

# Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective

Dementia

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## Abstract

Low-threshold support services are provided within the basket of services of German long-term care insurance as a part of respite care to support family carers and people with dementia. This study investigates various stakeholders' (providers, coordinators, volunteers, family carers and people with dementia) perspectives on low-threshold support service regarding its organisation and conceptualisation as well as how stakeholders and users value low-threshold support service using a qualitative approach. Twelve guided interviews and group discussions were conducted with 31 participants. Organisation and conceptualisation are characterised by the lowness of the service thresholds, which is perceived to be quick and simple forms of support with no user requirements. Multiple barriers such as the challenging behaviour of people with dementia and their initial refusal as well as their holding low-threshold support service in low esteem can hinder the utilisation of these services. Low-threshold support service within the scope of the long-term care insurance law can be separated into two types: low-cost (non-professional) services and high-cost

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services with comprehensive training for 'employed' volunteers (professional). Both types are constantly developing within the landscape of the German long-term care system, and low-threshold support service appears to be adapted to diverse needs. Therefore, it is important to avoid replacing non-professional services with professional services.

### Keywords

low-threshold support services, community health services, dementia, qualitative interviews, Germany

## Introduction

Worldwide, most of the frail elderly who need care, including people with dementia, live in the community and receive care predominantly from family carers. One of the major challenges for health and social care systems is ensuring the long-term care continuum and supporting families to enable their care-dependent relatives to remain in their homes for as long as possible (World Health Organization, 2012). Each country takes a somewhat different approach to service delivery (Moise, Schwarzingler, Um, & Dementia Experts' Group, 2004). However, in most countries, great efforts are undertaken to establish and strengthen community services. Triggered by the global shortage of registered nurses (Heinen et al., 2013; Oulton, 2006), a trend towards developing semi-professional services is apparent.

From an international perspective, respite care would appear to pursue a similar purpose to that of the services framed under the umbrella term 'low-threshold support services' (LSSs) in Germany. According to Lee and Cameron (2004), respite care encompasses a wide range of services with multiple dimensions to relieve family carers. Trained or untrained staff as well as volunteers can provide support for hours to weeks. Furthermore, the support can be spontaneous and involve overnight stays. Zarit, Gaugler and Jarrott (1999) also characterise in-home respite care as house cleaning or bathing clients. Consequently, respite workers can be companions, homemakers or even nurses. At the moment, no studies demonstrate any effects of respite care (Lee & Cameron, 2004; Maayan, Soares-Weiser, & Lee, 2014). Greenwood, Habibi and Mackenzie (2012) found in an interview study on family carers' experiences with respite care, indicating that trust in the respite care worker and the quality of life of the cared-for are important benefits for family carers. Further benefits are the delay of institutionalisation socialisation and encouraging stimulation (Neville, Beattie, Fielding, & MacAndrew, 2015).

Similar to the figures for most industrialised countries, the number of people with dementia is expected to increase in Germany (Bickel, 2001; Rothgang, Iwansky, Müller, Sauer, & Unger, 2010). Currently, there are approximately 1.4 million people with diagnosed or suspected dementia, and most of them (approximately 60%) reside at home (Rothgang et al., 2010). Since 2002, Germany's statutory long-term care insurance (LTCI) has aimed at supporting people with dementia and their families by providing a subsidy for people with limited competence in the activities of daily living and an increased need for supervision (§45a-c SGB XI). This subsidy requires a care dependency assessment that is granted as a supplement, regardless of whether the person also receives LTCI benefits based on individual care levels. Recently, some legal innovations have been enacted. Since January 2015 the above-mentioned supplementary benefit was slightly raised. It currently amounts to 104€ (basic) or 204€ (augmented) per month depending on the individual need. A more significant change

concerns purpose and target group eligible for these benefits. This is also reflected in the legislative text which was changed into 'low-threshold support **and respite service**'. Whereas before these benefits could be used for care that is provided on an hourly basis such as LSSs, day or night care or short-term inpatient respite care provided directly to the people with dementia the scope of services was extended by respite services directly supporting the informal carer such as counselling or household help.

However, in the present study the focus is set on services directly delivered to people with dementia. All respite services concerning just the family carers as counselling or household help were excluded.

According to the German LTCI, LSSs are divided into group services (social care groups) and individual care and supervision at home to relieve family carers, to promote activity among people with dementia and to promote social inclusion. Typically, these services involve social activities rather than nursing care. This type of care is provided by trained volunteers who are supervised by health, nursing and social care professionals, the so-called coordinators. In most cases, the coordinators also lead the groups; they are the contact persons for the users, and they are responsible for the administrative work. In addition, providers assume higher level coordinating roles. However, not all LSSs are attached to larger organisations, such as welfare organisations.

The scientific literature and evidence concerning the effectiveness, cost efficiency and outcomes of LSS as a service within the German LTCI are quite limited. According to Gräbel, Römer and Donath (2009), by engaging people with dementia in social activities such as playing games and performing physical exercises, well-trained staff and affectionate contacts are the main expectations of family carers who send their relatives to LSS social care groups. For family carers who utilise LSS at home, it was found to be particularly important that volunteers arrive on time and work autonomously (Gräbel, Luttenberger, Bleich, Adabbo, & Donath, 2011).

Most evidence on LSS is found in the grey literature in a number of theses (Dumke, 2008; Fringer, 2011; Graf, 2011; Hochgraeber, 2010; Schmidt, 2005; Schrön, 2005; Ulbrecht, 2010). The results indicate that the work of LSS volunteers can help families maintain their daily lives and routines and prevent the institutionalisation of the people with dementia (Fringer, 2011). From the perspective of the people with dementia, one valued outcome of participating in social care groups was that they found personal meaning in attending the groups and perceived their members as a familiar community (Hochgraeber, 2013; Hochgraeber, Riesner, & Schoppmann, 2013).

## **Aims and objectives**

The current study aimed to investigate the development of LSS within the German policy framework from the perspectives of the stakeholders (providers and coordinators, volunteers, family carers and people with dementia). The study addressed two research questions: (1) How do stakeholders evaluate the current organisation and conceptualisation of LSSs in Germany? and (2) What is the value of LSSs as a part of Germany's community care system from the providers' and users' perspectives?

## **Methods**

This study is part of a larger mixed-method study (*NisA-Dem*) with a cross-sectional design (Hochgraeber, Bartholomeyczik, & Holle, 2012). This paper describes the qualitative analysis of group discussions and individual interviews to present deeper insight into the different perspectives.

## Data collection

Data were collected in two regions of Germany. The qualitative sample was recruited based on the personal inquiries of participants in the quantitative part of the study and by systematically asking the participating family carers and volunteers who completed the questionnaires if they were willing to be interviewed.

Group discussions were conducted with one perspective at a time with the intention of gaining collective information on LSS and stimulating discussion about differences and experiences. Bohnsack's *collective orientation* model served as a conceptual framework (Bohnsack, 2002). A flexible interview guide was used to moderate the discussions (Hochgraeber et al., 2012). Two researchers conducted each of the group discussions; one researcher moderated the discussions, and the other recorded the main topics and contents and identified each person who spoke. All discussions and interviews were also audio-recorded and transcribed verbatim.

Group discussions and individual interviews took place at the service provider facilities and at the responsible research institute from April to June 2012. Seven group discussions and five individual interviews were conducted (Table 1). Overall, 31 people participated; all but two volunteers and one family carer were female. The duration of the individual interviews was between 35 and 77 min. The duration of the group discussions was between 24 and 98 min. The discussions began with a short introduction of the topic and an explanation of the procedure, followed by an initial question about how the participants first became involved with LSS. Notes were recorded after each interview and each group discussion. The group discussion with the people with dementia was short (24 min), and the content of the discussion only partially answered the research questions. The people with dementia were very interested in their surroundings and in talking about other things such as the weather or the flowers on the table. Nevertheless, these results provided valuable insights into their perspectives.

All interviewees provided written informed consent. The ethical committee of the German Association of Nursing Sciences approved the study and gave its ethical approval for the *NisA-Dem* study.

## Data analysis

Participants' responses in both the interviews and the group discussions were very focused on facts and on answering the interview questions. Therefore, the previously intended analysis strategy (Hochgraeber et al., 2012), Bohnsack, Pfaff and Weller's documentary

**Table 1.** Study sample (number of interviews, group discussions and participants).

|                      | Number of<br>Individual interviews | Number of group discussions<br>(number of participants) |
|----------------------|------------------------------------|---|
| People with dementia |                                    | 1 (3)   |
| Family carers        | 1                                  | 2 (3, 2)  |
| Volunteers           |                                    | 2 (8, 4)  |
| Coordinators         | 1                                  | 2 (2, 4)  |
| Providers            | 3                                  |   |

method (2010) had to be changed because the data were not appropriate for such an open and inductive strategy.

A more focused and content-related method was employed instead. The group discussions and individual interviews were transcribed verbatim and analysed using content analysis according to Burnard (1991) using the MAXQDA 11 software. The data were analysed by a team of three researchers to ensure intersubjectivity. The transcripts were read intensively, and their main themes were identified. Open coding and the selection of passages that were relevant to the research questions were performed. Then, the codes were organised, reduced and transferred into themes and subthemes (see Table 2). This resulted in four sets of codes, one for each stakeholder perspective. Then, the research team discussed and adapted the lists of codes and reviewed the original transcripts to validate the codes.

## Results

In summary, two themes and six subthemes (Table 3) were identified, reflecting the stakeholders' perceptions of the performance of LSS for people with dementia. The first theme was the *organisation and conceptualisation of LSS*. Mainly, the providers and coordinators described their established services, including how these services were run as well as their motivations. One essential point that emerged a number of times was the *lowness of the service thresholds*, which refers to users' service access. *Service utilisation*

**Table 2.** An example of the categorisation process.

| Example   | Pre-considerations, first coding   | Subthemes  | Themes                  |
|---|--|--|-------------------------|
| <p>Interviewee 2: <i>But they feel well there.</i></p> <p>Interviewee 1: <i>Yes, they feel well, but there is no large cognitive challenge anymore.</i></p> <p>[. . .]</p> <p>Interviewee 2: <i>She [person with dementia] likes to do it. She is proud. She comes home [. . .] with her sheet, 'Look what I painted, I did it for you'</i></p> | <p>Interviewee 2 put the focus on occupation and well-being of the PwD</p> <p><b>(occupation and well-being as outcomes)</b></p>                               | <p>Valued effects of LSS: enhancing functional abilities versus enhancing well-being</p> | <p>The value of LSS</p> |
| <p>Interviewee 1: <i>I look at the painting with a different view. For example, I study the lines and estimate if she [person with dementia] is able to stay in lines, how flexible is her wrist. I view it from this perspective and not as an occupational therapist</i> (Carer Discussion 2§17–25)</p>                                       | <p>In comparison with the opinion of interviewee 2, interviewee 1 emphasises physical training and precision</p> <p><b>(functional ability as outcome)</b></p> | <p>Valued effects of LSS: enhancing functional abilities versus enhancing well-being</p> | <p>The value of LSS</p> |

**Table 3.** Themes and subthemes.

| Themes                                       | Subthemes   |
|--|---|
| 1. Organisation and conceptualisation of LSS | <ul style="list-style-type: none"> <li>● Lowness of the service thresholds</li> <li>● Service utilisation</li> <li>● Service delivery</li> </ul>  |
| 2. Value of LSS                              | <ul style="list-style-type: none"> <li>● Valued effects of LSS: enhancing functional abilities versus enhancing well-being</li> <li>● Low-cost versus high-cost care</li> <li>● Role of volunteers</li> </ul> |

and delivery strategies were also discussed. The *value of LSS* was the other theme. Here, the status and value of LSS were controversial discussions. The *role of volunteers* appeared as another crucial subtheme.

### *Organisation and conceptualisation of LSSs*

The stakeholders described different motivations for establishing LSS. One reason was the economic desire to fill a market niche. Others had realised a need to provide supervision and social care for people with dementia within their private or occupational environments. Their motivation to initiate a LSS was to fill a gap in the German health care system to provide better care and enhance the well-being of people with dementia and family carers.

All participants reported that the stakeholders' personal engagement and sense of responsibility were essential to establishing a successful service. Therefore, the success of LSS depends on the coordinator and his communication and supervising skills.

In the following, the three subthemes of organisation and conceptualisation are described.

### *Lowness of the service thresholds*

The volunteers stated that it was important for users to receive quick and simple support. Simple in this context indicates that family carers should have one central contact point with as little bureaucracy as possible. '[...] *that the relatives do not have to go from one point to another and have to ask again and again and have to submit papers to the insurance and so on, but that it is fast and simple*' (Volunteer Discussion 2§146). The stakeholders agreed and added the importance of accessibility. Affordability and the fact that users do not have to meet formal eligibility criteria were additional factors to ensure low thresholds.

For volunteers, low thresholds referred to offering a place where people with dementia could interact with their peers with no requirements. At the same time, the volunteers stated the need for individualised care and for providing users with a contact person. The coordinators confirmed the importance of this contact person as factor to facilitate access to LSS.

### *Service utilisation*

All interviewees discussed the utilisation of and access to LSS as well as barriers and facilitators.

Pick-up and return services for group care comprised a solution that all participants appreciated. One family carer stated the following:

*[...] a pick-up and return service is certainly a relief; without it, imagine the time. She has to be here [in the group] at half past three, then you have to be prepared at half past two, then the stairs down, into the car with the wheelchair, then driving, and here you cannot park directly in front of the house, taking the wheelchair loading and unloading and going across the street. Then, I have to go back home and have to be here early again to pick her up at five. [...] I do not have any relief, that is even more work. (Carer Discussion 2§112)*

The people with dementia also emphasised this pick-up service. They not only valued it in terms of mobility but also appreciated it as an enjoyable part of their participation in the service.

The family carers perceived the so-called challenging behaviour of their relatives with dementia as a barrier to utilising LSS because they believed that they could not expect the volunteers to manage these behaviours. Other barriers included the people with dementias' initial refusal to participate in extramural services and families' difficulties in securing the costs of the service. Furthermore, the stakeholders were concerned with users' understanding of the term 'low-threshold'. They suspected that this concept could be understood as a label for low-quality care and that it could be another barrier to service utilisation.

The stakeholders reported on their experiences that household aids can open the door for families to use also LSS. A particular advantage of LSS compared with highly professional services such as home care nursing was the flexibility of the LSS with regard to family carers' emerging needs:

*I like it that I can decide when somebody should come, when I think that I need somebody, when I need some relief. That's what the service is about: my relief and that I can decide because it is very flexible, and that's the good thing about it. (Carer Discussion 2§62)*

The volunteers and coordinators viewed home care nursing services as important gatekeeper for people with dementia to access LSS. However, the family carers served a bridging function because they were typically the contact persons for providers. The coordinators explained that counselling, having people with dementia make non-committal visits to social care groups and having volunteers visit potential clients' homes were the most successful recruitment strategies.

The coordinators suspected additional barriers to utilising LSSs based on location. For example, a hospital or a nursing home as provider with secure wards may have a high service threshold. For the family carers, limited family budgets were also a problem. Furthermore, the coordinators exhibited a lack of knowledge about the available services and the purpose of these services.

### **Service delivery**

LSSs are provided by volunteers on a daily basis. They perceived the structured and routine organisation of group services (i.e. the same days, same schedule and same people) as helpful in providing continuity, which is important for promoting feelings of security among people with dementia. However, the volunteers stated that it was important for the people with dementia and family carers to know that a professional nurse was always available in the case of an emergency. *'It is reassuring. Even with such (...) if they have a physical problem,*

anyway that there is somebody who always has the newest knowledge and who can help immediately' (Volunteer Discussion 2§245). The volunteers used professional, structured strategies. They completed intensive training, participated in team case conferences, recorded comprehensive documentation and wrote protocols for each meeting and the volunteers internalised these procedures: 'It has to be recorded, yes, you must not forget this' (Volunteer Discussion 1§246). In contrast, some coordinators refused to utilise these strategies because they did not perceive them as necessary for providing good person-centred care.

### **The value of LSSs**

The second theme across all perspectives was the value of LSS. Here, stakeholders described their views of LSS and service utilisation in three subthemes.

#### **Image of service utilisation**

Service utilisation is associated with two types of stigmatisation, i.e. the negative views of dementia in general and the welfare stigma in particular, which accumulated and led to non-utilisation in some cases. The coordinators reported on some families' strategies for hiding their service utilisation; for example, some families select services in neighbouring cities:

*I think the media presence [of the topic dementia] is still too little. It is still insufficient, and it is represented too negatively, that's the point. And then (...) then according to the motto, Hm, my neighbour should not know that my relative is demented, and then they sweep it under the mat before somebody recognises it. I try to manage it behind closed doors, and that is the problem. Few have the courage to say, okay, I really need help, support me. (Player Discussion 1§29)*

As a solution, the coordinators and providers wanted to improve the image of LSS and the general image of dementia. They attempted to improve the image by avoiding using the terms *low-threshold* and *dementia*. Furthermore, they made services available in public, easily accessible places and recommended intensive public relations.

#### **Valued effects of LSS: Enhancing functional abilities versus enhancing well-being**

The family carers emphasised a need for structured and predefined concepts of LSS that keep people with dementia active and promote their personal abilities. These carers did not wish for the people with dementia to simply be kept busy or entertained during their participation in services. They stated the clearly defined expectation that the service enhances functional abilities and physical outcomes. In contrast, other carers focused on the participation of people with dementia in (meaningful) activities and well-being as outcomes of low-threshold support (see Table 2).

#### **Low-cost versus high-cost care**

Coordinators stated that the value of the services was important for their successful implementation and organisation. They emphasised the public presentation of services and the public's view of volunteers as crucial. In particular, the image of volunteers as direct care providers had to improve. The coordinators discussed the controversial topic

of costs. One opinion was that low costs reduce the value of the performance and the service. Furthermore, the coordinators suspected that service quality could be judged by price and, as such, recommended reasonably high hourly rates for care (e.g. 25 Euros). Higher costs could also enhance policy makers' appreciation of LSS care and the volunteers' status: '*[...] they have to spend more political money, the employees need to be at another wage level - that would be important [...]*' (Player Discussion 2§95).

The coordinator in this quote referred to the volunteers as 'employees'. Some coordinators employed their volunteers and thereby linked them to the organisation and valued them. They argued that they can provide more continuous and high-quality care when volunteers are linked to the organisation.

In contrast, other coordinators held the opinion that LSS should be affordable for all in need. The valuation of volunteers should primarily emerge from the families' appreciation. Nevertheless, all coordinators agreed that the services required more external appreciation.

### *The role of volunteers*

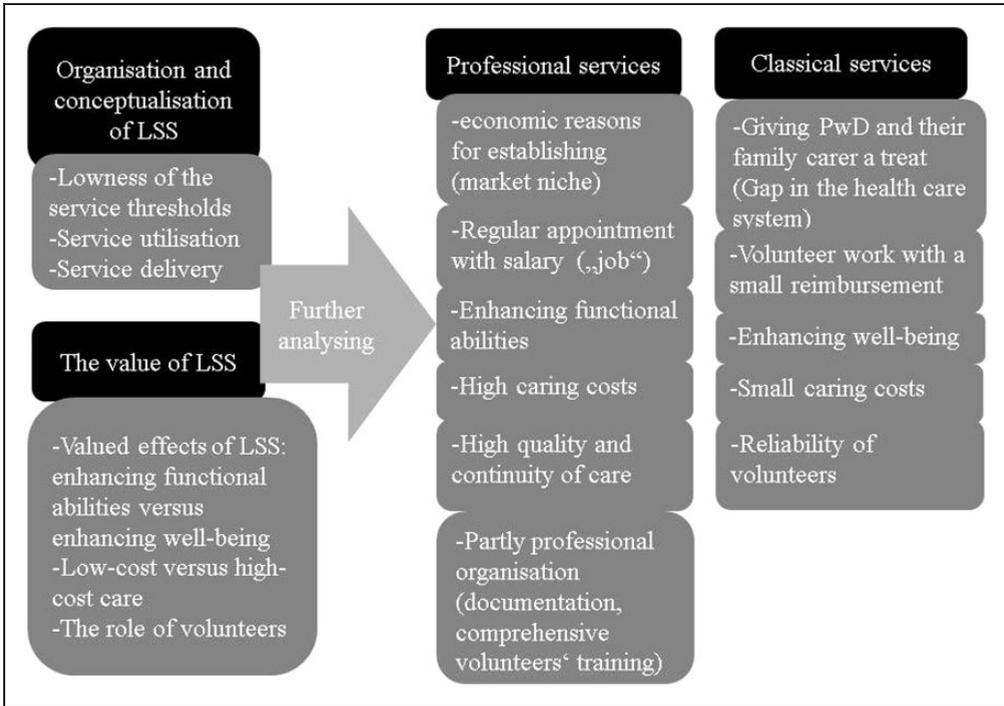
Volunteers have an essential role in LSS. They provide the direct care and are therefore in contact with the people with dementia. The volunteers' attitudes towards their engagement reflect its meaning. They discussed the people with dementia with person-centred attitudes, treating them in the same manner that they treated others and valuing them. In addition, they attempted to promote the well-being of people with dementia, quality of life and happiness. The volunteers' main focus was the people with dementia, but they also considered the family carers' situations and needs. They stated that the well-being of the people with dementia and the family carer are mutually dependent.

*[...] on the other side, it is clear that the family is just comfortable if the people with dementia is really cared for in a good way. So they can just do something for themselves in peace. But the opposite is also true [...].* (Volunteer Discussion 2§118)

In addition to person-centred attitudes, the volunteers showed professional attitudes, as expressed in their use of the term 'job'. '*I found a new vocation, although I am in the café [...] just on Thursdays or if I have to deputise somebody*' (Volunteer Discussion 1§18). The volunteers described their career development as stepwise. First, they received a few hours of training, followed by an internship in a social care group. Then, they visited the families (possibly with a coordinator for the first visit). One volunteer had advanced her career and led a support group for family carers. Then, she began to give oral presentations to interested people and family carers.

After analysing themes and subthemes, it was obvious that the investigated services tended towards one of two directions. Some services developed in a professional direction with different features, whereas the others demonstrated the classic side of LSS as intended by law. Figure 1 shows an overview of the features of professional versus classic services. As a result, the transcripts and themes as well as subthemes were controlled if they confirmed one of the both directions.

Professional services are characterised by certain coordinators' demand for higher prices to demonstrate that they value their volunteers and to demonstrate higher quality. They refer to their workers as employees, establishing a continuous commitment to providing a continuity and quality of care. Furthermore, the interviewees stressed that LSSs were developed because of economic considerations. The volunteers' attitudes and self-



**Figure 1.** Development of the two types of services.

awareness demonstrated that they perceived their engagement as a (new) vocation rather than simply a charitable leisure time activity. The volunteers participated in professional activities such as case conferences, comprehensive documentation and comprehensive training. Some family carers displayed outcome-oriented attitudes and expected special therapeutic effects and behaviours, confirming a certain professional demand. This demand can hardly be fulfilled when volunteers only have limited hours of training. For this purpose, professional, qualified staff would appear to be necessary.

The other type of services is classic volunteering, which was the intention of the law. The services should be affordable for all, and volunteers were to receive appreciation and personal benefits by engaging with the people with dementia rather than by receiving money. The intention to implement LSS was stimulated by the perceived needs of family carers and people with dementia. All volunteers were intensively engaged and showed high identification with caring for the people with dementia.

## Discussion

Different stakeholder perspectives (coordinators and providers, volunteers, family carers, people with dementia) were assessed in the current study. As we initially expected, the perspectives slightly differed, and the participants set their priorities according to their roles. Overall, the results are complementary and provide a comprehensive view of LSS.

This study shows that the organisation of LSS differs according to the lowness of the service thresholds. Low thresholds refer to services that are easy to utilise (in participants'

words, quick and simple forms of support) and are a crucial intention of the people with dementia subsidies called for in the German LTC insurance law (§45b SGB XI). That is, LSSs were intended to engage people with dementia in activities and relieve family carers as well as to provide this care to all people in need. In a study on service-related needs, Górska et al. (2013, p. 1107) found that people with dementia required '*enhanced access to non-pharmacological interventions to support identity and social engagement*'. The results of the recent study show that the thresholds of services were not always low.

As it is the case for other types of respite services (Neville et al., 2015), an important aspect in LSS is the role of volunteers. They provide the direct care for the people with dementia, and therefore, their attitudes and behaviour are crucial. The results show that the volunteers feel a high sense of responsibility for people with dementia, but they do not forget the family carers; they consider both groups of users and see them as one entity with different needs. All investigated perspectives support the importance of people with dementia and family carers. It does not appear to be useful to separate these groups, but it is necessary to meet both needs for a successful service. Accordingly, in the quantitative part of the *NisA-Dem* study, the aspect that family carers considered to be most important was the well-being of the people with dementia (Hochgraeber, Dortmann, Bartholomeyczik, & Holle, 2014). In a study on respite care, Greenwood et al. (2012) described the '*centrality of the cared for*' and observed that family carers consider the benefits for the care recipient to be more important than the benefits for themselves. Two studies found service utilisation can depend on whether not only the family carers, but also the person with dementia benefit from the service (Beisecker, Wright, Chrisman, & Ashworth, 1996; MaloneBeach, Zarit, & Spore, 1992). Furthermore, in a study on person-centred respite care, the authors concluded that person-centredness is not embedded in service providers' organisational cultures, and they suggested shared cultures at all organisational levels (Kirkley et al., 2011). In a recently published literature review, Neville et al. (2015) concluded that current respite care services do not meet the optimal balance between the needs of the person with dementia, family carers and staff. Consequently, the aim of LSS should extend beyond relieving family carers and include the well-being and social activities of the people with dementia not only at the higher organisational level but also at the volunteer level.

The main result of this study is the distinction between the LSS with volunteers in the classic sense and the professional services with 'employed volunteers'. This is a consequence of certain aspects of organisation and value. Coordinators justified professional LSS as establishing continuous, high-quality care provision. Górska et al. (2013) confirmed the '*continuity of care concerning the personnel involved*' as a service-related need of people with dementia. Employing volunteers with regular work contracts was confirmed in the quantitative part of the study (Hochgraeber, Dortmann, Bartholomeyczik, & Holle, 2015). Here, 31.5% of the volunteers were marginally employed, and 14.1% were part-time or full-time employees. Therefore, in contrast to the classic volunteers, they had employment relationships with obligations and rights. In the proper sense, these people are referred to as 'employed volunteers'. The classic volunteering has developed from serving without extrinsic reward to helping people with little reimbursement to working for salaries and at different levels of employment. In Germany, the social care provided in the field of LTC often falls within the range of tasks provided by professional registered nurses or nursing aides. Therefore, using volunteers to provide social care to people with dementia is a quite new development, although in other countries, it appears to be relatively normal.

Coordinators argued that professional services offer better continuity and a higher quality of care. The value of LSS and the different desired effects (enhancing well-being versus enhancing functional ability) from the family carers' side showed that users' desires can also affect LSS. The question of costs is generally difficult. Both the professional (high-cost) and classic (low-cost) services appear to be justifiable. However, one important condition for a low threshold is service affordability.

For users, the development of LSS in the two directions described above means that services with diverse orientations are available. They appear to find it important that providers explain their orientations and make clear what they as the users can expect. Therefore, providers should consider what they want or are able to offer as well as what users need.

If the new trend towards professionalising volunteers' tasks holds, there must be a better structure and an allocation and partitioning of responsibilities amongst professionals, volunteers and 'employed volunteers'. Mainly, the status of 'employed volunteers' between professionals and volunteers can entail the likelihood of greater knowledge while maintaining high motivation and flexibility in their activities. In German nursing homes, all three groups typically provide care. In this setting, there are clear structures and definitions, which are also important in maintaining volunteer and civic engagement rather than displacing these individuals. For the community setting, this structure is still needed.

A second consideration is the withdrawal of 'employed volunteers' and the division of low-threshold support amongst professional nurses and classic volunteers. However, compared with a graduated system in which professional nurses hold authority and delegate tasks and the upcoming nursing shortage, this does not appear to be a better solution.

For both types, it is necessary to adapt the conditions of LSS because classic services with engaged volunteers cannot be measured with the same standard as a professional, business-based service with comprehensively trained and 'employed volunteers' or professional nurses.

### *Limitations*

One study limitation is that we only included the perspectives of the family carers and people with dementia who utilised LSS. Especially with regard to barriers, it is important to ask non-users why they do not use these services and what they expect in terms of organisation. We attempted to involve the people with dementia in group discussions with moderate success. Few statements from these discussions could be used because it was rather difficult to maintain the participants' focus during the groups. Furthermore, volunteers depend on their employers. Therefore, they are unlikely to present arguments that would give their employers bad reputations or suggest problems. The group discussions and interviews were guided by special questions that addressed the main topics of LSS, and thus, the participants could not have completely free discussions even though there were long narratives in the data. The responses and topics addressed in the group discussions differed from the interview responses; it might have been the case that the participants omitted certain aspects in the presence of other people.

### **Conclusion**

Although under the same law, types of LSS in Germany appear to be quite diverse, they all contribute to the care of community-dwelling people with dementia. The participants agreed

that the image of LSS has to improve because there remains a stigma regarding the use of these services. The results show two types of LSS. One type trends towards more professional services, whereas in the other type, the services are provided by classic volunteers.

Therefore, political conditions must either strengthen a clearly defined and structured allocation of the responsibilities of care amongst volunteers in the classic sense, ‘employed volunteers’ and professional nurses, or withdraw the ‘employed volunteers’. The first way appears to be a better solution, but it requires structural adaption following political debates. Future research should confirm these results in larger studies with greater involvement of people with dementia. Furthermore, non-users of services should be involved to obtain their perspectives on and barriers to LSS use. Another point is the legal changes which should be considered in further studies.

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