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Needs and quality of life of people with middle-stage dementia and their family carers from the European Actifcare study. When informal care alone may not suffice

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ABSTRACT

Objective: The Actifcare (Access to timely formal care) study investigated needs of people with dementia and their families during the phase in which formal care is being considered, and examined whether higher need levels are related to lower quality of life (QOL).

Method: From eight European countries 451 people with dementia and their carers participated. Needs were measured with the Camberwell Assessment of Need for the Elderly. QOL was measured with the QOL-AD, and carer quality of life was measured with the CarerQol. The relationship between needs and QOL was analysed with multiple regression analyses.

Results: Needs were expressed in the domains of psychological distress, daytime activities, company and information. People with dementia rated their unmet needs significantly lower than their carers: the mean number of self-rated unmet needs was 0.95, whereas the mean proxy ratings were 1.66. For met needs, the self-rated mean was 5.5 and was 8 when proxy-rated. The level of needs reported was negatively associated with QOL for both.

Conclusion: The study results show that informal carers reported almost twice as many needs as people with dementia. The domains in which needs are expressed should be the primary focus for interventions to support QOL. The perspectives of people with dementia are informative when identifying needs.

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Introduction

Dementia has a major impact on a person's life. It leads to difficulties in different domains, such as self-care, meaningful activities and social contacts. Thus, people with dementia and their informal carers experience a wide range of needs that are subject to change as the disease progresses. Unmet needs can be defined as those needs in a particular area of an individual's life in which insufficient or inadequate support is provided or appropriate support is unavailable (van der Roest et al., 2007). For met needs, sufficient and adequate support is available through either informal or formal care.

A number of studies have investigated these needs from various perspectives (Bakker et al., 2014; Black et al., 2013; Miranda-Castillo et al., 2010; Miranda-Castillo, Woods, & Orrell,

2013; van der Roest et al., 2009). The needs of people with dementia are often measured using proxy-ratings (van der Roest et al., 2007). Few studies have incorporated the self-rated needs of people with dementia. It is important to be aware of the subjective needs of people with dementia to provide more appropriate person-centred care. In terms of needs assessment, there are often discrepancies in perspectives. Typically, people with dementia report a significantly lower number of (unmet) needs than their caregivers. The reasons for this discrepancy could be lack of awareness of difficulties, lack of knowledge about the existence of services, barriers to accessing services and unsatisfactory service offerings (Bakker et al., 2014; van der Roest et al., 2009). A review of the literature investigating self-rated needs found that the domains in which needs are expressed by people with early

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to moderate dementia are related to their well-being and not to instrumental activities (van der Roest et al., 2007). For example, needs were reported in the areas of receiving respect from others and needing to find a way to cope with their situations. Other studies have indicated the needs expressed by community-dwelling people with dementia in the areas of psychological distress, daytime activities and company (Miranda-Castillo et al., 2013).

Previous studies have generally focused on a broad range of dementia severity or on people with young onset dementia. In the Actifcare study, our focus was on a group of people that could be said to be in the middle-stage of dementia, in that it was considered that they were likely to start using formal care in the near future. Investigating this group is important because it allows us to focus on the specific needs of individuals who are potentially in transition from informal care exclusively to a combination of formal and informal care; it is in particular in the middle stage, that people with dementia are likely to have increasing care demands due to disease progression. The focus on people who do not use formal care but only rely on informal care does not imply that they do not have (unmet) needs. However, thus far, their needs have predominantly been addressed through informal care. Studies have shown that providing care influences the life of a carer to a large extent, with consequences that include depression, physical illness, and poor quality of life (Etters, Goodall, & Harrison, 2008). Informal carers of people with dementia are at increased risk of feeling socially isolated and financially burdened (Alzheimer's Association 2012, 2013). This finding is particularly true for carers co-resident with the person with dementia, where informal carers typically provide many hours of care, often increasing as the disease progresses.

In the present study, we expected to find that people with middle-stage dementia and their informal carers who do not yet use formal care do experience met and unmet needs. We hypothesized that for people with dementia and their informal carers, higher levels of met and unmet needs are reflected in lower quality of life ratings compared to those who express fewer needs.

We aimed (1) to describe the domains and level of needs in a group of people with middle stage dementia and their informal carers who do not yet use formal care and (2) to describe the relationship of needs and quality of life from different perspectives (i.e. self- and proxy-rated).

Methods

Study design and participants

The data considered in this paper are baseline data from the European prospective cohort study Actifcare (Access to timely formal care), carried out in The Netherlands, Germany, United Kingdom, Ireland, Sweden, Norway, Portugal and Italy. In this study, 451 dyads of community-dwelling people with dementia and their caregivers were followed for one year, and data were collected about service use, needs, quality of life (QOL) and several other domains. People were included with (1) mild to moderate dementia determined by their specialist, according to the DSM-IV-TR criteria (2) an informal carer who was in close contact with the person with dementia at least once a week (3) no use of formal care yet at baseline, defined as home nursing care, day care service (including help with personal care), community or long-term medical care, nursing

and social care structures. It did not include domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. For all included dyads (4) formal care was expected to be necessary within one year based on the expert opinion of a clinician. Participants were recruited from various settings such as general practitioners, memory clinic and community mental health teams. In addition participants were recruited via advertisements that were placed in local and national newspapers. The complete design of the Actifcare study has been described elsewhere in detail (Kerpershoek et al., 2016).

Data collection and assessments

Ethical permission was obtained in all countries separately. Written informed consent was obtained from both the person with dementia and caregiver according to the national procedures in each country. Demographic information and service use details were collected, and two trained researchers administered a wide range of scales. The visit lasted approximately 90 min.

Needs assessments

The needs of people with dementia were measured with the Camberwell Assessment of Need for the Elderly (CANE) (Orrell, 2004). This comprehensive interview-based questionnaire is designed to map the needs and amount of help (received and needed) for older people. Twenty-four areas are covered, and these areas can be subdivided into three main domains: psychological, physical, and environmental. With this instrument, needs are identified as being absent (score 0), met (score 1), or unmet (score 2). If a need is rated as met, one must indicate which type of care (i.e. informal or formal care) ensures that the need is met. The instrument has good reliability and validity (Reynolds et al., 2000). In this study, the person with dementia, the informal carer, and a trained researcher completed the CANE at baseline. The trained researcher made an estimation based on all available information from extensive interviews with both the people with dementia and their carers, including the CANE ratings of each participant. In these analyses, we considered all three perspectives in order to make best use of the available information. For the analyses in this study, we used the total number of needs (both met and unmet), since both indicate situations that require care. Having a need, either met or unmet, could signal that care is necessary.

Quality of life assessment

Quality of life was measured with the Quality of Life-Alzheimer's Disease Scale (QOL-AD), which was self-rated by the person with dementia and proxy-rated by the informal caregiver. The scale is designed for dementia and covers thirteen domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life overall. All domains are scored on a four-point Likert scale (poor, fair, good, excellent), in which higher scores indicate higher QOL (ranging from 16-52). The scale has good validity and reliability (Logsdon, Gibbons, McCurry, & Teri, 2002).

To measure QOL of the carer, the CarerQoL was used. This scale was developed to measure the impact of providing

informal care (Brouwer, van Exel, van Gorp, & Redekop, 2006). It consists of seven items that are scored on a three-point scale (no, some, many); these answers are combined to form a sum score. In addition, there is a VAS-scale in which the informal carer indicates on a scale from zero to ten how happy he/she is at the moment. We used the sum- and VAS-scores for our analyses.

Statistical analysis

Proportions or means were calculated as descriptors and used to determine the number of met and unmet needs. Linear regression analysis was performed to assess the relationship between carer QOL and needs, and the CarerQol sumscore and CarerQol VAS were dependent variables. The independent variables were the sum of needs from the informal carer perspective scored on the CANE. In addition, linear regression analyses were performed to assess the relationship between QOL and needs for the person with dementia, with the QOL-AD as dependent variable, and the self-rated sum of needs as independent variable. We used the backward method in regression, with a cut-off score of $p = 0.10$. In stepwise regression analysis, the backward method is recommended over the forward method because it decreases the chance of creating a suppressor effect; this process ensures that a predictor is significant merely when another variable is held constant (Field, 2009). The demographic variables (gender, age, education) and living situation (living together with the person with dementia) were covariates. In cases of missing values, we used a different method for each questionnaire. For the QOL-AD, CarerQol and CANE, if at least 80% of the items were present, we rescaled the score (total score divided by the number of available items, multiplied by maximum number of items). SPSS version 24 was used to perform the analyses.

Results

A total of 451 dyads participated in the study. The characteristics of the people with dementia and their caregivers are summarized in Table 1. Among the people with dementia nearly half (48%) were diagnosed with Alzheimer's Disease. The majority (78%) had a CDR score of 1, and 72% lived together with a carer. Most of the caregivers were female (66%), and the majority had a spousal relationship (60%). The means of the main outcome scores are summarized in Table 2.

Aim 1: different perspectives on (un)met needs

The people with dementia reported the most unmet needs in the domains of company (15%), information (13%) and daytime activities (9%), as shown in Figure 1. The caregivers reported unmet needs more frequently compared with the people with dementia; however, the needs were in the same domains: company (24%), information (10%) and daytime activities (28%). In addition, the caregivers noted unmet needs in the domains of psychological distress (12%) and benefits (11%), as shown in Figure 2. The researchers rated the unmet needs slightly higher than the caregivers (in similar domains): company (28%), information (13%), daytime activities (29%), psychological distress (14%) and benefits (10%), as shown in Figure 3.

Analysis of the number total needs showed a significant difference between perspectives: ($t = 18.1, p = .000$) when

Table 1. Group characteristics ($N = 451$).

Person with dementia	
Male ($n, \%$)	207 (46)
Age (mean, range, SD)	77.4 (47–92) 7.9
Education (mean years, SD)	9.8, 4.5
Marital status ($n, \%$)	
Married	310 (68)
Widowed	109 (24)
Single	8 (2)
Other	24 (6)
Living together with carer ($n, \%$)	325 (72)
Dementia type ($n, \%$)	
Alzheimer's disease	218 (49)
Vascular dementia	52 (12)
Mixed dementia	56 (12)
Lewy body dementia	6 (1)
Other	119 (26)
CDR sum of boxes (mean, range, SD)	7.1 (2–16) 2.4
Caregiver	
Male ($n, \%$)	151 (33)
Age (mean, range, SD)	66.4 (25–92) 13.3
Range	
Education (mean years, SD)	11.91, 4.4
Marital status ($n, \%$)	
Married	363 (80)
Widowed	10 (2)
Single	31 (7)
Other	47 (11)
Caregiver relation ($n, \%$)	
Spouse	271 (60)
Child	137 (30)
Other	43 (10)

Note: PwD: person with dementia. CDR: clinical dementia rating scale.

Table 2. Questionnaire scores ($N = 451$).

CarerQol sum (mean, range, SD)	9.42, [0–13], 0.2
CarerQol VAS (mean, range, SD)	6.37, [0–10], 1.9
Sum of met needs (mean, range)	
Pwd	5.58, [0–18], 3.2
Carer	8.03, [0–18], 3.2
Trained researcher	8.15, [0–19], 3.3
Sum of unmet needs (mean, range)	
Pwd	0.95, [0–10], 1.4
Carer	1.69, [0–13], 1.9
Trained researcher	1.87, [0–17], 2.0
Total needs (mean, range, SD)	
Pwd	6.11, [0–22], 3.5
Carer	9.52, [0–19], 3.5
Trained researcher	9.69, [0–20], 3.7

Note: CarerQol: Carer Quality of Life. PwD: person with dementia; VAS: visual analogue scale.

comparing people with dementia to carers, and ($t = -19.5, p = .000$) when comparing people with dementia to trained researchers. The mean number of self-reported unmet needs rated by the person with dementia was 0.95; it was 1.66 when rated by the informal caregiver and 1.85 when rated by the trained researcher. For met needs, the people with dementia rated a mean of 5.5 met needs, while the carer and trained researcher rated an average of 8 met needs.

Aim 2: investigating the relationship between needs and QOL

Quality of life of the people with dementia

In the linear backward regression analysis with the self-rated QOL-AD as the dependent variable, the only significant independent variable remaining in the final model was the self-rated sum of needs and education, in which QOL and needs were significantly related in a negative manner, while education was positively related. This implies that QOL decreases as the number of needs increase, and QOL is increased if the number of years of education is higher.

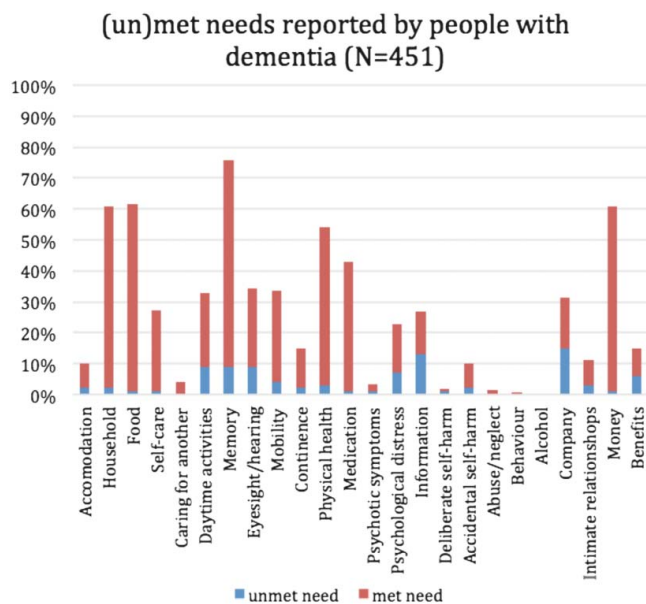


Figure 1. (Un)met needs reported by the people with dementia.

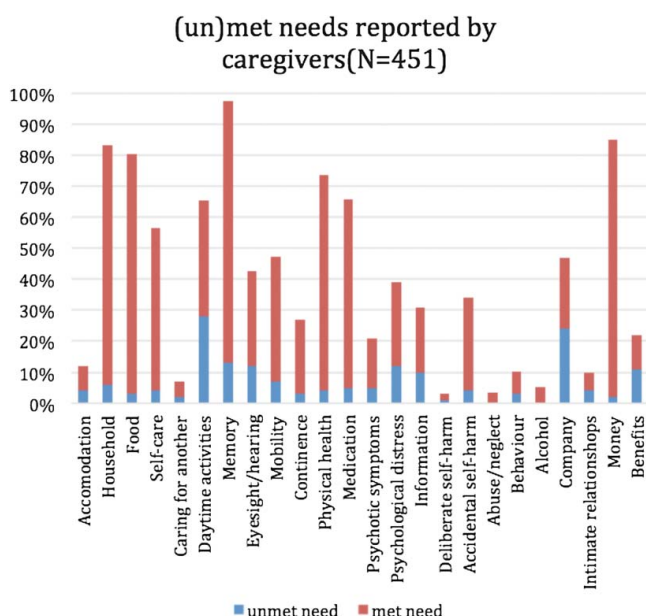


Figure 2. (Un)met needs rated by the caregivers.

When the dependent variable was proxy-rated QOL, the self-rated sum of needs was also significantly correlated in a negative manner, as well as the CDR sum of boxes.

Covariate education was also significant in a positive direction, as well as gender (being female). The other covariates were not significant (age, living situation). This implies that QOL decreases as the number of needs and disease severity increase. In addition, QOL is increased for females, and if the

Table 3. Final regression models for QOL-AD, only displaying the independent variables remaining after the backward selection procedure.

	QOL-AD self		QOL-AD proxy	
	Coefficient	p-Value	Coefficient	p-Value
Needs (self-rated*)	-.482	.000	-.289	.000
Gender	*	*	1.317	0.22
Education	.445	.000	.409	.000
CDR	*	*	-.405	.001

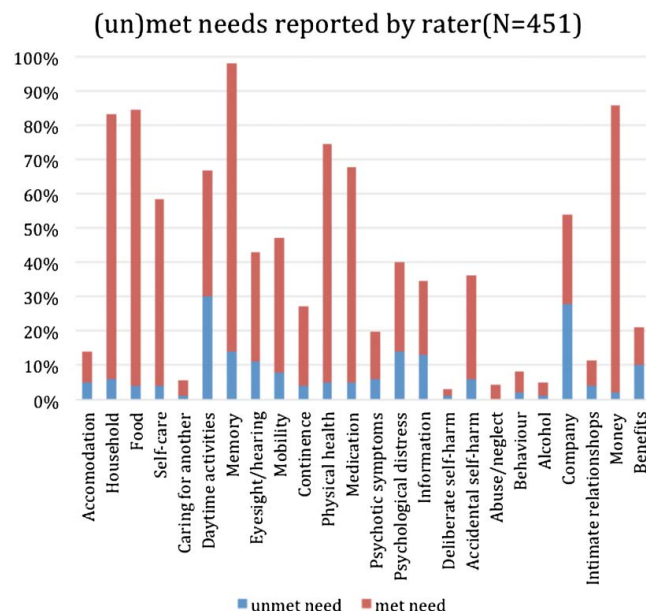


Figure 3. (Un)met needs rated by the trained researcher.

number of years of education is higher. The results can be found in Table 3.

Final regression models for QOL-AD, displaying only the independent variables remaining after the backward selection procedure.

Care-related quality of life of the carer

Linear backward regression analysis assessing the relationship between carer QOL and needs, with the CarerQol sum as the dependent variable, showed that the only significant independent variable remaining in the final model was the sum of needs rated by the carer. Care-related QOL and needs were negatively associated, which means that the care-related QOL decreased as the sum of needs increased. None of the covariates (i.e. carer age, gender, education and living situation) were significant.

In linear backward regression analysis, with CarerQol VAS as the dependent variable, the sum of needs rated by the carer was again a significant independent variable. This means that participants rate their QOL lower if the sum of needs is higher. The covariate living situation was also associated with carer QOL; if an informal carer lived with the person with dementia, the carer QOL was lower. None of the other covariates (carer age, gender, education) were significant. The results are shown in Table 4.

The final regression models for CarerQol sum and VAS, displaying only the independent variables remaining after the backward selection procedure.

Discussion

This study investigated needs from different rating perspectives in a sample of people with dementia and informal carers who do not yet use formal care but are expected to do so

Table 4. Final regression models for the CarerQol sum and VAS, only displaying the independent variables remaining after the backward selection procedure.

	CarerQol sum		CarerQol VAS	
	Coefficient	p-Value	Coefficient	p-Value
Needs (carer*)	-.012	.000	-.120	.000
Living situation	*	*	-.467	0.20

within one year. This study design allowed us to examine the domains and level of needs during the phase in which informal care may need to be supplemented by formal care, thereby providing important insight into how we can support this group of people who find themselves at a tipping point in their caregiving situations.

Aim 1: different perspectives on (un)met needs

Overall, the people with dementia reported fewer needs than the informal carers and researchers. This finding aligns with that of a previous study and might be explained by the will to remain autonomous, a feeling that makes a person trivialize their needs assessments (van der Roest et al., 2009). Acknowledging and reporting needs might be related to the willingness to engage in professional care. The difference in perspective of the person with dementia and the carer may in addition lead to conflicts in decision-making regarding the acceptance of care. Professionals should pay more attention to and be trained in dealing with these decisional conflicts (Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010).

The fact that people with dementia indicated a lower number of needs might also be due to a lack of insight, as insight seems to be related to disease severity in dementia patients, which declines as the disease progresses (McDaniel, Edland, & Heyman, 1995). However, different studies report conflicting findings about changes in awareness in people with dementia and the relation with change in other cognitive and psychosocial variables (Clare, et al., 2012a). Helping people with dementia at an early stage of the disease to gain insight into their needs could help them seek support earlier. This should however be carried out carefully in an individually tailored manner as awareness is related to personality (Clare, Nelis et al., 2012b).

The domains in which (un)met needs most frequently occurred aligned with those reported by previous studies of community-dwelling people with dementia (Bakker et al., 2014; Miranda-Castillo et al., 2013; van der Roest et al., 2007): psychological distress, daytime activities and company. In addition, we found a large number of unmet needs in the area of information, which aligned with our qualitative findings (to be published) and those of previous studies (Brodsky, Thomson, Thompson, & Fine, 2005). The amount of information about available services is not sufficient, likely leading to non-use of services, as depicted by lower QOL scores. Information is a need that could be easily met, particularly at the phase in which people are starting to use formal care. Information should be particularly tailored to an individual's needs and wishes and must fit the stage of the disease. The fact that people experience this need should raise concern in the current health care system and requires more attention. From all three perspectives 'company' is the largest unmet need. From the literature it is well-known that loneliness has a negative influence on one's overall health (Holmén & Furukawa, 2002), and that feelings of loneliness can even predict dementia onset (Holwerda et al., 2012). This emphasizes the importance of social interventions. Meeting needs concerning company is important for an additional reason: in the current healthcare system the social network is increasingly involved in providing care (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016). Investing in a solid and reliable social network is thus important both to decrease loneliness and to expand your care network.

Aim 2: investigating the relation between needs and QOL

When considering the reported met needs in our sample, they were predominantly met by informal care, as no formal care was used by our sample population. Previous studies have shown that as a primary caregiver, providing care is emotionally challenging and leads to being prone to depression, social isolation and physical complaints (Etters et al., 2008; Schulz 2004). In our sample, there was indeed a significant relationship between the sum of met and unmet needs and care-related QOL. As the number of needs increased, care-related QOL (the sum- and VAS-score) decreased. In addition, the VAS score was lower when the informal carer lived with the person he/she was caring for. This finding might be related to the increased number of hours of informal care when you co-resident (Conde-Sala, Garre-Olmo, Turró-Garriga, López-Pousa, & López-Pousa, 2010; Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002).

In this cohort, we also found a significant negative relationship between the needs and QOL of the person with dementia. The results are aligned with those from previous studies (Hoe, Hancock, Livingston, & Orrell, 2006; Miranda-Castillo et al., 2010) that found that higher QOL in the person with dementia was related to a lower number of unmet needs. From a psychosocial point of view, our aim should always be to increase quality of life. If this can be done by ensuring that a person's needs are met or by diminishing needs, this should be our focus. Ways of meeting needs in this sample are ensuring that the needs for daytime activities, company and information are fulfilled in a timely manner. This could be achieved by informing informal carers about their options and helping them find tailored solutions.

Limitations and strengths

One of the limitations in this design is selection bias; the people who refuse service use are not likely to participate in a study concerning needs and service use, as they might refuse all types of interference. In addition, unravelling the relationship between needs and QOL is, of course, a more complex task than our relatively simple model can perform. Including predictors, such as depressed mood, quality of relationship and self-concept, in the model might account for a large percentage of the variance (Woods et al., 2014). This complexity will be investigated with the longitudinal data of this cohort. The strengths of this study are the size and variability of the cohort, as it represents people from eight European countries.

Conclusion

The study results show that informal carers reported almost twice as many needs as people with dementia, which is in line with previous research. These differences in perspective may lead to conflicts in decision-making regarding accepting care. Professionals should pay more attention to and be trained in dealing with these decisional conflicts.

As our large European cohort consists of community-dwelling people with dementia who do not yet use formal care, the informal carer provides most of the care. We found that this might have an influence on quality of life because QOL decreased as needs increased (for both the person with dementia and informal carer). This specific group is an

important target for future research, as the amount of people with dementia will increase, and the demand for caregivers to provide care at home will increase accordingly. Improving information provision and promoting social interventions are important future research directions. In the follow-up of this study, we will delve deeper into the relationship between needs and QOL and investigate other predictors that could be targets for intervention.

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Disclosure statement

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