was a useful route back to work after an illness of their own and also meant having something meaningful to do. The participants expressed that the dementia disorder itself, with the variety of symptoms as they had experienced from work or other life experiences, fascinated them and they wanted to learn more about dementia and the health care services offered in the local authority and they liked to spend time with elderly people.

The interviews revealed four sets of two dimensional experiences of being a supporter expressed via opposite pairs of words: flexibility vs rigidity; being compensated vs feeling used; affiliation vs abandonment; and satisfaction vs lack of satisfaction. The dimensions represent continuums on which individual experiences can vary between individuals and over time. *Flexibility vs rigidity* concerns the freedom to choose what to do as a supporter and when. *Being compensated vs feeling used* relates to experiences of being treated as a valued professional whose costs are covered by public money and being treated as a person who is seen to be doing this for personal reasons and therefore expected to cover any financial costs associated with the supporter role. *Affiliation vs abandonment* refers to the supporters' need to be seen as a member of the wider professional health team and not to be left alone in their work. *Satisfaction vs lack of satisfaction* focuses on the personal feelings and experiences of being a supporter. Each of these categories is discussed below.

### ***Flexibility vs rigidity***

Within this category participants described experiences of various kinds along the dimension. There were stories about a certain kind of freedom to explore different kinds of activities and possibilities to choose time and place for being together, but also experiences of being captured in monotonous activities with small chances of change. Among the positive experiences of being a supporter most often mentioned was flexibility. Participants felt that they were able to undertake the work and use the time relatively freely. They also prepared themselves, planned ahead and read things they knew were of interest to the person with dementia.

I prepare for and plan the work beforehand, reading things or finding out about activities that might be of interest to the person with dementia. I find this a challenging experience, and it encourages me.

Many of these work tasks were filled with activities, something the participants appreciated doing such as going for a walk, skiing, driving around in a car, shopping, going to the swimming pool, visiting family members, museums, local sights or cultural events. Some supporters accompanied the person with dementia for visits to the doctor, hospitals, the hairdresser and other appointments. They also described simply having a good time together, eating or just talking.

The salary is low, but I am free. Still, it is hard sometimes to break up when we are having a good time. Sometimes it is also hard to come up with something to do.

The supporters accompanied the person with dementia to various activities that they were unable to manage on their own. When these activities became difficult to fulfil because of behavioural or psychological symptoms, or where the person with dementia was in the later stage of the disorder, activities became more limited and this reduced motivation to be a supporter.

Some participants explained that it was important to have some common interests and spend time to get along with the person with dementia and their families. In this aspect, the participants appreciated the possibility of making changes in cases where they did not get along with the person with dementia or their family carers. Then again these families could be offered another supporter or other services that were more beneficial to their specific needs. The participants described difficulties in managing to complete their work within the allotted time frame. For some supporters this was acceptable, but for others it was difficult and discouraging.

### ***Being compensated vs feeling used***

This category relates to the participants' feelings about having a salary, and being reimbursed for costs related to activities. All participants stated that salary was not an important factor for being a supporter, but they were concerned about the procedure of getting reimbursed for costs linked to activities such as driving and when the person with dementia did not understand that they had to pay for themselves. They were not concerned about being reimbursed for their own costs linked to activities. Some explained that they had not been given enough information regarding reimbursement procedures. Some received no help when requesting reimbursement or had only been reimbursed for some costs. Others had no problems being reimbursed for their costs when cooperating with the carers, but had experiences difficulty in telling the people with dementia that there was no more money to spend; a situation further complicated by the lack of awareness concerning money and costs on the part of the person with dementia. Several participants explained that not being reimbursed was one of the main reasons for giving up their roles as supporters.

It is difficult to say that there is no more time to spend together and sometimes we do spend more time than what is set and I get paid for but, that does not matter so much. What troubles me more is that I am not reimbursed for my expenses connected my work. I have tried to ask for help to solve this but so far this has not been solved.

However, a few participants' felt no need to be paid for their work or the associated expenses, because they had made a friend with whom they really enjoyed spending time:

I do not need payment or for this work, because I have a friend with whom I very much like to spend time.

Five supporters received education about dementia and regular support, which they appreciated. They also appreciated that this had been provided during paid hours.

### ***Affiliation vs abandonment***

Most supporters wanted to belong to the wider staff of the dementia team consisting of nurses, occupational therapists and social workers, and be kept informed about beneficial treatment and services these families were provided with to the same extent as other staff members. But many described a feeling of abandonment and exclusion from the wider team of professionals. This lack of affiliation and feedback on their work from the local authority reduced motivation to continue being a supporter. In some cases the local authority provided some training and instruction but most supporters felt excluded from being part of the dementia team, sending signals of lower status and lack of affiliation. In this way the supporters missed out on the support that staff members provide to each other. Many of the participants expressed that they had not been in contact with their administrator after signing the confidentiality agreement and had not received enough information about the person with dementia or working tasks. Furthermore, some did not know where to ask for counselling. Those who had tried to contact their administrator for counselling reported that these individuals were often very busy and rarely returned their calls. These factors were experienced as discouraging.

The supporters described how they often developed close relationships with the families, but also expressed concern about the difficulty of remaining 'professional' because of their separation from the wider dementia care team. They expressed a need for occasional counselling when it was difficult to deal with the person with dementia, when they felt that they were exploited by the families or that the work tasks were ambiguous. Supporters who had been recruited because they knew the person with dementia found it stressful and difficult to quit their job and continued to work despite these feelings:

I think it's frightening to see how the disorder develops, and I can imagine how it would be easy to give up being a supporter if you did not know the person with dementia.

The participants felt that they were often left to handle tasks themselves and appreciated talking to health personnel or other supporters in the dementia care team so that they could receive advice and hear about others' experiences. Only five supporters attended regular counselling sessions with two leaders in the local authorities together with other supporters. Different situations were discussed and supporters received feedback; sessions they described as being important and motivating:

It is lonely, but it is not that bad if I only have someone to call for help with the problems that arise. As a supporter, you have no relation to anyone in the local authority.

Some participants learned that when the person with dementia was placed in an institution on a permanent basis, staff members caring for the person with dementia had little information about the supporters' work.

### ***Satisfaction vs lack of satisfaction***

This category included a variety of feelings related to the meaning of being a supporter. For some, their experiences were very enriching while others felt more

uncertain. Also, some supporters stated that there were periods of time when the work felt very meaningful and other periods when this was not the case:

At first she wanted me to be a friend – to be something more than just a supporter – and it was difficult to set a limit, but now it is all right.

Some participants explained how being a supporter had been self-developing and that, by spending time with a person with dementia, they had learned a lot about the disorder, the course of the disorder and how the disorder can affect a person. The feeling of satisfaction through self-development constituted a motivating factor. A few described that they were provided, together with carers, education about dementia, communication techniques and local authority services before they began their employment; something they found valuable, applicable to their work and inspiring. To be able to help the families some participants described the importance of being knowledgeable about other age-related disorders, available services and brochures concerning dementia. Some explained that they were regularly provided with education together with other supporters; something they appreciated. Participants described feeling uncertain in situations when the persons with dementia would ask them if they were getting sicker, were experiencing a lot of BPSD or had problems taking guidance in certain activities and this discouraged them from working as a supporter. The supporters felt that their own contribution was greatest in the earlier stages of dementia. In the later stages of the disorder having a supporter has little meaning for the person with dementia; however it still provided relief for carers. In these situations, they needed knowledge to be able to respond appropriately. Other participants did not feel they needed knowledge about what it entails to be a supporter but found it motivating to learn about dementia and positive to add to their own knowledge.

Supporters felt that establishing a relationship with the person with dementia and/or their carers could take from one hour to six months and they put a lot of effort into making this a reality. They took great pleasure in the mere fact of being able to see how important these hours were for the person with dementia and their carers. The supporters also explained that they were provided with a lot of positive feedback from the person with dementia and their carers, something that gave them a feeling of being appreciated:

It is nice to feel that you have some knowledge and have more to learn. I have what is important for me to be a supporter, but the supporters do need a bit of support and a course about dementia. I think so!

## **Discussion**

The main findings in this study show that all the supporters experience their work as meaningful and of importance for the people with dementia and their carers. This factor gave the supporters great pleasure and motivated them to keep working as supporters. The positive feeling one experiences when helping others has been confirmed by Ryan et al. (2004) and Dulin and Dominy (2008) and can predict job satisfaction and happiness. A supporter can also receive confirmation through others, as illustrated by Buber (1923) in his description of how human life finds its meaning in relationships. The supporters described different kinds of demands of being a supporter, such as feeling that it was difficult working as a paid professional

and at the same time being a friend and building a friendship, an argument also developed by Gough and Modig (1996) and Möller (1998). Furthermore, this study describes the supporters' motives for becoming a supporter and factors that can encourage and discourage them from continuing to work as a supporter in the dementia care sector.

The findings show that the supporters' experiences are placed at different points on continuums of flexibility vs rigidity; being compensated vs feeling used; affiliation vs abandonment; and satisfaction vs lack of satisfaction. To be a supporter entails being subjected to mixed messages from people with dementia, their families, and the local authority.

The supporters felt that they were contributing to social inclusion for the families and being a supporter was experienced as a flexible job when it came to the freedom of being able to choose the time and place for being together as well as the possibility to make changes in cases where they were unable to forge a relationship with the person with dementia, or their carers. This flexibility encouraged the supporters to continue their work, but they also felt it was difficult to adhere to time limits when with the person with dementia. Working as a supporter sometimes meant being left to meet financial costs, and this was one of the reasons why some had thoughts about quitting as the role of supporter.

These supporters did not feel treated as part of the staff caring for the person with dementia and thus missed out on the emotional support team members provide each other. They had little contact with their administrator and no employment contract with a detailed job description and information regarding job-related costs. Together, these factors discouraged the supporters from continuing their work and gave them a feeling of lack of affiliation. A report from the Norwegian county governors confirms that these supporters' experiences are not unusual (Statens helsetilsyn [Norwegian county governors] 2008), despite Norwegian legislation and recommendations from other studies (Lauber et al. 2000; Ryan et al. 2004; HOD 2006).

Based on other studies, it is clear that health personnel as well as supporters and carers require education and counselling to fulfil their work and carer obligations, even if they are hired on a self-employed basis and work as 'paid friend' (Parker, Mills, and Abbey 2008; Brodaty and Donkin 2009; Moniz-Cook and Manthorpe 2009; Johannessen 2009), to keep up with the demands of dementia care. According to Axelsson and Bihari Axelsson (2006) and Åhgren (2008), it is also important that an administrator integrates the employee in such way that everyone is informed about the care tasks and receives supervision to develop personal qualities if the organisation wants to succeed in its care tasks; something other studies can also confirm (Severinsson and Kamaker 1999; Fagerberg 2003). In dementia care, complex and multiple needs for differentiated care services often have to be addressed, meaning that cooperation between different departments within the health care sector is thus greatly needed (Hassan and Arnetz 2009; Hardy and Kingston 2009).

Throughout their efforts of being a professional 'paid friend,' the participants felt in need of counselling and knowledge, and experienced the role of supporter as lonely. This is confirmed by Lauber et al. (2000) and Fagerberg (2003). For some of the supporters, education provided together with carers was useful, something also Jansson et al. found in their study (1998) in terms of information about dementia, the duration of the disorder, BPSD, how to communicate and how to act together with a person with dementia. They expressed the need for knowledge about dementia and

communication skills, similar to the needs of carers in studies by Moniz-Cook and Manthorpe (2009) and Brodaty and Donkin (2009). It is of importance that the administrators in the dementia care sector focus on collaboration between health professionals, persons with dementia and carers reflecting Norwegian legislation and recommendations of the Norwegian Government's Dementia Plan strategy (HOD 2006, 2008).

The findings of this study provide us with some clues about what encourages and what discourages dementia care supporters from continuing in their roles. However, despite similar findings by Johannessen (2009), some of the supporters in this study had remained in their roles for at least one year, and some up to 10 years. There were, however, few informants to chose from in most cases. Of course, the findings are influenced by the fact that it is people who still work as supporters who were participants.

Very little research has been conducted in this field, reflecting limited interest in focusing on how it is to be a supporter in this service opportunity in dementia care (Johannessen 2009). The qualitative methods used in this study have enabled us to contribute to the narrow knowledge base (Dellve et al. 2002). Although the findings cannot be generalized in a statistical sense, we argue that our findings can be transferable to other contexts (Malterud 2001). With increasing demand for dementia care services it is important that policymakers understand the dynamics of recruiting and retaining supporters. This service has the potential for significant development to help support increasing numbers of older and younger people developing dementia as well as their family carers. But it is important that lessons are learned from early experiences, as described in this study, to inform the development of future services.

In conclusion, it seems likely that greater flexibility, adequate compensation, a sense of affiliation and satisfaction, together with the potential for building good relationship with families, are factors that will encourage dementia care supporters to continue with their work.

### Acknowledgements

This study was supported by the Nordic School of Public Health, Gothenburg, Sweden, and Ageing and Health, Norwegian Centre of Research, Education and Service Development, Norway.

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