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# **QUALIDEM**

## **User Guide**

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## Ordering Information

This QUALIDEM User guide is free of charge. It is available from the following websites:

<http://www.dzne.de/en/sites/witten/projekte/qol-dem.html>

<http://www.emgo.nl/team/190/rose-mariedroes/publications/>

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# 1. Introduction

Healthcare research that focuses on person-centered outcomes, particularly for dementia as a chronic and currently incurable syndrome, is an international priority [1, 2]. Ensuring quality of life (QoL) is a major goal of dementia care [3] and research [4]. The World Health Organization defines QoL as the 'individuals' 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' [5]. This broad definition focuses on subjective experience, culture-specific influence and how they interact.

Subjectivity and multidimensionality are the common denominators in definitions of dementia-specific QoL [6]. Subjectivity here means that everyone can provide an individual evaluation of their own QoL determined by personal values. The content of what is considered important in life can vary considerably across people [7, 8], and this is referred to as the subjective nature of the concept of QoL. Multidimensionality means that in fact QoL consists of a number of related concepts or domains. The domains are arrived at through consensus. For instance, good social relationships are important for people, and it is generally accepted that mood disturbances do not contribute to a good QoL. In an operational definition of QoL one has to identify indicators that apply to the vast majority of the people who are to be assessed [6]. According to Dröes et al. [9], people with dementia in meeting centers, day care centers and nursing homes report the following domains as important for their QoL: affect, self-esteem/self-image, attachment, social contact, enjoyment of activities, sense of aesthetics in living environment, physical and mental health, financial situation, security and privacy, self-determination and freedom, being useful/giving meaning to life, and spirituality. These domains were mainly confirmed in one recent and one ongoing meta-synthesis which investigated factors that affect the QoL of people with dementia. O'Rourke et al. identified the four factors relationship (together vs. alone), agency in life today (purposeful vs. aimless) wellness perspective (well vs. ill), sense of place (located vs. unsettled) and the experience of connectedness or disconnectedness within each factor [10]. The first results of an ongoing meta-synthesis break down these four factors by O'Rourke et al. in 14 factors described by people with dementia as important for their QoL: family, social contact and relationships, self-determination and freedom, living environment, positive emotions, negative emotions, privacy, security, self-esteem, health, spirituality, care relationship, pleasant activities and future prospects [11].

The QUALIDEM is a dementia-specific Qol instrument that allows a proxy-based Qol rating in all stages of dementia. The instrument structure and content are based on the adaption-coping model [12] and the following Qol definition: *'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'*. This means that Qol of people with dementia is the result of a successful or unsuccessful adaptation of the individual to the physical, psychological, and social consequences of the dementia syndrome.

## 2. The QUALIDEM

### 2.1 Adaption-Coping-Model

Dröes and later Dröes and colleagues developed the adaptation-coping model in order to explain behavior problems of people with dementia partly as a consequence of the adaptation process [12-14]. The model is based on the stress-appraisal-coping-theory of Lazarus and Folkman [15] and the crisis theory of Moos and Tsu [16]. The adaptation-coping model offers a starting point for Qol research through the formulation of adaptive tasks (see table 1) that people suffering from dementia may be confronted with. These adaptive tasks can be interpreted as important domains of Qol in dementia [17, 18].

**Table 1: The seven adaptive tasks mentioned in the adaptation-coping model RM Dröes [12]**

---

|   |   |
|---|---|
| A | Dealing with own disability                             |
| B | Developing an adequate care relationship with the staff |
| C | Preserving an emotional balance                         |
| D | Preserving a positive self-image                        |
| E | Preparing for an uncertain future                       |
| F | Developing and maintaining social relationships         |
| G | Dealing with the nursing home environment               |

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Besides the emphasis on personal tasks, i.e. dealing with own disability, preserving an emotional balance, preserving a positive self-image, and preparing for an uncertain future, the adaptation-coping model also stresses the importance of the person-environment system with the adaptive tasks 'developing an adequate care relationship with the staff', 'dealing with the nursing home environment', and 'developing and maintaining social relationships'. Apart from the obvious need for social relationships, other work on Qol in dementia has largely neglected the need for developing an adequate care relationship and dealing with the nursing home environment, or only marginally referred to them [18].

Earlier work of Dröes et al. [19] and De Lange [20], using the participant observation technique on wards of nursing homes in which the adaptation-coping model was used as a theoretical framework, led to an extensive description of behavior that can be interpreted as outcome of the adaptation process. This description contained not only negative behavior as an indication of unsuccessful adaptation (e.g. agitation, crying), but also positive behavior indicative of successful adaptation: e.g. having positive contacts with other residents or nurses, or showing an interest in the living environment.

## **2.2 Development and translation of the QUALIDEM**

Next to the adaption-coping model and the definition of Qol, the QUALIDEM was developed based on a literature review and discussions in focus groups with people with dementia. Starting from the definition – *‘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’* – it was possible to think in terms of Qol domains and the behavior associated with these domains. The experience of the development team in the nursing home setting and particularly the extensive descriptions of behaviors within several domains by J De Lange [20] provided sufficient material to write the items [21]. The formulation of the items was carried out meticulously.

TP Ettema, RM Dröes, J de Lange, GJ Mellenbergh and MW Ribbe [21] paid a lot of attention to the wording, and double-barreled questions, negative wording, jargon and value-laden words were carefully avoided [22]. This resulted in a large pool of items, which was reviewed by all the authors and then reduced. From the start, a balance of indicative and contra-indicative items was aimed for to prevent response biases, such as the acquiescence bias (the tendency to respond positively to items) [22, 23].

The first set of items that were discussed in the development team totaled 95 items. Twenty items were removed. The remaining 75 items were discussed in two expert panels: one consisting of nursing assistants and one of nursing home physicians and psychologists. Before the meeting all members of the panels judged the items on the relevance to Qol in dementia, the formulation, the ability to observe the behavior described in the item, and whether the item applies to all stages of the disease. Their observations were discussed during the meeting. As a result, another 25 items were removed. Fifty items were then tested in a pilot study (n = 20; three independent observers) resulting in the removal of one item and the rephrasing of some others.

Next the QUALIDEM was tested in ten different nursing homes with 238 residents participating. Further analysis of the results led to the first version which is presented in this user guide (psychometric properties are described in paragraph 3.3).

A particular point of attention was the use of an adjectival scale with five response options. A preference for an even or an uneven number of response options could not be found in the literature at that time (Ten Brink, 1992). However, the pilot test revealed a clear preference of the respondents for the middle response option, which made us reconsider the choice between four or five response options in this first version of the QUALIDEM. We expected a more even dispersion of the scores with four response options and on empirical grounds decided to continue with four response options.

The QUALIDEM was originally developed in The Netherlands. To make the instrument accessible in English, it was translated following the procedure of forward and backward translation. All items were translated from Dutch into English by a (bilingual) native English speaker and translated back to Dutch by a second bilingual translator. Differences between the original and translated versions were discussed, before a definite English translation of the item was established [21].

The same procedure was used to translate the QUALIDEM into German [24]. The German version was revised in 2015 to the German QUALIDEM version 2.0. Based on the results of cognitive interviews the wording of the items 2, 19 and 29 was modified [25].

## **2.3 QUALIDEM – Content and structure**

QUALIDEM consists of two consecutive versions to be used in the different stages of dementia (Table 2). Quality of life among people with mild to severe dementia is assessed using the 37-item version, which covers the following nine domains of QoL: *Care relationship, Positive Affect, Negative Affect, Restless tense behavior, Positive self-image, Social Relations, Social Isolation, Feeling at home, and Having something to do*. The domains *Positive self-image, Feeling at home, and Having something to do* cannot be assessed in people with very severe dementia. The second version, for people with very severe dementia, consists of 18 items covering six domains of QoL. Three additional items were not scalable during the development of the QUALIDEM but we do recommend these are included in further research on the instrument. These items are: *enjoys meals, does not want to eat, and likes to lie down (in bed)* [21].

**Table 2: Subscales and Items of the consecutive QUALIDEM versions used in different stages of dementia**

| Mild to severe dementia (GDS: 2 – 6) <sup>1</sup>    |   | Very severe dementia (GDS: 7) <sup>2</sup> |   |
|--|---|--|---|
| <b>Care relationship</b>                             |   | <b>Care relationship</b>                   |   |
| 4  | Rejects help from nursing assistants            |  |   |
| 7  | Is angry  | 7  | Is angry                                    |
| 14   | Has conflicts with nursing assistants           | 14   | Has conflicts with nursing assistants       |
| 17   | Accuses others                                  |  |   |
| 24   | Appreciates help that he or she receives        |  |   |
| 31   | Accepts help                                    | 31   | Accepts help                                |
| 33   | Criticizes the daily routine                    |  |   |
| <b>Positive Affect</b>                               |   | <b>Positive Affect</b>                     |   |
| 1  | Is cheerful                                     |  |   |
| 5  | Radiates satisfaction                           | 5  | Radiates satisfaction                       |
| 8  | Is capable of enjoying things in daily life     | 8  | Is capable of enjoying things in daily life |
| 10   | Is in a good mood                               |  |   |
| 21   | Has a smile around the mouth                    | 21   | Has a smile around the mouth                |
| 40   | Mood can be influenced in positive sense        | 40   | Mood can be influenced in positive sense    |
| <b>Negative Affect</b>                               |   | <b>Negative Affect</b>                     |   |
| 6  | Makes an anxious impression                     | 6  | Makes an anxious impression                 |
| 11   | Is sad  |  |   |
| 23   | Cries   | 23   | Cries                                       |
| <b>Restless tense behavior</b>                       |   | <b>Restless tense behavior</b>             |   |
| 2  | Makes restless movements                        | 2  | Makes restless movements                    |
| 19   | Is restless                                     | 19   | Is restless                                 |
| 22   | Has tense body language                         | 22   | Has tense body language                     |
| <b>Positive self-image</b>                           |   |  |   |
| 27   | Indicates he or she would like more help        |  |   |
| 35   | Indicates not being able to do anything         |  |   |
| 37   | Indicates feeling worthless                     |  |   |
| <b>Social Relations</b>                              |   | <b>Social Relations</b>                    |   |
| 3  | Has contact with other residents                | 3  | Has contact with other residents            |
| 12   | Responds positively when approached             | 12   | Responds positively when approached         |
| 18   | Takes care of other residents                   |  |   |
| 25   | Cuts himself/herself off from environment       | 25   | Cuts himself/herself off from environment   |
| 29   | Is on friendly terms with one or more residents |  |   |
| 34   | Feels at ease in the company of others          |  |   |
| <b>Social Isolation</b>                              |   | <b>Social Isolation</b>                    |   |
| 16   | Is rejected by other residents                  | 16   | Is rejected by other residents              |
| 20   | Openly rejects contact with others              | 20   | Openly rejects contact with others          |
| 32   | Calls out                                       | 32   | Calls out                                   |
| <b>Feeling at home</b>                               |   |  |   |
| 13   | Indicates that he or she is bored               |  |   |
| 28   | Indicates feeling locked up                     |  |   |
| 36   | Feels at home on the ward                       |  |   |
| 39   | Wants to get off the ward                       |  |   |
| <b>Having something to do</b>                        |   |  |   |
| 26   | Finds things to do without help from others     |  |   |
| 38   | Enjoys helping with chores on the ward          |  |   |
| <b>Remaining items to be used in future research</b> |   |  |   |
| 9  | Does not want to eat                            |  |   |
| 15   | Enjoys meals                                    |  |   |
| 30   | Likes to lie down (in bed)                      |  |   |

<sup>1</sup> QUALIDEM for people with mild to severe dementia (37-items) 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*. GDS = Global Deterioration Scale 26. Reisberg B, Ferris SH, de Leon MJ, Crook T: **The Global Deterioration Scale for assessment of primary degenerative dementia**. *Am J Psychiatry* 1982, **139**(9):1136-1139..

<sup>2</sup> QUALIDEM for people with very severe dementia (18-items) subscales: *Care relationship, Positive Affect, Negative Affect, Restless tense behavior, Social Relations, and Social Isolation*.

## **2.4 Scoring the QUALIDEM**

The scores on the subscales are calculated by adding up the item scores. Please note that the indicative items are scored opposite to the contra-indicative items. That is, the response option 'Never' counts as zero for an indicative item, but three for a contra-indicative item. The higher the score on a subscale, the better the person does on this particular QoI domain.

The author's advice against calculating an overall score, because the subscales differ in content and adding up the subscale scores will result in loss of information. However, it can sometimes be necessary to calculate an overall score for statistical or methodological reasons. In such cases the authors recommend calculating an overall QUALIDEM score, and additional computations for each subscale. This approach is demonstrated in several studies [27, 28].

The scores on the subscales provide a QoI profile. For example when evaluating a new practice innovation, one might hypothesize that an effect is expected on one or some, but not all domains of QoI. A QoI profile helps the researcher to more accurately evaluate the outcome of the intervention. The capital letters on the far right indicates which subscale the question belongs to. In Table 3 the scores for each item are recorded beneath the response options and Table 4 shows the ranges of subscale scores.

**Table 3: QUALIDEM indicative and contra-indicative items**

| No. | Item   | Response options |             |                |                 |                      |   |
|-----|--|------------------|-------------|----------------|-----------------|----------------------|---|
|     |  | Never<br>0       | Rarely<br>1 | Sometimes<br>2 | Frequently<br>3 |                      |   |
| 1.  | Is cheerful <sup>1</sup>                                     | 0                | 1           | 2              | 3               | B                    |   |
| 2.  | Makes restless movements <sup>1,2</sup>                      | 3                | 2           | 1              | 0               | D                    |   |
| 3.  | Has contact with other residents <sup>1,2</sup>              | 0                | 1           | 2              | 3               | F                    |   |
| 4.  | Rejects help from nursing assistants <sup>1</sup>            | 3                | 2           | 1              | 0               | A                    |   |
| 5.  | Radiates satisfaction <sup>1,2</sup>                         | 0                | 1           | 2              | 3               | B                    |   |
| 6.  | Makes an anxious impression <sup>1,2</sup>                   | 3                | 2           | 1              | 0               | C                    |   |
| 7.  | Is angry <sup>1,2</sup>                                      | 3                | 2           | 1              | 0               | A                    |   |
| 8.  | Is capable of enjoying things in daily life <sup>1,2</sup>   | 0                | 1           | 2              | 3               | B                    |   |
| 9.  | Does not want to eat <sup>1,2</sup>                          | 3                | 2           | 1              | 0               | NA <sup>3</sup><br>9 | J |
| 10. | Is in a good mood <sup>1</sup>                               | 0                | 1           | 2              | 3               | B                    |   |
| 11. | Is sad <sup>1</sup>  | 3                | 2           | 1              | 0               | C                    |   |
| 12. | Responds positively when approached <sup>1,2</sup>           | 0                | 1           | 2              | 3               | F                    |   |
| 13. | Indicates that he or she is bored <sup>1</sup>               | 3                | 2           | 1              | 0               | NA<br>9              | H |
| 14. | Has conflicts with nursing assistants <sup>1,2</sup>         | 3                | 2           | 1              | 0               | A                    |   |
| 15. | Enjoys meals <sup>1,2</sup>                                  | 0                | 1           | 2              | 3               | NA<br>9              | J |
| 16. | Is rejected by other residents <sup>1,2</sup>                | 3                | 2           | 1              | 0               | G                    |   |
| 17. | Accuses others <sup>1</sup>                                  | 3                | 2           | 1              | 0               | NA<br>9              | A |
| 18. | Takes care of other residents <sup>1</sup>                   | 0                | 1           | 2              | 3               | F                    |   |
| 19. | Is restless <sup>1,2</sup>                                   | 3                | 2           | 1              | 0               | D                    |   |
| 20. | Openly rejects contact with others <sup>1,2</sup>            | 3                | 2           | 1              | 0               | G                    |   |
| 21. | Has a smile around the mouth <sup>1,2</sup>                  | 0                | 1           | 2              | 3               | NA<br>9              | B |
| 22. | Has tense body language <sup>1,2</sup>                       | 3                | 2           | 1              | 0               | D                    |   |
| 23. | Cries <sup>1,2</sup>   | 3                | 2           | 1              | 0               | C                    |   |
| 24. | Appreciates help he or she receives <sup>1</sup>             | 0                | 1           | 2              | 3               | A                    |   |
| 25. | Cuts himself/herself off from environment <sup>1,2</sup>     | 3                | 2           | 1              | 0               | F                    |   |
| 26. | Finds things to do without help from others <sup>1</sup>     | 0                | 1           | 2              | 3               | I                    |   |
| 27. | Indicates he or she would like more help <sup>1</sup>        | 3                | 2           | 1              | 0               | NA<br>9              | E |
| 28. | Indicates feeling locked up <sup>1</sup>                     | 3                | 2           | 1              | 0               | NA<br>9              | H |
| 29. | Is on friendly terms with one or more residents <sup>1</sup> | 0                | 1           | 2              | 3               | F                    |   |
| 30. | Likes to lie down (in bed) <sup>1,2</sup>                    | 3                | 2           | 1              | 0               | NA<br>9              | J |
| 31. | Accepts help <sup>1,2</sup>                                  | 0                | 1           | 2              | 3               | A                    |   |
| 32. | Calls out <sup>1,2</sup>                                     | 3                | 2           | 1              | 0               | NA<br>9              | G |
| 33. | Criticizes the daily routine <sup>1</sup>                    | 3                | 2           | 1              | 0               | A                    |   |
| 34. | Feels at ease in the company of others <sup>1</sup>          | 0                | 1           | 2              | 3               | F                    |   |
| 35. | Indicates not being able to do anything <sup>1</sup>         | 3                | 2           | 1              | 0               | NA<br>9              | E |
| 36. | Feels at home on the ward <sup>1</sup>                       | 0                | 1           | 2              | 3               | H                    |   |
| 37. | Indicates feeling worthless <sup>1</sup>                     | 3                | 2           | 1              | 0               | NA<br>9              | E |
| 38. | Enjoys helping with chores on the ward <sup>1</sup>          | 0                | 1           | 2              | 3               | I                    |   |
| 39. | Wants to get off the ward <sup>1</sup>                       | 3                | 2           | 1              | 0               | H                    |   |
| 40. | Mood can be influenced in positive sense <sup>1,2</sup>      | 0                | 1           | 2              | 3               | B                    |   |

**Remarks:**

<sup>1</sup> People with mild to severe dementia (GDS 2 - 6).

<sup>2</sup> People with very severe dementia (GDS = 7).

<sup>3</sup> NA = Not applicable

**Table 4: Subscales with their range in scores**

| Subscale   | Number of items (score range) |                      | Score |
|--|-------------------------------|----------------------|-------|
|  | mild to severe dementia       | very severe dementia |       |
| A: Care relationship                             | 7 (0 – 21)                    | 3 (0 – 9)            | A     |
| B: Positive Affect                               | 6 (0 – 18)                    | 4 (0 – 12)           | B     |
| C: Negative Affect                               | 3 (0 – 9)                     | 2 (0 – 6)            | C     |
| D: Restless tense behavior                       | 3 (0 – 9)                     | 3 (0 – 9)            | D     |
| E: Positive self-image                           | 3 (0 – 9)                     | NA                   | E     |
| F: Social Relations                              | 6 (0 – 18)                    | 3 (0 – 9)            | F     |
| G: Social Isolation                              | 3 (0 – 9)                     | 3 (0 – 9)            | G     |
| H: Feeling at home                               | 4 (0 – 12)                    | NA                   | H     |
| I: Having something to do                        | 2 (0 – 6)                     | NA                   | I     |
| J: Remaining items to be used in future research |                               |                      |       |

## 2.5 Terms of use of the QUALIDEM

The QUALIDEM instrument is an openly accessible instrument and free of charge. Users shall not modify, abridge, condense, adapt, recast or transform the QUALIDEM in any manner or form, including but not limited to any minor or significant change in wording or organization of the instrument without the prior written agreement of Dr. Teake P. Ettema (for the Dutch and English versions) or Martin N. Dichter, MScN (for the German version). In case of publication, users are requested to cite the main publication reference about the QUALIDEM in the reference section of the respective paper or presentation:

### When the original Dutch QUALIDEM version is used, please refer to:

- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument - validation. *Int J Geriatr Psychiatry*, 22(5), 424-430. doi: 10.1002/gps.1692.
- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry*, 22(6), 549-556. doi: 10.1002/gps.1713.

**When the English QUALIDEM version is used please refer to:**

- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry*, 22(6), 549-556. doi: 10.1002/gps.1713.
- Dichter, M. N., Ettema, T. P., Schwab, C. G. G., Meyer, G., Bartholomeyczik, S., Halek, M., & Dröes, R. M. (2016). QUALIDEM - User Guide. Witten.

**When the German QUALIDEM version is used please refer to:**

- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry*, 22(6), 549-556. doi: 10.1002/gps.1713.
- Dichter, M., Bartholomeyczik, S., Nordheim, J., Achterberg, W., & Halek, M. (2011). Validity, reliability, and feasibility of a quality of life questionnaire for people with dementia. *Z Gerontol Geriatr*, 44(6), 405-410. doi: 10.1007/s00391-011-0235-9.

### 3. Using the QUALIDEM

QUALIDEM was developed to assess the QoL of people with dementia aged  $\geq 65$  years. The assessment is a proxy rating carried out by the nursing staff. The proxy rating is based on observations and interactions with the person with dementia during the two weeks (original Dutch version) or one week (German version 2.0) before assessment takes place. The QUALIDEM enables the assessment of the QoL of people with mild to severe dementia and people with very severe dementia. Whether the instrument or its individual sub scales can be used in nursing homes to assess younger people or residents with other diseases has not yet been investigated. One study examined the applicability and validity of QUALIDEM in shared housing arrangements, and showed good applicability and validity of the instrument when compared to two other instruments [29]. Moreover, RT Koopmans, M van der Molen, M Raats and TP Ettema [30] demonstrated the applicability of the QUALIDEM in the final phase of dementia.

The decision to use the QUALIDEM should be based on the importance of the QoL domains represented in the QUALIDEM for a particular target group and/or care setting. QUALIDEM was initially developed as an instrument for recording dementia-specific QoL within research projects. This means that with QUALIDEM individual quality of life can be assessed and then analyzed and interpreted at group level in research projects.

However, to date there have only been isolated attempts at evaluating the individual QoL of people with dementia in nursing homes using the QUALIDEM[31]. Although results are promising, scientific investigation is required before application in practice can be recommended. In contrast to blood pressure values, for example, values for individual QoL of people with dementia as measured with QUALIDEM cannot be used as the only criterion for, or against, a specific therapy. Nevertheless, the individual QoL values for people with dementia in different domains can be important as an additional source of information in the care process.

Within scientific research the QUALIDEM can be used for different purposes:

- Effectiveness studies of non-pharmacological (especially psychosocial) interventions
- Effectiveness studies of pharmacological interventions
- Studies evaluating the quality of care of people with dementia
- Evaluation of new models and structures of care for people with dementia
- Evaluation of the QoL of people with dementia over the course of illness and care
- Studies investigating factors that determine or influence the QoL of people with dementia

### 3.1 Basic information for using the QUALIDEM

The QUALIDEM items should be assessed by nurses (when possible, the respective key nurse) who have a close relationship to the people with dementia. Taking into account their working hours, these nurses should also be able to observe the people with dementia at various times of the day [21] and observations should be based on the week (seven days) before the actual assessment is made. The instrument can be filled in by one single nurse or jointly by several nurses. The joint assessment of the QoL by more than one nurse can increase the reliability and validity of the values determined [21, 32]. The assessment of the QoL of each resident with the QUALIDEM will take approx. 10 minutes [24] on average. It is important to check the form to ensure that each item has been answered completely.

Please observe the following written instructions when answering the items (see also T Ettema, J de Lange, R-M Dröes, D Mellenbergh and M Ribbe [33]):

The responses to the items must be based on the remarks or behavior of the person with dementia as observed during the previous week. To ensure that the assessment is actually based on the remarks and behavior observed during that week, and not earlier, it might be helpful to refer to the nursing records before, or during, the assessment of the QoL. In practice this has proved to be useful.

- Only one answer box may be ticked per question. If it is not possible to decide between two answers, then the box that best matches the observations during the last week should be ticked. Any answer is better than leaving the question unanswered. For some items (No.: 9, 13, 15, 17, 21, 27, 28, 30, 32, 35, 37) the abilities of the person with dementia may not allow for an exact rating, in which case the response option 'not applicable' can be used.
- It is also possible to add comments regarding the answer given (Remarks field).
- When answering the items, in addition to the remarks the resident made towards the assessing nurse, remarks made to other members of the nursing team, relatives and other residents should also be considered. When in doubt, the assessing nurse should confer with the other members of staff.
- A reply can never be incorrect. The answer selected must always be the one that corresponds best to the actual situation.
- The assessing nurse should not reflect too long on an answer. Often the first answer that comes to mind is the best one.
- For the evaluation of the QoL it is of the utmost importance that the QUALIDEM questionnaire is completely filled in. If you are uncertain, please confer with other members of the nursing staff.

- Each item must be answered independently from other items. For instance, an emotion or a behavior that is contrary to the question being answered should be disregarded. For example, when answering the item 'Is cheerful', only the resident's cheerfulness during the last week is to be assessed. Whether the resident was also sad during the same period is of no relevance when answering the question.

### **3.2 Definition of QUALIDEM Items**

In the following the content of all QUALIDEM Items is explained in detail. First of all, we present a short definition of the item and, in some cases, a description of specific features that are to be taken into consideration when it is indicated that answering the item is 'important'. Finally, two or three examples are given of behavior or other expressions of affect of people with dementia as addressed by the item.

For the 18 items that are also used in case of very severe dementia, examples are provided related to the stage of dementia (mild to severe or very severe) of the person being assessed. These examples are meant to clarify the content of the items, not describe every relevant situation. The actual situation can, of course, be different.

The definitions and examples of each item were developed using individual and focus group-based cognitive interviews. These definitions and examples for all QUALIDEM items were discussed in a one-day workshop with the first author of the original QUALIDEM to develop the final definitions and examples [25].

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## 1. Is cheerful



### Definition

Prevailing mood is very positive, expressed by positive statements or behavior, positive and friendly facial expression or shining eyes. Cheerfulness is shown over a longer period, i.e. longer than a particular situation or moment. Nevertheless, the same person can have sad moments as well, even on the same day.



### Important

- 'Is cheerful' is understood as a very positive emotion. This is stronger or more intense than the behavior assessed under item 10 'Is in a good mood' or item 5 'Radiates satisfaction'.
- Cheerfulness is not the result of a short-term nursing intervention as assessed under the item 'Mood can be influenced in a positive sense'.



### Examples (mild to severe dementia)

- *The resident is looking forward to the upcoming visit of her relatives. When they arrive, she is happy and gives them a hug.*
  - *The resident is enjoying an activity taking place in the open plan kitchen or the social contacts there and is laughing.*
  - *The resident is listening to music and shows her/his happiness by humming along with the music or smiling.*
  - *The resident is glad to see other residents or nurses and greets them cheerfully and exuberantly.*
- 

## 2. Makes restless movements



### Definition

Restless movements of the resident, whether standing, sitting or lying in bed. The reason for the restlessness is not important for the answer.



### Examples (mild to severe dementia)

- *The resident in her wheelchair moves around the open plan kitchen or up and down the corridors of the living area tirelessly or agitated with no apparent aim.*
  - *The resident repeatedly stands up and walks around or changes seats before getting up again a short time later.*
  - *The resident fiddles with the buttons on her blouse or with a serviette. She knocks on the table or repeatedly moves her legs.*
  - *The bedridden resident hits the bed rails or drums with her hands on the bedside table.*
  - *The resident turns over/rolls around in bed or tries to do this as far as she is able to.*
  - *The resident tries to get out of bed or climb over the bedrail, if there is one.*
- 



### Examples (very severe dementia)

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### 3. Has contact with other residents



#### **Definition**

Verbal or nonverbal interaction between the resident and at least one other resident. The duration of the interaction is not decisive here, but it should take longer than just a short greeting. The verbal statements do not always have to make sense but it is important that there is some kind of interaction.



#### **Important**

- A resident who is pushed to the open plan kitchen in a wheelchair by a nurse but who just sits there and stares and therefore has no interaction with other residents, is considered to have no contact with other residents.
- It is not relevant which person initiates the contact.
- Contrary to item 12 'Responds positively when approached', only the contact with other residents is relevant here. The contact is not positive per se, it can also be a negative (e.g. quarrelsome).
- The resident who has contact with other residents may also withdraw during other parts of the day or course of the week (see item 25 'Cuts himself/herself off from environment').



#### **Examples (mild to severe dementia)**

- *At lunchtime, the resident greets the others at her table and joins in the conversation.*
- *The resident in a wheelchair greets another resident either verbally or by touching. Both residents then take part in an activity (e.g. community singing, church service).*
- *The resident accuses another resident of stealing her wristwatch; they then begin to argue until a nurse settles the dispute.*



#### **Examples (very severe dementia)**

- *The bedridden resident, who can hardly express herself verbally, smiles when a resident she knows comes into her room. Both residents greet each other with their hands and the bedridden resident listens to what her visitor tells her (at least gives the impression of listening by looking at the other resident while he talks or by the comments she gives).*

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#### 4. Rejects help from nursing assistants

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##### **Definition**

Verbal comments or nonverbal behavior of the resident expressing not accepting help or assistance from care staff. 'Help' = nursing/caring actions.



##### **Important**

- Care staff = all the staff directly involved in nursing or caring, including, for instance, social service staff.
- The rejection of care behavior does not only apply to the nurse carrying out the proxy rating. If one or more members of the nursing staff have experienced such behavior within the past week, this should be taken into consideration when answering this item. If you are uncertain if this behavior has occurred, please check with the care team.



##### **Examples (mild to severe dementia)**

- *The female resident rejects, either verbally or nonverbally, help from a male nurse with washing in the morning.*
  - *The resident rejects, either verbally or nonverbally, assistance from a nurse during meals.*
- 

#### 5. Radiates satisfaction

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##### **Definition**

Relaxed, even-tempered or neutral mood of resident, expressed, for example, by a relaxed facial expression and body language or by statements confirming satisfaction or contentment.



##### **Important**

- The satisfaction reflects the general emotional state of the resident and not just a reaction resulting from, for example, a specific (nursing) activity, as assessed under the item 40 'Mood can be influenced in a positive sense'.
- A satisfied appearance, although it expresses a positive mood, is less intense than the behavior referred to in item 10 'Is in a good mood' or item 1 'Is cheerful'.



##### **Examples (mild to severe dementia)**

- *The resident is sitting in the open plan kitchen; her face shows she is relaxed. She takes part in a conversation or is daydreaming.*
- *The resident waits patiently and relaxed until a nurse has time to help her.*



##### **Examples (very severe dementia)**

- *The resident is lying relaxed in bed, looking at a photo on the bedside table.*
  - *The resident is lying in bed, relaxed and watching television or listening to the radio.*
-

---

## 6. Makes an anxious impression



### Definition

Verbal comments or nonverbal behavior indicate that the resident is frightened. The resident's fear can be either short-term and/or long-term. The fear may be caused by a particular situation or may be generalized, i.e. not related to a specific situation.



### Examples (mild to severe dementia)

- *The resident is afraid of the night and the dark. She asks the night nurse to leave a small lamp on for better orientation.*
- *The resident, who is being helped out of bed into a wheelchair by two nurses, tenses up and holds on to whatever is available because she is very afraid, e.g. of falling.*
- *The resident reacts negatively with a trembling voice and tense body to a nurse who is new to her.*



### Examples (very severe dementia)

- *The resident has consumed a warm lunch with the help of a nurse. Afterwards, she is offered a cold dessert (e.g. yoghurt or ice cream). The resident initially reacts with uneasiness and anxiety because she is unable to process the shift to cold food at short notice.*
  - *The nurse is helping a bedridden resident to change her position in bed in order to relieve pressure. The resident's whole body stiffens and she holds on tightly to the bedrail or bedside table.*
- 

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## 7. Is angry



### Definition

Verbal comments or nonverbal behavior expressing a person's annoyance. The resident's anger may be caused by a particular situation or may be unrelated to any specific situation.



### Important

The duration of a resident's annoyance is irrelevant for answering the item.



### Examples (mild to severe dementia)

- *The resident leaves the open plan kitchen after a conflict with another resident, slamming the door.*
- *The resident calls for a nurse in a rude way and complains that she has been waiting a long time for assistance.*



### Examples (very severe dementia)

- *The bedridden resident, who is hardly able to express herself verbally, makes grumbling/abusive sounds.*
  - *The resident is angry for no apparent reason and cannot express herself verbally. However, her facial expressions and gestures (e.g. narrowed eyes, wagging her index finger) or flushed face reflect her annoyance.*
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## 8. Is capable of enjoying things in daily life

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### **Definition**

The ability of the resident to enjoy situations and activities in daily life and to express this either verbally or through nonverbal behavior.



### **Important**

When answering this item it is important to take into consideration the entire daily routine, since it is possible that the resident can only enjoy certain situations, e.g. activities in the evening.



### **Examples (mild to severe dementia)**

- *The resident enjoys the warm midday meal or afternoon coffee and expresses this verbally or nonverbally.*
- *The resident enjoys taking part in various activities (e.g. listening to the daily newspaper being read aloud, community singing) and shows this by smiling or listening attentively or by joining in the singing.*
- *The resident likes to put on her best skirt on Sunday, or being helped to do this.*
- *The resident enjoys smoking a cigarette after the midday meal.*



### **Examples (very severe dementia)**

- *The bedridden resident enjoys a piece of chocolate given to her as dessert after lunch and shows this by smiling.*
  - *The bedridden resident looks forward to and enjoys the weekly visit from her daughter and shows this with a smile or a shine in her eyes.*
-

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## 9. Does not want to eat



### Definition

Verbal comments and nonverbal behavior that show clearly that the resident does not want to eat one or more of the three main meals.



### Important

- Refusing a snack or a drink should not be taken into consideration when answering this item.
- For residents who are not fed orally the item should be answered with 'not applicable'.



### Examples (mild to severe dementia)

- *The resident refuses verbally to eat the midday meal and pushes her plate away.*
- *The resident, who can hardly speak and who is assisted with eating, spits out the food after the first spoonful and will not open her mouth again.*



### Examples (very severe dementia)

- *The bedridden resident who is assisted during mealtimes refuses to open her mouth and turns her head away.*

---

## 10. Is in a good mood



### Definition

Prevailing mood is positive, expressed by positive comments or behavior. This good mood is not limited to single moments, such as greeting a person, but can be observed over a longer period. The same person can also have sad moments on the same day.



### Important

- 'Is in a good mood' is considered a positive emotion. It is stronger or more intense than the behavior assessed under the item 'Radiates satisfaction', but weaker than the behavior recorded under the item 'Is cheerful'.
- The good mood is not the result of a short-term (nursing) action, as assessed under the item 'Mood can be influenced in a positive sense'.



### Examples (mild to severe dementia)

- *The resident enjoys the informal banter or social contacts in the open plan kitchen and actively takes part in both.*
- *The resident is sitting in front of an open window, smiling and enjoying the sunshine and the pleasant warm air.*

---

## 11. Is sad



### Definition

Sad or downhearted mood of the resident which can last for varying lengths of time. The mood of a resident can change on any given day from sad to being 'in a good mood' or 'cheerful'.



### Important

- Contrary to item 23 'Cries', the sadness recorded with the item 'Is sad' is not necessarily accompanied by tears.
- 'Is sad' refers to less intense sadness than the item 'Cries'.



### Examples (mild to severe dementia)

- *The resident is sitting hunched up at the table. She tells a nurse that she doesn't want to be a burden to her. She doesn't cry but it is clear to the nurse that the resident is sad, even if she doesn't know exactly why.*
  - *The resident is looking at photos of friends and members of her family. She seems to be in low spirits. When a nurse enquires, she says she is sad that so many people who are dear to her are deceased.*
  - *The resident is talking to a nurse and mentions that she is often sad because her children live so far away from the home and can visit her only rarely.*
-

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## 12. Responds positively when approached



### Definition

The resident reacts positively to verbal or nonverbal contact initiated by another person, such as another resident, a nurse or relative.



### Important

Contrary to item 40 'Mood can be influenced in a positive sense', a change in the emotional mood is not relevant when answering this item.



### Examples (mild to severe dementia)

- *The resident, who is often restless or seems anxious when alone, relaxes in the company of other residents. She calms down and takes part in a conversation.*
- *The resident in a wheelchair, who can hardly speak anymore and cannot join conversations, participates in a group singing old songs. Although she can't sing with them, she tries to hum the tunes and enjoys the opportunity of expressing herself in the company of others and of listening to the music.*



### Examples (very severe dementia)

- *The bedridden resident, who can no longer speak and who spends most of the day daydreaming, wakes up when a relative pays her daily visit and holds the visitor's hand.*

---

## 13. Indicates that he or she is bored



### Definition

Verbal comments that show that the resident feels bored.



### Important

- For residents with mild to severe dementia who are no longer able to express themselves verbally, this item should be answered with 'not applicable'.
- When answering this item, comments made to others (staff members, relatives, other residents) than the nurse carrying out the assessment should be taken into consideration.



### Examples (mild to severe dementia)

- *The resident mentions to a nurse that she is bored.*
- *The resident asks a nurse repeatedly when the community singing will start. Again and again, she goes into the room where the singing takes place. When she sees that there is no one else in the room, she goes back and asks the nurse again when the singing will start.*
- *During the weekend, a resident mentions to a nurse: 'There's nothing going on here today.'*
- *The resident asks a nurse whether she has some task or activity for her to do.*

---

#### 14. Has conflicts with nursing assistants



##### **Definition**

Disputes or disagreements between the resident and one or more of the nurses. The conflict may arise in particular situations or (almost) continuously. A conflict may be expressed either verbally or nonverbally.



##### **Important**

- Nurses = all staff directly involved in nursing or caring, including, for instance, social service staff.
- The conflict can be with all nurses involved in the care for the resident, not just the nurse carrying out the assessment with QUALIDEM. Any conflict between any member of the nursing staff and the resident within the past week should be taken into consideration when answering this item.



##### **Examples (mild to severe dementia)**

- *The resident would like to leave the living area, but since she has lost her way several times this is only possible if she is accompanied by a nurse. However, because none of the nurses have time at the moment, the resident is put off until later. The resident doesn't understand why she can't go on her own. She wants to go out immediately and voices this angrily.*
- *The resident would like to smoke a cigarette or light a candle in her room. This is not allowed without supervision in the institution. Although the nurses have informed her about this several times, she tries to do it again and gets into an argument with a nurse who explains her that this is not allowed*



##### **Examples (very severe dementia)**

- *The bedridden resident shows resistance to the nurses who want to relieve pressure by changing her position. The resident tries to hit, pinch or scratch the nurses.*
  - *The resident, who is more or less bedridden, would like to have a glass of water within reach on her bedside table. The nurse refuses to put the glass there because recently the resident has spilled the water while trying to drink in bed. The nurse asks the resident to use the bell if she wants a drink. The resident rejects this suggestion and scolds at the nurse.*
-

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## 15. Enjoys meals



Verbal comments and nonverbal behavior that show clearly that the resident enjoys one or more of the three main meals.

### **Definition**



For residents who do not eat orally the item should be answered with 'not applicable'.

### **Important**



### **Examples (mild to severe dementia)**

- *The resident tells a nurse that she is looking forward to the midday meal or that it tasted good.*
- *The resident asks a nurse during lunch whether she can have a second helping.*
- *The resident puts only a small amount of food on her fork or spoon and then enjoys it when it is in her mouth.*



### **Examples (very severe dementia)**

- *A bedridden resident, who can no longer speak, smiles after a meal and sighs contentedly.*

---

## 16. Is rejected by other residents



### Definition

Verbal comments and behavior showing that other residents reject or avoid contact with the person with dementia who is being assessed.



### Important

- The direct behavior and verbal comments of the fellow residents of the person being assessed are decisive for answering this item.
- The comments and behavior of the person being assessed are of no consequence here.



### Examples (mild to severe dementia)

- *The resident is banished by her table companions due to her behavior during the midday meal. They demand that she leaves the table because they do not want to eat with her.*
- *The resident, who drools excessively, is banished by the other residents. Shortly after the resident joins the residents at another table, those residents get up and leave the table.*



### Examples (very severe dementia)

- *The resident in a wheelchair, who frequently calls out loudly, is ordered verbally by other residents to stop shouting. One of the residents complains to a nurse about the shouting.*
  - *The resident in a wheelchair who has unpleasant odorous wounds, is avoided by the other residents because of the bad smell.*
- 

## 17. Accuses others



### Definition

Verbal accusations made by the resident against a nurse, a resident or another person.



### Important

For residents with mild to medium dementia who can no longer express themselves verbally, this item must be answered with 'not applicable'.



### Examples (mild to severe dementia)

- *The resident accuses a nurse of not taking her home after she allegedly promised to do so.*
  - *The resident accuses a nurse of, for instance, trying to poison her.*
  - *The resident accuses another resident of her or lying to her.*
-

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## 18. Takes care of other residents



### Definition

Behavior or verbal statements, which show that the resident cares for other residents, for example helping with walking, eating, finding their way, giving comfort, warning a nurse when another resident is in need.



### Examples (mild to severe dementia)

- *The resident notices that her table companion, who can hardly express herself verbally, is feeling cold. She calls a nurse and informs her accordingly.*
  - *The resident asks her table companion how she is feeling and listens to her problems. She tries to comfort the table companion.*
  - *The resident reminds her table companion to take her medication, which she otherwise regularly forgets.*
  - *The resident pours a cup of coffee for another resident or pushes her into the open plan kitchen in her wheel chair.*
  - *The resident hands out sweets to the others at her table.*
- 

## 19. Is restless



### Definition

Restless, agitated behavior of the resident, for example rapid breathing, a worried look or calling out.



### Important

- *Contrary to item 2 'Makes restless movements', the restlessness recorded under this item is not necessarily indicated by movement of the extremities or the head.*
- *The reason for the resident's restlessness may be anxiety, tension or overstimulation of the senses, for example.*



### Examples (mild to severe dementia)

- *The resident is restless before her doctor pays her a visit, because this is something special for her. She shows her restlessness by asking the nurse at short intervals when the doctor will be coming.*
- *The resident is restless and cannot sleep because she dreads a hospital visit the next day.*
- *The resident suffers from frightening hallucinations which make him anxious. He shows this by restless behavior such as rapid breathing, nervous glances or calling.*
- *The resident is afraid and calls out because she cannot find her room.*



### Examples (very severe dementia)

- *The bedridden resident gets restless or upset when she notices that two nurses enter her room to prepare her for a change of position in bed.*
  - *The bedridden resident is upset and calls for a member of her family. Her anxiety is shown by her tremulous voice and rapid breathing.*
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## 20. Openly rejects contact with others



Verbal comments and nonverbal behavior used by the resident to reject or refuse contact with fellow residents, staff or relatives.

### Definition



In contrast to item 16 'Is rejected by other residents', the behavior and verbal comments of the person being assessed are relevant for answering this item.

### Important



### Examples (mild to severe dementia)

- *The resident refuses visits from her son.*
- *A nurse pushes the resident in a wheelchair to a table in the open plan kitchen. When the resident recognizes her table companions, she orders the nurse to bring her to another table. While being moved to the other table, she tells the nurse that she wants to have nothing to do with those residents.*



### Examples (very severe dementia)

- *The bedridden resident rants and raves when another resident enters her room.*
  - *The bedridden resident turns her head away when her daughter comes to visit her and also during the visit does not have eye contact with her.*
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**21. Has a smile around the mouth****Definition**

A smile or laugh the resident shows either in response to the current situation or longer-term. This should not be related only to greeting a person.

**Important**

If a resident is unable to control her facial expressions due to an illness, this item must be answered with 'not applicable'.

**Examples (mild to severe dementia)**

- *The resident is looking out of the window and smiles while watching the birds flying around in the trees.*
- *The resident smiles when looking at some of her old photos.*

**Examples (very severe dementia)**

- *The bedridden resident is humming a melody from her youth, her eyes are shining and she smiles.*
  - *The bedridden resident is visited by her daughter and small grandchildren. She smiles when she sees them and during the visit she repeatedly holds the children's hands or strokes their hair.*
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## 22. Has tense body language

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### **Definition**

Tense or cramped body language, shown, for instance, by the position of body or extremities or by clenching the teeth.



### **Important**

- The reason for the resident's tenseness can be fear, pain or general anxiety.
- The mere presence of contractures is not a sign of a tense body language.
- Changes in the state of the body due to illness or side-effects of medications are not to be considered when answering this question.



### **Examples (mild to severe dementia)**

- *The resident is sitting in a chair in her room, tensed up and her upper body leaning forward slightly. She is holding on tightly to both armrests and is staring expectantly out of the window at the home's car park, waiting for her son to arrive.*
- *The resident is afraid of being moved from her bed to a wheelchair because she had already fallen once. When the nurses start to lift the resident from the bed, her body tenses up and she tries to hold on to whatever is available.*
- *The resident is anxious and shows this by tensing his/her arms and legs, clenching his/her fists, or clamping his jaws on each other.*



### **Examples (very severe dementia)**

- *The bedridden resident is lying tensed up in bed, whimpering and arms crossed in front of her upper body. The reason for this is unclear to the nurse.*
  - *The bedridden resident is being repositioned by a nurse to relieve pressure. Since the resident is afraid to fall, her body tenses up and she holds on tightly to the bedrail or bedside table, preventing the nurse to accomplish her task.*
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**23. Cries****Definition**

The person emits a plaintive sound accompanied by tears. The reason for this may be a deeply sad mood, low spirits or pain.

**Important**

An uncontrolled flow of tears due to an eye disease, for example, is not to be taken into consideration when replying to this item.

**Examples (mild to severe dementia)**

- *At Christmas the resident feels the absence of her husband more profoundly than on other days. A nurse notices her sitting in her room, crying over an old family photo.*
- *The resident is sitting in a chair, crying. When the nurse asks what is going on, she says she has a severe pain in her hip.*

**Examples (very severe dementia)**

- *The bedridden resident, who can no longer express herself verbally, is lying in her bed, crying and whimpering slightly. Although the reason is unclear to the nurse, there is no doubt that the resident is crying.*
  - *The bedridden resident cries after being helped to change his position in bed. The nurse thinks this is probably caused by pain due to the patient's osteoporosis.*
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**24. Appreciates help that he or she receives****Definition**

Verbal comments or nonverbal behavior expressing a positive appreciation of nursing assistance or care. The assistance may be provided by nursing staff, other residents or relatives.

**Important**

The item 'Appreciates help that he or she receives' assumes a positive assessment by a resident of the nursing assistance or care provided, thus distinguishing it from the item 'Accepts help'.

**Examples (mild to severe dementia)**

- *The resident thanks the nurses verbally for helping her wash in the morning.*
  - *Two nurses take a resident in a wheelchair to bed after lunch. She can hardly speak but takes one of the nurse's hands and presses it, smiling with relief, thus expressing her gratefulness for the nurses' help and the opportunity to rest for a while.*
  - *The resident thanks a fellow resident for moving two chairs so that she can pass in her wheelchair.*
-

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## 25. Cuts himself/herself off from environment



Verbal comments or nonverbal behavior of the resident, illustrating temporary or permanent social withdrawal.

### Definition



- A 'prescribed separation' of a resident, e.g. for reasons of hygiene in case of an infectious disease, is of no relevance when answering this question.
- 'Cut off' does not necessarily mean a spatial separation from other persons.

### Important



### Examples (mild to severe dementia)

- *The resident refuses to take part in the social life and activating program in the home. She remains in her room except for mealtimes.*
- *The resident retreats more and more from the social life in the home. She refuses increasingly to take part in social activities.*
- *The resident retreats into a corner of the open plan kitchen or living area, for instances because she feels the other residents are too noisy.*



### Examples (very severe dementia)

- *The bedridden resident or resident in a wheelchair turns her head away when other people enter her room or speak to her.*
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## 26. Finds things to do without help from others



The resident's ability to keep herself/himself occupied in a meaningful and active manner.

### Definition



Relevant for answering this item is the active pursuit of an activity. This means that a resident who falls asleep in front of the television or shows no reaction to what she sees is not keeping herself busy at that moment.

### Important



### Examples (mild to severe dementia)

- *After breakfast, the resident regularly sits down at a window from which she can easily observe the entrance to the nursing home.*
  - *The resident has a doll that she dresses and undresses or feeds without help from others.*
  - *The resident tries to read a newspaper or a book, she listens to the radio or watches television.*
  - *The resident repeatedly unfolds a towel in order to fold it up again.*
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## 27. Indicates he or she would like more help



### Definition

The resident verbally expresses the desire or need for more help.



### Important

- For residents with mild to severe dementia who are no longer able to express themselves verbally, this item should be answered with 'not applicable'.
- When answering this item, statements should be taken into considerations that are made not only to the nurse carrying out the assessment but also to other members of the nursing staff, relatives or other residents.



### Examples (mild to severe dementia)

- *The resident states clearly to a nurse or relative that she requires more assistance.*
  - *The resident expresses her disappointment to another resident: 'Oh, I can't go into the garden on my own any more, but the nurses have got no time...'*
- 

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## 28. Indicates feeling locked up



### Definition

Verbal comments, expressing that the resident feels confined or trapped within the living area, the institution or the resident community.



### Important

- For residents with mild to severe dementia who are no longer able to express themselves verbally, this item should be answered with 'not applicable'.
- When answering this item, comments made to others than the nurse carrying out the assessment, such as members of the nursing staff, relatives and other residents, should also be taken into consideration.



### Examples (mild to severe dementia)

- *The bedridden resident mentions to a nurse that she feels trapped and confined to her bed due to her lack of mobility.*
  - *The resident mentions to a nurse that she feels trapped and observed.*
  - *The resident confides to a nurse that she feels as though she is in prison.*
  - *The resident mentions to her relatives that she misses the members of her former church congregation and that she feels trapped in the residential community.*
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### 29. Is on friendly terms with one or more residents



Attachment or closer relationship between one or more other residents.

#### Definition



#### Examples (mild to severe dementia)

- *The resident waits in front of another resident's room to go to a church service together.*
  - *The resident enters the open plan kitchen in the morning and walks to her usual place. When all the other residents have arrived, she realizes that her table companion is missing. This worries her and she asks one of the nurses where the other resident is.*
  - *The resident is a member of a small group of residents (a clique) who often sit together and join the activity program, and frequently spend time with each other outside the program. After her morning wash, the resident asks the nurse whether the other residents in the group have already gone to the open plan kitchen.*
- 

### 30. Likes to lie down (in bed)



Verbal comments and behavior that show clearly that the resident would like to lie down. How long this desire continues differs individually.

#### Definition



#### Important

For a bedridden resident who can no longer be mobilized on a chair or on the edge of the bed or in a sitting position in bed, this item should be answered with 'not applicable'.



#### Examples (mild to severe dementia)

- *The resident asks a nurse to take her to her bed after the midday meal. When she is lying down, she tells the nurse that she is relieved to be able to relax a little.*
- *The resident, who is usually helped out of bed by a nurse in the morning, refuses this help one morning. She says she feels tired and would like to stay in bed that day.*
- *The resident, who is normally able to get out of bed on her own and go to the open plan kitchen, for example, withdraws to her room several times during the day in order to lie down on her bed.*
- *The resident is helped back into bed by two nurses after being mobilized in a wheelchair. She cannot speak but shows her relief to be able to lie down and rest with a slight smile and relaxed breathing.*



#### Examples (very severe dementia)

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## 31. Accepts help



Verbal comments or nonverbal behavior expressing the resident accepting assistance or care. The assistance may be carried out by nursing staff, other residents or by relatives.

### Definition



The item 'Accepts help' assesses only the acceptance of help regardless of the resident's judgment of the offered help, distinguishing this item from item 24 'Appreciates help that he or she receives'.

### Important



- *The resident agrees that a nurse may help her wash in the morning and tolerates this.*
- *The resident whose mobility is gravely impaired accepts a nurse's suggestion to use a wheelchair to go for a walk in a nearby park.*

### Examples (mild to severe dementia)



- *The bedridden resident allows a nurse to carry out her intimate hygiene.*
- *The very anxious resident, who reacts defensively if nursing interventions are carried out too quickly, accepts help to change his position in bed when the two nurses helping him apply a validating approach.*

### Examples (very severe dementia)

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## 32. Calls out



### **Definition**

Loud and seemingly untargeted calling, shouting or groaning by a resident, the duration of which may vary per person.



### **Important**

- 'Calling' a nurse electronically by means of a bell is not relevant when answering this item.
- A targeted call, for instance, of a resident at a certain time each night because she needs a nurse to help her to the toilet is not to be taken into consideration when assessing this item.
- For residents who are no longer able to express themselves verbally (e.g. because of a tracheotomy), this item should be answered with 'not applicable'.



### **Examples (mild to severe dementia)**

- *The resident is sitting in the corridor shouting 'Mama!', 'Hello' or 'Help!'. The reason for this is unclear.*



### **Examples (very severe dementia)**

- *The bedridden resident who can hardly express herself verbally, groans continuously and so loud that it can be heard outside the resident's room.*
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### 33. Criticizes the daily routine



#### Definition

Negative comments from, or behavior of, the resident in connection with care procedures or other regulations in an institution.



#### Important

- Individual solutions already found to address the criticisms regarding routine procedures or regulations are not to be taken into consideration when answering this item. For example, to meet the individual desires of the resident, a later time was agreed for the evening meal instead of a fixed early time.
- Disliking routine procedures or regulations may be shown nonverbally by the refusing certain actions related to the routine.



#### Examples (mild to severe dementia)

- *The resident who has only recently moved into the home refuses the evening meal at 18:00 hrs. because she feels this is too early for her. She asks whether she can get her evening meal at around 20:00 hrs.*
  - *The resident is woken up in the morning to be washed, although she preferred to sleep longer. She expresses her annoyance and refuses to get up and to be helped with washing.*
  - *The resident is woken up by a nurse at the usual time in the morning, but because the resident hasn't slept well, she says she would like to sleep a bit longer. The nurse doesn't mind and continues her work by helping other residents. Ten minutes later the resident announces that she is awake and complains that the nurse didn't wake her up. She has forgotten her earlier request.*
  - *The resident is angry because her wardrobe or refrigerator is locked overnight.*
  - *The resident is angry because the terrace door is locked. She does not understand that the door is locked because of the bad weather.*
- 

### 34. Feels at ease in the company of others



#### Definition

Verbal comments or nonverbal behavior expressing to what extent a resident feels comfortable in the proximity of others, e.g. residents, relatives or friends.



#### Examples (mild to severe dementia)

- *The resident tells a nurse that she feels comfortable in the company of the other residents in the living area.*
  - *The resident enjoys eating together with other residents in the open plan kitchen. She remarks to her table companions that the meal taste much better when eaten with companions.*
  - *The bedridden resident, who is often sad when she is alone, enjoys being taken in a wheelchair to the other residents in the open plan kitchen for a few hours a day. She is more awake and more agile when she is with others than when she is alone.*
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**35. Indicates not being able to do anything**

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**Definition**

Verbal comments expressing that the resident feels incapable of doing anything.

**Important**

- For residents with mild to severe dementia, who are no longer able to express themselves verbally, this item should be answered with 'not applicable'.
- When answering this item, statements made to other persons than the person doing the assessment (e.g. other nursing staff members, relatives, or other residents) should also be taken into consideration.

**Examples (mild to severe dementia)**

- *After her morning wash, the resident mentions to the nurse that she is a burden to others and that she can no longer do anything.*
  - *The resident states that she can no longer play a part in the residents' community or in her family, and that she needs help all the time. She is sad and says she cannot do anything anymore.*
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**36. Feels at home on the ward**

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**Definition**

Verbal comments or behavior of the resident expressing he feels at home on the ward where he lives.

**Examples (mild to severe dementia)**

- *The resident has a friendly relationship to one or more of the other residents.*
  - *The resident tells a nurse that she feels comfortable in the home or that 'this' is her new home.*
  - *The resident enjoys helping the staff with activities in the living area.*
-

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### 37. Indicates feeling worthless

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#### **Definition**

Verbal comments of the resident expressing that he considers himself to be worthless and a burden to others.



#### **Important**

- For residents with mild to severe dementia who are no longer able to express themselves verbally, this item should be answered with 'not applicable'.
- When answering this item, statements made to members of the nursing staff other than the person who does the assessment, to relatives or other residents should also be taken into consideration.



#### **Examples (mild to severe dementia)**

- *The resident states that she has nobody that she is important to or who misses her.*
  - *The resident says she wants to die. She feels worthless because she feels she is a burden to others.*
  - *The resident says she can no longer play a part in the social network of the residents or in her family, which makes her feel worthless.*
- 

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### 38. Enjoys helping with chores on the ward

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#### **Definition**

Verbal comments or behavior showing the resident likes to be involved in household or caring activities on the ward or in the living area.



#### **Examples (mild to severe dementia)**

- *The resident helps lay or clear the dining table.*
  - *The resident helps to fold towels or to dry the small medication dishes.*
  - *The resident helps with the cooking and baking in the living area gives advice on how to prepare a specific meal.*
-

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### 39. Wants to get off the ward



#### Definition

Verbal comments or behavior that expresses the resident's wish to leave the living area or the care facility.



#### Important

- The desire to temporarily leave the living area or the care facility, for example to go out for a walk or to visit relatives, is not relevant for answering this question.
- Relevant for answering the item 'Wants to get off the ward' are comments or behavior suggesting the person doesn't want to stay in the care facility and does not intend to return to the care institution.



#### Examples (mild to severe dementia)

- *The resident remarks to a nurse, other residents or to her relatives that she would like to go home.*
  - *The resident repeatedly packs her clothes into a suitcase and tries to leave the care institution with it.*
  - *The resident stands waiting in front of the closed/locked entrance of the ward. She tries to leave the ward when a member of the staff or visitors enter or leave the ward.*
- 

### 40. Mood can be influenced in a positive sense



#### Definition

The possibility of positively influencing a resident's mood, for example by means of a conversation or comforting nursing/care.



#### Important

- The conversation, nursing/care can be initiated, for example, by nurses, other residents or relatives.
- The resident's mood changes in reaction to an external action or event (e.g. conversations, nursing care).



#### Examples (mild to severe dementia)

- *The resident is uncertain and annoyed because an unknown nurse wants to help her wash in the morning. At first, she refuses the assistance and to start washing. However, when a nurse she knows well comes in and speaks to her, her mood changes, she is more trusting and is prepared to start washing herself.*
- *The resident is sad and withdrawn. The nurse in charge doesn't know the reason why, but she notices that the resident's mood brightens up after speaking to her daughter on the phone.*



#### Examples (very severe dementia)

- *The bedridden resident is lying in bed half asleep and hardly reacts when a nurse talks to her. When the nurse puts a doll in her hands, the resident reacts and begins to stroke the doll.*
  - *The bedridden resident calls loudly for help. A nurse comes to her quickly and notices that the resident is very upset. She takes her hands and talks comfortingly to her. After a short time, the resident relaxes and calms down.*
-

### **3.3 Psychometric properties of the QUALIDEM**

The QUALIDEM is a relatively new dementia-specific QoL instrument. Nevertheless, several studies have been conducted on its psychometric properties [21, 24, 25, 32, 34-36] and further studies are in progress [37]. Currently no data are available for assessing the responsiveness to change and for establishing norm data for the interpretation of the QUALIDEM. Indications for the responsiveness of the QUALIDEM were given in some longitudinal [38, 39] and interventional studies [40]. These studies demonstrate a significant change in QUALIDEM scores. This user guide will be updated as soon as new data on psychometric properties become available.

#### **3.3.1 Reliability**

The strong internal consistency (Cronbachs alpha > 0.7) of most of the QUALIDEM subscales is supported by several studies [21, 24, 29, 34, 35]. However, depending on the particular study, in people with mild to severe dementia the subscales *Social Isolation* and *Having something to do* showed moderate to weak results for internal consistency (Cronbachs alpha: 0.24 – 0.62), and in people with very severe dementia the subscales *Negative Affect*, *Social Relations*, and *Social Isolation* appeared to have a weak to moderate internal consistency (Cronbachs alpha: 0.41 – 0.59).

Currently two studies are available which demonstrate the strong test-retest reliability of the QUALIDEM subscales over a period of one week [21, 32]. All QUALIDEM subscales showed Intra-Class Correlation Coefficients > 0.7, regardless of the severity of dementia of the assessed residents. The results for the inter-rater reliability of the QUALIDEM are heterogeneous. Two studies showed an insufficient inter-rater reliability (ICC < 0.7) for most of the QUALIDEM subscales. However, both studies also analyzed the inter-rater reliability data under the assumption of a collaborative rating by rater dyads, and this resulted in a satisfactory inter-rater reliability (ICC > 0.7) for most of the QUALIDEM subscales. A collaborative QUALIDEM rating by two or more nurses is therefore recommended [21, 32]. One new study [41], in which definitions and examples were described and applied for all items included in this user guide (see Chapter 3.2), shows promising results for the inter-rater reliability of all QUALIDEM subscales.

#### **3.3.2 Validity**

The scalability of the QUALIDEM subscales was confirmed by three studies, two Dutch and one German. All three studies demonstrated scalability for most of the subscales. For the Dutch QUALIDEM version, only the subscale social isolation showed weak scalability (Loevinger's coefficient  $H < 0.4$ ) [21, 34]. For the German QUALIDEM the results differ between the two QUALIDEM versions used in different stages of the disease (mild to severe or very severe). In the version for people with

mild to severe dementia the subscales *Social Isolation*, *Feeling at home*, and *Having something to do* showed weak scalability. In contrast, in the version for people with very severe dementia the two subscales *Care relationship* (Loevinger's  $H = 0.47$ ) and *Positive Affect* (Loevinger's  $H = 0.65$ ) showed medium to good scalability [35].

The procedure of constructing the instrument supports the validity of the QUALIDEM, because construction was founded on a literature-based definition of dementia-specific QoI and the adaptation-coping model [6, 21] and observational data collected in field studies [20]. As part of the instrument development process, a validation study was carried out [36]. The results of this one method multi-trait matrix yielded evidence for the construct validity of the QUALIDEM. However, the process of validation is a continual, almost never-ending task of seeing how the instrument performs in a variety of situations (e.g. different populations, settings) [22]. Therefore, further research is needed to investigate the validity of the QUALIDEM, also for the German version of the instrument.

## 4. Future development of the QUALIDEM

Because the QUALIDEM is a relatively new QoI-instrument more research is needed to support the evidence on validity and especially responsiveness. Furthermore, a task for future research is to generate norm data for each QUALIDEM subscale in different stages of dementia.

The subscales *Care Relationship*, *Positive Affect*, *Positive self-image*, *Restless tense behavior*, and *Social Relations* demonstrated satisfactory results for reliability and validity in almost all studies. Depending on the language version and the stage of dementia, the subscales *Negative Affect*, *Social Isolation*, *Feeling at home*, and *Having something to do* showed insufficient reliability. Based on the results on reliability and scalability in previous studies [21, 24, 34-36] and the overlapping content, we recommend removing the subscale *Social Isolation* in QUALIDEM version 2.0. The reliability results for the remaining eight QUALIDEM subscales have to be confirmed in future studies. Furthermore, based on the reliability and scalability results the development of new, or reformulation of items for the subscales *Negative Affect*, *Feeling at home*, and *Having something to do* is recommended.

Translation into other languages, such as Spanish or French, is recommended and is a precondition for QUALIDEM to be used in multinational studies, e.g. European studies.

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### 5.1.1 QUALIDEM 2.0 questionnaire for people with mild to severe dementia (37-items)

| No. | Item  | Never                                 | Rarely                                | Some-<br>times                        | Fre-<br>quently                       | Not<br>applicable                      | Scale |
|-----|---|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|--|-------|
| 1.  | Is cheerful                                     | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 2.  | Makes restless movements                        | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 3.  | Has contact with other residents                | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| 4.  | Rejects help from nursing assistants            | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | A     |
| 5.  | Radiates satisfaction                           | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 6.  | Makes an anxious impression                     | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | C     |
| 7.  | Is angry  | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | A     |
| 8.  | Is capable of enjoying things in daily life     | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 9.  | Does not want to eat                            | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |
| 10. | Is in a good mood                               | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 11. | Is sad  | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | C     |
| 12. | Responds positively when approached             | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| 13. | Indicates that he or she is bored               | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | H     |
| 14. | Has conflicts with nursing assistants           | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | A     |
| 15. | Enjoys meals                                    | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |
| 16. | Is rejected by other residents                  | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | G     |
| 17. | Accuses others                                  | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | A     |
| 18. | Takes care of other residents                   | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| 19. | Is restless                                     | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 20. | Openly rejects contact with others              | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | G     |
| 21. | Has a smile around the mouth                    | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>NA</sub> | B     |
| 22. | Has tense body language                         | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 23. | Cries   | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | C     |
| 24. | Appreciates help he or she receives             | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | A     |
| 25. | Cuts himself/herself off from environment       | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | F     |
| 26. | Finds things to do without help from others     | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | I     |
| 27. | Indicates he or she would like more help        | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | E     |
| 28. | Indicates feeling locked up                     | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | H     |
| 29. | Is on friendly terms with one or more residents | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| No. | Item  | Never                                 | Rarely                                | Some-<br>times                        | Fre-<br>quently                       | Not<br>applicable                      | Scale |
| 30. | Likes to lie down (in bed)                      | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |

|  |                            |                            |                            |                            |                             |   |
|--|----------------------------|----------------------------|----------------------------|----------------------------|-----------------------------|---|
| 31. Accepts help                             | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |                             | A |
| 32. Calls out                                | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> NA | G |
| 33. Criticizes the daily routine             | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 |                             | A |
| 34. Feels at ease in the company of others   | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |                             | F |
| 35. Indicates not being able to do anything  | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> NA | E |
| 36. Feels at home on the ward                | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |                             | H |
| 37. Indicates feeling worthless              | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 | <input type="checkbox"/> NA | E |
| 38. Enjoys helping with chores on the ward   | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |                             | I |
| 39. Wants to get off the ward                | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 0 |                             | H |
| 40. Mood can be influenced in positive sense | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |                             | B |

**Remarks:**

**Scores of the subscales**

| Subscales   | Numbers of items (score range) <sup>1</sup> | Scores |
|---|---|--------|
| A Care relationship                                     | 7 (0 – 21) <sup>1</sup>                     | A      |
| B Positive Affect                                       | 6 (0 – 18) <sup>1</sup>                     | B      |
| C Negative Affect                                       | 3 (0 – 9)                                   | C      |
| D Restless tense behavior                               | 3 (0 – 9)                                   | D      |
| E Positive self-image                                   | 3 (0 – 9) <sup>1</sup>                      | E      |
| F Social Relations                                      | 6 (0 – 18)                                  | F      |
| G Social Isolation                                      | 3 (0 – 9) <sup>1</sup>                      | G      |
| H Feeling at home                                       | 4 (0 – 12) <sup>1</sup>                     | H      |
| I Having something to do                                | 2 (0 – 6)                                   | I      |
| <i>J Remaining items to be used in future research.</i> | 3   |        |

**Please refer to the following references when using QUALIDEM:**

- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry*, 22(6), 549-556. doi: 10.1002/gps.1713.
- Dichter, M. N., Ettema, T. P., Schwab, C. G. G., Meyer, G., Bartholomeyczik, S., Halek, M. & Dröes, R. M. (2016). QUALIDEM - User Guide. Witten.

<sup>1</sup> If all items applicable. Please reduce the max. Subscale value by three points for each item which was not applicable.

### 5.1.2 QUALIDEM 2.0 score sheet for people with very severe dementia (18-items)

| No. <sup>1</sup> | Item  | Never                                 | Rarely                                | Some-<br>times                        | Fre-<br>quently                       | Not<br>applicable                      | Scale |
|------------------|---|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|--|-------|
| 2.               | Makes restless movements                    | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 3.               | Has contact with other residents            | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| 5.               | Radiates satisfaction                       | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 6.               | Makes an anxious impression                 | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | C     |
| 7.               | Is angry                                    | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | A     |
| 8.               | Is capable of enjoying things in daily life | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |
| 9.               | Does not want to eat                        | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |
| 12.              | Responds positively when approached         | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | F     |
| 14.              | Has conflicts with nursing assistants       | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | A     |
| 15.              | Enjoys meals                                | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |
| 16.              | Is rejected by other residents              | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | G     |
| 19.              | Is restless                                 | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 20.              | Openly rejects contact with others          | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | G     |
| 21.              | Has a smile around the mouth                | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>NA</sub> | B     |
| 22.              | Has tense body language                     | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | D     |
| 23.              | Cries                                       | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | C     |
| 25.              | Cuts himself/herself off from environment   | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> |  | F     |
| 30.              | Likes to lie down (in bed)                  | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | J     |
| 31.              | Accepts help                                | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | A     |
| 32.              | Calls out                                   | <input type="checkbox"/> <sub>3</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>NA</sub> | G     |
| 40.              | Mood can be influenced in positive sense    | <input type="checkbox"/> <sub>0</sub> | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> | <input type="checkbox"/> <sub>3</sub> |  | B     |

#### Remarks:

<sup>1</sup> Items labeled with the original numbers.

## Scores of the subscales

| Subscales   |                         | Numbers of items (score range) <sup>1</sup> | Scores |  |
|---|-------------------------|---|--------|--|
| A   | Care relationship       | 3 (0 – 9)                                   | A      |  |
| B   | Positive Affect         | 4 (0 – 12) <sup>1</sup>                     | B      |  |
| C   | Negative Affect         | 2 (0 – 6)                                   | C      |  |
| D   | Restless tense behavior | 3 (0 – 9)                                   | D      |  |
| F   | Social Relations        | 3 (0 – 9)                                   | F      |  |
| G   | Social Isolation        | 3 (0 – 9) <sup>1</sup>                      | G      |  |
| <i>J Remaining items to be used in future research.</i> |                         | 3   |        |  |

### Please refer to the following references when using QUALIDEM:

- Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2007). QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *Int J Geriatr Psychiatry*, 22(6), 549-556. doi: 10.1002/gps.1713.
- Dichter, M. N., Ettema, T. P., Schwab, C. G. G., Meyer, G., Bartholomeyczik, S., Halek, M. & Dröes, R. M. (2016). QUALIDEM - User Guide. Witten.

<sup>1</sup> If all items applicable. Please reduce the max. Subscale value by three points for each item which was not applicable.