Determinants of quality of life in family caregivers in MCI: a comparison with mild dementia


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Determinants of quality of life in family caregivers in MCI: a comparison with mild dementia

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ABSTRACT

Objectives: The aim of the current study was to investigate the health-related quality of life (HRQoL) of the family caregiver in MCI, explore possible determinants and study possible differences with mild dementia.

Methods: This secondary data analysis included 145 persons with MCI and 154 persons with dementia and their family caregivers from two Dutch cohort studies. HRQoL was measured with the VAS of the EuroQol-5D-3L version. Regressions analyses were conducted to examine potential demographic and clinical determinants of the caregiver’s HRQoL.

Results: The mean EQ5D-VAS in family caregivers of persons with MCI was 81.1 (SD 15.7), and did not significantly differ from family caregivers in mild dementia (81.9 (SD 13.0)). In MCI, patient measurements were not significantly associated with caregiver mean EQ5D-VAS. Concerning caregiver characteristics, being a spouse and a lower educational level were associated with a lower mean EQ5D-VAS (in a multiple linear regression model: unstandardized β −8.075, p = 0.013 and unstandardized β −6.162, p = 0.037 resp.). In mild dementia, the NPI item irritability showed an association with caregiver EQ5D-VAS in bivariate linear regression analyses.

Conclusion: Results indicate that especially family caregiver characteristics seem to influence family caregiver HRQoL in MCI. Future research should include other potential determinants such as burden, coping strategies and relationship quality.

Introduction

Mild cognitive impairment (MCI) is a common and important problem in older adults (Knopman & Petersen, 2014). Despite the fact that by definition activities of daily living are largely intact in persons with MCI (Petersen, 2004), supporting a family member with MCI can be challenging (Paradise et al., 2015), although the caring is on a different level than in dementia (Dean & Wilcock, 2012) and not all caregivers may actually identify themselves as providing care. The person with MCI may need assistance with (complex) tasks, behavioural problems may arise and the future may be uncertain. These changes may be significant stressors and lead to a reduced quality of life in the person with MCI and his or her caregiver. The World Health Organization defines quality of life as follows: ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (World Health Organization, 2012). The WHO also explains that this is a complex concept and affected by multiple factors such as a person’s physical and psychological health and social relationships (World Health Organization, 2012).

In the field of dementia, substantial research has been done into the quality of life of the family caregiver (Farina et al., 2017) and related caregiver outcomes such as caregiver burden (Chiao et al., 2015). Limited research has been done on the quality of life of family caregivers supporting a person with MCI (Carlozzi et al., 2018), although previous research showed that approximately one third of caregivers of people with MCI report considerable levels of burden (Bruce et al., 2008). Moreover, a study on outcome preferences for people with MCI and their caregiver showed that they both ranked quality of life of the patient and caregiver among the highest priorities, above for example patient functional status (Barrios et al., 2016). Accordingly, multiple studies suggest that quality of life of the patient and the caregiver should more often be an important outcome in scientific research (Carlozzi et al., 2018; Couch et al., 2020; Harrison et al., 2016).

Determinants of quality of life in caregivers may not be straightforward, and not solely related to cognitive functioning of the person with cognitive impairment (Leidi-Maimone et al., 2020). In dementia, studies examining quality of life in caregivers showed that neuropsychiatric symptoms are found to be associated with negative scores for quality of life of the family...
caregiver (Thomas et al., 2006). Furthermore, patient and family caregiver characteristics like gender, age and educational level may be of importance, although results are inconsistent (Leidi-Maimone et al., 2020). In addition, it was found that the impact of psychosocial interventions in MCI on caregiver QoL was especially associated with their own health and caregiver burden, and not with patient characteristics. However, the relatively small sample size might have influenced the results. A cross-sectional study on caregiver burden in MCI found that patient behavioural symptoms contributed most to caregiver burden (Paradise et al., 2015). A qualitative study on quality of life of caregivers in MCI (Carlolzi et al., 2018) found that caregiving influenced multiple aspects of the health-related quality of life (HRQoL). The most frequently discussed topic was social health, with a focus on role changes and inadequate support from others.

Systematic reviews show that interventions aiming to reduce burden and improve quality of life of family caregivers mainly focused on cognitive interventions on the person with MCI, sometimes together with psycho-education (Domínguez et al., 2018; Leung et al., 2017). The idea behind these interventions is that improving the cognitive functioning of a person with MCI will lead to a better quality of life, also in the family caregiver. However, the effects of these interventions seem limited and a further question is whether cognitive functioning is the most important determinant of quality of life of the family caregiver of a person with MCI. In order to optimize interventions aiming to reduce burden and improve quality of life, more research on quality of life of family caregivers in MCI and related factors is needed. In addition, as MCI is seen as a state with a higher risk of developing dementia, it could be insightful to make a comparison with mild dementia for a better understanding of the influence of a diagnosis of dementia and the associated reduced functioning in daily activities.

This leads to the following research questions:

1. What is the mean HRQoL of the family caregiver of a person with MCI, and is this different from caring for a person with mild dementia?
2. To explore possible determinants of the HRQoL of the family caregiver of a person with MCI, and do these differ from the determinants of the HRQoL of the family caregiver of a person with mild dementia?

Methods

Study design

A secondary data analysis was performed, using a selection of baseline data from two longitudinal studies: the Dutch Clinical Course of Cognition and Comorbidity in Mild Cognitive Impairment and Dementia (4 C study) (Liao et al., 2016) and from the LeARN study (Handels et al., 2012). The 4 C study is a multicenter study and focuses on the course of cognitive decline in three Dutch memory clinics. The LeARN study is also a multicenter study of four Dutch memory clinics, and aimed at the diagnostic accuracy and cost-effectiveness of biomarkers while taking into account quality of life of the patient and the family caregiver (Handels et al., 2012). The present study included data from the following memory clinics who had relevant parameters of patients and caregivers available: Maastricht University Medical Centre, Maastricht; Radboud University Medical Center, Nijmegen; and Amsterdam UMC, Amsterdam.

Study population

The population of the original studies consisted of participants with subjective and/or objective memory complaints. Syndrome diagnoses of MCI and dementia at baseline were made based on clinical assessment by a multidisciplinary team. Persons were included if there was a reliable informant who visited or contacted the patient at least once a week. In this study we will use the term family caregiver for the reliable informant since the majority (>95%) were spouses, children or siblings. The most important exclusion criteria were the presence of other neurological disorders that could affect cognitive performance and if the participant was expected not to be available for follow-up. The inclusion and exclusion criteria were comparable, the precise criteria are described in detail elsewhere (Handels et al., 2012; Liao et al., 2016) For this secondary analysis participants were selected if they were diagnosed with MCI or dementia and had data collected on family caregiver quality of life.

Primary outcome measure

HRQoL of the family caregiver was the primary outcome measure and was assessed with the Visual Analogue Scale (VAS) of the EuroQol-5D (EQ-5D) (EuroQol Group, 1990). This scale ranges from 0 to 100 and is a way to record how a person scores his or her current HRQoL state (that day), with a higher score indicating a better HRQoL. The VAS was used to obtain the subjective rating of the HRQoL in accordance with previous studies (Banning et al., 2020).

Caregiver measurements

Sociodemographic data such as age, gender, marital status and level of education were collected. Also, the Care Related Quality of Life (CarerQol) was used to assess the care-related quality of life of the informant (Brouwer et al., 2006). The CarerQol was not filled in by persons confirming the following remark: ‘If you do not provide informal care, you can skip the other questions.’ The CarerQol consists of seven care-related burden items with a visual analogue scale (VAS) for happiness. The seven items are: 1) fulfillment; 2) relational problems; 3) mental problems; 4) problems with daily activities; 5) financial problems; 6) support; and 7) physical problems. The items are scored on a three-point scale (no, some and many) and result in a sum score. For this study the different items were binary coded (no/any) to avoid small cell count.

Informal care was assessed using the Resource Utilisation in Dementia - Lite instrument (RUD lite) (Wimo et al., 2010). Caregivers were asked to report the amount of time spent on informal care concerning ADL (e.g., washing and grooming) and IADL (e.g., household activities, cooking), including supervision, during the last 30 days. Hours of informal caregiving were dichotomized into providing informal care or not.

Patient measurements

In the original studies sociodemographic data such as age, gender, marital status and level of education were collected. All persons underwent a clinical assessment, which included a psychiatric, neurological and physical examination. History of the patient was taken including medication use and exploring...
comorbidities. For this secondary analysis, only psychiatric, cardio-vascular and cerebrovascular co-morbidities were included in the analyses.

Neuropsychiatric symptoms were measured with the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994). The NPI is a structured interview with an informant and consists of the assessment of the frequency and severity of 12 neuropsychiatric symptoms in the past 4 wk (i.e., delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, nighttime behavior disturbances, and appetite/eating disturbances). Frequency (0 - 4) and severity (0 - 3) scores are multiplied to acquire a domain score per item, where higher scores indicate a more severe level of the neuropsychiatric symptom. For this study, presence of a neuropsychiatric symptom was included as a domain score (0-12) and furthermore domain scores were dichotomized (presence yes/no). Also, the total NPI score was used in the analyses.

Global cognitive functioning was assessed with the Mini-Mental State Examination (MMSE) (Folstein et al., 1975; Kok et al., 2002).

Activities of daily living were assessed by the Disability Assessment for Dementia (DAD) (Gélinas et al., 1999). The ability to perform ten different basic and instrumental activities in daily functioning in the 2 wk prior to the assessment was rated. The final DAD score is obtained by converting a sum score in a percentage from 0 to 100, a higher score indicates a higher level of daily functioning.

Statistical analyses

Data was analyzed using SPSS version 23. Baseline differences between groups were analyzed using t-tests for continuous variables and chi-square tests for categorical variables. A complete case analysis was carried out, see Supplementary Figure 1 (flow chart).

Bivariate and multiple linear regression analyses were performed to explore possible associations between caregiver and patient characteristics and quality of life of the caregiver as measured by the EQ5D-VAS. First, caregiver and patient characteristics were included in bivariate analysis. In case the \( p \) value was below 0.10 the variable was marked as potentially relevant and subsequently entered in the multivariable analysis.

In order to compare the determinants of the EQ5D-VAS, separate models were built for caregivers of persons with MCI and dementia. In addition, t-tests were performed in a subgroup of the sample who filled out the CarerQol questionnaire (i.e., those who identified themselves as caregivers) to explore differences in mean EQ5D-VAS across all seven CarerQol items.

Post-hoc analysis

In addition to the EQ-SD VAS, the single-item scores of the EQ-SD can be transformed into index values, also called utilities (Lamers et al., 2005). Due to the generic nature of the EQ-SD instrument, these utilities can be compared across different populations and health conditions. This utility score has a maximum of ’1’, indicating ‘full health’. As a post hoc analysis we therefore transformed the five EQ-SD item scores into utilities using the Dutch tariff (Lamers et al., 2005), and compared these between caregivers of people with MCI and dementia by performing a Mann-Whitney-U test.

Ethical considerations

For the 4C study the ethical committees of the institutes Alzheimer Centre Limburg of the Maastricht University Medical Center, and Radboudumc Alzheimer Center, Radboud University Medical Center approved the study. The 4C-MCI cohort was assessed by the METC azM/UM (NL25214.068.09/MEC 09-3-038) and the 4C-Dementia cohort by the CMO Arnhem-Nijmegen (CMO 0529, registration number 2010/046). For the Learn study, the ethical committee METC azM/UM approved the study (MEC 09-3-038). Written informed consent was obtained for all participants. Detailed information about both studies can be found elsewhere (Handels et al., 2012; Liao et al., 2016).

Results

Baseline characteristics

At baseline, 421 persons with cognitive problems and their family caregivers were included in the selection of centers of the original 2 studies. Of these, 299 persons and their caregivers had complete data, meaning data was available on all variables included for current analyses (Supplementary Figure 1; flow chart). Of these 299 persons, 145 were diagnosed with MCI and 154 were diagnosed with dementia. Comparison of the 122 persons and their caregivers with incomplete data versus the 299 persons and caregivers with complete data showed that persons with incomplete data were younger and the caregivers were more often spouses (see Supplementary Table 1). No significant differences on MMSE scores were found between persons with and without complete data.

Baseline characteristics of the caregivers and the persons with MCI and dementia are presented in Tables 1 and 2 respectively. The mean EQSD-VAS in caregivers of persons with MCI was 81.1 (SD 15.7), with a range of 20 to 100. The mean EQSD-VAS of caregivers of persons with dementia was 81.9 (SD 13.0), with a range of 40 to 100. The EQSD-VAS of caregivers was not significantly different in MCI and mild dementia. Furthermore, the utility scores, tested post-hoc, were not significantly different in MCI and mild dementia.

Results of bivariate analyses in MCI

Family caregivers who were older (unstandardized B = −0.232, \( p = 0.033 \)) and had a lower educational level (low/middle vs. high: 78.6 (SD 17.8) vs. 84.2 (SD 12.1) \( p = 0.032 \)) reported lower EQSD-VAS. Gender of the family caregiver was not associated with the EQSD-VAS. Regarding the relationship of the caregivers, children and ‘others’ reported a higher EQSD-VAS than spouses (unstandardized B 9.053, \( p = 0.001 \)). Also, in family caregivers providing care with IADL lower EQSD-VAS were reported, but this result was not significant (unstandardized B = −3.122, \( p = 0.084 \)), see Supplementary Table 2).

Caregivers who cared for a female person with MCI had a mean EQSD-VAS of 84.2 (SD 12.9) and caregivers who cared for a male person with MCI had a mean EQSD-VAS of 79.3 (SD 17.0), this difference was not significant (\( p = 0.068 \)). Characteristics such as education, MMSE score, or NPI-total score of the person with MCI were not associated with the caregiver EQSD-VAS (see Supplementary Table 2). A lower DAD percentage showed a direction towards a lower EQSD-VAS with bivariate linear regression, but this result was not significant (unstandardized B 0.156, \( p = 0.070 \)).
Results from multiple linear regression analysis in MCI

Collinearity statistics showed acceptable values (max VIF < 2.0), except for the variables age of the caregiver and relationship between the caregiver and the person with cognitive symptoms, with spouses being older than other caregivers (mainly daughters/sons). Therefore, these variables were not entered in the analyses together.

In the multivariable model with relationship, relationship was a significant predictor of the EQSD-VAS of the caregiver (unstandardized B 8.075, \( p = 0.013 \), R square of the model 0.125), with being a spouse being associated with a lower EQSD-VAS. The other predictors did not show a significant association anymore, see Table 3. In the multivariable model with age of the caregiver, education of the caregiver was a significant predictor of the EQSD-VAS of the caregiver (unstandardized B 6.162, \( p = 0.037 \), R square of the model 0.192), with a higher educational level being associated with a higher EQSD-VAS. Other variables did not predict the EQSD-VAS, see Table 4.

A comparison with mild dementia

In dementia, patient characteristics such as age, education and MMSE score were not associated with caregiver EQSD-VAS, which was comparable to the MCI-group. Unlike in MCI, the NPI item irritability showed an association with caregiver EQSD-VAS, with irritability being associated with a lower EQSD-VAS (see Supplementary Table 3).
In dementia, a multiple linear regression analysis was run with the NPI items with a p-value below 0.10 in the bivariate analyses. None of the separate NPI items were significant.

### Subgroup analysis with the CarerQol

A subgroup of caregivers who identified themselves as persons providing actual care to the person with MCI or dementia completed the CarerQol (MCI: 97 caregivers; dementia: 132 caregivers). In MCI, caregivers reporting problems with their own mental and/or physical health and caregivers reporting problems combining care tasks with daily activities had a lower mean EQSD-VAS (see Table 5). In dementia this was the same, but also caregivers reporting relational problems with the care receiver had a significantly lower mean EQSD-VAS.

### Discussion

This study focused on the Health-Related Quality of Life (HRQoL) of family caregivers in MCI, as measured with the EQ-SD VAS. Results indicated that the HRQoL of family caregivers in MCI did not differ from that in mild dementia, and furthermore showed that mainly caregiver characteristics were associated with their HRQoL.

We did not find a difference in HRQoL in family caregivers in MCI compared to mild dementia, neither did we find an association with global cognition. These findings are in line with previous studies in caregivers with dementia finding no or minimal association with cognition (Farina et al., 2020; Santos et al., 2014; Takai et al., 2011). A previous, cross-sectional, study on distress in MCI caregivers also found evidence that cognitive measures were not associated with caregiver distress (Seeher et al., 2014). The way a caregiver is able to cope with the situation might be more important than the objective impairments (Farina et al., 2017). Moreover, it might also be more important than the actual diagnosis since we did not find a difference between MCI and mild dementia. Some caregivers may be able to adapt to the start of their caregiver career (De Vugt & Verhey, 2013). Also, the HRQoL of the family caregivers was relatively high compared to Dutch population norms in the same age group (Janssen et al., 2019). This is a promising finding: caring for someone with MCI or mild dementia might have little impact on the caregiver’s HRQoL. Furthermore, caregivers may also experience positive aspects of the caregiving such as satisfaction, personal growth and improvement of the relationship between the caregiver and the care receiver (Lloyd et al., 2016).

In MCI, no association was found between family caregivers’ HRQoL and neuropsychiatric symptoms of the person with MCI. A possible explanation for not finding an association in MCI might be that the prevalence and severity of neuropsychiatric symptoms in MCI were relatively mild (mean NPI-total score of 13.7 (SD 14.1) in MCI; mean score 20.3 (SD 18.4) in dementia), which is in line with other studies (Lyketsos et al., 2002; Mortby et al., 2017). In dementia, the neuropsychiatric symptom irritability was significantly associated with caregivers’ HRQoL. However, although neuropsychiatric symptoms are thought to influence caregivers’ QoL in dementia (X. Liao et al., 2020), evidence is not consistent (Farina et al., 2017).

In the present study, being a spouse was associated with a lower HRQoL, which is in line with previous research (Farina et al., 2017). It should be noted that spouses are generally older, and age has been found to be associated with a lower HRQoL (Janssen et al., 2019).

A subgroup of the caregivers in our study completed the 7 items of the CarerQol, these data were used to explore a possible impact on the HRQoL of the caregivers. However, these results should be interpreted with caution because of selection bias (only family caregivers who identified themselves as carers filled in the CarerQol) and because the CarerQol partly, measures the
same outcome as the EQSD-VAS. Caregivers reporting problems with their own mental and/or physical health and caregivers reporting problems combining their care tasks with their daily activities had lower EQSD-VAS scores. This is in line with earlier studies that found that caregiver’s physical and mental health was most consistently associated with QoL (Farina et al., 2017; Leidi-Maimone et al., 2020). One of these studies, found that mental health related problems of caregivers themselves (depression and burn-out) were more associated with caregiver quality of life than patient-related variables (Takai et al., 2011).

In dementia, but not in MCI, caregivers reporting relational problems scored a significantly lower EQSD-VAS. An earlier study in dementia suggests that dyadic coping and relationship quality are important for the caregiver and functions as a mediator between stress and quality of life ( Häusler et al., 2016). It could be that caregiver resilience, support and dyadic coping get more important when the situation becomes more complex, and therefore be more important in dementia than in MCI.

This study has several strengths. First, it consists of two well-designed multicenter studies of memory clinic visitors. Furthermore, many patient and family caregiver factors were taken into account, and because of that, multiple possible determinants could be tested. However, as this was a secondary data analysis, specific characteristics such as coping strategies of caregivers were not available. Factors such as negative emotions, optimism and caregiver profiles showed to be associated with QoL in previous dementia research (Janssen et al., 2017; Kim et al., 2017; Ruisoto et al., 2019). Furthermore, the coefficients of the variables we tested and the R-squared values from the multiple regression models were quite low. This means only a small part of the variance could be explained. If we could have included the above variables in the analyses, we might have been able to explain a larger part of the variance. One other limitation relates to the sample size. The sample was stratified based on syndrome diagnosis and furthermore a selection was made based on availability of data, resulting in a smaller sample. Moreover, not all included informants identified themselves as family caregiver, this may have led to an underestimation of the results. However, since activities of daily living are largely intact in persons with MCI, this underestimation is likely small. Last, the present population consists of memory clinic visitors, limiting generalizability to the general population.

Conclusion

This explorative study was one of the first examining HRQoL in family caregivers of people with MCI. Results suggest that in MCI mainly caregiver characteristics explain family caregiver HRQoL as measured with the EQSD-VAS. Neither neuropsychiatric symptoms nor cognition of the person with MCI were associated with the HRQoL, which may point at resilience of caregivers being a relevant characteristic for further study. Being a spouse and being older was associated with a lower QoL. Mean HRQoL in caregivers in MCI did not differ significantly from caregivers in mild dementia. The HRQoL of the family caregivers was relatively high in both, this is a positive finding since caring for someone with MCI or mild dementia might have little impact on the caregiver’s QoL. The present study is a starting point, and future work is needed to further analyze determinants of family caregiver QoL in MCI such as burden, coping strategies, personality, positive aspects of caregiving and relationship quality.

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