

# Measures on the Quality of Life of Persons Living with Dementia

## Definition of Quality of Life (QoL)

The study of Quality of Life (QoL) is an important concept in social and health care, and has been used frequently in studies relating to these fields. There is a vast amount of literature on QoL in numerous populations across various settings.

The definition of QoL has evolved over time. At present, the World Health Organisation (WHO) defines it as:

“An individual's 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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”<sup>1</sup>

This definition reflects the multifaceted and complex nature of QoL. Measuring it is not straightforward as well. While there is a vast amount of literature on QoL, clinicians and researchers have different conceptualisations and operationalisations of the construct, and have yet to reach a consensus of how to measure the it.<sup>2</sup> Clinicians and researchers have been encouraged to be very specific and clear about QoL when studying it, specifically about its “what” and “how”; the concept’s “what” and “how” need to fit the topic of the study.<sup>2</sup> Following are some considerations for clinicians and researchers:

- The Concept: What are the aspects or determinants of QoL – being pain free, happiness, life satisfaction, being employed, etc.?
- The “What”: What are the domains that the QoL measure needs to include? Some examples include physical health, mental health, and everyday functioning in social activities.
- The “How”: What are the types of ratings to be included in the QoL measure – a self-report questionnaire, a physical test?

## Why measure QoL in Persons with dementia?

As dementia is a progressive condition with no treatment currently available to cure it or alter its progression, there have been an increasing number of psychosocial interventions implemented to support persons living with dementia and their families as the condition progresses.<sup>3</sup> These psychosocial interventions are evaluated by measures of their outcomes, which are used to gauge the impact of these interventions on persons living with dementia and their families. QoL is an outcome measure that is often tracked in such evaluations.<sup>3</sup>

Some authors shared that self-report is the most viable option in measuring QoL. However, as dementia affects individuals’ cognitive and language abilities, it is a challenge to measure QoL in persons living with dementia, who may not be valid and reliable informants of their own QoL.<sup>4</sup>

## Summary on Instruments that measure QoL in Persons Living with Dementia

Despite the difficulty and complexity in measuring QoL in persons living with dementia, several instruments have been developed to measure their QoL.

Two systematic reviews reviewed dementia-specific QoL measures and dementia-specific measures related to QoL<sup>4,5</sup> while another study reviewed observational measures used to evaluate the impact of visual arts interventions on the QoL and well-being of persons living with dementia.<sup>6</sup>

These reviews summed up, compared, and discussed:

- Purpose of each instrument
- Constructs/domains the instrument measures/observes
- Subscales of the instrument
- Number of items
- Data collection method
- The stages of dementia the instrument can be administered on
- How to use the instrument
- Psychometric properties of the instrument:
  - Reliability
  - Validity
- Responsiveness to change

The table below contains the lists of dementia-specific QoL measures and dementia-specific measures related to QoL being reviewed:

Direct Observational Tools	Self-Report and/or Proxy Reports
<ol style="list-style-type: none"> <li>1. AwareCare</li> <li>2. Behaviour Observation</li> <li>3. Bradford Well-being Profile (WBP)</li> <li>4. Creative-Expressive Abilities Assessment (CEAA) Tool</li> <li>5. Dementia Care Mapping (DCM)</li> <li>6. Greater Cincinnati Chapter Well-being Observation Tool (GCCWOT)</li> <li>7. INTERACT</li> <li>8. Menorah Park Engagement Scale (MPES)</li> <li>9. Observed Emotion Rating Scale (OERS)</li> <li>10. Positive Response Schedule (PRS) for Severe Dementia</li> <li>11. Quality of Interactions Scale (QuIS)</li> </ol>	<ol style="list-style-type: none"> <li>1. Affect and Activity Ratings</li> <li>2. Alzheimer's Disease Related Quality of Life (ADRQL)</li> <li>3. Bath Assessment of Subjective Quality of Life in Dementia (BASQID)</li> <li>4. Cornell-Brown Scale (CBS) for Quality of Life in Dementia</li> <li>5. Dementia Quality of Life Instrument (DQOL)</li> <li>6. DEMQOL/ DEMQOL-Proxy</li> <li>7. Discomfort Scale-Dementia of Alzheimer Type (DS-DAT)</li> <li>8. Pleasant Events Schedule-AD (PES-AD)</li> <li>9. Progressive Deterioration Scale (PDS)</li> <li>10. Psychological Well-being in Cognitively Impaired Persons (PWB-CIP)</li> <li>11. QUALIDEM</li> <li>12. Quality of Life Assessment Schedule (QOLAS)</li> <li>13. Quality of Life in Alzheimer's Disease (QOL-AD)</li> <li>14. Quality of Life in Late-Stage Dementia (QUALID)</li> </ol>

## Tools Used in the Singapore Context

DCM and Bradford Well-being Profile (WBP) are the two instruments most commonly used in Dementia Singapore to measure the influence of a project (for example, evaluation of a formal care setting, a new model of care, a programme or an activity) on the QoL and well-being of persons living with dementia. This is for the reason that these tools are not only able to evaluate the outcomes of a project by collecting information from subjects at both baseline level and upon its completion, but can also help to capture subjects' well-being throughout the process of a project. Furthermore, information collected through these tools can be used for multiple purposes, such as evaluation of a new programme or activity, quality improvement of existing practices and programmes, and care planning for individual clients or residents.

## References

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