

Unmet Needs and Health-Related Quality of Life in Young-Onset Dementia

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Objectives: *Young-onset dementia (YOD) causes specific challenges and issues that are likely to affect health-related quality of life (HRQOL). This study explored patient and caregiver HRQOL and its association with unmet needs in YOD. Methods:* *A cross-sectional design was used to study 215 community-dwelling YOD patients and their primary caregivers. Multiple linear regression analyses were performed to determine the relationship between unmet needs assessed with the Camberwell Assessment of Need for the Elderly scale and patient and caregiver HRQOL, controlling for other variables such as demographic characteristics, patient functional status, neuropsychiatric symptoms, and caregiver sense of competence. Results:* *Patient HRQOL was not associated with unmet needs. However, we found that the unmet needs of both patient and caregiver were related to several domains of caregiver HRQOL. Conclusions:* *This study shows that patient and caregiver unmet needs are related to caregiver HRQOL in YOD. However, the relationship between HRQOL and unmet needs is complex. The assessment of unmet needs within the context of HRQOL seems to be an important prerequisite for personalizing care in YOD. Adjusting supportive services to match the individual needs and preferences of these young patients and their caregivers is likely to enhance their quality of life.* (Am J Geriatr Psychiatry 2013; ■:■—■)

Key Words: Alzheimer disease, caregivers, quality of life, young-onset dementia

Health-related quality of life (HRQOL) is an increasingly important outcome measure in dementia research. In young-onset dementia (YOD),

defined as dementia occurring before the age of 65 years, specific issues and challenges may add to the negative impact of dementia on the HRQOL of both

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patients and caregivers. Younger patients are in a more active life phase, in which cognitive and functional impairments and changes in personality may adversely affect HRQOL through the loss of social roles, responsibilities, and identities.¹ In dementia patients aged older than 65 years, younger age has been associated with worse HRQOL.² In addition, behavioral problems, depression, insight into the disease, and impaired cognition have been associated with lower HRQOL.^{3,4} It is unclear whether the aforementioned associations exist within the YOD population. Obtaining a proper diagnosis is essential for patients and caregivers to understand and adjust to the changes that occur and to seek appropriate support. However, in YOD, the diagnosis is often substantially delayed,⁵ hindering the initiation of appropriate support and healthcare services. Research suggests that unmet needs lead to more behavioral problems and increased caregiver burden, both of which adversely affect HRQOL^{6,7} and increase the risk for institutionalization.^{8,9} Unmet needs might also directly be negatively associated with HRQOL in YOD because it may be especially difficult to meet the needs of YOD patients and their families.¹⁰

An unmet need can be defined as a need in a particular area of life of the individual for which insufficient or inadequate support is provided or appropriate support is unavailable.¹¹ A YOD patient might, for example, experience a need for meaningful daytime activities while attending a day care center that offers activities that are mainly focused on the elderly. The resulting lack of meaningful activities could consequently lead to a loss of HRQOL. It is necessary to better understand this relationship because HRQOL might be improved by addressing the unmet needs of YOD patients and their families.

Caregivers of younger patients experience high levels of caregiver burden¹² that may negatively impact their own HRQOL. Work-related and financial issues, conflicting roles, severe behavioral problems, and inadequate healthcare services can add to this burden and negatively influence caregiver HRQOL.⁵ In addition, the patient's level of cognitive impairment, the time committed to care, lack of respite services, the patients' younger age, and the presence of behavioral problems are related to decreased caregiver HRQOL, at least in late-onset dementia.^{13,14} We found one small study in YOD (Alzheimer disease) that addressed caregiver HRQOL in these patients.

The authors found that increased caregiver age and greater patient insight were significantly associated with better HRQOL in caregivers.¹⁵

In the current study, we explored the following: 1) HRQOL in YOD patients and possible differences with caregiver perspectives on patient HRQOL; 2) HRQOL in YOD caregivers compared with the general population; and 3) the relationship between unmet needs and both patient and caregiver HRQOL in YOD. We hypothesized that the number of unmet needs in YOD is related to both patient and caregiver HRQOL.

METHODS

Study Design and Selection of Participants

This cross-sectional study is part of a larger longitudinal study, the Needs in Young Onset Dementia (NeedYD) study. The design of the NeedYD study has been described previously.¹⁶ Baseline data from 215 patient–caregiver dyads were used. All patients were living at home at time of inclusion. Patients were consecutively referred from university medical centers (n = 56), regional hospitals (n = 10), community mental health services (n = 20), self-referred (n = 14), or recruited through YOD-specialized day care facilities (n = 115). Individuals with symptom onset before age 65 years were included in the study. Therefore, age at inclusion could be older than 65 years. The diagnosis of dementia was made by the clinician on the basis of clinical, neuropsychological, and brain imaging findings according to the criteria from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*,¹⁷ and the Dutch consensus guidelines¹⁸ that use internationally accepted criteria for diagnosing dementia subtypes.^{19–23} Clinical diagnoses were checked by the researcher against clinical patient files for each patient. Exclusion criteria were: 1) lack of informed consent of the participant; 2) living in a nursing home; or 3) dementia caused by human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), traumatic brain injury, Down syndrome, Huntington disease, or alcohol-related dementia.

The Medical Ethics Committee of the Maastricht University Medical Centre and the local ethics

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