

Procedure: A trained professional administers the QUALID in an interview format to an informant following the instructions below.

Informants may be either a family member or professional caregiver who is familiar with the general behavior of the person with dementia through regular contact. Informants must also have spent a significant portion of at least 3 out of the last 7 days with the person in order to accurately rate the items on the scale.

Give the informants a blank copy of the scale (provided below and on the next two pages), so that they may look at the items as they are read aloud. Then read them the following instructions:

I want to ask you some questions about [patient's name] quality of life. I want you to rate [his or her] behaviors using the responses under each question on this page.

(Point to the responses on the first question.)

There is no one right or wrong answer. I just want to know how you would rate [his or her] behavior from your observations.

Specifically, I want to know about his or her behavior over the past week only, not how he or she previously behaved. Remember that your answers should reflect his or her behavior over the past 7 days. If you are not sure what the question means, you can ask me about it. If you have difficulty choosing a rating for an item, just make your best guess. Again, indicate your observation about his or her behavior over the past week.

Scoring: The scale is scored by summing the responses. The possible scores range from 11 to 55, with 11 representing the highest quality of life.

The final items on the scale require that the interviewer make a judgment about the validity of the interview. Please rate the overall quality of the interview, which includes the informant's ability to understand the items and responses, the effort the informant put forth in answering questions, and the informant's familiarity with the person. These items are not included in the score, but offer information about the validity and usefulness of the ratings for that person.

Quality Of Life in Late-Stage Dementia Scale (QUALID)

Patient Name: _____

Patient Age: _____

Date: _____

Informant Name: _____

Informant's Relationship to Patient: _____

Which responses best describe the patient's behavior over the past week?

A. The patient smiles:

1. spontaneously once or more each day
2. spontaneously less than once each day
3. only in response to external stimuli; at least once each day
4. only in response to external stimuli; less than once each day
5. rarely, if at all

B. The patient appears sad:

1. rarely or never
2. only in response to external stimuli; less than once each day
3. only in response to external stimuli; at least once each day
4. for no apparent reason less than once each day
5. for no apparent reason once or more each day

C. The patient cries:

1. rarely or never
 2. only in response to external stimuli; less than once each day
 3. only in response to external stimuli; at least once each day
 4. for no apparent reason less than once each day
 5. for no apparent reason once each day or more
- D. The patient has a facial expression of discomfort—appears unhappy or in pain (looks worried, grimaces, has a furrowed or turned-down brow):
1. rarely or never
 2. less than once each day
 3. at least once each day
 4. nearly half of each day
 5. most of each day
- E. The patient appears physically uncomfortable—he or she squirms, writhes, frequently changes position:
1. rarely or never
 2. less than once each day
 3. at least once each day
 4. nearly half of each day
 5. most of each day
- F. The patient makes statements or sounds that suggest discontent, unhappiness, or discomfort (complains, groans, screams):
1. rarely or never
 2. only in response to external stimuli; less than once each day
 3. only in response to external stimuli; at least once each day
 4. without cause less than once each day
 5. without cause once or more each day
- G. The patient is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others):
1. rarely or never
 2. only in response to external stimuli; less than once each day
 3. only in response to external stimuli; at least once each day
 4. without cause less than once each day
 5. without cause once or more each day
- H. The patient enjoys eating:
1. at most meals and snacks
 2. twice a day
 3. at least once a day
 4. less than once each day
 5. rarely or never
- I. The patient enjoys touching/being touched:
1. almost always; almost always initiates touching
 2. more than half the time; sometimes initiates touching

3. half the time; never initiates touching, but doesn't resist touching
 4. less than half the time; often or frequently resists touching/being touched
 5. rarely or never; almost always resists touching/being touched
- J. The patient enjoys interacting or being with others:
1. almost always; almost always initiates interaction with others
 2. more than half the time; sometimes initiates interaction with others
 3. half the time; never initiates interaction, but doesn't resist interaction with others
 4. less than half the time; often or frequently resists interacting with others
 5. rarely or never; almost always resists interacting with others
- K. The patient appears emotionally calm and comfortable:
1. most of each day
 2. more than half of each day
 3. half of each day
 4. less than half of each day
 5. rarely or never

_____ Total Score (sum of all items; scores range from 11 to 55, with lower scores representing higher quality of life)

Quality of Interview (administrator's judgment):

- 0 Interview appeared valid
- 1 Some questions about interview, but probably acceptable
- 2 Information from interview of doubtful validity

Knowledge/Familiarity of Caregiver with the Person:

- 0 Very familiar; provides daily care
- 1 Somewhat familiar; often provides some care
- 2 Not very familiar; only dispenses medications, minimal contact