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# Achieving consensus on assessing health-related quality of life (HRQoL) in people with cognitive impairments (CI)—a Delphi study

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## HIGHLIGHTS

- The combination of all three assessment methods (self-report, proxy-report and observation) to assess HRQoL in individuals with CI across all stages of disease is to be preferred.
- If it is not feasable, self-report should be combined with a proxy-report.
- If self-report is not possible because of very severe CI, proxy-report should be combined with observation.
- The six domains physical capacity, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs should be assessed.

## ARTICLE INFO

*Keywords:*
Patient-reported outcomes
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## ABSTRACT

*Background:* The prevalence of impairments of cognitive functions is expected to increase. Enhancing the QoL of those affected is important. HRQoL in people with CI can be assessed by self-report, proxy-report or observation but there is uncertainty how to best assess HRQoL in people with CI, and which assessment method is most appropriate. Therefore the aim of our study was to use Delphi methodology in order to achieve consensus on how HRQoL should be assessed in people with CI and which content domains should be assessed.

*Methods:* The Delphi process consisted of three online survey rounds and a concluding consensus conference. Participants were experts as well as individuals and relatives of people affected by CI. The Delphi survey was developed based on existing literature and included 55 statements at the first round. Consensus was considered to be achieved when a minimum of 75 % of responses fell into the categories 6 (agree) and 7 (strongly agree) (positive consensus) or in categories 1 (strongly disagree) and 2 (disagree) (negative consensus).

*Results:* Consensus was reached for a total of 41 of 56 statements/substatements. In the 1st survey round 102 experts and 11 relatives participated. In the 2nd survey round 68 experts and 11 relatives continued to participate. In the 3rd survey round 41 experts and 9 relatives participated. In the consensus conference 17 experts and 4 relatives of individuals with CI and in the second one-hour online conference session 14 experts and 2 relatives of individuals with CI participated.

*Conclusion:* The combination of the three assessment methods self-report, proxy-report and observation across all stages of CI is the preferred method and should be used whenever possible. As domains Physical capacity, Psychological, Level of Independence, Social Relationships, Environment and Spirituality/Relogion/Personal Beliefs should be assessed.

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## 1. Background

Due to demographic aging, the prevalence of impairments of cognitive functions is expected to increase (Crimmins et al., 2011; Robert-Koch-Institut (RKI), 2021; World Health Organization (WHO), 2017). Cognitive impairments (CI) range from mild to moderate and to advanced impairments or severe forms of dementia such as Alzheimer's disease (AD) (Gauthier et al., 2022). They manifest as memory loss, learning difficulties, a declining ability to concentrate on a task, and lead to a decreased quality of life (QoL) (Georges et al., 2020).

Mild cognitive impairment (MCI) occurs as an intermediate stage between normal aging and dementia (Brijoux & Zank, 2023). MCI affects memory, attention, and thinking without significant limitations in daily life. Approximately 10–15 % of the population aged 65 and over are affected (Petersen, 2016).

Dementia is defined as the decline and loss of cognitive abilities in the areas of attention, learning and memory, orientation, judgment, and planning (executive functions), language, motor skills, as well as abilities for social interaction with others (social cognition) (Deutsche Alzheimer Gesellschaft e.v. Selbsthilfe Demenz, 2020). The prevalence of dementia was estimated by the WHO to be approximately 50 million worldwide in 2017. By 2050, it is expected to triple due to changes in the demographic structure of the world population (WHO, 2021).

As there is currently no promising treatment for individuals with CI, and medication trials can at most delay the progression of the disease (Alzheimer Forschung Initiative e.V. (AFI), 2023), the focus of care is not only on specific symptom improvement but also on enhancing the QoL of those affected. Therefore, it is essential to be able to measure the current status of QoL and the extent to which an intervention improves the QoL of the affected person. The WHO defines QoL as "individuals' perceptions 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" (WHO, 1998). The construct of health-related quality of life (HRQoL) considers QoL in the context of health and illness. It is multidimensional and encompasses aspects of physical, mental, emotional, and social functioning (Ferrans, 2005, p 15).

There is controversial about what, i.e., which content domains should be assessed in people with CI. When developing an adequate HRQoL instrument for people with CI the selection of the domains is the most crucial (Jonker et al., 2004). There are some reviews that provide an overview of quality of life instruments and their domains or subscales for people with CI (Algar et al., 2016; Bowling et al., 2015; Missotten et al., 2016; Yang et al., 2018; Perales et al., 2013. When looking at the listings in the reviews, the diversity and heterogeneity of the domains and subscales collected in the instruments become apparent. Jonker et al. (2004) provides an overview of the dimensions and domains of people with dementia and came to the conclusion that psychological well-being with the indicators 'sense of aesthetics', 'positive and negative affect', 'self-esteem' and 'feelings of belonging' is a central outcome of QOL. Other dimensions of Jonkers hierarchical model based on QOL approaches in dementia (Brod, Stewart & Sands, 1999; Lawton, 1994; Rabins, Kasper, Kleinman & Black, 1999; Volicer 1999; Walton, 1999) are 'Personal aspects not related to dementia', 'Personal aspects related to dementia' and 'Environmental factors'. The WHO has released a user manual for domains and items in assessing QOL independently of diseases with the six domains 'Physival Capacity', 'Psychological ', 'Level of Independence', 'Social Relationships', 'Environment ' and 'Spirituality/Religion/ Personal Beliefs' (WHO, 1998).

In addition to what should be assessed, there is uncertainty how to best assess HRQoL in people with CI, and which assessment method is most appropriate, especially in individuals with severe CI (Bowling et al., 2015; FLandeiro et al., 2020; Heuer & Willer, 2020; Kahle--Wrobleski et al., 2017). HRQoL in people with CI can be assessed by three different means. It can be assessed through self-reporting, where the affected individual provides their own assessment. It can also be reported by a family member, friend, or caregiver who assesses HRQoL by placing themselves in the position of the person concerned (proxy-reported). Additionally, it can be assessed through observation by an external observer who interprets the behavior of the person concerned and draws conclusions about their HRQoL condition. The most suitable method of assessment, depending on the stage of CI, is a subject of debate (Landeiro et al., 2020). According to the WHO definition of quality of life, the gold standard for assessing quality of life is self-assessment. However, in the case of CI, especially in cases of severe impairment, it may be necessary to deviate from this and resort to alternative methods such as proxy assessment and observation. Each of these methods has its advantages and disadvantages, and their application is discussed within the different stages of the condition's severity.

People with CI have deficits in memory, concentration, attention, communication, and judgment, which can lead to both a misunderstanding of questions and an inability to communicate their subjective state. The self-assessment of QoL in CI is particularly distorted by the current affect (Berwig et al., 2011). Filling out questionnaires or conducting interviews with individuals with neurological deficits can introduce fatigue. Questions may be misunderstood due to language impairments related to neurological deficits. The deficits vary depending on the severity of the condition and progressively worsen as the stages of the condition advances. With the progression of the condition, the assessment of what is important for HRQoL may also change. For instance, in MCI, it may be important to still manage household tasks independently, whereas in the advanced stage, safety and comfort may take priority (Heuer & Willer, 2020; Hickey & Bourgeois, 2000).

In the advanced stages of the disease and in longitudinal studies, it is common to interview family members or caregivers of the affected individuals, known as proxies, to assess QoL of the affected individuals (Bowling et al., 2015; Heuer & Willer, 2020; Landeiro et al. 2020). A distinction can be made between the proxy-patient perspective (proxy assessement of patient HRQoL from the patient`s view) and the proxy-proxy-patient perspective (proxy assessement of patient HRQoL from the proxy`s view) (Pickard & Knight, 2005). The subjective quality of life of individuals with dementia is better captured through proxy rating from the proxy-patient perspective (Pickard & Knight, 2005). According to Albert et al. (1996), the assessment of HRQoL through proxies is a reliable measure. However, proxy reporting is influenced by the proxy's health status, their level of stress, and the relationship between the proxy responder and the person concerned (Hickey & Bourgeois, 2000; Landeiro et al., 2020; Robertson et al., 2017). Furthermore, HRQoL and emotional well-being are often underestimated in proxy-reported assessments (Heuer & Willer, 2020; Hickey & Bourgeois, 2000; Logsdon et al., 1999; Sands et al., 2004) and cognitive abilities are overestimated (Heßmann et al., 2018; Zucchella et al., 2015). Boyer et al. (2004) found poor agreement between the affected individual and family members for emotional well-being in their study. Additionally, not all family members or caregivers are suitable to provide assessments of the HRQoL of individuals with CI due to their own health status, education level, and ability to understand questions (Heuer & Willer, 2020; Hickey & Bourgeois, 2000). Logsdon et al. (2002) concluded that the assessment of HRQoL by caregivers does not replace the self-assessment of the affected individuals.

Observations are an acceptable method when self-reporting is no longer possible (Schölzel-Dorenbos et al., 2010). They are frequently used in severe stages of CI but can also be applied independently of cognitive abilities (Missotten et al., 2016). It is recommended to use observations even in cases of cognitive-linguistic deficits in individuals with the condition (Dichter et al., 2016). Observations often serve the purpose of assessing the effects of interventions, such as creative interventions, on HRQoL in people with CI (Algar et al., 2016). However, the reliability of HRQoL assessment through observation instruments is limited, as observing behaviors, moods, gestures, and facial expressions can be challenging, especially in advanced stages of the disease (Heuer & Willer, 2020). Furthermore, only objective aspects, not subjective aspects of HRQoL, can be measured through observations (Heuer &

Willer, 2020). Algar et al. (2016) recommend not relying solely on the method of observations to assess HRQoL but also incorporating self-report or proxy reporting.

Against this background, the aim of our study was to use Delphi methodology in order to achieve consensus on how HRQoL should be assessed in people with CI and which content domains should be assessed.

## 2. Methods

### 2.1. Study design

A Delphi survey is a method for collecting opinions, assessments, and perceptions on issues for which there is uncertain or incomplete knowledge. It is a quantitative method and aims to achieve a high degree of agreement among participants (Häder, 2014). Initially, we pre-structured the issue based on the current literature and then, through multiple rounds of participation, sought to minimize the variability in responses.

The Delphi process consisted of three online survey rounds and a concluding consensus conference with audio recording.

It was conducted as part of the accompanying research project "GeLang BeLLa" within the funding initiative "Gesund ein Leben lang" (Healthy Throughout Life) (Funding: Federal Ministry of Education and Research; Funding code 01GL1905A; Project duration: September 1, 2021, to July 31, 2023; Website: www.begleitforschung-bella.de). GeLang BeLLa accompanies and connects 141 subprojects of consortia and single projects.

This paper follows the reporting guidelines for Delphi procedures in health sciences, as outlined by Spranger et al. (2022).

### 2.2. Participants

This study included two types of participants: experts (first group) and individuals and relatives of people affected by CI (second group).

Ethics approval was granted by the Ethics Committee of Otto-von-Guericke-University Magdeburg (Registration No. 161/22). Participation in the Delphi survey was voluntary and required the consent of both target groups.

#### 2.2.1. Experts

To establish an interdisciplinary panel of experts, the selection of experts focused on individuals in the German-speaking region with expertise in Patient-Reported Outcomes, Quality of Life Research, and/or Research on Dementia/ CI. These experts had various backgrounds, including practitioners (neurologists, gerontologists, psychologists), as well as researchers in the fields of healthcare research, rehabilitation, cognitive neurology, neurophysiology, psychology, nursing sciences, and public health. We searched for experts with the mentioned expertise on the Internet and identified authors of relevant publications. From this search, we built an Excel contact database with 500 potential participants, and invited them to the Delphi through informational emails. Additionally, we recruited experts through informational letters as part of the GeLang-BeLLa project, targeting those with the mentioned expertise. This included four single projects and six subprojects as part of consortia. Further, we created a flyer for experts and a Delphi website (https://www.begleitforschung-bella.de/e-delphi-befragung/). The flyer was distributed at conferences and included a QR code leading to the website. We also posted a message on Twitter (now X) about the Delphi and personally reached out to known experts in the field.

The experts were invited to the Delphi either by email and consented to participate by actively engaging in the 1st round of the Delphi survey, thereby indicating their agreement. Alternatively, they provided their consent to participate, also through implicit action, by reaching out to the project coordinator and expressing their intention to participate. This act constituted their agreement for the storage and processing of their contact information for the purpose of the survey. The consent for the collection, storage, processing, and use of survey data was obtained prior to the online survey. Experts who participated in the in-person consensus conference were offered travel cost reimbursement.

#### 2.2.2. Individuals affected by CI and relatives of people with CI

Individuals with CI of all severity levels and relatives of individuals with CI were recruited through various institutions and events, including dementia self-help groups for people with dementia and their relatives, advisory centers, clinical institutions dealing with dementia, senior citizens' organizations as well as nursing homes.

A flyer about the Delphi survey was created. The flyer was distributed in the mentioned institutions, and individuals with CI and relaties were recruited through direct outreach in self-help groups and the clinic of the Institute for Cognitive Neurology and Dementia Research at Otto-von-Guericke-University Magdeburg. Additionally, the flyer was posted on the website of Demenznetz–Magdeburg, and a Twitter post was made about the Delphi.

To encourage participation, individuals with CI and their relatives were offered a compensation of €10 for each survey round and €15 for participating in the consensus conference.

Individuals with CI and relatives expressed their interest in participating in the Delphi survey by contacting the project coordinator via email. They provided their consent to participate by signing a data protection consent form. This consent form allowed for the processing and storage of their contact information and the collection, processing, storage, and use of anonymous data gathered from the online surveys and audio recordings of the consensus conference. The consent form also explicitly stated that all information would be treated confidentially and would not allow for any personal identification. Participants provided their names and email addresses on the consent form, which were necessary for sending them all relevant information about the Delphi, participation links, and the results.

### 2.3. Data collection instrument

The Delphi survey was developed based on existing literature on assessing HRQoL in people with CI (Algar et al., 2016; Bowling et al., 2015; Dichter et al., 2016; Heuer & Willer, 2020; Hughes et al., 2021; Landeiro et al., 2020; MHEcon, Nguyen, Comans & Scuffham, 2018; Missotten et al., 2016; Robertson et al., 2017; Yang et al., 2018; Zucchella et al., 2015) as well as the WHO Quality of Life (WHOQOL) User Manual for domains and items in assessing QoL (WHO, 1998). The survey underwent a pretest by 14 researchers and was subsequently optimized. The final version (see Feißel et al., 2023) included a glossary, six statements for self-reported assessment, 14 statements for proxy assessment, six statements for observational assessment, one for the combination of all three assessment methods, 6 statements for domains and 23 for subdomains, and finally, two open fields for "comments and suggestions" and "additional uncertainties or questions that should be integrated into the Delphi". One example of a statement is as follows: "The assessment of HRQoL in people with CI should always be supported by another person". The statements were formulated in a closed-ended manner, and participants rated their level of agreement. Response options were provided on a seven-point Likert scale, ranging from "strongly disagree" (1) to "strongly agree" (7) (Franzen, 2019). The survey is typically used for all rounds of a Delphi and may only be adjusted or expanded if suggested by the participants.

### 2.4. Delphi-process

**1st Online Survey Round:** In the 1st survey round, all identified experts from the contact database were invited to participate. Additionally, all individuals with CI and relatives, who had expressed interest in participating in the Delphi, were contacted by the project coordinator. Each of them received a letter explaining the background and purpose of the survey, along with information about the Delphi process. They were also provided with a link to the 1st survey round and instructions regarding data protection using the "e-Delphi" software (www.e-Delphi.org). Four weeks were allowed for completing the survey. A reminder was sent after two weeks.

**2nd Online Survey Round**: For the 2nd survey round, all participants from the first survey were invited to participate again. They received a letter providing information about the response rate from the 1st survey round, along with a renewed explanation of the Delphi's objectives and the purpose of the 2nd survey round. Furthermore, the experts received the results from the 1st survey round of experts, and individuals with CI and relatives received the results from their respective group. This allowed them to review and potentially revise their assessments. It was emphasized that the survey for each round was very similar and would only be minimally adjusted or supplemented based on the open-text responses from the previous round. Invited participants received a link to the 2nd survey round via Delphi software, along with data protection guidelines. Again, four weeks were allocated for completing the survey, and a reminder was sent after two weeks. Additionally, all participants received an invitation along with an information sheet for the concluding hybrid consensus conference, along with a link to the registration form.

**3rd Online Survey Round**: For the 3rd survey round, all participants from the second survey were invited once again. They received a letter containing information about the response rate from the 2nd survey round, the purpose of the 3rd survey round, and the results of the 2nd survey round. This time, all invitees received the results from all participants of the 2nd survey round, allowing them to reconsider and potentially revise their assessments. They were sent a link to the 3rd survey round via Delphi software, along with data protection guidelines. Again, four weeks were allocated for completing the survey, and a reminder was sent after two weeks. Additionally, they were once more invited to the consensus conference.

**Consensus Conference:** The consensus conference was organized as a hybrid full-day event in March 2023, in Magdeburg. The objective was to discuss and subsequently vote on statements for which no consensus had been reached after the 3rd survey round. During the conference, the results from the previous online survey rounds were presented, and the further procedure was explained.

In preparation for the conference, voting cycles were prepared for statements that were still open for discussion in various categories: Self-report (1 cycle), Proxy report (2 cycles), Observation (1 cycle), and Domains and Subdomains (3 cycles). Heterogeneous small groups consisting of all registered experts, individuals with CI, and relatives were formed. These voting cycles were discussed in the small groups during the conference, with the most important points noted. Subsequently, these points were presented in the plenary session, and the statements from each voting cycle were voted on in real-time using the "eduVote" (SimpleSoft, 2021) voting software.

### 2.5. *Defining and achieving consensus*

There are numerous ways proposed to define the consensus criteria (Williamson et al., 2017). According to Bennett et al. (2012) consensus was considered to be achieved when a minimum of 75 % of the participants agreed with a statement, means in our Deplhi when 75 % of responses fell into the categories 6 (agree) and 7 (strongly agree) (positive consensus) on a 7-point Likert scale. Additionally, consensus was deemed to be present when a minimum of 75 % of responses were in categories 1 (strongly disagree) and 2 (disagree) (negative consensus). If during the conference a statement received results just below the 75 % threshold, the voting would be repeated, allowing participants to reconsider and potentially change their opinions or maintain their stance.

### 2.6. *Sample size*

We aimed to recruit 100 people for the first survey round. Assuming a response rate of 20 %, 500 experts, individuals with CI and relatives of people with CI were invited to participate.

For the consensus conference, invitations were extended to all individuals who had participated in at least one of the three online survey rounds, as well as experts in the mentioned research fields and individuals affected by CI and relatives who had not participated in the online surveys. Depending on the number of participants in the online surveys, it was anticipated that there would be between 20 and 50 participants in the consensus conference.

### 2.7. *Statistical analysis*

For each survey round, the response rate was calculated. After each survey round, each statement was analyzed descriptively using statistical software SPSS 28 to examine the response distribution across the seven response categories. Consensus was reached with the 75 % criterion (see 2.5.). The results were also graphically represented in a diagram.

Following the 1st survey round, each statement was evaluated separately for experts as well as individuals with CI and relatives of individuals with CI. Starting from the 2nd survey round, the assessment of statements by both experts as well as individualls with CI and relatives was analyzed together.

In a final report of the Delphi, statements for which consensus was reached, were color-coded. The open-text responses were reviewed and clustered after each survey round to identify relevant feedback and potentially make adjustments to the Delphi survey for the subsequent survey round.

## 3. Results

### 3.1. *Delphi-process*

The 1st survey round started in December 2022. The 2nd survey round commenced in January 2023. The 3rd survey round began in February 2023. There was a five-week gap between each survey round. Experts and individuals affected by CI had four weeks to participate in each round. In the fifth week, the results of the respective survey round were evaluated. Two weeks after the start of each survey round, a reminder was sent.

The consensus conference was conducted over two days. The first session was a hybrid full-day event. During this session, six out of seven voting cycles were discussed and voted on. The second session was held as a one-hour, purely online event, during which the seventh voting cycle was discussed and voted on.

### 3.2. *Response*

For the 1st survey round, 531 experts were invited, and 102 experts participated, resulting in a response rate of 19.2 % (Fig. 1). Out of the 102 experts, 68 continued to participate in the 2nd survey round, yielding a response rate of 66.6 %. In the 3rd survey round, 41 experts participated, resulting in a response rate of 60.3 %. Additionally, 11 relatives of individuals with CI participated in both the 1st and 2nd survey rounds, and 9 relatives participated in the 3rd survey round.

During the first hybrid session of the consensus conference, 21 people participated, including 17 experts and 4 relatives of individuals with CI. Of these participants, 11 joined online, and 6 attended in person. In the second one-hour online conference session, 16 people participated, comprising 14 experts and 2 relatives of individuals with CI. Individuals with CI could not be recruited for either the survey rounds or the consensus conference.

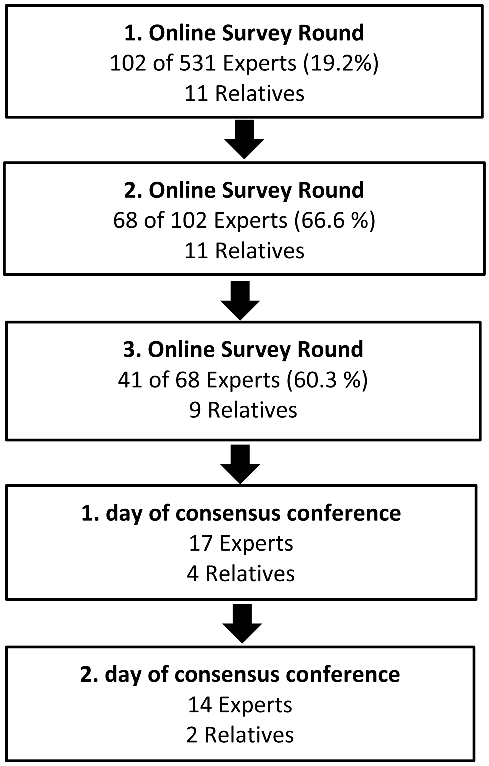

**Fig. 1.** Response in the Delphi-process.

### 3.3. *Consensus on statements*

In the 1st survey round, consensus was reached for 12 out of 55 statements/substatements among experts and 22 out of 55 statements/substatements among relatives. During the 1st survey round, there were frequent open-text responses. These responses were grouped into the following clusters: Disease stages, HRQoL construct, domains and subdomains, combined assessment of HRQoL (self-report and/or proxy report and/or observation), individual assessment of HRQoL, proxy assessment by relatives vs. caregivers, development of an instrument for HRQoL assessment.

It was often suggested that a combination of the three assessment methods (self-report, proxy report and observation) would be optimal. As a result, starting from the 2nd survey round, an additional statement about the combined assessment of HRQoL in individuals with CI was included.

In the 2nd survey round, consensus was reached for 14 out of 56 statements/substatements. After the 2nd survey round, there were fewer open-text responses related to the clusters "Disease stages", "HRQoL construct“, "Domains and subdomains", "Combined assessment of HRQoL (self-report and/or proxy report and/or observation)", and "Proxy assessment by relatives vs. caregivers". No additional statements were integrated into the Delphi.

In the 3rd survey round, consensus was reached for 20 out of 56 statements. There were only occasional open-text responses, and none of them led to the integration of new statements into the Delphi.

During the consensus conference, the 36 statements/substatements for which consensus was not achieved in the 3rd survey round were discussed and voted on. Statements 9, 13, 35c, 37 g, and 38 were voted on twice because the results of the first vote were just below the 75 % threshold required for consensus. Ultimately, consensus was reached for 21 of the 36 statements during the conference. As a result, consensus was achieved for a total of 41 out of the 56 statements/substatements in the entire Delphi process (see Table 1). Table 2 suammarizes the results of the three methods to assess HRQoL in people with CI. Table 3 shows the

**Table 1**
Results of the Delphi-process.

| Statements | 1st round | | 2nd round | 3rd round | Consensus-conference | Final result |
|---|---|---|---|---|---|---|
| | E | R | | | | |
| **Voting cycle 1: self-report** | | | | | | |
| 1. Collecting PROs to assess HRQoL in people with cognitive impairment is useful. | + | – | + | + | / | + |
| 2. Self-report of HRQoL by people with cognitive impairment can be considered the gold standard, i.e., the optimal means of collecting. | – | – | – | – | – | – |
| 3. PROs to assess HRQoL should be self-reported at most in people with mild to moderate cognitive impairment. | – | – | – | – | – | – |
| 4. PROs to assess HRQoL should be self-reported in people with mild to moderate cognitive impairment if assessment is conducted by interview. | – | – | – | – | + | + |
| 5. People with severe cognitive impairment are also able to self-report their HRQoL when the assessment is conducted by interview. | – | – | – | – | – | – |
| 6. Assessment of HRQoL should be conducted in people with severe cognitive impairment only if supportive communication strategies are used such as Voice my Choice, an image-based category sorting system to enable people with cognitive impairment to express feelings and choices in specific contexts. | – | – | – | – | + | + |
| **Voting cycle 2: proxy-report (I)** | | | | | | |
| 7. The assessment of HRQoL in people with cognitive impairment should always be supported by another person (proxy). | – | – | – | – | – | – |
| 8. Assessing HRQoL in combination of self-reported and proxy-reported is most likely to avoid bias. | – | + | – | – | + | + |
| 9. The HRQoL of people with cognitive impairment should be reported only through proxies. | * | – | * | * | / | * |
| 10. The HRQoL of people with advanced cognitive impairment should be reported via proxies. | – | – | – | – | – | – |
| 11. To assess HRQoL longitudinally, i.e., at | – | – | – | – | + | + |

(*continued on next page*)

**Table 1** (*continued*)

| Statements | 1st round | | 2nd round | 3rd round | Consensus-conference | Final result |
|---|---|---|---|---|---|---|
| | E | R | | | | |
| multiple points in time to map processes, proxies should report. | | | | | | |
| 12. Proxy-reported HRQoL is influenced by one’s physical and mental health. | – | – | – | + | / | + |
| 13. The HRQoL of people with cognitive impairment assesed by proxies is underestimated. | – | – | – | – | – | – |
| **Voting cycle 3: proxy-report (II)** | | | | | | |
| 14. Proxies tend to overestimate the cognitive ability of people with cognitive impairment. | – | – | – | – | – | – |
| 15. Proxies tend to underestimate the mental well-being of people with cognitive impairment. | – | – | – | – | – | – |
| 16. Proxies’ reported HRQoL is rated lower when there is more stress in their own lives. | – | – | – | – | + | + |
| 17. Not all proxies are suited to provide assessments of HRQoL by people with cognitive impairments due to their own health status, level of education, and ability to understand questions. | – | + | – | – | + | + |
| 18. Proxy-reported HRQoL is influenced by the relationship between the proxy and the cognitively impaired person. | – | + | + | + | / | + |
| 19. Proxy-reported HRQoL and self-reported HRQoL differ more for individuals with severe deficits because proxies have less insight into the cognitively impaired person’s perceived HRQoL. | – | – | – | – | + | + |
| 20. The reliability of proxy-reported HRQoL is doubtful. | – | – | – | – | – | – |
| **Voting cycle 4: observation/ combined assessment** | | | | | | |
| 21. Observations can be used to assess HRQoL regardless of the cognitive abilities of the cognitively impaired person. | – | – | – | – | + | + |
| 22. Observations should be used to assess HRQoL in advanced cognitive impairment due to severe cognitive-linguistic deficits. | – | + | – | + | / | + |
| 23. Observations should be used to assess the impact of interventions on HRQoL in people with cognitive impairment. | – | – | – | + | / | + |
| 24. Assessing HRQoL via observations requires intensive training. | – | – | – | – | – | – |
| 25. The reliability of observational assessment of HRQoL is limited because observation of behaviors, moods, gestures, and facial expressions is challenging in the advanced stage of the disease. | – | – | – | – | + | + |
| 26. Instead of subjective aspects, only objective aspects of HRQoL can be measured by observation. For example, within the domain "social relationships", it is not possible to measure the quality of relationships, but only the frequency of meeting friends. | – | – | – | – | – | – |
| 27. Assessment of HRQoL in people with cognitive impairment should always be collected in combination of self-report, proxy-report, and observation. | / | | – | – | + | + |
| **Voting cycle 5: domains „Physival Capacity“ and „Psychological“** | | | | | | |
| 28. The domain "Physical Capacity" should be assessed as part of the HRQoL in people with cognitive impairment. | + | + | + | + | / | + |
| 29. For the domain "Physical Capacity ", the following subdomains should be assessed as part of HRQoL in people with cognitive impairment. | | | | | | |
| a. Pain and discomfort | + | + | + | + | / | + |
| a. Energy and fatigue | – | + | – | + | / | + |
| a. Sleep and rest | – | + | + | + | / | + |
| 30. The domain "Psychological" should be assessed as part of the HRQoL in people with cognitive impairment. | + | + | + | + | / | + |
| 31. For the domain "Psychological", the following subdomains should be assessed as part of HRQoL in people with cognitive impairment. | | | | | | |
| a. Positive feelings | + | – | + | + | / | + |
| a. Thinking, learning, memory and concentration | – | – | – | – | + | + |
| a. Self-esteem | – | – | – | + | / | + |

(*continued on next page*)

**Table 1** (*continued*)

| Statements | 1st round E | 1st round R | 2nd round | 3rd round | Consensus-conference | Final result |
|---|---|---|---|---|---|---|
| a. Bodily image and appearance | – | – | – | – | + | + |
| a. Negative feelings | + | – | + | + | / | + |
| **Voting cycle 6: domains „Level of Independence“ and „Social Relationships“** | | | | | | |
| 32. The domain "Level of Independence" should be assessed as part of the HRQoL in people with cognitive impairment. | – | + | – | + | / | + |
| 33. For the domain "Level of Independence", the following subdomains should be assessed as part of HRQoL in people with cognitive impairment. | | | | | | |
| a. Mobility | – | + | + | – | + | + |
| a. Activities of daily living | + | + | + | + | / | + |
| a. Dependence on medication or treatments | + | – | – | – | – | – |
| a. Work capacity | – | + | – | – | + | + |
| 34. The domain "Social Relationships" should be assessed as part of the HRQoL in people with cognitive impairment. | + | + | + | + | / | + |
| 35. For the domain "Social Relationships", the following subdomains should be assessed as part of HRQoL in people with cognitive impairment. | | | | | | |
| a. Personal relationships | + | + | + | + | / | + |
| a. Social support | + | + | + | + | / | + |
| a. Sexual activity | – | – | – | – | + | + |
| **Voting cycle 7: domains „Environment“ and „Spirituality/ Religion/ Personal Beliefs“** | | | | | | |
| 36. The domain "Environment" should be assessed as part of the HRQoL in people with cognitive impairment. | – | – | – | – | + | + |
| 37. For the domain "Environment", the following subdomains should be assessed as part of HRQoL in people with cognitive impairment. | | | | | | |
| a. Physical safety and security | – | + | – | – | + | + |
| a. Home environment | – | + | – | + | / | + |
| a. Financial resources | – | – | – | – | – | – |
| a. Health and social care: accessibility and quality | – | + | – | – | + | + |
| a. Opportunities for acquiring new information and skills | – | + | – | – | – | – |
| a. Participation in and opportunities for recreation/ leisure activities | – | + | – | – | + | + |
| a. Physical environment (pollution/noise/ traffic/climate) | – | – | – | – | + | + |
| a. Transport | – | + | – | – | – | – |
| 38. The domain "Spirituality/Religion/ Personal Beliefs" should be assessed as part of the HRQoL in people with cognitive impairment. | – | – | – | – | + | + |

E Experts; PROs Patient Reportet Outcomes; R Relatives.
+ positive consensus.
* negative consensus.
- no consensus.
/ statement not voted.

**Table 2**
Overview of statements of methods for assessing HRQoL with consensus.

| Self-report | Proxy-report | Observation |
|---|---|---|
| • Possible for mild to moderate CI if assessment is conducted by interview.<br>• Possible for severe CI if supportive communication strategies are used. | • To assess longitudinal HRQoL.<br>• Proxy-report is influenced by:<br>  • the proxy’s physical and mental health/ stress in own life<br>  • the relationship between the proxy and the cognitively impaired person.<br>• Not all proxies are able to provide assessments of HRQoL of people with CI.<br>• There are stronger differences between proxy-reported HRQoL and self-reported HRQoL in cases of severe CI. | • Use independently of the cognitive abilities.<br>• Use with advanced CI.<br>• Use to assess effects of interventions on HRQoL in people with CI.<br>• Reliability of assessment by observation is limited because observation of behaviors, moods, gestures, and facial expressions is challenging at advanced stages of the disease. |
| • The combination of self-report and proxy report most likely to avoid bias.<br>• The combination of all three assessment methods to assess HRQoL in individuals with CI across all stages of disease is to be preferrred. | | |

domains and subdomains with consensus.

## 4. Discussion

In this Delphi study consensus was reached for a total of 41 of 56 statements/substatements on how HRQoL should be assessed in people with CI and which content domains should be assessed. As a result the combination of all three assessment methods (self-report, proxy-report and observation) to assess HRQoL in individuals with CI across all stages of disease is the preferred method and should be used whenever possible. Thereby the six domains Physical Capacity, Psychological, Level of Independence, Social Relationships, Environment, and Spirituality/Religion/Personal Beliefs should be assessed (Table 3 and Fig. 2).

These aspects can be easily categorised according to the Jonker et al. (2004) model. This model is based on Lawton’s model of QoL in people with dementia (Lawton, 1994). The Jonker et al. (2004) model can be divided into three different hierarchical levels and its extension

**Table 3**
Overwiev of domains and subdomains with consensus.

| Domains | Subdomains |
|---|---|
| **Physical Capacity** | |
| | Pain and discomfort |
| | Energy and fatigue |
| | Sleep and rest |
| **Psychological** | |
| | Positive feelings |
| | Thinking, learning, memory and concentration |
| | Self-esteem |
| | Bodily image and appearance |
| | Negative feelings |
| **Level of Independence** | |
| | Mobility |
| | Activities of daily living |
| | Work capacity |
| **Social Relationships** | |
| | Personal relationship |
| | Social support |
| | Sexual activity |
| **Environment** | |
| | Physical safety and security |
| | Home environment |
| | Health and social care: accessibility and quality |
| | Participation in and opportunities for recreation/ leisure activities |
| | Physical environment (pollution/noise/traffic/climate) |
| **Spirituality/Religion/ Personal Beliefs** | |

illustrates the interplay of hierarchical relationships between QoL dimensions in dementia. At the lowest hierarchical level, a distinction is made between personal aspects related and unrelated to dementia and environmental factors. The domains ’physical capacity’, ’level of independence’ and ’social relationships’ obtained in the present study can be assigned to the lowest personal level with reference to dementia. The domains ’spirituality/religion/personal beliefs’ and ’environment’ can be assigned to the middle personal level without reference to dementia. Finally, the ’psychological’ domain can be assigned to the highest level, as ’psychological well-being or QoL’, which results from the assessment of the individual domains of the aspects related to dementia. This is an attempt to fit the concept of CI and the results of the study into a model that is highly relevant to the topic. Jonker’s (2004) model helps to understand the process of QoL in people with dementia. Similarly, the commonalities described are helpful in orienting the available measurement methods (Gertz & Berwig, 2008).

Nevertheless, the combination of all three assessment methods is most ressource-intensive. It is time consuming, therefore cost-intensive and consequently not always feasible. In this case, the Delphi participants agreed that a self-report should be combined with a proxy-report, in a way that is feasible for the person concerned. This ensures to maintain patient-centeredness while, at the same time preventing an overestimation of HRQoL. In the literature individuals with CI have been shown to tend to present their situation better than it actually is, whereas proxys tend to underestimate, or provide a lower rating of the HRQoL of people with CI (Heßmann et al., 2018; O’Shea et al., 2020). Contrary to the literature, no consensus was found on the latter in our Delphi. According to the Delphi consensus, a combination of self-report and proxy-report seems to be most likely to avoid biases. We found consensus that self-report is possible particularly for mild to moderate CI when assessment is conducted through interviews. This is in line with Bowling et al. (2015) and Logsdon et al. (2002). With the group of participants, consensus was reached that even with severe CI self-report is possible when supportive communication strategies are used. One example of supportive communication are visual based category-sorting materials (VoiceMyChoice (VMC)). They faciliate improved interaction between people with dementia and their caregivers and can assist people with dementia in better communicating personal decisions (Bourgeois et al., 2016). Thus, VMC could possibly also be used for interviews.

If the combination of self-report and proxy-report is not possible because self-report is unfeasible in case of very severe CI, observation can be used as supplementary method to proxy-report to counteract biases in the proxy-report, which is also recommended by Algar et al. (2016). The Delphi participants agreed that proxy-report and observation can be used regardless of the extent of the CI. So far, observation has primarily been used in cases of advanced CI, as reported by Missotten et al. (2016) and Schölzel-Dorenbos et al. (2010). According to the Delphi results, the combination of proxy-report and observation can be

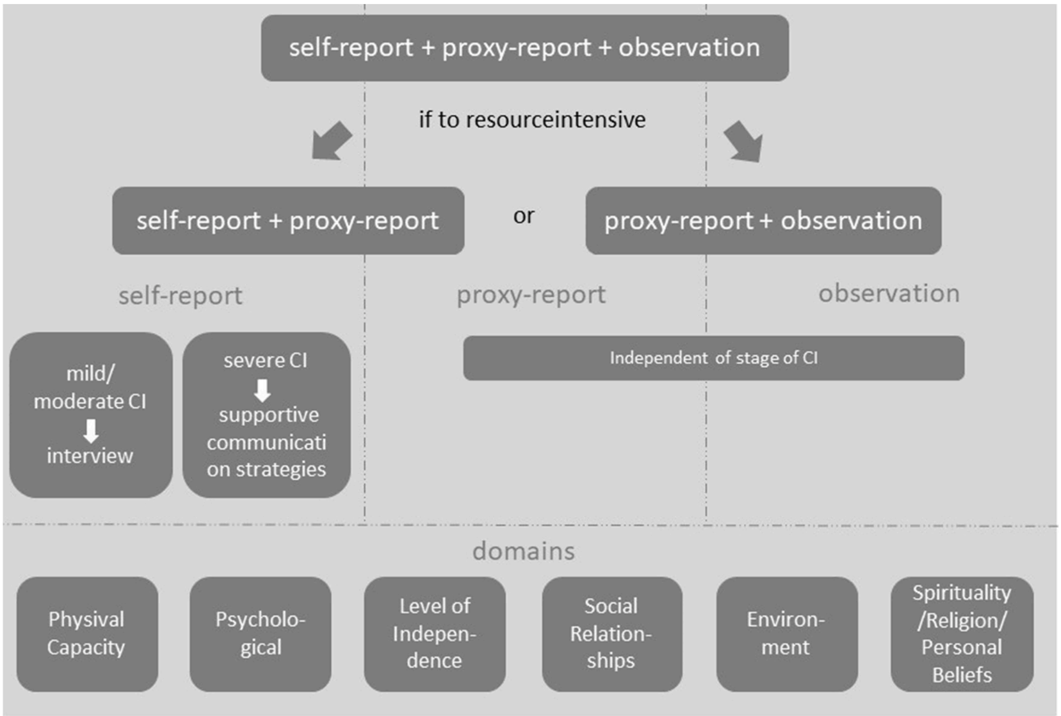

**Fig. 2.** Overview of Delphi-results.

helpful in interventions on HRQoL in individuals with CI. This suggestion is backed by the literature (Algar et al., 2016).

All of the combinations recommended as a consequence of the Delphi include proxy-report. Therefore, they all are suitable for longitudinal analysis, according to the Delphi consensus: proxy-report is recommended to assess HRQoL in longitudinal analysis, because it can be used even when the cognitive ability of dementia patients deteriorates over time.

For the domains and subdomains, the statements of the Delphi rounds were formulated according to the WHOQOL user manual (WHO, 1998). All six domains (Physical Capacity, Psychological, Level of Independence, Social Relationsips, Environment, Spirituality/Religion/Personal Beliefs) and 19 of 23 subdomains reached consensus. In comparison to assessing QoL in people independent of diseases according to the WHO, the subdomains 'Dependence on medication or treatments', 'Financial resources', 'Opportunities for acquiring new information and skills' and 'Transport' seem to play less of a role in people with CI, according to the Delphi consensus. These results of domains and subdomains could be taken into account in the development of a new instrument. Gertz and Berwig (2008) show that, based on the hierarchical levels of Jonker et al. (2004), individual QoL domains can be distinguished at different hierarchical levels. These hierarchical levels can be used to support the development of domain-specific QoL measurement instruments. At the same time, it is shown that subdomains of different QoL instruments also represent several domains, sometimes at different hierarchical levels (Gertz & Berwig, 2008). In general domains and subdomains with relevance were identified in the Delphi. When developing items for a new instrument, people with CI and relatives of people with CI should also be involved from the beginning. Overall the assessment, especially self-report should be short and adjusted to the needs of the person concerned (Alzheimer's Society, 2023). Questionnaires should be presented graphically in such a way that they are appealing, and easy to understand. Simple language should be used wherever possible. Here, it is also important to reduce the visual input and to use appropriately large font sizes and types (Boynton & Greenhalgh, 2004).

### *Challenges*

HRQoL assessed as a single point measurement can be very specific, depending on the situation and therefore potentially misleading. One significant challenge is the longitudinal assessment of HRQoL in people with CI. Proxies provide the opportunity to better assess the waves of feelings, both positive and negative moments. So proxy-report is recommended to assess HRQoL in longitudinal analysis, best used in addition to self-report. Moreover, measurement instruments need to be developed based on the cognitive abilities of the target group, which poses significant challenges for comparability in longitudinal assessments.

Furthermore, there is the question of how to handle response shift effects in measurement, especially in individuals with neurodegenerative diseases.

In the case of CI, the individual's current state of HRQoL on a given day can have a significant impact, and avoiding distortion in this regard is quite challenging. Here it would also be helpful to combine self-report with proxy-report and engage proxies in discussions about daily fluctuations to obtain a more accurate picture. This challenge is in line with the often high dynamic course of CI, which can be problematic. Sanghera and Coast (2020) show the evidence on how to measure Quality-Adjusted Life-Years when health fluctuates and report from either approaches on recall by changing the timeframe or approaches on timing of assessment by administering the questionnaire more frequently.

### *Strength and limitations*

As a key strength in the Delphi, we suceeded in deriving comprehensive statements on the methods of assessing HRQoL in people with CI as well as on the domians and subdomains from the literature and the WHO-model of QoL. In addition, we successfully built up a comprehensive contact database of 500 experts in order to contact them for participation in the Delphi.

Nevertheless, from the participants of the Delphi it was noted that the statements were sometimes formulated too absolutely and therefore it was not possible to provide a clear answer. For example, it is not always right or wrong that proxies can provide a reliable assessment or that the physical conditions of the proxies certainly have an impact, but they can act in opposite directions depending on the dyad.

Moreover, the term CI was not further specified and therefore ranges from MCI to severe dementia. Some participants criticized this as ambiguous definition. According to Landeiro et al. (2020) further research in this regard should, however, take into account the levels of disease severity. A differentiation between life situations (retirement, age, frailty) is missing, too. In the case of a 50-year-old, not yet retired individual with MCI who is physically fit and capable of working probably different domains and subdomains are more important than in the case of an 85-year-old retired person with severe dementia. For proxies we did not distinguish between the type of family member and between informal caregivers resp. family members and professional caregivers . Heßmann et al. (2018) for example, reported differences in assessments based on the relationship between the affected individual and the proxy. In this context, the assessment differences were lowest among spouses and life partners.

The drop-off in experts participating across the Delphi rounds (from 102 to 41) may have biased the results towards the opinions of those who remained engaged throughout. A higher deductible would have strengthened the conclusions.

It should also be noted that, for the Delphi study, only relatives of individuals with CI could be recruited, not the affected individuals themselves. They could have potentially contributed an additional perspective to the statements. The involved relatives were predominantly from Magdeburg, where the consensus conference also took place. Personal, outreach recruitment and the local conduct of the conference were important for the recruitment of those affected and their relatives.

## 5. Conclusions

The combination of the three assessment methods self-report, proxy-report and observation across all stages of CI is to be preferred to the use of a single method, but depends on the available resources. If it is not feasible, the combination of self-report and proxy-report or the combination of proxy-report and observation should be carried out depending on the stage of CI. Self-report is possible for mild to moderate CI by interview and for severe CI by using supportive communication startegies. Proxy-report and observation can be carried out regardless of the stages of disease. As domains Physical capacity, Psychological, Level of Independence, Social Relationships, Environment and Spirituality/Relogion/Personal Beliefs should be assessed. Future patient-centered research on HRQoL should take these findings into consideration. Further Follow-up research is needed to validate whether the recommended approaches enhance accuracy and appropriateness of HRQoL assessment compared to alternatives.

## Authors agreement

All authors have seen and approved the final version of the manuscript being submitted. We confirm that this article has not previously been published, either in whole or in part and that no similar manuscript is in press or under review elsewhere.

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## CRediT authorship contribution statement

**A. Feißel:** Writing – original draft, Project administration, Data curation, Conceptualization. **M. Berwig:** Writing – review & editing. **L. Boyer:** Writing – review & editing. **T. Bratan:** Writing – review & editing. **C. Schlüfter:** Writing – review & editing. **J. Loss:** Writing – review & editing, Funding acquisition. **C. Apfelbacher:** Writing – review & editing, Funding acquisition, Conceptualization.

## Declaration of competing interest

The authors have no competing interests to declare.

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## References

Albert, S. M., Del Castillo-Castaneda, C., Sano, M., Jacobs, D. M., Marder, K., Bell, K., … Stern, Y. (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society, 44*(11), 1342–1347. https://doi.org/10.1111/j.1532-5415.1996.tb01405.x

Algar, K., Woods, R. T., & Windle, G. (2016). Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia (Basel, Switzerland), 15*(4), 832–857. https://doi.org/10.1177/1471301214540163. S.

Alzheimer Forschung Initiative e.V. (AFI). Leqembi (Lecanemab): Neues Alzheimer-Medikament. https://www.alzheimer-forschung.de/forschung/aktuell/ban2401/.

Alzheimer's Society. (2023). *Surveys of people with dementia. https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/surveys*. https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/surveys.

Bennett, W. L., Robinson, K. A., Saldanha, I. J., Wilson, L. M., & Nicholson, W. K. (2012). High priority research needs for gestational diabetes mellitus. *Journal of Women's Health, 21*(9), 925–932. https://doi.org/10.1089/jwh.2011.3270. *2002*S.

Berwig, M., Leicht, H., Hartwig, K., & Gertz, H. J. (2011). Self-rated quality of life in mild cognitive impairment and Alzheimer's disease. *GeroPsych, 24*(1), 45–51. https://doi.org/10.1024/1662-9647/a000029. S.

Bourgeois, M. S., Camp, C. J., Antenucci, V., & Fox, K. (2016). VoiceMyChoice: Facilitating understanding of preferences of residents with dementia. *AAR, 05*(06), 131–141. https://doi.org/10.4236/aar.2016.56013. S.

Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., … Manthorpe, J. (2015). Quality of life in dementia: A systematically conducted narrative review of dementia-specific measurement scales. *Aging & Mental Health, 19*(1), 13–31. https://doi.org/10.1080/13607863.2014.915923

Boyer, F., Nowella, J. L., Morrone, I., Jolly, D., & Blanchard, F. (2004). Agreement between dementia patient report and proxy reports using the Nottingham Health Profile. *International Journal of Geriatric Psychiatry*, (19), 1026–1034. https://onlinelibrary.wiley.com/doi/pdfdirect/10.1002/gps.1191?download=true.

Boynton, P. M., & Greenhalgh, T. (2004). Selecting, designing, and developing your questionnaire. *BMJ (Clinical research ed.), 328*(7451), 1312–1315. https://doi.org/10.1136/bmj.328.7451.1312. S.

Brijoux, T., & Zank, S. (2023). Auswirkungen kognitiver Einschränkungen (Demenz) auf Lebensqualität und Versorgung. In R. Kaspar, J. Simonson, C. Tesch-Römer, M. Wagner, & S. Zank (Eds.), *Hohes Alter in Deutschland. Die Studie D80+.* (Hg, pp. 173–196). Berlin, Heidelberg: Springer (Schriften zu Gesundheit und Gesellschaft - Studies on Health and Society, Band 8)S.

Brod, M., Stewart, A. L., & Sands, L. (1999a). Conceptualization of quality of life in dementia. *Ent Health Aging*, (5), 7–19. S.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999b). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQOL). *The Gerontologist*, (39), 25–35. S.

Crimmins, E. M., Kim, J. K., Langa, K. M., & Weir, D. R. (2011). Assessment of cognition using surveys and neuropsychological assessment: The health and retirement study and the aging, demographics, and memory study. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 66*(1), i162–i171. https://doi.org/10.1093/geronb/gbr048. Suppl 1Suppl.

Dichter, M. N., Schwab, C. G. G., Meyer, G., Bartholomeyczik, S., & Halek, M. (2016). Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements-a systematic review. *Journal of Clinical Epidemiology, 70*, 233–245. https://doi.org/10.1016/j.jclinepi.2015.08.002. S.

Deutsche Alzheimer Gesellschaft e.v. Selbsthilfe Demenz (2020). Infoblatt 1: Die Häufigkeit von Demenzerkrankungen. https://www.deutsche-alzheimer.de/fileadmin/Alz/pdf/factsheets/infoblatt1_haeufigkeit_demenzerkrankungen_dalzg.pdf .

Feißel, A.; Boyer, L.; Bratan, T.; Schlüfter, C.; Loss, J.; Apfelbacher, C. (2023). Assessing health-related quality of life in people with cognitive impairment - a Delphi study protocol. DOI: 10.17605/OSF.IO/WZUR9.

Ferrans, C. E. (2005). Definitions and conceptual models of quality of life. In J. Lipscomb, C. C. Gotay, & C. Snyder (Eds.), *Outcomes assessment in cancer: Measures, methods, and applications* (Hg, pp. 14–30). England: Cambridge University Press. S.

Franzen, A. (2019). Antwortskalen in standardisierten Befragungen. *In Baur, N. & Blasius, J. (Eds.): Handbuch methoden der empirischen sozialforschung: Band 1. 2., vollständig überarbeitete und erweiterte auflage* (pp. 843–854). Wiesbaden: Springer VS. S.

Georges, J.; Miller, O.; Bintener, C. (2020). Estimating the prevalence of dementia in Europe. DOI: 10.13140/RG.2.2.16880.81923.

Gauthier, S., Webster, C., Servaes, S., Morais, J. A., & Rosa-Neto, P. (2022). Life after diagnosis: Navigating treatment, care and support. In *World Alzheimer Report 2022*. London, England: Alzheimer's Disease Internationa. https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf.

Gertz, H.-J., & Berwig, M. (2008). Ist die Lebensqualität von Demenzpatienten messbar? Ein kritischer Diskussionsbeitrag. *Der Nervenarzt, 79*(9), 1023–1035. https://doi.org/10.1007/s00115-008-2530-2. S.

Häder, M. (2014). Delphi-Befragungen. Wiesbaden: Springer Fachmedien Wiesbaden.

Heßmann, P., Dreier, M., Brandes, I., Dodel, R., Baum, E., Müller, M. J., & Balzer-Geldsetzer, M. (2018). Unterschiede in der Selbst- und Fremdbeurteilung gesundheitsbezogener Lebensqualität bei Patienten mit leichter kognitiver Beeinträchtigung und Demenz vom Alzheimer-Typ. *Psychiatrische Praxis, 45*(2), 78–86. https://doi.org/10.1055/s-0042-121169. S.

Heuer, S., & Willer, R. (2020). How is quality of life assessed in people with dementia? A systematic literature review and a primer for speech-language pathologists. *American Journal of Speech-Language Pathology, 29*(3), 1702–1715. https://doi.org/10.1044/2020_AJSLP-19-00169. S.

Hickey, E. M., & Bourgeois, M. S. (2000). Health-related quality of life (HR-QOL) in nursing home residents with dementia: Stability and relationships among measures. *Aphasiology, 14*(5–6), 669–679. https://doi.org/10.1080/026870300401388. S.

Hughes, L. J., Farina, N., Page, T. E., Tabet, N., & Banerjee, S. (2021). Psychometric properties and feasibility of use of dementia specific quality of life instruments for use in care settings: A systematic review. *International Psychogeriatrics, 33*(9), 917–931. https://doi.org/10.1017/S1041610218002259. S.

Jonker, C., Gerritsen, D. L., Bosboom, P. R., & van der Steen, J. T. (2004). A model for quality of life measures in patients with dementia: Lawton's next step. *Dementia and Geriatric Cognitive Disorders, 18*(2), 159–164. https://doi.org/10.1159/000079196. S.

Kahle-Wrobleski, K., Ye, W., Henley, D., Hake, A. M., Siemers, E., Chen, Y.-F., & Liu-Seifert, H. (2017). Assessing quality of life in Alzheimer's disease: Implications for clinical trials. *Alzheimer's & Dementia, 6*, 82–90. https://doi.org/10.1016/j.dadm.2016.11.004. S.

Landeiro, F., Mughal, S., Walsh, K., Nye, E., Morton, J, Williams, H., Ghinai, I., Castro, Y., José, L., Roberts, N., Wace, H., Handels, R., Lecomte, P., Gustavsson, E.R-D., Belger, M., Jhuti, G.S., Bouvy, J.C., Potashman, M.H., Tockhorn-Heidenreich, A., Gray, A.M. & on behalf of the ROADMAP consortium (2020). Health-related quality of life in people with predementia Alzheimer's disease, mild cognitive impairment or dementia measured with preference-based instruments: a systematic literature review. Alzheimer's research & therapy, 12(1), 154. 10.1186/s13195-020-00723-1.

Lawton, M. P. (1994). Quality of life in Alzheimer disease. *Alzheimer Disease and Associated Disorders, 8*, 138–150. Suppl 3S.

Logsdon, R., Gibbson, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21–32. S.

Logsdon, R., Gibbson, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, (64), 510–519. S.

MHEcon, L. L., Nguyen, K. H., Comans, T., & Scuffham, P. (2018). Utility-based instruments for people with dementia: A systematic review and meta-regression analysis. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research, 21*(4), 471–481. https://doi.org/10.1016/j.jval.2017.09.005. S.

Missotten, P., Dupuis, G., & Adam, S. (2016). Dementia-specific quality of life instruments: A conceptual analysis. *International Psychogeriatrics, 28*(8), 1245–1262. https://doi.org/10.1017/S1041610216000417. S.

O'Shea, E., Hopper, L., Marques, M., Gonçalves-Pereira, M., Woods, B., Jelley, H., Verhey, F., Kerpershoek, L., Wolfs, C., de¿Vugt, M., Stephan, A., Bieber, A., Meyer, G., Wimo, A., Michelet, M., Selbaek, G., Portolani, E., Zanetti, O., Irving, K., et al., ActifCare Consortium. (2020). A comparison of self and proxy quality of life ratings for people with dementia and their carers: A European prospective cohort study. *Aging & Mental Health, 24*(1), 162–170. https://doi.org/10.1080/13607863.2018.1517727. S.

Perales, J., Cosco, T. D., Stephan, B. C. M., Haro, J. M., & Brayne, C. (2013). Health-related quality-of-life instruments for Alzheimer's disease and mixed dementia. *International Psychogeriatrics, 25*(5), 691–706. https://doi.org/10.1017/S1041610212002293

Petersen, R. C. (2016). Mild cognitive impairment. *Continuum (Society for Social Work Administrators in Health Care), 22*(2), 404–418. https://doi.org/10.1212/CON.0000000000000313. DementiaS.

Pickard, A. S., & Knight, S. J. (2005). Proxy evaluation of health-related quality of life a conceptual framework for understanding multiple proxy perspectives. *Medical Care*, (43), 493–499. S.

Rabins, P. V., Kasper, J. D., Kleinman, L., & Black, B. S. (1999). Concepts and methods in the development of the ADRQL, an instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Mental Health and Aging*, (5), 33–48. S.

Robert Koch-Institut (RKI) (2021). PSYCHISCHE GESUNDHEIT IN DEUTSCHLAND · Bericht Teil 1 – Erwachsene //Erkennen - Bewerten - Handeln. Schwerpunktbericht zur psychischen Gesundheit der Bevölkerung in Deutschland. Teil 1 – Erwachsenenalter. Fokus: Depression und kognitive Leistungsfähigkeit. Unter Mitarbeit von Robert Koch-Institut. Hg. v. Robert Koch-Institut. Berlin (Gesundheitsberichterstattung des Bundes. Gemeinsam getragen). https://www.rki.de/DE/Content/GesundAZ/P/Psychische_Gesundheit/EBH_Bericht_Psyschiche_Gesundheit.pdf?_blob=publicationFile.

Robertson, S., Cooper, C., Hoe, J., Hamilton, O., Stringer, A., & Livingston, G. (2017). Proxy rated quality of life of care home residents with dementia: A systematic review. *International Psychogeriatrics, 29*(4), 569–581. https://doi.org/10.1017/S1041610216002167. S.

Sands, L. P., Ferreira, P., Stewart, A. L., Brod, M., & Yaffe, K. (2004). What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? *The American Journal of Geriatric Psychiatry, 12*(3), 272–280. https://doi.org/10.1097/00019442-200405000-00006. S.

Sanghera, S., & Coast, J. (2020). Measuring quality-adjusted life-years when health fluctuates. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research, 23*(3), 343–350. https://doi.org/10.1016/j.jval.2019.09.2753. S.

Schölzel-Dorenbos, C. J. M., Krabbe, P. F. M., & Olde Rikkert, M. G. M. (2010). Quality of life in dementia patients and their proxies: A narrative review of the concept and measurement scales. In R. R. Preedy, V.R. & Watson (Ed.), *Handbook of disease burdens and quality of life measures* (pp. 3671–3689). Springer. S. https://link.springer.com/content/pdf/10.1007/978-0-387-78665-0_213.pdf?pdf=inline%20link

SimpleSoft. Eduvote. Buchholz Wengst GbR. Braunschweig. https://www.eduvote.de/.

Spranger, J., Homberg, A., Sonnberger, M., & Niederberger, M.. Reporting guidelines for Delphi techniques in health sciences: A methodological review (172). https://reader.elsevier.com/reader/sd/pii/S1865921722000769?token=B2EE5972B5800C81C8ECAFE21A1A5C4583512D9466D605F731AAB0814E19A4979E5EDD967A07E0513F92F451CF337661&originRegion=eu-west-1&originCreation=20220901074857.

Volicer, L. (1999). *Enhancing the quality of life in advanced dementia*. Philadelphia: Brunner/Mazel.

Williamson, P.R., Altman, D.G., Bagley, H., Barnes, K.L., Blazeby, J.M., Brookes, S.T., Clarke, M., Gargon, E., Gorst, S., Harman, N., Kirkham, J.J., McNair, A., Prinsen, C. A.C., Schmitt, J., Terwee, C.B., & Young, B. (2017). The COMET Handbook: version 1.0. Trials, 18(Suppl 3), 280. 10.1186/s13063-017-1978-4.

World Health Organization (WHO). (1998). *Programme on mental health whoqol user manual*. https://www.who.int/tools/whoqol.

World Health Organization (WHO) (2017). Global action plan on the public health response to dementia 2017–2025. Geneva (WHO document production services). https://iris.who.int/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1.

World Health Organization (WHO). (2021). *Global status report on the public health response to dementia*. World Health Organisation. https://apps.who.int/iris/rest/bitstreams/1367115/retrieve.

Yang, F., Dawes, P., Leroi, I., & Gannon, B. (2018). Measurement tools of resource use and quality of life in clinical trials for dementia or cognitive impairment interventions: A systematically conducted narrative review. *International Journal of Geriatric Psychiatry, 33*(2), e166–e176. https://doi.org/10.1002/gps.4771

Zucchella, C., Bartolo, M., Bernini, S., Picascia, M., & Sinforiani, E. (2015). Quality of life in Alzheimer disease: A comparison of patients' and caregivers' points of view. *Alzheimer Disease and Associated Disorders, 29*(1), 50–54. https://doi.org/10.1097/WAD.0000000000000050. S.