

**Self-reports and Caregivers' Proxy Reports of Unmet Needs of Persons with Dementia: Implications
for Both Partners' Health-related Quality of Life**

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Abstract

Objectives: This study examined in a large sample of dementia caregiving dyads the associations between both partners' reports of unmet needs in persons with dementia (PwDs) and both partners' health-related quality of life (HRQOL). **Methods:** This was a cross-sectional self-report survey of 521 community-dwelling dyads in a pragmatic trial in the Netherlands. The Camberwell Needs Assessment was used to measure PwDs' unmet needs. Both partners' self-reported their HRQOL using the EuroQol-5. **Results:** Controlling for covariates, PwDs' self-reported greater unmet needs were significantly associated with PwDs' and caregivers' lower self-reported HRQOL (actor effect; $b = -0.044$, $\beta = -0.226$, $z = -3.588$, $p < .001$ and partner effect; $b = -0.021$, $\beta = -0.131$, $z = -2.154$, $p = 0.031$). Caregivers' proxy reports were greater than PwDs' self-reported unmet needs ($\Delta = 0.66$, $\chi^2(1) = 55.881$, $p < .0001$). **Conclusion:** Clinicians should use caution in relying on caregiver proxy reports of PwDs' needs and HQOL alone regarding healthcare decision making.

Introduction

Maximizing the health-related quality of life of persons with dementia and their informal caregivers as a unit is an important healthcare goal. Although many factors likely affect the health-related quality of life of persons with dementia and caregivers, many clinicians focus on the unmet needs of the person with dementia as a central factor. Unmet needs are defined as “particular areas of life for a person for which insufficient or inadequate support is provided or appropriate support is not available”.¹ Existing research shows that unmet needs lead to more behavioral problems in persons with dementia and caregiver burden which in turn negatively influence health-related quality of life of persons with dementia.² Yet, unmet needs are subjective, and associations between unmet needs and both partners’ outcomes may be inaccurate depending on whose perspective is assessed. Most research has relied on proxy reports of the persons with dementia’s unmet needs. No study using a large sample has examined whether self-reports and caregiver proxy reports of unmet needs in persons with dementia affect both dyad members’ health-related quality of life, controlling for potential covariates.

Drawing from interdependence theory, the present study examined intrapersonal and interpersonal associations between unmet needs appraisals of persons with dementia and health-related quality of life of caregivers and care recipients using the Actor-Partner Interdependence Model (APIM)³. The APIM allows concurrent examination of the impact of a person’s explanatory variable on his or her own outcome (actor effect) and on the outcome of the partner (partner effect)³. Our hypotheses are as follows.

Hypothesis 1a and b: Higher self-reported unmet needs in persons with dementia will be associated with worse health-related quality of life in persons with dementia, and higher proxy reports by caregivers of persons with dementia’s unmet needs will be associated with caregivers’ worse health-related quality of life (actor effects).

Hypothesis 2a and b: Higher self-reported unmet needs in persons with dementia will be associated with worse health-related quality of life in caregivers, and higher proxy reports by caregivers of persons with dementia’s unmet need will be associated with worse health-related quality of life in persons with dementia (partner effects).

Hypothesis 3: Caregivers' proxy reports of the unmet needs of the person with dementia will be higher than the self-reports of unmet needs of the person with dementia.

Method

This was a secondary analysis of baseline data from the COMPAS (Case management of persons with dementia and their caregivers) project, a non-randomized, controlled, prospective, observational, cohort study registered with the Dutch Trials Registry (NTR3268) and published elsewhere⁴. See prior publication for participant characteristics⁴. The Medical Ethics Committee of the VU University medical center approved this study in November 2010 and all participants gave written consent. The informal caregiver signed on behalf of the person with dementia if they were unable to understand and reproduce the study goals. Primary informal caregivers (n=521) and persons with dementia were recruited from various regions of the Netherlands from April 2011 to November 2012. Persons with dementia were eligible for this study if they lived at home, had an established/formal diagnosis of dementia, were not terminally-ill, were not anticipated to be admitted to a long-term care facility within 6 months, and had an informal caregiver. The informal caregivers were eligible if they were the primary informal caregiver responsible for caring for the person with dementia, had sufficient language proficiency and were not severely ill.

Unmet Needs. The Camberwell Assessment of Need for the Elderly (CANE) is a comprehensive assessment that includes physical, psychological, social, and environmental needs of the older person based on 24 items. The CANE has good content, construct and consensual validity in addition to appropriate criterion validity⁵. Reliability is generally very high: $\kappa > 0.85$ for all staff ratings of interrater reliability⁵. The CANE was administered to the person with dementia as well as the primary caregiver proxy report.

Health related quality of life. Health related quality of life was assessed using the EuroQol-5 Dimensions (EQ-5D), which is the most widely used preference based generic instrument and has well-established psychometric properties.⁶ It has been validated in individuals with mild to moderate cognitive impairment. The EQ-5D includes five dimensions: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Participants answer with the responses: no problems, some problems, or

severe problems. The set of five responses defines a health state. The 243 (3^5) possible health states are weighted using a valuation set from a sample of the Dutch general population known as the Dutch EQ-5D tariff⁷, resulting in a utility score. This utility reflects the relative desirability of a particular health state and is measured on a scale from 0 (death) to 1 (full health). Some health states are regarded as being worse than death, resulting in negative utilities.⁷ The informal caregiver as well as the person with dementia completed their own EQ-5D questionnaires.

Covariates. Age, sex, education, presence of case manager, Mini Mental State Examination (MMSE)⁸, General Health Questionnaire⁹, Neuropsychiatric Inventory¹⁰, Neuropsychiatric inventory of caregiver distress¹⁰, sense of competence¹¹, multimorbidity of the Pwd¹², relationship of the caregiver were included in the regression models.

Analysis and Results

To examine hypotheses 1 and 2, that there would be actor and partner effects of proxy and self-reports of person with dementia's unmet needs on the person with dementias' and caregivers' self-reports of health related quality of life, we used the Actor Partner Interdependence Model (APIM) with structural equation modeling in R (Lavaan package¹³). To examine hypothesis 3, that caregivers would overestimate person with dementia's unmet needs, we tested the equivalence of each dyad member's means using a Wald χ^2 test in the Lavaan package. Each model was adjusted for the covariates listed in the method section. For the results, we report both the standardized (β) and unstandardized slopes (b). Standardized slopes (β) are interpreted identically to unstandardized slopes (b), except that "one-unit increase" is replaced with "1-SD increase".

As shown in Figure 1, for every one unit increase in self-reported unmet needs (range: 0-13), there was a 0.044 decrease in self-reported health related quality of life (actor effect; $b = -0.044$, $\beta = -0.226$, $z = -3.588$, $p < .001$) and a 0.021 decrease in caregiver self-reported health related quality of life (partner effect; $b = -0.02$, $\beta = -0.131$, $z = -2.154$, $p = 0.031$). Greater caregiver proxy reports of the person with dementia's unmet needs were not significantly associated with lower self-reported health related quality of life (actor effect; $b = -0.003$, $\beta = -0.031$, $z = -0.571$, $p = 0.569$) or the person with dementia's self-reported health related quality of life (partner effect; $b = 0.003$, $\beta = 0.024$, $z = 0.756$, $p = 0.756$). In a separate analysis, caregiver

reports of unmet needs (mean= 1.30, SD= 1.87) were greater than the person with dementia's self-reported unmet needs (mean= 0.57, SD= 1.06) ($\Delta = 0.66, \chi^2(1) = 55.881, p < .0001$) while health related quality of life did not differ between the informal caregiver (mean= 0.84, SD= 0.18) versus for the person with dementia (mean= 0.81, SD= 0.21).

Discussion

This study shows that self-reported unmet needs of persons with dementia are associated with poor health-related quality of life in both persons with dementia and their informal caregivers. In other words, to the extent that an unmet need is meaningful to the person with dementia, it is also meaningful for their well-being. And, this in turn likely influences the well-being of the caregiver. These findings emphasize the importance of giving voice to the person with dementia in their own healthcare management. Not only is it important for the self but also the caregiver.

In contrast to the above findings, caregivers' proxy reports of unmet needs in persons with dementia were not significantly associated with caregivers' own or their care recipient's health related quality of life. Thus, caregivers' views of their partner's unmet needs may have less importance to the person with dementia; they may not align with the person with dementia's current values. In line with this, we found that caregivers reported greater unmet needs in persons with dementia than persons with dementia reported for themselves. These findings are consistent with prior research on unmet needs in persons with dementia² but extend them by utilizing a large sample, controlling for covariates. Although caregivers are an important source of information and are greatly important to the well-being and care of the person with dementia, these findings emphasize the need for multiple reports of clinical outcomes.

There are some limitations to this study. We did not have information about the caregivers' own unmet needs, and this study was cross-sectional which does not allow us to determine directionality or causality of the associations. Future research should examine both partners own unmet needs and their associations with both partners' own health-related quality of life longitudinally. Independent ratings of unmet needs may also shed light on whether the caregiver or care recipient appears to be more accurate.

The results of this study have important clinical and research implications. They suggest that healthcare professionals should collect information about unmet needs from both persons with dementia and caregivers to maximize predictive accuracy of quality of life in caregiving dyads. This is especially important given that interventions for persons with dementia and their caregivers often measure unmet needs as a way of tailoring or to assess whether the intervention was successful¹⁴.

Figure 1. Actor Partner Interdependence Model

A= actor effect; P= partner effect. This model was adjusted for age, sex, education, presence of case manager, Mini Mental State Examination (MMSE)⁸, General Health Questionnaire⁹, Neuropsychiatric Inventory¹⁰, Neuropsychiatric inventory of caregiver distress¹⁰, sense of competence¹¹, multimorbidity of the Pwd¹², relationship of the caregiver. *** indicates a p-value <0.0001 and * indicates a p-value <0.05.

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