

# **A Structured Review of Generic and Specific Instruments for Measuring the Subjectively Assessed Quality of Life of Seniors**

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## **Abstract**

The objective of the study is to offer a review of the instruments designed for measuring the subjectively assessed quality of life of seniors. At present it is possible to notice an increase of interest in the issue of the quality of life of specific groups of population; in addition, there is a large number of tools for its measuring. The aim of the present study is to provide a systematic review of generic and specific instruments for measuring quality of life of seniors which have been published in peer-reviewed journals and whose psychometric parameters have been verified. The search procedure formed a part of a larger retrieval search in which we analyzed 4829 abstracts in EBSCO and ProQuest Central full-text databases. We found 831 instruments which claimed to be measuring quality of life and were verified their reliability or validity. We identified 3 groups of instruments suitable for use in the senior age-group: generic methodologies applicable to adults in general, 7 generic tools and 9 specific tools designed exclusively for the senior age. The paper presents the measures designed for seniors who were analyzed and compared with regard to their psychometric parameters, purpose and theoretical framework utilized for their construction. In conclusion the authors of the study provide recommendations for the use of the selected methodologies for measuring the subjectively assessed quality of life of seniors.

**Keywords:** quality of life, generic instruments, specific instruments, review, seniors

## **Introduction**

Already in the 1990s many publishing authors (e.g. Farquhar, 1995; O'Boyle, 1997; Grundy & Bowling, 1999) pointed out the fact that there is a significant increase in the number of older people who live longer, more healthy and lead more active lives, and for this reason it is necessary to reassess the way how the quality of life in this age group is conceptualized and measured. At the same time they emphasize that in the construction of instruments for its measuring, the knowledge of understanding the concept of quality of life coming from subjective statements of older people should be applied. Older people usually welcome the attention paid to their personal view.

At the theoretical level but also at the empirical level it is necessary to distinguish between the quality of life in general (QoL) and health related quality of life (HRQoL) which is especially in seniors perceived as a key indicator. HRQoL may be simply defined as perception of the impact of health and sickness on several dimensions of a person's life (French, Irwin, Fletcher & Adams, 2002), for example the physical, mental or social dimensions. It is possible to state that HRQoL is a part of the general concept of QoL and it only represents the part of QoL which is directly related to the person's health (Davis et al., 2006). Similarly, Leow et al. (2013) described HRQoL as aspects of individual's life that is impinged on by health, disease and its treatment, and is a fundamental component of successful ageing covering life expectancy, life satisfaction, mental and psychological health, physical health and functioning.

The most general and most frequently encountered division in the description of instruments for measuring the quality of life is their categorization into generic and specific scales. Generic scales are suitable to compare findings within different populations or groups as well as with different disease groups and also after using certain interventions, and at the same time they are economically not demanding (Patrick & Deyo, 1989; Hart, Redekop, Bilo, Meyboom-de Jong & Berg, 2007). The instruments related to a specific illness evaluate special states and are focused on certain diagnostic groups. Specific scales are also able to capture more sensitively, and to quantify, even minimal changes which are important for the doctors as well as for the patients themselves (Wiebe, Guyatt, Weaver, Matijevic & Sidwell, 2003). These measures may be more responsive to clinically important changes in QoL brought on by the disease, compared to the generics scales (Ettema et al., 2005; Banerjee et al., 2009). Majority of generic (general) instruments for measuring the quality of life, including generic and specific scales of health related quality of life, have multidimensional nature as they examine for instance physical, social, emotional, environmental, mental or spiritual dimension, or the influence of the illness on the individual dimensions (Babincak, 2013; Kelley-Gillespie, 2009).

The objective of this study is to provide a structured overview and description of generic QoL and HRQoL tools and also specific instruments intended for measuring the quality of life in persons of senior age which have resulted from a more widely conceived analysis of two full text databases, EBSCO and ProQuest Central.

## **Methods**

### **Search strategy**

The search scheme was supposed to include as many (peer reviewed) publications as possible dealing with measuring some of the aspects of quality of life associated with evaluation of psychometric or clinimetric quality of measurement. In the first step there were 4829 abstracts identified. These were analyzed by a focus group and the tools for measuring the quality of life encountered in them were gradually summarized and arranged in alphabetical order. In total

there were 831 different tools found. Then further selection and categorization of these tools into groups followed – by their content, focus or by target group for which they are intended. Besides generic tools which are used in adult persons in general and are usable also for senior age (e.g. SF-36, WHOQOL-BREF, Health Utility Index, etc.), the analysis brought a list of 7 generic and 9 specific tools constructed exclusively for identifying subjectively assessed quality of life in seniors. There were 16 tools included in the overview and in the description of instruments from the aspect of their theoretical framework, purpose, descriptive and psychometric characteristics.

## **Results**

The tables 1 and 2 include seven generic and nine identified specific instruments developed for the senior population of people over 60 years old. Six of the seven generic measurements are self-assessed or can also use interview form of administration. Among the specific instruments there are five self-assessed tools and in cases of two of them, the use of a questionnaire is recommended in a structured interview, namely when administered to older people with vision problems. Especially, the OMFAQ can be administered only by a trained interviewer. Four of the specific instruments are used by proxy and they are assessed by caregiver or other medical professionals. This proxy-rating is mostly used for very old and severely demented persons. The proxy report can be related to how caregivers or other related persons imagine they would feel if they were in a similar circumstance. Self-assessment questionnaire can provide information from an individual or a patient that is not easily obtained from other sources. As Moyle and Murfield noted (2013) “it is generally accepted that self-report is the ‘gold standard’ by which HRQoL should be assessed” (p. 110).

Table 1 Generic QoL and HRQoL self-assessed quality of life instruments

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (domain)</i>	<i>Psychometric properties</i>
CASP-19 (Hyde et al., 2003)	This is a self enumerated QoL scale for early old age people.	It is base on models of human needs satisfaction and self-actualization.	19	Control (4), Autonomy (5), Self-realization (5), Pleasure (5)	4-point Likert scale: 0 = never to 3 = often. High score indicates a better QoL.	SA; Item No.10 – “I look forward to each day.” (Autonomy)	Cronbach’s alpha. Factor analysis. Face validity. Content validity. Construct and concurrent validity.
Leiden-Padua questionnaire – LEIPAD (DeLeo et al., 1998)	An internationally applicable instrument to assess QoL in the elderly.	Developed under the auspice of the European office of the WHO.	49	Core instrument scales: Cognitive function (5), Depression/anxiety (4), Life satisfaction (6), Physical function (5), Self-care (6), Sexual function (2), Social function (3) Moderator scales: Self-perceived personality disorders (5), Anger, resentment and irritability (4), Social desirability (3), Self-esteem (4), Faith in God (2)	Core scales use 4-point response format from 0 = best to 3 = worst condition. Moderator scale use dichotomy response format: 0 = yes, 1 = no. Lower score indicates a better QoL.	SA or interview; Item No.3 – “Are you able to dress all by yourself?” (Self-care scale)	Cronbach’s alpha. Test-retest reliability. Factor analysis. Concurrent validity.
Older Americans Resource and Services Multidimensional Functional Assessment Questionnaire – OMFAQ (Fillenbaum & Smyer, 1981)	Instrument for evaluation of QoL of the elderly that provides a comprehensive profile of personal functioning and service use.	The OARS Program forms the clinical facet of the Duke University Center for the Study of Aging and Human Development.	120+24+10	Part A: Activities of daily Living (14), Economic resources (15), Mental health (21), Physical health (16), Social resources (9), Demographic items (11), Informant items (10); Interview section: Interview-specific (4), Interviewer assessments (15), Interview ratings (5) Part B: Services assessment	6-point response scale: 1 = level of functioning excellent, 6 = level of functioning totally impaired.	OMFAQ must be administered by a trained interviewer; Item No.59 – “Can you prepare your own meals...” (Activity of daily living)	Cronbach’s alpha. Inter-rater reliability (ICC). Test-retest reliability. Content and consensual validity. Criterion validity. Responsiveness to change.

Table 1 continued

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (dominant)</i>	<i>Psychometric properties</i>
Older People's Quality of Life Questionnaire – OPQOL (Bowling, 2009, 2013)	Measure of quality of life in older age.	It is grounded in lay views from the baseline QoL survey, integrated with theory from a synthesis of the literature.	32-35 full 13 brief	Life overall (4), Health (4), Social relationship and participation (7-8), Independence, control over life, freedom (5), Home and neighbourhood (4), Psychological and emotional well-being (4), Financial circumstances (4), Religion/culture (2; can be eliminated).	5-point Likert response scale: 1 = strongly disagree to 5 = strongly agree. Higher score represents higher QoL.	SA or interview; Item No.1 – “I enjoy my life overall.” (Life overall)	Cronbach's alpha. Factor analysis. Face validity. Content validity. Construct validity (convergent and discriminant).
Quality of Life in Later Life – QuiLL (Evans et al., 2005)	Assessment of QoL in later life.	The conceptual framework derives from Campbell et al. & Lehman (in Evans et al., 2005).	64 full, 27 short	Social, Self, Safety, Occupy time, Neighborhood, Living situation, Health, Finances, Family + Overall quality of life	7-point Likert scale: 1 = terrible to 7 = delighted. High score indicates a good level of life quality.	SA or interview; “How do you feel about financial situation?” (Finances)	Cronbach's alpha. Inter-rater reliability (ICC). Test-retest reliability. Concurrent and discriminant validity. Responsiveness to change.
Quality of Life Profile-Seniors Version – QOLPSV (Raphael et al., 1995a; Raphael et al., 1995b)	Profile was designed to evaluate the QoL of community-dwelling older people.	Toronto Quality of life model	111 full, 54 short, 24 brief	Being: Physical (12), Psychological (12), Spiritual (12), Belonging: Community (12), Physical (12), Social (12), Becoming: Growth (13), Leisure (13), Practical (13)	Completion in 2 stages: 5-point scales of importance and enjoyment (1. stage) and degree of control (2. stage)	SA or interview (up to 1 hour); “Being able to have clear thoughts.” (Psychological Being)	Cronbach's alpha. Construct validity. Responsiveness to change.

Table 1 continued

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (dominant)</i>	<i>Psychometric properties</i>
WHOQOL-OLD (Power et al. & WHOQOL-OLD Group, 2005)	The module represents an empirical assessment of older adult's quality of life from the respondent's point of view.	It was developed on the basis of WHO definition of the QoL.	24	Sensory abilities (4), Autonomy (4), Past, present and future activities (4), Social participation (4), Death and dying (4), Intimacy (4)	5-point scales measures frequency, intensity and satisfaction. High score indicates better QoL.	SA, for use in conjunction with WHOQoL-BREF or WHOQoL-100. Item No. 3 – "How much freedom do you have to make	Cronbach's alpha. Factor analyses. Convergent validity. Discriminant group validity.

Table 2 Older people specific quality of life instruments

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (domain)</i>	<i>Psychometric properties</i>
Age-Related Hormonal Decline of Quality of Life Questionnaire – A-RHDQoL (McMillan et al., 2003)	Individualized questionnaire measuring QoL in older men with age-related hormonal decline.	No theory	21	Family life, Social life, Work, Health, Physical appearance, Physical capabilities, Physical stamina, Energy, Sex life, Sleep, Bodily pain, Stress-tolerance, Memory, Concentration, Travel, Holidays & leisure, Household tasks, Confidence, Motivation, Society's reaction, Worry about future	7-point scale of impact of the difficulties: -3 = very much better to 3 = very much worse; then importance on the 4-point scale: 3 = very important to 0 = not at all important. Respondents can also use the option: not applicable (N/A).	SA; Item No. 6a) – „If my hormone levels had not declined with age, my physical capabilities would be: ...“ Item No. 6b) – “This aspect of my life is: ...”	Cronbach’s alpha. Factor analyses (Unforced FA, Forced I-FA) Content and preliminary construct validity.
Aging Males' Symptoms scale – AMS (Heinemann et al., 1999)	To measure and to compare HRQoL of aging males over time or before/after androgen replacement therapy.	HRQoL	17	Psychological (5), Somato-vegetative (7), Sexual (5)	5-point scale of severity: 1 = none to 5 = extremely severe	SA; Item No. 10 – “Decrease in muscular strength feeling of weakness.” (Somato-vegetative factor)	Cronbach’s alpha. Test-retest reliability. Factor analyses. Construct validity.
Nursing Home Vision-Targeted Health-Related Quality of Life questionnaire – NHVQoL (Dreer et al., 2007)	To assess vision-targeted HRQoL in older adults residing in nursing homes.	HRQoL	57	General vision (6), Reading (3), Ocular symptoms (9), Mobility (7), Psychological distress (10), Activities of daily living (6), Social activities/hobbies (8), Adaptation/coping (2), Social interaction (6)	4-6-points scale measure the amount of difficulty, frequency of problem, trueness of statement and degree of difficulty of the symptoms. High score represents the highest functional level.	Structured interview; Item No.3 – “How much of the time do you worry about your eyesight?” (Psychological distress)	Cronbach’s alpha. Test-retest reliability. Construct validity.

Table 2 continued

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (domains)</i>	<i>Psychometric properties</i>
Quality of Life in Late-Stage Dementia scale – QUALID (Weiner et al., 2000)	Proxy-informant based scale designed to assess the QoL in patients with advanced dementia in long-term settings.	No theory	11	Factor of behavioral signs of discomfort (4), Factor of behavioral sign of social interaction (4), Factor of signs of negative affective mood (3)	5-point Likert scale: 1 = never to 5 = always	Structured proxy interview by professional caregiver or family member; Item No. 5 – “Appears physically uncomfortable.”	Cronbach’s alpha. Inter-rater reliability (ICC). Factor analysis. Criterion validity. Construct validity.
Quality of life instrument for the Japanese elderly with dementia (QLDJ) Yamamoto-Mitani et al., 2002)	A proxy-rated instrument to assess the QoL of the Japanese elderly with dementia.	HRQoL	24	Interacting with surroundings (8), Expressing self (10), Experiencing minimum negative behaviors (6)	4-point Likert scale: 0 = not at all applicable to 3 = very much applicable	proxy by caregiver	Cronbach’s alpha. Inter-rater reliability (ICC). Test-retest reliability. Factor analysis. Construct validity.
Quality of life questionnaire for dementia – QOL-D (Terada et al., 2002)	Disease-specific HRQoL questionnaire to assess QoL in the elderly with dementia.	WHO definition of QoL.	31	Positive affect (7), Negative affect and action (6), Ability of communication (5), Restlessness (5), Attachment with others (4), Spontaneity and activity (4)	4-point response scale: 1 = never to 4 = frequent. High score indicates better QoL.	SA or by proxy; “Irritable among others.” (Negative affect and action)	Cronbach’s alpha. Inter-rater reliability (ICC). Factor analysis. Content validity. Construct validity.
Quality of life questionnaire for elderly Japanese patients with glaucoma (Uenishi et al., 2003)	A questionnaire evaluates the QoL of elderly Japanese glaucoma patients.	No theory	31	Social and daily life (8), Psychological (8), Physiological (8), Satisfaction of daily life (7)	3-point response: 4 = yes, 2 = sometimes, 0 = no. Higher score represented worse QoL.	SA or interview; Item No. 11 – “Do you feel nervous?” (Psychological)	Cronbach’s alpha.



Table 2 continued

<i>Name, original authors, publication year</i>	<i>Purpose</i>	<i>Theoretical framework</i>	<i>Items</i>	<i>Domains/scales/subscales (no. of items)</i>	<i>Response format and scoring</i>	<i>Administration and example of item (donovan)</i>	<i>Psychometric properties</i>
Vienna List (Porzolt et al., 2004)	A proxy-rating measurement for QoL in very old and severely demented persons.	WHO definition of QoL	40	Communication (15), Aggression (4), Bodily contact (5), Mobility (6), Negative affect (10)	5-point Likert scale: 1 = never, 5 = always	by proxy; "Worries about others." (Communication)	Cronbach's alpha. Factor analysis. Discriminative, content- and criterion-related validity.
Visual Symptoms and Quality of life questionnaire – VSQ (Donovan et al., 2003)	The questionnaire assesses visual symptoms/dysfunctions and impact on vision-specific QoL for people undergoing second eye cataract extraction.	No theory.	32 full, 14 short	Symptom and visual dysfunction (18), Vision-specific quality of life (9), Vision (3), Administrative issues (2)	4-7-points response formats, that measure level of difficulties and frequency of problems with vision	SA; Item No. 3 – "How would you describe the colours that you see now?" (Symptom and visual dysfunction)	Cronbach's alpha. Test-retest analysis (ICC, linear weighted kappa). Factor analyses. Content and construct validity. Responsiveness.

SA = self-administrated

The oldest instrument (OMFAQ) was published in 1981 and twelve of the other instruments were published after the year 2000. The shortest instrument has 11 items (QUALID) and the longest has 154 items (OMFAQ). We can conclude that all analyzed instruments are multidimensional, except the A-RHDQOL, which is an individualized tool. The number of domains varies between three (e.g. AMS, QLDJ) to twelve (e.g. LEIPAD, OMFAQ). Physical, psychological and social issues are the most frequently occurring domains within the analyzed instruments. They also include economic situation, sexual function, activities of daily living, communication, etc. Only one instrument (LEIPAD) assesses cognitive function and only four incorporate domains related to health status (OMFAQ, OPQOL, QuiLL, A-RHDQOL).

Each of the instruments produces a score profile across all domains and eleven include also global judgments of QoL, namely CASP-19, LEIPAD, OPQOL, QuiLL, WHOQOL-OLD, A-RHDQoL, AMS, QUALID, QLDJ, Quality of life questionnaire for elderly Japanese patients with glaucoma, VSQ. The analyzed instruments use 3- to 7-point scale as a response format and they measure intensity, frequency, satisfaction, level of functioning, impact of difficulties on the QoL and importance of various domains for the QoL. Reported completion times ranging from 5 minutes (QUALID) to 1 hour (QOLPSV).

Majority of the generic and disease-specific questionnaires were developed with the addition of qualitative methods (e.g. interview, responses to open-ended questions, etc.) to derive items and check face validity by observing patients completing the instruments. In general, there were these steps followed: initial development work, a pilot study with psychometric testing and then modification or creating a final version of the questionnaire. Majority of the currently available language versions was translated following international standards for linguistic and cultural translation of quality of life instruments. The research versions are available from the authors on request. Some of the described instruments have a shortened or brief version (OPQOL, QuiLL, QOLPSV, VSQ). Short instruments, as the CASP-19, OPQOL-brief, QUALID, AMS, VSQ-short, can be used as a screening assessment, as part of a single assessment process, and as a monitoring tool and outcome measure.

Internal consistency reliability was verified for all instruments. Values attained for Cronbach's alpha in subscales of the instruments ranged from 0,43 (domain sexual function in LEIPAD) to 0,96 (domain Activities of daily living in NHVQoL). Lower levels of reliability value were reported also for these domains: Control ( $\alpha = 0,59$ ; CASP-19), Social function and Life satisfaction (both  $\alpha = 0,61$ ; LEIPAD) or Autonomy ( $\alpha = 0,65$ ; CASP-19). Seven instruments have evidence of test-retest reliability with time interval between tests about two weeks.

Content validity is not widely reported (Haywood et al., 2004). The testing content validity of analyzed instruments occurred only in three generic and four specific tools. The content validity of the questionnaires was tested with individual cognitive interviews with the members of the focus groups that consisted of older people, patients and clinicians. These groups help to reduce validity and reliability errors in three ways: 1. they check that all relevant domains have been included, 2. they determine the dimensions that make up the domains, and 3. they ensure correct and understandable item wording (Bischoping & Dykema, 1999).

Most instruments in this review were assessed for construct validity through comparisons with other QoL instruments (e.g. SF-36, NHP or global subjective judgments of health status). Only four measures had demonstrable responsiveness to change, namely OMFAQ, QuiLL, QOLPSV, VSQ.

Each of analyzed generic instruments were developed using a QoL theory or framework. On the other hand, we found the absence of theory in the majority of specific QoL instruments for older people. Suggested a-theoretical approach to measuring the quality of life is typical not only for age-specific tools (Babincak, 2013). Theoretical framework is usually replaced by a factor-analytical approach where the structure of the measured quality of life is the result of a statistic procedure and is not based on a specific theory. Another problem is a too wide and vague theory or definition of the measured attribute. An example of this fact may be the often quoted WHO conceptualization which defines QoL as 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, expectation, standards and concerns (WHOQOL Group, 1998). But in fact many tools based on this concept do not evaluate the position of the person in various contexts of life but the satisfaction in life or indicators of their health.

## **Conclusion**

The review identified 16 instruments that have been evaluated for use with people over 60 years (especially for age range 65-75 years). The list includes seven generic and nine older-people-specific instruments, one of which is individualized (A-RHDQOL). The content of the questionnaire (e.g. OPQOL, CASP-19) reflects older people's own definitions and interpretations of QoL. Proxy assessment of QoL applied mainly to people with severe dementia, because a central problem for QoL assessment in people with advanced dementia is low reliability due to memory, language impairment and reduced self-awareness (Weiner, 2006). Given the multidimensional nature of the concept of quality of life, the length of time to complete a survey instrument with this age group may be greater than with a younger adult sample. Most of the presented tools can be regarded as useful, practical, differentiating, less time consuming instruments for investigation of quality of life of seniors.

We can summarize that:

1. Compared with the generic instruments we discovered the absence of theory in the majority of specific QoL instruments designed for older people, although this a-theoretical approach to measuring QoL is typical not only for these age group. As Davis et al. (2006) notes, for the researchers it is inevitable to create theoretically supported tools of measuring the quality of life and to verify postulated assumptions empirically.
2. Some of instruments contain the items that are not included in the total score, but offer information about the validity and usefulness of the ratings for the interviewer (e.g. QUALID scale).
3. Majority of the instruments provide multiple evidences of reliability and validity. The OMFAQ is highlighted as an instrument that addresses most relevant assessment domains for seniors. It is important to note, although the length of the instrument can increases respondent burden, there is good evidence of its reliability, validity and responsiveness.
4. Most of the described tools have been translated into other languages and adapted to better address cultural issues specific to a population.
5. In the group of seniors, generic and specific tools designed exclusively for the people over 60 years old may be applied, as well as generic methodologies applicable to adults in general. We found slight prevalence of specific tools in comparison to the generic ones. Physical, psychological and social issues are the most frequently occurring domains within the analyzed instruments.

Regarding the limitations of the realized overview we would like to state that the primary identification of the studies was based only on two full-text databases which do not cover the whole spectrum of publications in this area. The consequence may be the fact that other existing

tools relevant for senior age were not included in this overview. The acquired findings on the quality of life of seniors may specifically help us in care planning or in using interventions in order to improve their quality of life or to prevent the decline of its level.

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