Summary

The construction of a dementia-specific Quality of Life instrument rated by professional caregivers in residential settings: the QUALIDEM

During the last fifteen to twenty years Quality of Life (QOL) has been recognized as an important outcome of the care for people with dementia, but the first instrument to assess QOL in dementia did not appear until the late 1990s. Many researchers felt the need for such an instrument, as most behavioral observation scales focus on behavioral and psychological symptoms (BPSD), not on positive aspects of life. Within a study on the effects of integrated emotion-oriented care (that ran from 1996 to 2000) the researchers therefore conducted a qualitative study using the method of participant observation, to assess variables that could not be measured with the existing quantitative measures. After completing the study, the researchers expressed the need for a good QOL instrument. This thesis describes the development and evaluation of such a QOL instrument. The aim of the project was an instrument that can assess QOL of all residents with dementia living in nursing homes.

The project started in December 2001 with a literature study in order to conceptually define QOL in dementia (chapter 2). A broad orientation was preferred to avoid omissions within the dementia-specific concept of QOL, and QOL was therefore studied in the elderly population, in chronic disease, and in dementia respectively. Adaptation proved an important outcome in many studies investigating interventions aimed at improving QOL in chronic disease. In 1991 Dröes presented the adaptation-coping model as a hypothetical framework to describe and explain psychosocial problems of people with dementia. The results of our literature study provided sufficient support to qualify adaptation as an important indication for QOL in both chronic disease and dementia. The following conceptual definition of QOL in dementia could then be offered: dementia-specific QOL is the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia.

A second literature study was conducted to identify and discuss instruments that had been used to assess QOL or elements of QOL in dementia up to 2003 (chapter 3). Six dementia-specific QOL measures, eight generic QOL measures, and three dementia-specific QOL-related measures were found. The measures vary considerably in scale content and in method of data collection. The severity of the dementia of the people studied affects the method of data collection: self-report for people with mild dementia, and proxy-report for people with severe...
dementia. But the content of a scale also depends on the disease. The review showed that a dementia-specific instrument is to be preferred in this particular population.

As the aim was to assess QOL of all people with dementia in residential settings we opted for an observational measure, to be scored by the certified nursing assistants (CNAs) of the ward. The development of the QOL instrument (which became known as the QUALIDEM\(^1\)) is described in chapter 4. To further complete the overview on the content of QOL, a discussion was held in a focus group of dementia patients. The results of both literature studies, the focus group discussion and of the participant observation of the study into integrated emotion-oriented care, provides us with sufficient material to start the process of item writing. Support for content validity was obtained using the method of test construction. Jacomine de Lange (the researcher of the participant observation study) and Teake Ettema wrote a pool of 95 items describing observable behavior on the different QOL domains. The items were reduced to 75 after a discussion with the other members of the research project. These items were presented to two expert panels: one consisting of nursing home physicians and psychologists, and one of CNAs and activity therapists. Their comments led to a further reduction of the item pool and to rephrasing of some of the items. The remaining fifty items were tested in a group of twenty residents with dementia in one nursing home. The items were scored independently by three CNAs. One item (enjoys music) was rejected because of the total lack of agreement between observers, and twelve items were rephrased. The middle response category of the original five response categories was removed as it was most frequently chosen. This could be an indication that observers preferred not to make a decision in the direction of either end of the scale. Four response categories might result in more evenly dispersed scores.

To compare the scores on the QUALIDEM with a personal QOL evaluation of the person with dementia, we looked for a self-report measure to assess QOL directly from the participating residents. Within the residential setting we decided on the COOP/WONCA Charts (chapter 5). These Charts are a simple and attractive measure, with illustrated response options, and they are easy to administer. Although this instrument has not been used often in people with dementia, verbal reports from other researchers gave cause to believe that the COOP/WONCA Charts would be suited for people with dementia. Within the field survey that was conducted to test the psychometric properties of the QUALIDEM, part of the gathered data were also used to assess the suitability of the COOP/WONCA Charts as a self-report measure in dementia research. The Charts needed some modification before presentation to people with dementia. Approximately 60% of the participants answered the questions in such a manner that the interviewer was confident that they had understood the questions. Agreement between two interviewers was excellent, but test-retest reliability with a period of one week between tests was disappointing. Some recommendations were made to improve the application of this instrument in dementia research.

To test the psychometric properties of the QUALIDEM a field survey was performed in ten nursing homes across the Netherlands. A total of 238 people with dementia participated in this study. For unidimensionality a non-parametric model from item-response theory, the Mokken scaling model, was used and scalability coefficients were computed (chapter 6). This resulted in

\(^1\)The manual of the QUALIDEM was published on the website of the Trimbos-institute in 2005 and can be downloaded free of charge. www.trimbos.nl
a 37 item rating scale consisting of nine unidimensional subscales (care relationship, positive affect, negative affect, restless tense behavior, positive self image, social relations, social isolation, feeling at home, and having something to do). Reliability coefficients varied from .60 to .90, and inter-rater reliability ranged between .47 and .79. To improve the reliability of the QOL assessments with the QUALIDEM it is advisable to have two observers score the QUALIDEM independently, discuss the results and come to an agreement on a definite score in the case of different scores. With the subscales residents of nursing homes in the stages up to severe dementia can reliably be ranked on the respective QOL domains, providing a QOL profile. In very severe dementia fewer items are applicable, leading to a QOL profile of six subscales. In addition we found no evidence of differential item functioning (DIF) between people with different levels of dementia severity.

In the field survey other variables were also assessed for validation purposes (chapter 7). Most of the correlations (90.5%) between the subscales of the QUALIDEM and other behavioral observation measures supported of convergent and discriminant validity. Low to moderate correlations with dementia severity and need of care confirmed that the QUALIDEM does not measure disease severity. Support for concurrent validity was found in correlations with QOL ratings by the head nurse of the ward. However, the QUALIDEM did not correlate with the QOL ratings by the closest relatives or with the COOP/WONCA Charts. The results of the field survey provide sufficient support for the reliability and validity of the QUALIDEM for it to be used in care evaluation and research in residential settings.

The major results and some relevant issues in QOL research are discussed in chapter 8, as are the limitations of this study, its scientific and societal relevance, its relevance for dementia care, and some recommendations.