ORIGINAL ARTICLES

Quality of life of people with dementia in nursing homes in Austria: A cross-sectional study

Daniela Deufert,* Karoline Schermann

Department of Nursing Science and Gerontology, UMIT - University for Health sciences, Medical informatics and Technology, Hall in Tyrol, Austria

ABSTRACT

Background: The preservation and promotion of the quality of life (QoL) is a central objective in the provision of nursing care for people with dementia (PwD). Long-term care facilities face the major challenge to promote the QoL of the ever-growing group of PwD by providing adequate nursing care.
Objective: The aim of the study was to outline the QoL of residents with dementia in Austrian nursing homes.
Methods: A cross-sectional study was carried out. The data were collected through the Quality of Life in Dementia Questionnaire (QUALIDEM) and the Functional Assessment Staging Test (FAST).
Results: 147 people with mild to moderately severe dementia and 80 people with severe dementia residing in 23 nursing homes were included in the study. In people with mild to severe dementia, the highest scores were observed in the QUALIDEM-subscales *positive affect* and *feeling at home*, indicating a high QoL in these areas. The lowest scores with respect to the QoL were found in the categories *restless tense behavior and having something to do*. People with a very severe dementia had the lowest scores in the QUALIDEM-subscales *social relations*, *restless tense behavior and having something to do*, indicating a low QoL in these areas. The categories with the highest scores were *positive self-image and feeling at home*.
Conclusion: The results of the study provide first data and clues for possible developments or necessary changes in the care of PwD in long-term care facilities in Tyrol/Austria.

Key Words: Dementia, Quality of life, QUALIDEM, Nursing home, Austria

1. INTRODUCTION

Dementia diseases are among the most common progressive psychiatric diseases in higher age.[1,2] The prevalence of dementia diseases has been found to increase with age. According to Alzheimer's Disease International, in 2015, 46.8 million people worldwide suffered from Alzheimer's disease.[3]

It is now estimated that in Austria currently approximately 130,000 people live with dementia. Due to the increasing age of the population, the number of people with dementia

(PwD) will double until the year 2050 and thus the need for assistance and care will rise further.[4] This expected significant increase of PwD will confront society with increasing challenges with regard to medical and nursing care in the years to come.

Due to the disease's progression, dementia is the most common reason for admission to a long-term care facility.[5,6] Also in Austria, dementia-type illnesses are the most common reason (approximately 43%) for nursing home admissions.[7] At the moment, approximately 47,000 PwD live in

nursing homes (NH) in Austria. Caring for PwD is a very complex task as there is no cure for this type of progressive disease, only the possibility of slowing its progression. As a consequence of dementia, independence and autonomy in day-to-day life as well as the preservation of the emotional well-being becomes a major challenge for the affected. In this context, not the medical therapy but the way how the PwD are being cared for and how they are treated is a key factor that determines how the PwD experience everyday life and how they feel. A key objective in the care of PwD is the preservation and promotion of the quality of life (QoL).[8–10]

The QoL became a key concept in the last few years, especially in context with chronic diseases like dementia. There is, however, no uniform definition for quality of life of people with dementia and also the conceptualization varies.[11–13] QoL is being referred as a multidimensional concept, whereby physical, mental and social well-being are regarded core dimensions of the QoL of PwD.[14–17]

Long-term care facilities face the major challenge of supporting the QoL of a continuously growing group of PwD by providing adequate care. Additionally, the QoL is gaining increasing importance as quality indicator in the long term care of elderly people.[18, 19]

Many PwD enter the NH at a mid-to-late stage, when caring for them at home is no longer possible.[20] Main reasons for this are the increase in care dependency of the PwD on the one hand,[21] and the appearance of behavioral and psychological symptoms of dementia (BPSD) on the other hand.[22] In an advanced stage of the disease cognitive impairments occur which often result in overall care dependency as well as the need for 24-hour supervision.[23] Therefore, people with a severe level of dementia form the major part of the residents with dementia.[20]

When we assess the QoL of PwD, we have to differentiate between the single stages of the disease. People with a mild to moderately severe dementia are still able to provide information concerning their QoL.[24] People in an advanced stage of dementia are often no longer able to adequately and reliably provide information concerning their QoL. For PwD it is becoming increasingly difficult to tell what makes a "good life".[25] In the course of a dementia disease, different aspects of life are of particular significance for the individual QoL. In the early stages of dementia, the QoL of PwD is often affected by deficits in organizing everyday life or in independent living.[8, 10] Over the course of the disease the independence in activities of daily living decreases continuously.[26] Thus, factors which affect independence, like for example dressing, are no longer as relevant in the stage of mild dementia as in the early stages of the disease. In the late

stages of dementia, the affected are normally totally dependent on the help of others. Although in this stage people often develop disorientation, loss of mobility and challenging behavior, every affected experiences dementia in an individual way and requires continuous adjustments of care.[27]

There are several international studies on the QoL of PwD which have been conducted in NH's or residential institutions.[8, 28–30] In Austria, there is still very little research on the QoL of PwD in long-term care facilities. The aim of the study was to present first data on the QoL of residents in Austrian NH's with mild to severe as well as very severe dementia.

2. METHODS

A cross-sectional observational study was conducted to examine the QoL of PwD. Twenty-three NHs in Tyrol, Austria, were invited to participate in the study. The chosen NHs are a convenience sample, drawn from 89 Tyrolean residential institutions. A random selection of institutions was not possible due to the resource requirements of the NHs for participating in the study. Potential study participants were screened by nurses working at the participating NHs based on defined criteria. The inclusion criteria for the residents were: living in the NH for at least four weeks, documented diagnosis of dementia or Mini Mental State Examination (MMSE) ≤ 24 points.[31] Exclusion criteria were other mental or behavior disorders not based on dementia.

2.1 Data collection

Data were collected from November 2013 until July 2015 using a convenience sample of 227 residents. The data were assessed by the caregivers (registered nurses and nursing aids) at the NHs together with study assistants, which were trained in the assessment instruments QUALIDEM and FAST. It was essential that the caregivers knew the resident well and had to be able to evaluate the situation of the resident during the last two weeks retrospectively. The items of the instruments were read aloud to the caregivers by the study assistants and the answers were documented directly.

Gender, age and length of stay in the NH were assessed via the nursing documentation (medical report) system. For the description of residents' need of care, the levels defined by the Austrian care allowance system were used (with levels ranging from 1 to 7). Thus, need of care is determined by the specific amount of personal care and assistance required by the care dependent person. In order to allocate people to one of the seven care levels, the time allotted monthly to care and assistance needs is assessed. Basically, care level 1 requires a minimum need of 65 hours of care per month.[32]

2.1.1 *Quality of life*

The QoL was assessed using the German version of the Quality of Life in Dementia Questionnaire (QUALIDEM), a proxy-rated dementia-specific instrument which is specifically designed for institutionalized residents with dementia.[13, 33] Through external assessment (proxy-rater) behavior is assessed and the QoL is illustrated on a multidimensional scale. QUALIDEM has two versions. The 37-item version is used to assess the QoL in people with mild to moderately severe dementia, with nine subscales describing the QoL: *care relationship, positive affect, negative affect, restless tense behavior, positive self-image, social relationship, social isolation, feeling at home* and *having something to do*. The four response options are: *never, rarely, sometimes* and *frequently*. The subscale sum scores were calculated separately and were linearly transformed to values between 0 and 100. A higher score indicates a better QoL. The three domains *positive self-image, feeling at home* and *having something to do* cannot be assessed in people with severe to very severe dementia.[26, 34] Thus, the 18-item version has 6 subscales and is used to assess the QoL of people with severe dementia. The German version of the QUALIDEM showed good psychometric properties. The subscales for both versions showed a moderate to high internal consistency. The Cronbach's α value ranged between 0.64 and 0.87 in the 37-item version and between 0.61 and 0.83 in the 18-item version.[19] The results for the intra-rater reliability show a high correlation ($r \geq 0.70$) for all subscales. The weighted kappa value ranged between 0.52 and 0.77 in the 37-item version and between 0.24 and 0.69 in the 18-item version.[34]

2.1.2 *Severity of dementia*

The level of dementia was assessed using the Functional Assessment Staging Test (FAST).[35, 36] The FAST was developed for use with Alzheimer's disease (AD) patients to stage a patient's level of disability with respect to AD. The FAST is derived from Axis V of the Brief Cognitive Rating Scale (BCRS), which itself is derived from the Global Deterioration Scale (GDS).[37] The stages of dementia as defined by FAST are: Stage 1: normal aging, Stage 2: possible mild cognitive impairment, Stage 3: mild cognitive impairment, Stage 4-6: mild to moderately severe dementia and Stage 7: severe dementia[36, 38]

The coefficient of scalability of the FAST was reported to be 0.98.[39] Rater consistency and rater agreement were calculated using the intraclass correlation coefficient (ICC); excellent reliability was reported (fixed effect ICC = 0.86; random effect ICC = 0.87).[39]

Although currently there are no data available on the test-theoretical quality criteria of the German version of FAST, it has already been used in previous studies.[13, 34] Due to the comparability with these studies we also chose FAST as instrument for assessing the degree of dementia.

2.2 Statistical analysis

The data were analyzed with SPSS for Windows Version 20.0 (IBM SPSS Inc., Chicago, IL). Results are presented as Mean (M), $\pm$ Standard Deviation (SD) or as number (N) and percentage (%). Between groups, comparisons were tested for statistical significance via the χ^2 test for categorical variables and via the Mann-Whitney U-test or Student's t-test for continuous variables as appropriate. Statistical significance was established at $p < .05$.

2.3 Ethical consideration

This study was approved by the Research Committee for Scientific and Ethical Questions (RCSEQ) of UMIT - University for Health Sciences, Medical Informatics and Technology, Hall in Tyrol. The participants and/or their relatives and legal representatives were informed about the study and gave their written consent.

3. RESULTS

3.1 Sample characteristics

A total of 236 residents participated in the study. Based on the severity of dementia, the sample was divided into two sub-samples, namely people with mild to moderately severe dementia (FAST 4-6) and people with severe dementia (FAST 7). The data of nine participants had to be excluded from further data evaluation as they were tested FAST 1-3.

Table 1 lists the demographic characteristics of the study population. Most of the participants in both groups were female and the average age was 84.7 years in the FAST 4-6 group and 82 years in the FAST 7 group. The length of stay in the nursing home was higher in the FAST 7 group (4.3 vs. 3.1; $p = .007$), as well as the level of care need (4.1 vs. 5.4; $p = .000$).

3.2 Quality of life

For the QoL assessment of people with severe cognitive decline (FAST = 7), the 18 item-version of QUALIDEM was used.[28] The QUALIDEM results of people with mild to moderately severe dementia (FAST 4-6) and severe dementia (FAST 7) are illustrated in Table 2. The results showed QoL subscale scores ranging from 42.2 (subscale *social relations*) to 77.0 (subscale *positive affect*).

People with mild to moderately severe dementia (FAST 4-6) had the highest scores in the domains *positive affect, feeling at home* and *social isolation*. They had lower mean scores and thus a lower QoL in the domains *something to do* and *restless tense behavior*.

Table 1. Characteristics of the study sample

	FAST 4-6 (N = 147)	FAST 7 (N = 80)	p-value
Age (years), Mean (± SD; range)	84.7 (±7.8; 55-97)	82.0 (10.8; 44-101)	.03§
Gender (female), N (%)	112 (76.2)	64 (80.0)	.51#
MMSE value, Mean (± SD)	15.9 (6.2)	7.8 (7.2)	.000§
Missing N (%)	30 (20.4)	29 (36.2)	
Level of care need*, N (%)			
None	2 (1.4)	0	
1	1 (0.7)	0	
2	11 (7.5)	0	
3	31 (21.1)	5 (6.3)	
4	43 (29.3)	3 (3.8)	
5	40 (27.2)	33 (41.3)	
6	19 (12.9)	34 (42.5)	
7	0	5 (6.3)	
Level of care need, Mean (± SD)	4.1 (1.3)	5.4 (0.9)	.000§
Length of stay in NH, years, Mean (± SD; range)	3.1 (2.9; 0.2-13.6)	4.3 (3.3; 0.06-14.0)	.007§

Note. *According to the Austrian levels of care allowance; Level of care need, Level 1 = 65 hours/monthly – Level 7 = 180 hours/monthly; §t-test; #χ^2-test

Residents with a FAST 7 score reached the highest scores in the domains *social isolation*, *care relationship* and *positive affect*. This group had the lowest QoL in the domains *social relations*, *restless tense behavior* and *negative affect*.

A comparison of the two groups showed that people with mild to moderately severe dementia had higher QoL scores in all QUALIDEM categories. Statistically significant differences were observed in the QUALIDEM categories *positive affect* (p = .000), *restless tense behavior* (p = .000) and *social relations* (p = .000) (see Table 2). Also the QUALIDEM total score was statistically significantly higher in the FAST 4-6 group (p = .000).

Table 2. Quality of life according to the degree of dementia severity

QUALIDEM Subscales§	FAST 4-6 Mean (SD)	FAST 7 Mean (SD)	p-value##
Care relationship	70.6 (23.5)	66.7 (23.1)	.233
Positive affect	77.0 (21.1)	62.2 (27.2)	.000**
Negative affect	65.4 (25.9)	61.3 (22.7)	.233
Restless tense behavior	59.4 (31.0)	42.5 (33.1)	.000**
Positive self-image#	73.1 (27.2)		
Social relations	62.4 (18.5)	42.2 (20.4)	.000**
Social isolation	75.0 (21.7)	71.5 (27.0)	.294
Feeling at home#	75.6 (22.4)		
Something to do#	45.3 (29.8)		
Total score	78.2 (15.3)	68.9 (15.2)	.000**

Note. ##t-test; *p < .05; **p < .001; § higher score (maximum value = 100) indicate better QoL; # cannot be assessed in people with severe dementia

3.3 Behavior of the PwD

The three most frequently observed positive behaviors in the group with mild to moderately severe dementia were *responds positively when approached*, *feels at ease in company of others* and *is in a good mood*. *Is restless*, *is sad* and *is angry* were the most frequently observed negative behaviors in this group. The most frequently observed positive behav-iors in the group with severe dementia were *mood can be influenced in a positive sense*, *has a contented appearance* and *is in a good mood*. The three most frequently observed negative behaviors in this group were *makes restless move-ments*, *is restless* and *has tense body language* (see Table 3).

Table 3. Behavior of the PwD according to the degree of dementia severity

QUALIDEM Subscales and Items	FAST 4-6 % (N)*	FAST 7 % (N)*
Care relationship		
Rejects help from nursing assistants**	32.1 (44)	------
Is angry	42.9 (63)	41.6 (32)
Has conflicts with nursing assistants	24.5 (36)	25.7 (20)
Accuses others**	34.3 (47)	------
Appreciates help that he or she receives**	15.0 (22)	------
Accepts help	5.1 (7)	9.8 (7)
Criticizes the daily routine**	17.5 (24)	------
Positive affect		
Is cheerful**	82.5 (113)	------
Has a contented appearance	88.5 (130)	77.2 61)
Is capable of enjoying things in daily life**	89.1 (131)	------
Is in a good mood	89.8 (132)	71.1 (54)
Has a smile around the mouth	81.0 (111)	68.1 (49)
Mood can be influenced in a positive sense	87.0 (128)	79.5 (62)
Negative affect		
Makes an anxious impression	32.7 (48)	43.6 (34)
Is sad**	40.1 (55)	------
Cries	17.0 (27)	16.3 (13)
Restless tense behavior		
Makes restless movements	39.4 (58)	56.3 (45)
Is restless	43.5 (64)	56.3 (45)
Has tense body language	36.1 (53)	63.8 (51)
Positive self-image		
Indicates he or she would like more help**	19.0 (26)	------
Indicates not being able to do anything**	31.3 (43)	------
Indicates feeling worthless**	26.3 (36)	------
Social relations		
Has contact with other residents	85.7 (126)	43.8 (35)
Responds positively when approached	97.2 (143)	85.1 (68)
Takes care of other residents**	35.0 (48)	------
Cuts oneself off from environment	68.0 (100)	76.3 (58)
Is on friendly terms with one or more residents**	64.3 (88)	------
Feels at ease in company of others**	89.9 (123)	------
Social isolation		
Is rejected by other residents	28.5 (42)	26.3 (21)
Openly rejects contact with others	29.2 (43)	25.2 (20)
Calls out	11.6 (17)	26.3 (21)
Feeling at home		
Indicates that he or she is bored**	73.0 (100)	------
Indicates feeling locked up**	81.1 (111)	------
Feels at home on the ward**	85.4 (117)	------
Wants to get off the ward**	72.9 (100)	------
Having something to do		
Find things to do without help from others**	56.9 (78)	------
Enjoys helping with chores on the ward**	34.3 (47)	------

Note. *Nurses report that resident shows behavior either sometimes or frequently; **Items cannot be assessed in people with severe dementia (FAST = 7)

4. DISCUSSION

Generally, also this study confirmed that people with mild to moderately severe dementia had a better QoL in all domains of the QUALIDEM in comparison to people with severe dementia.[26] People with mild to moderately severe dementia (FAST 4-6) presented the highest QoL results in the domains

positive affect, *feeling at home* and *social isolation*. A reduced QoL was detected in the domains *something to do* or *restless tense behavior*.[39] It seems that keeping people with cognitive decline engaged and stimulated constitutes a major challenge for carers. Especially at the beginning of the disease, the QoL of PwD is affected by the experience

of a loss of control and behavioral competence. However, in this stage it is possible to maintain the autonomy and thus the QoL of the affected through an efficient use of their resources and activation, whereby the confrontation with their own deficiencies should be avoided as far as possible. This requires appropriate advisory and supervision competencies of the qualified nursing staff.[25]

People with severe dementia suffered in particular from impairments in the domains *social relations* and *restless tense behavior*, as well as in the domain *negative affect* just as people with milder dementia. Higher scores and thus a better QoL in the subscales *social isolation* and *positive affect* were also detected in people with severe dementia. Previous studies produced the highest scores in the subscale *social isolation* in people with severe or very severe dementia too.[40,41] Also in our study, people with severe dementia showed increased *restless tense behavior*.[26,41] It is to be noted that such behavior may influence and reduce the QoL-assessment of PwD.[30] The proxy-rated QoL is often negatively influenced by psychiatric symptoms.[42]

PwD living in long term care facilities have the risk of social isolation or loneliness.[43] Taken as a whole, in this study the domain *social relations* is apparently most affected by the increasing cognitive decline. Nevertheless, Moyle et al.[44] were able to show that social interaction had an essential influence on the QoL of PwD. Also in our study it became obvious that a large majority of people with severe dementia isolated themselves from their environment. This social withdrawal, in particular of PwD in an advanced stage and with more severe cognitive decline, was also detected in earlier studies.[43] It should also be noted that social contacts contribute significantly to cognitive health and have an important influence on the well-being of PwD.[45–47] PwD need intensive guidance and care which gives them support and stability. Therefore it is necessary that the qualified nurses, on the one hand, encourage the relation between relatives and residents with severe dementia, and, on the other hand, that they themselves maintain the relation.[25] Nursing staff has to be aware of the fact that PwD are vulnerable, particularly to changes in their psychosocial environment, but are not always able to react to these changes adequately.[48] The later stages of the disease are often characterized by limitations in activities of daily living as well as severe cognitive impairments and the appearance of BPSD. Care and support in special care units offers the possibility to maintain the QoL of PwD accordingly[49] and to ease the interaction with

PwD.[25] A dementia-specific environment may serve as therapeutic instrument[50] as well as a means for orientation and promotion of social interaction.[51] Its deficit-compensating effect can help improve the QoL of PwD.[25]

However, insufficient QoL of PwD in long-term care facilities is often caused by a lack of staff resources, insufficient training or insufficient social competencies of the carers.[49] Thereby it is necessary that specially trained nurses are sensitive to the individual needs of the PwD to plan and implement appropriate individual measures. The QoL of PwD can be promoted through needs-oriented individual care.[25]

Due to its subjective components, the QoL, if possible, should be assessed by means of patient self-reports.[52] Despite their progressive cognitive decline, it is possible to collect valid data on the QoL in earlier-to-mid stage patients through self-assessment. The reliability of QoL self-reports in later stages of the disease has been questioned.[53] It should be taken into account that the results of proxy measures, like in our study, can be lower and also may differ from the results of self-assessment.[42,54,55]

5. CONCLUSIONS

The results of the study provide first data and clues for possible changes and developments in the care of PwD in long-term care facilities in Austria. The overall QoL of the residents was considered high by the carers, whereby people with severe dementia were deemed to have a lower QoL than people with less cognitive impairments. The experiencing and behavior of PwD depends on their mental, social and physical environment.[25] In order to guarantee the individual adaptation to the needs of PwD and to maintain their QoL, concepts like for example "Understanding Diagnostics"[56] need to be further developed in the future and training programs to encourage independence and the organization of day-to-day life on the one hand, and, on the other hand, to facilitate social relations, have to be extended and intensified in the future as they can have positive effects on the QoL of residents with dementia in Austria.

CONFLICTS OF INTEREST DISCLOSURE

The authors have no conflicts of interest to declare for this study.

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