





BMJ Open Systematic review of 29 self-report instruments for assessing quality of life in older adults receiving aged care services

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ABSTRACT

Background Quality of life (QoL) outcomes are used to monitor quality of care for older adults accessing aged care services, yet it remains unclear which QoL instruments best meet older adults', providers' and policymakers' needs. This review aimed to (1) identify QoL instruments used in aged care and describe them in terms of QoL domains measured and logistical details; (2) summarise in which aged care settings the instruments have been used and (3) discuss factors to consider in deciding on the suitability of QoL instruments for use in aged care services.

Design Systematic review.

Data sources MEDLINE, EMBASE, PsycINFO, Cochrane Library and CINAHL from inception to 2021.

Eligibility criteria Instruments were included if they were designed for adults (>18 years), available in English, been applied in a peer-reviewed research study examining QoL outcomes in adults >65 years accessing aged care (including home/social care, residential/long-term care) and had reported psychometrics.

Data extraction and synthesis Two researchers independently reviewed the measures and extracted the data. Data synthesis was performed via narrative review of eligible instruments.

Results 292 articles reporting on 29 QoL instruments were included. Eight domains of QoL were addressed: physical health, mental health, emotional state, social connection, environment, autonomy and overall QoL. The period between 1990 and 2000 produced the greatest number of newly developed instruments. The EuroQoL-5 Dimensions (EQ-5D) and Short Form-series were used across multiple aged care contexts including home and residential care. More recent instruments (eg, ICEpop CAPability measure for Older people (ICECAP-O) and Adult Social Care Outcomes Toolkit (ASCOT)) tend to capture emotional sentiment towards personal circumstances and higher order care needs, in comparison with more established instruments (eg, EQ-5D) which are largely focused on health status.

Conclusions A comprehensive list of QoL instruments and their characteristics is provided to inform instrument choice for use in research or for care quality assurance in aged care settings, depending on needs and interests of users.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Compared with the largest review of the topic to date, the current review contains an additional 16 quality of life instruments and provides a structured index of domains.
- ⇒ This review provides the first quantified demonstration of how self-reported measures of quality of life have developed over the past 40 years and the aged care setting where these instruments have been used.
- ⇒ Our review only included instruments applied to populations of older adults accessing aged care services.
- ⇒ Our review identifies current quality of life instruments used in aged care settings internationally and represents a first step in supporting choice of suitable instruments to be used for monitoring and evaluating quality of care in aged care service settings.

INTRODUCTION

Globally, the demand for aged care services has increased.¹ Aged care services are designed to support older adults who require assistance to maintain independence for as long as possible (also known as home aged care, community aged care, social care) as well as supporting older adults who can no longer live at home (also known as assisted living facilities, long-term care (LTC), nursing homes, care homes or residential aged care). As the accountability of aged care services becomes increasingly important globally,^{1 2} there is a need to establish long-term and comprehensive measures of aged care service quality. Measures need to be easily operationalisable and capable of capturing information reflective of public expectations for high-quality, person-centred aged care services. One way to determine the quality and person-centredness of aged care services is to assess care outcomes which are

important to clients and which are achieved at the client level.

Of aged care quality indicators used globally, recipient quality of life (QoL) outcomes are among the most highly valued and meaningful by aged care consumers and families.^{3 4} QoL is broadly defined as an individual's perception of their physical health, psychological state, social relationships and environmental context.⁵ Despite the significance of QoL outcomes to aged care clients, and despite extensive development and experimentation with quality measures in aged care settings (eg, pressure injuries, falls, use of physical restraints, medication errors, involuntary weight loss), internationally, the collection of QoL outcomes is limited,⁶ however, more recent efforts on how QoL in aged care should be defined is emerging.⁷

Fundamental to the challenge of measuring QoL is selecting an instrument for use from the large variety of available QoL instruments. Despite the continued development of new instruments, no universally accepted measure has emerged, in part because there are no agreed conceptual criteria on what an instrument should contain, and no single measure can suit every purpose or application. Dimensions of QoL prioritised for measurement also vary across disciplines,⁸ and new instruments are regularly being developed to reflect new and more niche perspectives about factors of life quality.⁹ Despite efforts by the Organisation for Economic Co-operation and Development (OECD) to formalise the measurement of QoL, advice on how researchers can effectively use available instruments is lacking.⁶ Researchers and aged care providers who wish to measure QoL in older adults receiving care in home and residential settings tend to select instruments based on what is familiar to them within their discipline or organisation, what is most often used by others, or they create ad hoc purpose-built, non-standardised instruments.¹⁰

Despite the problems and barriers intrinsic to the collection of QoL outcomes, several countries have incorporated existing QoL measures into routine aged care evaluation and reporting practices.^{10 11} In Iceland and Canada, QoL scores of aged care residents are derived from data about the use of physical restraints, behavioural symptoms, among other objective measures.^{11 12} However, such measures do not provide insight into the experience of care, and therefore, do not necessarily correlate with the subjective experiences of clients. For example, a recent Australian study found no significant correlation between client care satisfaction and the use of physical restraints in aged care settings.¹³

Elsewhere, subjective client-reported measures are used alongside traditional objective indicators of QoL (ie, medication use, health status, mobility, pressure injuries). For example, departments of health in the UK, Denmark, Austria, Finland and the Netherlands routinely collect QoL outcomes using versions of the Adult Social Care Outcomes Toolkit (ASCOT),¹⁴ a QoL questionnaire which captures emotional and subjective sentiment

towards personal circumstances and levels of satisfaction regarding care needs.¹⁵

In Australia, improving the QoL of aged care clients has been a stated policy objective for the last decade. In 2019, a new set of Aged Care Quality Standards which are applicable to aged care providers across all aged care settings were introduced,¹⁶ which state care providers should take steps to continuously improve client QoL. However, to date, no questionnaires or standardised measures to track client QoL have been mandated for use in Australia, although latest commissioned reports recommend universal QoL reporting in aged care.¹⁷ Recent reports of mistreatment and abuse of Australian aged care recipients underscore the need for standardised, comparable QoL measures.¹⁸

Previous reviews on QoL instruments have focused on their psychometric properties such as validity and reliability,^{19 20} with one review providing a comprehensive analysis of how instrument contents differ.²¹ However, these reviews are directed at younger adults (<65 years of age), do not describe how the instruments have been used within the aged care context, and review a limited set of instruments and instrument properties. Another review with aims matching our own is based on outdated evidence.²²

A comprehensive review of current validated and implemented instruments that measure QoL both objectively and subjectively is needed to support the choice of instruments that are fit for purpose in aged care settings. In our review, our objective is to inform researchers, aged care practitioners and managers about the breadth, variety, and content of available measures of QoL that have been successfully applied in aged care settings. Specifically, we aimed to (1) identify QoL instruments used in aged care and describe them in terms of QoL domains measured and logistical details; (2) summarise in which aged care settings the instruments have been used and (3) discuss factors to consider in deciding on the suitability of QoL instruments for use in aged care services.

METHODS

Search strategy

Studies were included in this review if they (1) contained the term 'quality of life', (2) studied and described an aged care population and (3) administered a standardised QoL instrument (ie, verbal QoL questionnaire or QoL self-assessment survey) on study participants, (4) represented original peer-reviewed articles and were not a systematic review or a conference proceeding. Search terms were therefore a combination of QoL assessment and older persons descriptors in aged care (ie, (QoL OR assessment) AND (older adults OR elder*) AND (care homes OR nursing homes OR residential aged care OR community care OR social care OR home-based care)). Articles were retrieved from the databases PsycINFO, PubMed, Cochrane, CINAHL and Embase from the

earliest records until 29 January 2021 and included studies focusing on implementation or routine care. See online supplemental file for further information.

Studies were also identified through citations from relevant literature reviews focusing on QoL in older adults and checking reference lists of the included articles.

Study selection, data extraction and analysis

Database search results were exported into a reference citation manager. A random selection of 25% of the abstracts was screened by the research team. Inter-reviewer agreement was 90%, with disagreement on the inclusion of one paper, which was brought to the larger research team. Selected full-text articles were then obtained for the final screening. Final study selection was completed by two independent authors (JS and GTK) with a third author (JW) helping to resolve disagreements. Studies were excluded if: (1) study population had a mean age lower than 65; (2) if <50% of the study population was not accessing aged care services (eg, home/social care or residential/LTC); (3) the study was not peer-reviewed and did not improve primary research (eg, systematic reviews and conference proceedings); (4) study did not directly measure QoL and (5) only a portion of the instrument was described. Instruments were excluded if they were designed for children or adolescents or not a standardised instrument (ie, newly designed questionnaires for the purposes of a study without validated psychometric properties).

A purpose-designed data collection form on Excel workbook was tested and then used to capture qualitative and quantitative data and other relevant details of the included studies. Once an initial extraction of study details was complete, an evaluation of the identified QoL instruments was carried out. Information on the instrument properties was extracted, including: (1) domain measured; (2) administration details and (3) context of instrument application. Additional instrument details included mode of administration (eg, in person, on-line, paper form), the settings in which the instruments had been used, socio-demographic details of respondents, number of items, length of instrument, number of translations and versions, target population, required cost and any necessity for training. These details were principally extracted to gauge feasibility of applying the instrument in aged care settings. In addition, study-specific details were extracted including sample size, study design and setting (aged care service type, country where performed). Efforts were made to contact study authors for original QoL instruments.

Thematic analysis

Identified instruments were analysed using a thematic analysis approach.²³ Facets of QoL (ie, health status, lived environment, social interaction levels) addressed by identified instruments were coded under domain categories. The review team (JS and GTK) examined the full

set of instrument item domains, and combined domains under common headings when domains between instruments were indistinguishable or significantly associated. For example, question items such ‘depression levels’ and ‘depression diagnosis’ were clustered around the theme ‘psychological health’. Coding was undertaken by two reviewers (JS and GTK) and any discrepancies that arose were solved through discussion with the third member of the review team (JW). Themes were gradually assembled into larger similar domains. Once these domains were reviewed and amended by the review team, they were further refined and defined. In addition to instrument domains, the target populations of instruments were also recorded. It was anticipated that domains might overlap and that instrument items could conceivably be categorised across several domains; however, the categories provided by this technique afforded some order to the otherwise unmanageably large range of domains attributed to developed instruments. The review team included academics with backgrounds in psychology and aged care (JS), sociology (GTK), health economics and psychometrics (JR) and epidemiology/public health (JW), helping to minimise disciplinary biases. Results were synthesised as a narrative review.

Patient and public involvement

No patient involved.

RESULTS

Identification of instruments

The PRISMA diagram summarises the search results, screening and reasons for exclusion of studies (figure 1). The database search produced an initial 2612 records of which 292 articles reporting on 29 QoL instruments were included. Table 1 and online supplemental file contain details on the instruments included in the final review. The instruments are either: (1) the original instruments if no revised version was found or (2) the latest revised version. A breakdown of when the instruments were first developed can be found in figure 2.

Instrument domains

The identified QoL instruments were designed for use with three distinct populations groups (adults, older adults and adults living with dementia), and covered nine QoL domains in their assessment (table 1). Thirteen instruments were designed for use with adults generally, 10 were designed for use with older adults and 7 were designed for adults living with dementia.

Instrument developers often associated instruments with specific domains. However, there was no clear consensus regarding domains classification and definition. Consequently, we amalgamated similar domains between instruments under common domain definitions developed for this review. Based on a recent exhaustive systematic review of older people’s understandings of QoL, we further adjusted and expanded on domains

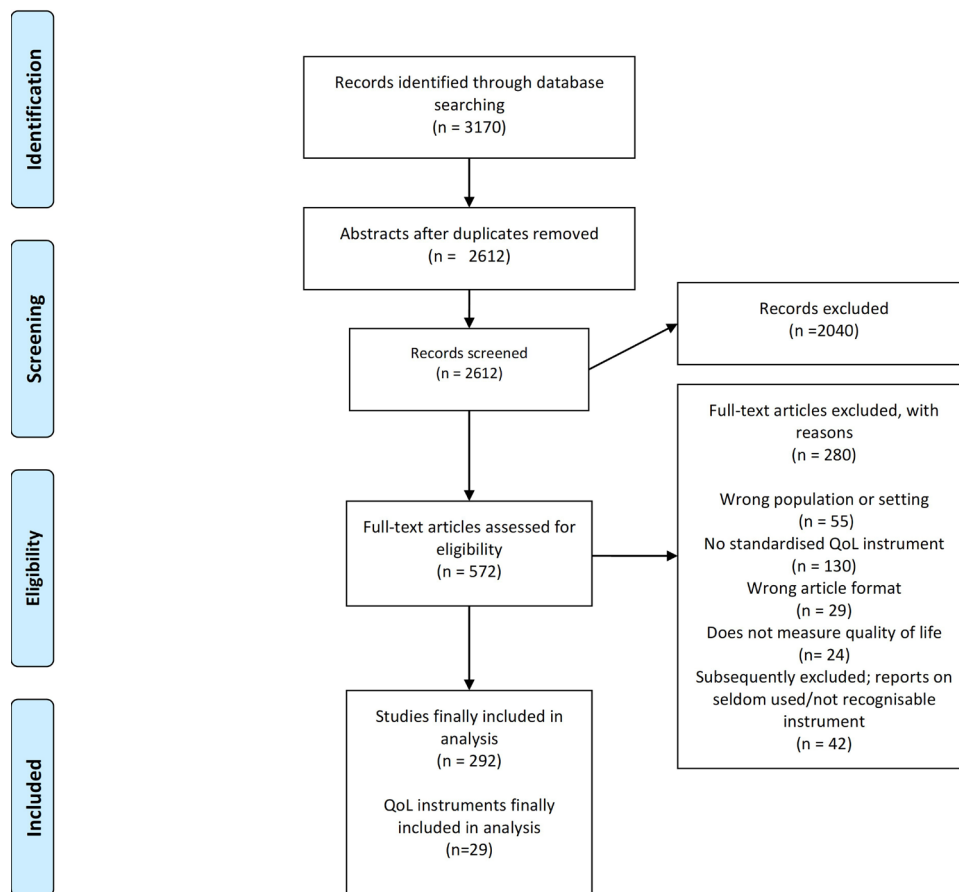


Figure 1 PRISMA diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; QoL, quality of life.

identified in this review to incorporate aspects of QoL which are important to older people in OECD countries.²⁴

The final nine instrument domains were: physical health, mental health, emotional state, social connection, environment, personhood, autonomy, spiritual connection and overall QoL.

Physical health refers to instrument items that addressed functional status, physical conditions and their related symptoms, pain, and perceptions of overall health. *Mental health* refers to items that capture mental and cognitive health conditions, as well as clinical symptoms that would indicate mental health problems. *Emotional state* refers to items which capture experiences of positive and negative emotions which are not obviously symptoms of mental health. This includes items which explore feelings of peace, calm, happiness and loneliness, among others.

Two domains identified relate to external circumstance and resources. *Social connection* refers to items addressing the frequency and quality of social interactions. Items addressing feelings of belonging, friendship and support were also categorised under this domain. *Environment* refers to items addressing living conditions and deployable resources. Included in this domain are items addressing satisfaction with social care services as well as items which ask respondents to reflect on the

emotional, psychological and physical effects of living conditions.

Three domains related to existential beliefs and concerns of respondents. The domain *personhood* relates to items addressing levels of satisfaction with personally and culturally meaningful activities which provide joy and a sense of identity. This domain also refers to items that address identity continuity, and effects of ageing on identity and sense of self. *Autonomy* relates to items addressing capacity and satisfaction with one's ability to manage activities of daily living. Emotion-centric items associated with dependence and autonomy are also categorised as relating to autonomy. Finally, the domain *spiritual connection* covers feelings of faith, and inner peace, as well as involvement in religious or spiritual practices like prayer. We also included an *overall QoL* theme, relating to single items asking respondents to rate their QoL as a whole.

Domains were often inter-related and multiple items were categorised across multiple domains. 'Emotional state', examined by 26 instruments, was the most frequently included theme. This was followed by 'social connection', examined by 24 instruments (82.3%), and 'physical health' which was examined by 19 instruments (65.5%). Although spiritual connection is significant to the QoL of many older adults,²⁴ only one instrument, the JoLS, examined this domain. Of the instruments

Table 1 Instrument domains

Target population	Instrument acronym	Physical health	Emotional state	Mental health	Social-connection	Environment	Personhood	Autonomy	Spiritual feeling	Overall question
Adult population	15-D	✓	✓	✓		✓				
	A-QoL-8D	✓	✓	✓	✓			✓		
	COMQOL	✓	✓	✓	✓	✓				
	DUKE	✓	✓	✓	✓	✓				
	EQ-5D	✓		✓		✓				✓
	HUI2/3	✓	✓	✓						
	MANSA	✓		✓	✓	✓				✓
	NHP	✓	✓	✓	✓	✓	✓	✓		
	OHIP	✓	✓	✓	✓	✓		✓		
	SF series	✓	✓	✓	✓			✓		
	SWLS		✓			✓		✓		✓
	WHOGOL-BREF	✓	✓	✓	✓	✓	✓	✓		✓
Older adults	ASCOT				✓	✓	✓	✓		
	ICECAP-O		✓		✓		✓	✓		
	Inter-RAI (LTCF)		✓		✓	✓	✓	✓		
	LTC-QoL		✓		✓	✓	✓			
	JoLS		✓		✓	✓	✓		✓	
	NHVQOL	✓	✓		✓	✓	✓	✓		
	OPQOL		✓		✓	✓	✓	✓		✓
	PGCMS		✓	✓	✓		✓	✓		✓
	WHOGOL-AGE	✓	✓		✓	✓	✓	✓		✓
	WHOGOL-OLD	✓	✓		✓		✓	✓		✓

Continued

Table 1 Continued

Target population	Instrument acronym	Physical health	Emotional state	Mental health	Social-connection	Environment	Personhood	Autonomy	Spiritual feeling	Overall question
Adults living with dementia	ADRQOL	✓	✓		✓	✓	✓	✓		
	CAD-EOLD	✓	✓	✓						✓
	DEMQOL		✓	✓	✓					✓
	D-QOL		✓	✓	✓		✓	✓		✓
	QoL-AD		✓	✓	✓	✓	✓	✓		✓
	QUALID		✓	✓	✓	✓				
	QUALIDEM		✓	✓	✓	✓	✓	✓		

ASCOT, Adult Social Care Outcomes Toolkit; DEMQOL, Dementia Quality of Life; EQ-5D, EuroQoL-5 Dimensions; LTC, long-term care; NHVQOL, Nursing Home Vision-Targeted Health-related QoL; QoL, quality of life; SF, Short Form; WHOQOL-BREF, WHO Quality of Life-Bref.

analysed, the WHO Quality of Life-Bref (WHOQOL-BREF) covered the largest range of domains. Overall, the instruments commonly captured objective and subjective concepts of the quantity or length of life and QoL, which varied between individuals' health status and their ability to achieve physical, mental and social well-being.

Features of QOL instruments

All instruments contained multiple items, smallest being five items (ICEpop CAPability measure for Older people, ICECAP-O) and the largest containing 57 items (Nursing Home Vision-Targeted Health-related QoL, NHVQOL). However, some instruments were comprised of items which were abstract and/or difficult to answer, meaning the number of items did not uniformly determine expected completion times. Estimated completion times ranged from 1 to 3 min (Short Form-8, SF-8) to 40–60 min (Inter-RAI-LTC).

The fewest response options were found within simple yes/no questionnaires (ie, Philadelphia Centre Geriatric Moral Scale, PGCMS), while other instruments offered response options along a unipolar scale (ie, EuroQoL-5 Dimensions-5-level, EQ-5D-5L). Half of the instruments used five-point or four-point unipolar Likert scales (14/29, 48.3%). Items asked individuals about the frequency, intensity, strength of agreement or truth of specific and non-specific thoughts, feelings, experiences and statements. Instruments were named after academic affiliation (3/29, 10.3%) as with the Duke Health Profile (DUKE) and organisational affiliation (5/29, 17.2%) as with the World Health Organization Quality of Life (WHOQOL) instruments. However, for the majority of cases (21/29, 72.4%), instruments were named after their key concept or approach. For example, all of the instruments designed for adults living with dementia referenced this target population in their titles.

Furthermore, most instruments were developed with a theoretical influence^{15 25–45} (20/29, 69.0%), with the WHO definition of QoL⁴⁶ ('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') most frequently reported (8/21, 38.1%). Other theories included the capabilities approach,^{47–51} Seligman's and Keye's well-being theory,^{52–56} salutogenesis framework,⁵² Lehman's conceptualisation of QoL,⁵⁷ gap theory^{58–60} and adaptation-coping model.^{61 62}

Dementia-specific instruments were based on theories such as the Kitwood's Dementia Care Mapping Approach⁶³ and the Lawton model,⁶⁴ which proposes a conceptual understanding of the relationship between domains of health-related QoL and other areas of impact for individuals with dementia. Other disease-state specific instruments (eg, oral health) was developed using Locker's conceptual model of oral health⁶⁵ and the WHO's International Classification of Impairments, Disabilities and Handicaps.⁶⁶ One instrument (Health Utility Index, HUI) applied the von Neumann-Morganstern utility

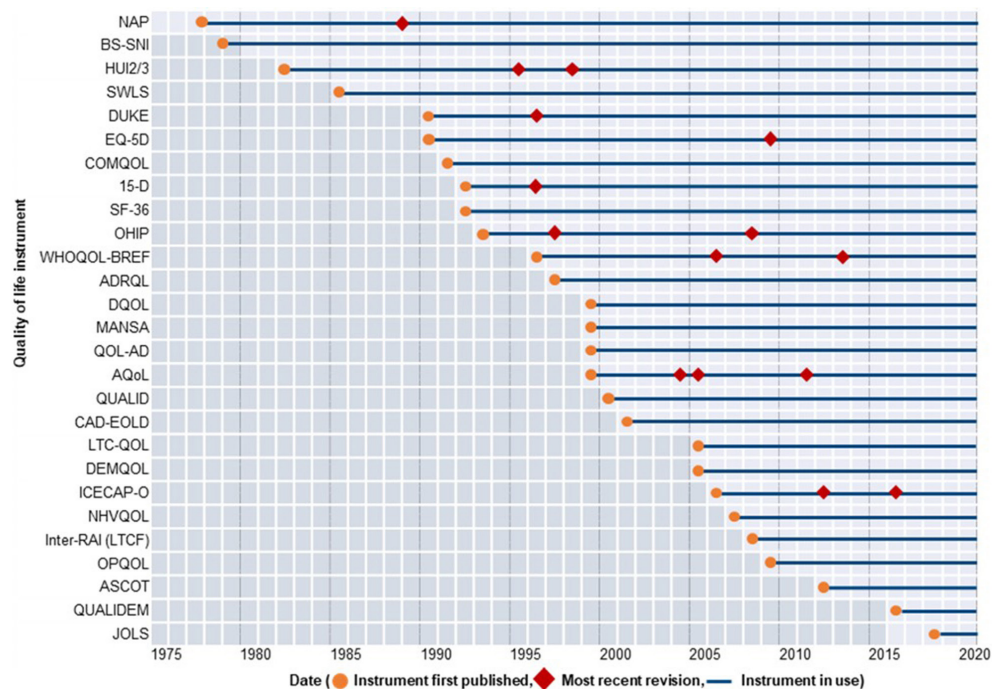


Figure 2 Historical development of quality of life instruments for older adults. ASCOT, Adult Social Care Outcomes Toolkit; EQ-5D, EuroQoL-5 Dimensions; SF-36, Short Form 36; QOL, quality of life.

theory⁴⁷ and the multiattribute framework,^{33 67} however, these frameworks were not related to QoL and were more focused on economics more generally.

It was unclear if the more commonly used instruments (eg, SF series, EQ-5D, and interRAI-LTC) were developed using a theoretical approach, however the development for these standardised, non-disease-specific instruments were conducted using a rigorous, reiterative approach to describe and value health states (eg, EQ-5D was developed from 14 members in 5 different countries, SF series from the Medical Outcomes Study Approach). Furthermore, more recent instruments (eg, ICECAP-O) were developed from the ground up using qualitative research to define their QoL conceptual attributes (eg, capability) rather than as an overarching theoretical approach.

Table 2 presents a comparison of the logistical factors associated with instrument use. Of the 29 instruments identified, 12 were designed for self-completion, 14 were intended to be administered via interview and 3 were designed for completion via proxy or via interview with a carer. Some instruments, such as the ASCOT, are currently available in interview, self-completion and proxy versions.¹⁵

The SF series and the EQ-5D instruments were relatively short and simple to administer. Both instruments are short, contain simple, straightforward question items, are readily and freely available, have dedicated websites which offer user support, are accompanied by detailed user manuals, have been translated into a variety of languages, and can be administered by either interview or self-completion.

The extent of instrument translation varied. Some instruments were available in English only (eg, Comprehensive

Quality of Life Scale (COMQOL), Nursing Home Vision-related Quality Of Life (NHVRQOL) and Long Term Care Quality Of Life assessment scale (LTC-QOL)), while others were available in up to 32 languages (eg, 15-D, WHOQOL-BREF), and 180 languages (eg, EQ-5D) other than English.

Table 2 further provides available information about the psychometric properties of the instruments. Reliability and validity metrics for older adult populations were searched for each included instrument and summarised according to the the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) taxonomy.⁶⁸ All instruments were tested for both reliability and validity with the majority of instruments having good validity (16/21, 76.2%) and validity (16/21, 76.2%). There were 10 instruments (47.6%) that had been tested for responsiveness, with ASCOT-SCT4, ICECAP-O and EQ-5D able to adequately detect clinically important interventional changes.

Development of the instruments over time

Almost half of the instruments we identified had been first developed in between 1990 and 1999. As shown in figure 2, the oldest instrument was developed in 1975 (Philadelphia Geriatric Centre Moral Scale, PGCMS), while the newest instrument was developed in 2018 (Joy-of-Life Scale, JoLS). Since 2000, 13 instruments have been designed. The 1990s saw the development of eleven new instruments.

Many of the newer measures contained fewer items or were accompanied by SF versions. Further, over the past 15 years, there have been significant efforts to move towards questionnaires that focused more on social

Table 2 Summary of QoL instrument psychometric properties and administration characteristics

Instrument acronym	Developmental history and theoretical influence	Psychometric properties*			Administration characteristics					User guide	Website†
		Validity	Reliability	Responsiveness	Items (length)	Intended administration†	Translations	Fee	Registration		
15-D (1992) ²⁷	WHO ²⁷	Good ⁸⁸	Good ⁸⁸	Good ⁸⁸	15 (5 mins)	I	32	None	Yes	Yes	Yes
ADRRQL (1997) ²⁵	Concepts of QoL ⁸⁹	Poor ⁷⁰	Poor ⁷⁰	-	40 (10–15 mins)	P	6	Dependent on use	Yes	Yes	Yes
A-QoL-8D (2011) ⁹⁰	WHO ^{90,91}	Good ^{26,90}	Good ⁹²	-	35 (5 mins)	S	5	None	Yes	Yes	Yes
ASCOT-SCT4 (2012) ¹⁵	NHS Outcomes Framework ¹⁵ ⁹³⁻⁹⁷	Good ⁹⁸	Good ⁸⁰	Good ⁸⁰	9 (5–10 min)	S; I	3	Dependent on use	Yes	Yes	Yes
CAD-EOLD (2001) ⁹⁹	Not stated ⁹⁹	Fair ¹⁰⁰	Fair ¹⁰⁰	-	14 (N/A)	P	1	Unknown	Unknown	Yes	N/A
COMQOL (1991) ²⁸	WHO ²⁸	Fair ^{101,102}	Fair ^{101,102}	-	44 (45 mins)	S	N/A	Not stated	Not stated	N/A	Yes
DEMQOL (2005) ²⁹	WHO ⁴⁶ , Kitwood's ⁶³ Dementia Care Mapping Approach, Lawton ^{64,103,104} , Wilson and Cleary ¹⁰⁵	Poor-Good ^{29,70}	Fair ^{29,70}	-	29 (less than 10 mins)	I	3	Not stated	Recommended	Yes	Yes
DUKE (1990) ³⁰	WHO	Fair ^{30,106}	Fair ^{30,106}	Fair ¹⁰⁷	17 (10 min)	S	21	Dependent on use	Recommended	N/A	Yes
DQOL (1999) ³¹	Brod, Krueger ^{31,108}	Poor-Good ⁷⁰	Fair ⁷⁰	-	29 (10 mins)	I	4	Not stated	Not stated	No	Yes
EQ-5D (1990) ³²	Not stated ¹⁰⁹	Excellent ¹¹⁰	Excellent ¹¹⁰	Good ¹¹⁰	6 (2–5 mins)	S	180	Dependent on use	Yes	Yes	Yes
HUI (1996) ³³	von Neumann-Morganstern utility theory ¹¹¹ , multi-attribute framework ^{33,67}	Fair ¹¹²	Fair ¹¹²	- ¹¹³	8 (3 mins)	P	38	Dependent on use	Yes	Yes	Yes
ICECAP-O (2006) ³⁴	Nussbaum, Robeyns and Sen's capabilities foci ⁴⁷⁻⁵¹	Good ¹¹⁴	Good ¹¹⁴	Good ^{80,114}	5 (5–10 mins)	S	8	None	Yes	Yes	Yes
interRAI (LTCF) (2008) ¹¹⁵	Not stated ¹¹⁶	Good ^{117,118}	Good ^{117,118}	-	50 (40–60 mins)	I	11	Yes	Recommended	Yes	Yes
JoLS (2019) ³⁵	Salutogenesis ⁵² , well-being theory ⁵²⁻⁵⁶	Good ¹¹⁹	Good ¹¹⁹	-	13 (N/A)	I	1	Not stated	Not stated	No	N/A
MANSA (1999) ³⁶	Lehman ⁵⁷	Fair ^{36,120,121}	Fair ¹²⁰	-	25 (30 mins)	S	3	None	Not stated	Yes	N/A
NHP (1980) ¹²²	Not stated	Poor to good ¹²³⁻¹²⁶	Poor to good ¹²³⁻¹²⁶	Fair ^{124,127-129}	45 (10 minutes)	I	19	Not stated	Not stated but licensing required	Yes	N/A
NHVQOL (2007) ¹³⁰	Not stated	Good ¹³⁰	Good ¹³⁰	Good ^{131,132}	57 (10–15 min)	I	N/A	Not stated	Not stated	Yes	N/A
OHIP (1993) ³⁷	Locker ⁶⁵ , WHO ⁶⁶	Good ¹³³	Good ¹³³	-	49 (17 mins)	I	8	Not stated	Not stated	Yes	N/A
OPQOL (2009) ³⁸⁻⁴⁰	WHO, Gap theory ^{58,60,134}	Good ^{135,136}	Good ^{135,136}	-	13 (N/A)	I	3	Not stated	Not stated	No	N/A
PGCMS ⁴¹ (1975)	Lawton ^{41,104}	Good ¹³⁷⁻¹³⁹	Good ¹³⁷⁻¹³⁹	-	17 (10 mins)	I	5	None	Recommended	Yes	N/A
QOL-AD (1999) ⁴²	Lawton ¹⁰⁴	Fair ⁷⁰	Poor ⁷⁰	-	26 (10–15 mins)	I; P	9	Dependent on use	Recommended	Yes	Yes
LTC-QOL (2005) ¹⁴⁰	Not stated	Good ^{141,142}	Good ^{141,142}	-	9 (N/A)	P	N/A	Not stated	Not stated	No	Yes
QUALID (2000) ¹⁴³	Not stated	Poor-Fair ⁷⁰	Poor-Fair ⁷⁰	Poor ⁷⁰	11 (5 mins)	P	3	Dependent on use	Recommended	No	Yes

Continued

Table 2 Continued

Instrument acronym	Psychometric properties*				Administration characteristics				User guide	Website†	
	Developmental history and theoretical influence	Validity	Reliability	Responsiveness	Items (length)	Intended administration†	Translations	Fee			Registration
QUALIDEM (2007) ⁴³	Adaptation-coping model ⁶¹ ⁶²	Poor-Excellent ⁷⁰	Fair ⁷⁰	-	40 (10 mins)	P	2	Not stated	Not stated	Yes	N/A
SF-36 (1992) ⁴⁴	Not stated	Good ¹⁴⁴⁻¹⁴⁸	Good ¹⁴⁵⁻¹⁴⁷	Fair ¹⁴⁹⁻¹⁵¹	36 (10 mins)	S	N/A	None	Recommended	Yes	Yes
SWLS (1985) ¹⁵²	Not stated	Good ^{153 154}	Good ^{153 154}	-	7 (1-3 mins)	S	33	None	Recommended	Yes	Yes
WHOQOL-AGE 2013 ⁴⁵	WHO ⁴⁵	Good ^{155 156}	Good ^{155 156}	-	13 (N/A)	S	N/A	None	Yes	Yes	Yes
WHOQOL-BREF (1996) ⁴⁵	WHO ⁴⁵	Good ¹⁵⁷	Excellent ¹⁵⁷	Good ^{158 159}	32 (15-20 mins)	S	27§	None	Yes	Yes	Yes
WHOQOL-OLD (2006) ⁴⁵	WHO ⁴⁵	Good ¹³⁵	Good ¹³⁵	-	24 (N/A)	S	N/A	None	Yes	Yes	Yes

*Psychometric properties were defined according to the terminology from the CONSORT Standards for the selection of health status Measurement Instruments taxonomy⁶⁸ of validity (which is further defined as criterion, content and construct), reliability (commonly known as test-retest) and responsiveness (defined as the ability of a measure to detect clinically important changes following an intervention).¹⁴ Properties can be defined as excellent, good, fair or poor. Where possible, psychometric properties are recorded according to the most recent systematic review of the instrument's psychometric properties, and if this was not applicable then a search of articles assessing the psychometric properties of the instrument for older samples are summarised.

†S=Self-administered; I=interview-administered; p=proxy.

‡Please refer to online supplemental material for specific website links related to the instruments.

§Based on available WHOQOL-100 translations, of which the WHOQOL-BREF is a shorter version.

¶EQ-5D, EuroQoL-5 Dimensions; LTC, long-term care; N/A, not available; NHS, National Health Service; NHVQOL, Nursing Home Vision-Targeted Health-related QoL; SF-36, Short Form 36; WHOQOL-BREF, WHO Quality of Life-Bref.

health, care and participation. Examples of these instruments include the Quality of Life In Late-Stage Dementia (QUALID, 2000), the ICECAP-O (2006) and the ASCOT (2012). Finally, instruments that were purpose built for older people have become more prevalent, although the oldest instrument identified was designed for older people initially in 1975 (PGCMS). The 1990s in particular produced a significant influx of instruments designed for older adults and for adults living with dementia.

Application context

Table 3 presents a summary of the six contexts in which the selected articles have used the QoL instruments. These contexts included: home care (ie, services offered at home and in the community to support independent living, also known as community-aged care, social care), support centre (ie, a place which provides care and/or recreational opportunities and facilities for older adults who cannot be fully independent. These include but are not limited to senior centres and adult day centres), residential aged care (ie, a place that provides older adults with accommodation and personal care, as well as access to nursing and general healthcare services, and are commonly known as nursing homes, LTC, care homes or residential aged care facilities), associated living group facilities (ie, primarily provides personal care in a home-like, social and group setting, for instance group living homes, supportive housing units, other special accommodations), training facilities (ie, places that offer improvement in a particular area, such as cognitive training facilities, off-site training facilities, exercise clinic or memory clinic), and primary care (ie, healthcare provided in the community for older adults).

Some instruments were used in one or a few studies and across a limited sample of older people (eg, COMQOL, DUKE, Oral Health Impact Profile (OHIP)), while others were used extensively across study types, countries and aged care settings (eg, EQ-5D, QOL-AD, SF series). The latter have also been used in range of study designs such as randomised control trails, quasi-experimental and observational studies.

The SF series (SF-36, SF-12 and SF-8) was the most rigorously adopted instrument used to assess QoL in aged care settings (76 studies), followed by the EQ-5D (49 studies) (see table 3). The HUI2/3 was applied to the greatest number of older adults (N=572 411), followed by the inter-RAI (N=566 885) and the ASCOT (N=32 433). Despite the ASCOT being the third most recently developed instrument (developed in 2012), it has been used in large cohort studies assessing over 30 000 older adults. The EQ-5D and the SF-36 were the most widely applied instruments across settings (eg, senior centres, clinics, assisted living facilities and residential aged care facilities).

Generic preference-based instruments were further identified and include the ASCOT, SF-6D, EQ-5D⁶⁹ measures which incorporate weighted scoring algorithms based on the preferences of general population sample



Table 3 Application of QoL instruments across country, context setting and study design

Instrument	No of articles	Countries of use	Context of use							Population total	Mean age (SD)	Study design [¶]
			Home care* [†]	Support centre [†]	Residential aged care	Assisted living group facilities [‡]	Training facilities [§]	Primary care				
15D	3	Finland			✓	✓	✓	✓		227	83 (0.5)	O; R
ADPQOL	14	Denmark; Germany; Norway; USA; Spain	✓		✓	✓	✓	✓		2544	83 (3.4)	N; O; R
AQoL	6	Australia; Malaysia			✓	✓	✓	✓	✓	1136	76 (4.3)	O; R
ASCOT	9	Australia; The Netherlands; UK; Japan; Germany	✓	✓	✓					32 433	80 (3.4)	O; R
CAD-EOLD	2	Belgium			✓					101	85(-)	O; R
COMQOL	1	Australia	✓		✓					187	78(-)	O
DEMQOL	13	Australia; The Netherlands; UK; USA		✓	✓					5537	85 (3.0)	N; O; R
DUKE	1	France			✓					1306	85(-)	O
D-QoL	9	Australia; France; Japan; Norway; The Netherlands; UK; USA	✓		✓	✓	✓			1826	84 (1.7)	O; R
EQ-5D	52	Australia; Belgium; Canada; China; Denmark; Germany; Hong Kong; Hungary; Lebanon; Malaysia; New Zealand; Romania; Singapore; South Korea; Spain; Sweden; The Netherlands; UK	✓		✓	✓	✓	✓	✓	22 866	82 (3.5)	N; O; R
HUI2/3	7	Canada; Germany	✓		✓		✓			572 411	82 (3.1)	O; R
ICECAP-O	5	Australia; Germany; The Netherlands; Spain	✓		✓					763	82 (3.4)	O
InterRAI	5	Canada; Germany	✓		✓					566 885	79 (1.1)	O; R
JoLS	1	Norway			✓					188	87.4(-)	O
MANSA	3	The Netherlands	✓		✓			✓		468	71 (2.9)	O
NHP	8	Finland; Germany; Spain; The Netherlands; Turkey	✓		✓					2653	81 (3.8)	N; O; R
NHVQOL	7	Australia; Nepal; USA			✓			✓		1381	81 (2.8)	N; O; R
OHIP	1	Sweden			✓			✓		41	87 (-)	O
OPQOL	5	Australia; Italy; Philippines; Norway	✓		✓			✓		706	79 (5.9)	O

Continued

Table 3 Continued

Instrument	No of articles	Countries of use	Context of use						Population total	Mean age (SD)	Study design [†]
			Home care*	Support centre†	Residential aged care	Assisted living group facilities‡	Training facilities§	Primary care			
PGCMS	2	The Netherlands; Germany	✓		✓				364	84.3 (0)	O
QoL-AD	39	Australia; Brazil; Canada; Denmark; Estonia; Finland; France; Germany; Norway; Spain; Sweden; Switzerland; The Netherlands; UK; USA	✓		✓	✓			10 576	84 (3.2)	N; O; R
QoL-LTC	1	Australia			✓				28	86(-)	O
QOLNHR	1	USA			✓				62	82(-)	O
QUALID	22	Australia; Italy; Norway; Spain; Sweden; The Netherlands		✓	✓			✓	6061	85 (1.2)	O; R
QUALIDEM	19	Germany; Japan; Switzerland; The Netherlands			✓		✓		3526	84 (2.0)	N; O; R
SF-8	5	Japan; USA	✓		✓		✓		910	81 (5.2)	N; O
SF-12	24	China; Germany; Hong Kong; China; Japan; Sweden; The Netherlands; USA	✓		✓		✓		5460	81 (4.4)	O; R
SF-36	47	Australia; Belgium; Canada; China; Germany; Iran; Italy; Nepal; Malaysia; New Zealand; Norway; South Africa; Spain; Sweden; The Netherlands; Taiwan; Turkey; UK; USA	✓	✓	✓		✓	✓	11 333	79 (5.7)	N; O; R
SWLS	6	Canada; Italy; Hong Kong; The Netherlands; USA	✓		✓		✓		4379	82 (2.8)	N; O
WHOQoL-100	2	China; Iran			✓				297	85 (5.2)	O; R
WHOQoL-AGE	1	Poland	✓						176	75(-)	O
WHOQoL-BREF	23	Brazil; Croatia; Czech Republic; Finland; Germany; Hong Kong; Hungary; Indonesia; Italy; Jordan; Poland; Portugal; Spain; Sri Lanka; The Netherlands; Turkey			✓		✓		6624	78 (6.1)	N; O; R
WHOQOL-OLD	4	Brazil; Czech Republic; Turkey	✓	✓	✓		✓		581	78 (5.5)	O

Continued

Table 3 Continued

Instrument	Context of use					Primary care	Population total	Mean age (SD)	Study design†
	No of articles	Countries of use	Home care*	Support centre†	Residential aged care				

*Services offered at home and in the community to support independent living.
†A place providing care and recreation facilities for older adults who cannot be fully independent. This includes senior centre, adult day centre and day centre.
‡Includes group living homes, supportive housing units, sheltered housing units, special accommodation.
§Includes cognitive training facilities, off-site training facilities, exercise clinic and memory clinic.
¶Study designs types include observation studies (O), non-randomised trials (N) and randomised control trials (R).
ADRQOL, Alzheimer's Disease-Related Quality of Life; AQoL-8D, Assessment of Quality of Life instrument – 8D Version; ASCOT, Adult Social Care Outcomes Toolkit; CAD-EOLD, Comfort Around Dying-End of Life in Dementia; COMQOL, Comprehensive Quality of Life Scale; 15-D, 15-Dimensional instrument; DEMQOL, Dementia Quality of Life measure; DQOL, Dementia Quality of Life instrument; DUKE, Duke Health Profile; EQ-5D, EuroQoL-5 Dimensions; HUI, Health Utility Index; ICECAP-O, ICEpop CAPability measure for Older people; JOLS, Joy-of-Life Scale; LTC, long-term care; LTC-QoL, Long Term Care Quality Of Life assessment scale; MANSA, Manchester Short Assessment of quality of life; NHP, Nottingham Health Profile; NHVQOL, Nursing Home Vision-Targeted Health-related QoL; OHIP, Oral Health Impact Profile; OPOOL, Older Peoples Quality Of Life; PGCMS, Philadelphia Geriatric Centre Moral Scale; QoL, quality of life; QOL-AD, Quality of Life in Alzheimer's Disease; QUALID, Quality of Life in Late-Stage Dementia; QUALIDEM, Dementia Specific Quality of Life instrument; SF-8, Short Form 8; SWLS, Satisfaction With Life Scale; WHOQOL-AGE, World Health Organization Quality of Life Scale - AGE; WHOQOL-BREF, WHO Quality of Life-Bref; WHOQOL-OLD, World Health Organization Quality of Life Scale - OLD.

and are therefore amenable for economic evaluation in addition to quality assessment. Generic non-preference-based instruments (eg, WHOQoL-Bref, OPQOL) were also recognised and are not suitable for economic evaluation but can be suitable for quality assessment.

DISCUSSION

This review provides a comprehensive examination of standardised QoL instruments and how they have been used in aged care settings over time. We identified 293 studies reporting on 29 instruments which have been used to gauge older adults' QoL in multiple aged care settings. In the last decade, QoL instruments have tended to highlight emotional and subjective needs of the older adult's personal circumstances, compared with earlier instruments that were fixated on older adults' physical health condition.

Although previous reviews have reported on the use of QoL instruments in aged care settings, knowledge of how QoL measures have been applied in aged care settings is incomplete. Existing reviews have focused on condition-specific instruments, such as those suitable for adults living with dementia⁷⁰ or hip fractures,⁷¹ or on analysing particular instrument properties, such as suitability for economic analysis.^{69 72 73} We found one recent review with aims similar to our own, however, that review focused on and was restricted to instruments which had undergone feasibility testing in aged care environments, and identified only 13 instruments.²⁰ Furthermore, the review did not consider instrument feasibility (ie, time to administer) or the contexts of instrument application (ie, number and type of respondents),²⁰ which is useful information on how instruments can be used for specific purposes, such as for research or for care quality assurance in aged care settings.

Our review enriches current knowledge by providing a broad and inclusive analysis of the characteristics of QoL instruments used across multiple contexts in which aged care is delivered. Similar to Garratt *et al*,⁵⁹ we found a significant increase in the production of instruments designed for older people and/or adults living with dementia over time; all identified instruments designed after 2000 were population specific (eg, age, neurological condition). We also identified a degree of convergence over time towards greater coverage of subjective and person-centred conceptualisations of life quality, and a decrease in focus on physical health. Five out of the nine instruments designed after 2005 did not equate poorer physical health and limited capacity for independence as an indication of reduced life quality. Rather, instruments such as the ASCOT or ICECAP-O tended to capture emotional and subjective sentiment towards personal circumstances and levels of satisfaction regarding current physical health and higher-order needs (ie, companionship, dignity, love). This convergence has largely been a result of recent policy reform in the UK and Western

Europe, which has sought to ensure that the higher-order needs of aged care recipients are accommodated.^{35 74 75}

Several factors will inform the suitability of identified instruments for use in aged care settings. Decisions about instrument suitability will need to take into account the extent of instrument alignment with current evidence on older adults' QoL; logistical factors involved with administration—shorter tools written in plain language are often more appropriate for many older people⁷⁶; whether or not instruments have been psychometrically tested; and evidence of instrument appropriateness for use with targeted aged care populations. Amenability to economic evaluation and instrument alignment with policy objectives of state and national governments may also influence decisions around instrument suitability, particularly when selecting instruments for quality assurance and indicator purposes.

No single instrument stood out unequivocally as best suited for use in aged care settings. The suitability of instruments, particularly those designed for specific aged care populations such as adults living with dementia, will vary across aged care contexts and populations and the aims or goals of instrument administration. Moreover, we noticed a positive correlation between QoL domain coverage and the number of instrument items, suggesting that ideals of instrument comprehensiveness trade-off against ideals of instrument simplicity and ease of use. For example, while the SF series and EQ-5D instruments are readily available and are logistically feasible for use in aged care settings, they do not adequately capture aspects of life quality which are often important to older people (ie, existential and spiritual matters^{24 77}) and only partially emulate outcomes reflective of the current aims of aged care services in Australia⁷⁸ and other OECD nations. Furthermore, instruments that capture a multidimensional profile can be very useful in specific circumstances, for example for intervention trials where detailed information on individual QoL domains may be required. However, there are situations in which a profile is less useful, and a single index is required. This is especially so in evaluative studies, for example, in assessing cost-effectiveness.

Other instruments, such as the ASCOT and ICECAP-O, designed to capture aspects of QoL important to older people, were less frequently used, have been less psychometrically validated^{69 73} but may be more suited to Australia's aged care context. The ASCOT and ICECAP-O have been designed in mind for European policy objectives—namely to establish methods of capturing the effectiveness and quality of social care services for older adults⁷⁵—which are analogous to current policy objectives in Australia. Both instruments have been elsewhere endorsed by some organisations^{4 79} for use for performance monitoring in Australia, although use alongside the SF series and the EQ-5D may be warranted as neither the ASCOT or ICECAP-O consider physical and mental health domains. Nonetheless, being conceptually focused, the ASCOT and ICECAP-O are better equipped

to facilitate a more targeted assessment and are amenable to economic analysis.⁸⁰

Adults living with dementia make up 53% of residential care clients in Australia, 48% in the USA, and 69% in the UK.⁶ There is a fundamental need to determine and capture what is important to aged care clients living with dementia to form a coherent basis for guiding quality improvement and policy decisions.⁶ Of dementia-specific instruments identified in this review, the QoL-AD was the most widely used, although elsewhere this instrument has been found less psychometrically sound compared with other dementia-specific instruments such as the Dementia Quality of Life (DEMQOL).⁸¹ However, compared with the QoL-AD, we found other dementia-specific instruments to be more exclusively health-orientated and to cover fewer domains. The QoL-AD may be suitable for use in the Australian aged care context as it is currently capable of supporting economic analysis of care services⁸² alongside the DEMQOL⁸³ and non-dementia-specific measures (ASCOT, ICECAP, EQ-5D⁶⁹).

Evidently, consideration of a multitude of factors is necessary for the meaningful collection of QoL outcomes in aged care. It is also evident that no single instrument will be suitable for use for aged care clients generally. As has already been suggested by the Council on the Ageing, should the collection of QoL outcomes be mandated in Australia, given the heterogeneity of aged care settings and clients, inclusions of QoL metrics should allow providers a degree of flexibility to apply instruments relevant to aged care clients in question.³⁶ Effective collection will require instruments which are embedded with person-centred content, are phrased and administered using culturally sensitive and age-appropriate language, and which allow for economic evaluation and comparison between providers.^{7 84} Developments in this space are, however, encouraging, with recent studies identifying leading QoL dimensions relevant to older people receiving aged care services⁷ to support economic evaluation.⁸⁵

Strengths and limitations

We limited the inclusion criteria to instruments used for older adults receiving aged care services. This decision was justified on pragmatic grounds in order to keep the review more focused on measures for use with older adults; extensive literature and inconsistent phrasing remain significant challenges for those conducting systematic reviews on the topic of QoL. It is unlikely that any search strategy could collate a definitive list of instruments; however, the approach taken in the current work is able to complement the selective reviews already in existence. In contrast to the psychometric focus of previous reviews,^{20 70} our objective was to inform researchers and care providers about the domains available, the thematic differences among instruments, and their use within aged care. While we have provided a preliminary overview of the psychometric properties of the included instruments to further guide instrument choice and use, collatable evidence relating to psychometric properties of many

instruments used in aged care homes has been systematically and comprehensively reviewed elsewhere.²⁰ Further research should investigate the psychometric properties of this wider set of instruments, with a specific focus on content and construct validity. Merging these strands of work should strengthen the methodological quality and our understanding of the subject.

Implications

Our work identifies current QoL instruments used in aged care settings internationally. It represents a first step in supporting choice of suitable instruments to be used for monitoring and evaluating quality of care in aged care service settings. Implementation of regular measurement of QoL in aged care and publication of such information will likely encourage more comprehensive benchmarking for organisations and service providers. Ability to examine benchmarks and trends over time may also enable aged care consumers and their families to make evidence-based decisions that are personally relevant, needs-specific and to support maintenance of QoL as they age. Although some aged care providers in Australia have incorporated QoL instruments to track quality of care on their own initiative,⁴ no providers currently publicise QoL outcomes to inform consumer choice. Notwithstanding, evidence demonstrates QoL instruments are reliable, used and readily accepted by care staff and can lead to an enhanced understanding of older adults' needs.^{86 87}

Conclusion

Ultimately, tracking the physical, emotional, social and existential needs of older people requires standardised measurement and valuation of QoL measures that are applicable across the aged care sector. Our comprehensive overview of available instruments, their characteristics and use in aged care settings, provides an important resource for governments, aged care services and the aged care workforce. The evidence we created may support decision-making when choosing QoL measures for research and for care quality monitoring in aged care. The wide variety of QoL instruments identified in our review serves as an important reminder that the choice of the most appropriate instrument will depend on the domains of interest, psychometric properties and feasibility of administration in various aged care contexts.

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REFERENCES

- House of Commons and Health Committee. *Accountability Hearing with the Care Quality Commission: Government and Care Quality Commission Responses to the Committee's Seventh Report of Session 2012–13*. London, 2013.
- Malley J, Holder J, Dodgson R, et al. *Regulating the quality and safety of long-term care in England, in regulating long-term care quality: an international comparison*. New York: Cambridge University Press, 2014: 180–210.
- Kumpunen S, Trigg L, Holder J. Helping older people to use quality information to choose residential care. *JLTC* 2019;87–98.
- Council of the Ageing (COTA) and C. Irlam, *measuring quality and consumer choice in aged care*. Canberra, 2018.
- Theofilou P. Quality of life: definition and measurement. *Eur J Soc Psychol* 2013;9:150–62.
- OECD and E. Union. *A good life in old age?* Paris: OECD Publishing, 2013.
- Cleland J, Hutchinson C, McBain C, et al. Developing dimensions for a new preference-based quality of life instrument for older people receiving aged care services in the community. *Qual Life Res* 2021;30:555–65.
- Feeny D. *Preference-based measures: utility and quality-adjusted life years, in assessing quality of life in clinical trials*. New York: Oxford University Press, 2005: 405–31.
- Hennessy CH, Moriarty DG, Zack MM, et al. Measuring health-related quality of life for public health surveillance. *Public Health Rep* 1994;109:665.
- Meagher G, Cortis N, Charlesworth S, et al. *Meeting the social and emotional support needs of older people using aged care services*. Sydney: Macquarie University, UNSW Sydney and RMIT University, 2019.
- Gallant NL, Peckham A, Marchildon G, et al. Provincial legislative and regulatory standards for pain assessment and management in long-term care homes: a scoping review and in-depth case analysis. *BMC Geriatr* 2020;20:1–14.

- 12 The Registry of Senior Australians (ROSA). *International and national quality and safety indicators for aged care. Report for the Royal Commission into aged care quality and safety*, 2020.
- 13 Jeon Y-H, Casey A-N, Vo K, *et al.* Associations between clinical indicators of quality and aged-care residents' needs and consumer and staff satisfaction: the first Australian study. *Aust Health Rev* 2019;43:133–41.
- 14 OECD. *United Kingdom: highlights from a good life in old age? monitoring and improving quality in long-term care*. Paris: OECD Publishing, 2013.
- 15 Netten A, Burge P, Malley J, *et al.* Outcomes of social care for adults: developing a preference-weighted measure. *Health Technol Assess* 2012;16:1–166.
- 16 Aged Care Quality and Safety Commission. *Guidance and resources for providers to support the aged care quality Standards*, 2019.
- 17 The Royal Commission into Aged Care Quality and Safety. *Royal Commission into aged care quality and safety final report*. Canberra, 2021.
- 18 Tracey R, Briggs L. *Royal commission into aged care quality and safety: interim report: neglect*. Canberra: The Royal Commission into Aged Care Quality and Safety, 2019.
- 19 Cooke PJ, Melchert TP, Connor K. Measuring well-being: a review of instruments. *Couns Psychol* 2016;44:730–57.
- 20 Aspden T, Bradshaw SA, Playford ED, *et al.* Quality-Of-Life measures for use within care homes: a systematic review of their measurement properties. *Age Ageing* 2014;43:596–603.
- 21 Linton M-J, Dieppe P, Medina-Lara A. Review of 99 self-report measures for assessing well-being in adults: exploring dimensions of well-being and developments over time. *BMJ Open* 2016;6:e010641.
- 22 Schiaffino KM *Other*. Other measures of psychological well-being: the affect balance scale (ABS), general health questionnaire (GHQ-12), life satisfaction Index-A (LSI-A), Rosenberg self-esteem scale, satisfaction with life scale (SWLS), and State-Trait anxiety index (STAI). *Arthritis Rheum* 2003;49:S165–74.
- 23 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- 24 van Leeuwen KM, van Loon MS, van Nes FA, *et al.* What does quality of life mean to older adults? A thematic synthesis. *PLoS One* 2019;14:e0213263.
- 25 Rabins PV, Kasper JD. Measuring quality of life in dementia: conceptual and practical issues. *Alzheimer Dis Assoc Disord* 1997;11 Suppl 6:100–4.
- 26 Richardson J, Sinha K, Izzi A, *et al.* Modelling utility weights for the Assessment of Quality of Life (AQoL)-8D. *Qual Life Res* 2014;23:395–404.
- 27 Sintonen H. *The 15-D Measure of Health Related Quality of Life: Reliability, Validity and Sensitivity of its Health State Descriptive System. Working Paper 41*, 1994.
- 28 Cummins RA. *Comprehensive quality of life scale-Intellectual/cognitive disability*. School of Psychology: Deakin University, 1997.
- 29 Smith S, Lamping D, Banerjee S, *et al.* Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technol Assess* 2005;9:iii–93.
- 30 Parkerson GR, Broadhead WE, Tse CK. The Duke health profile. A 17-item measure of health and dysfunction. *Med Care* 1990;28:1056–72.
- 31 Brod M, Stewart AL, Sands L, *et al.* Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *Gerontologist* 1999;39:25–36.
- 32 EuroQoL Group. EuroQoL—a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199–208.
- 33 Torrance GW, Feeny DH, Furlong WJ, *et al.* Multiattribute utility function for a comprehensive health status classification system. health Utilities index mark 2. *Med Care* 1996;34:702–22.
- 34 Coast J, Flynn TN, Natarajan L, *et al.* Valuing the icecap capability index for older people. *Soc Sci Med* 2008;67:874–82.
- 35 Haugan G, Rinnan E, Espnes GA, *et al.* Development and psychometric properties of the Joy-of-Life scale in cognitively intact nursing home patients. *Scand J Caring Sci* 2019;33:801–14.
- 36 Priebe S, Huxley P, Knight S, *et al.* Application and results of the Manchester short assessment of quality of life (Mansa). *Int J Soc Psychiatry* 1999;45:7–12.
- 37 Slade GD, Spencer AJ. Development and evaluation of the oral health impact profile. *Community Dent Health* 1994;11:3–11.
- 38 Bowling A, Banister D, Sutton S, *et al.* A multidimensional model of the quality of life in older age. *Ageing Ment Health* 2002;6:355–71.
- 39 Bowling A, Gabriel Z. An Integrational model of quality of life in older age. results from the ESRC/MRC HSRC quality of life survey in Britain. *Soc Indic Res* 2004;69:1–36.
- 40 Bowling A. *Ageing well: quality of life in old age. Bowling, a. (2005) ageing well: quality of life in old age*. Open University Press, Maidenhead, UK, 2005.
- 41 Lawton MP. The Philadelphia geriatric center morale scale: a revision. *J Gerontol* 1975;30:85–9.
- 42 Logsdon RG, Gibbons LE, McCurry SM, *et al.* Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging* 1999;5:21–32.
- 43 Ettema TP, Dröes R-M, de Lange J, *et al.* QUALIDEM: development and evaluation of a dementia specific quality of life instrument—validation. *Int J Geriatr Psychiatry* 2007;22:424–30.
- 44 Ware JE, Sherbourne CD. The mos 36-item short-form health survey (SF-36). I. conceptual framework and item selection. *Med Care* 1992;30:473–83.
- 45 World Health Organization, WHOQOL user manual. *Division of mental health and prevention of substance abuse: World Health organization*, 2012.
- 46 World Health Organization. *Constitution of the world Health organization*. WHO: Geneva, 1946.
- 47 Nussbaum M. Capabilities as fundamental entitlements: SEN and social justice. *Fem Econ* 2003;9:33–59.
- 48 Robeyns I. Sen's capability approach and gender inequality: Selecting relevant capabilities. *Fem Econ* 2003;9:61–92.
- 49 Robeyns I. The capability approach: a theoretical survey. *J Human Dev* 2005;6:93–117.
- 50 Sen A. *Choice, welfare and measurement*. Oxford: Basil Blackwell, 1982.
- 51 Sen A. *Capability and Well-Being, in the quality of life*. Oxford: Oxford University Press, 1993.
- 52 Antonovsky A. *Unraveling the mystery of health: how people manage stress and stay well*. San Francisco, CA, US: Jossey-Bass, 1987: 218.
- 53 Keyes CLM. Promoting and protecting mental health as flourishing: a complementary strategy for improving national mental health. *Am Psychol* 2007;62:95–108.
- 54 Keyes C. *Mental health as a complete state: how the salutogenic perspective completes the picture, in bridging occupational, organizational and public health*. Netherlands: Springer, 2014: 179–92.
- 55 Keyes CLM, Westerhof GJ. Chronological and subjective age differences in flourishing mental health and major depressive episode. *Ageing Ment Health* 2012;16:67–74.
- 56 Seligman ME. *Flourish: a visionary new understanding of Happiness and well-being*. Simon and Schuster, 2012.
- 57 Lehman AF. A quality of life interview for the chronically mentally ill. *Eval Program Plann* 1988;11:51–62.
- 58 Calman KC. Quality of life in cancer patients—an hypothesis. *J Med Ethics* 1984;10:124–7.
- 59 Garratt A, Schmidt L, Mackintosh A, *et al.* Quality of life measurement: bibliographic study of patient assessed health outcome measures. *BMJ* 2002;324:1417.
- 60 Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999;48:1507–15.
- 61 Finnema E, Dröes RM, Ribbe M, *et al.* A review of psychosocial models in psychogeriatrics: implications for care and research. *Alzheimer Dis Assoc Disord* 2000;14:68–80.
- 62 Dröes R-M, Boelens-Van Der Knoop ECC, Bos J, *et al.* Quality of life in dementia in perspective. *Dementia* 2006;5:533–58.
- 63 Kitwood T, Bredin K. Towards a theory of dementia care: personhood and well-being. *Ageing Soc* 1992;12:269–87.
- 64 Lawton M. *A multidimensional view of quality of life in frail elders, in the concept and measurement of quality of life in the frail elderly*. San Diego, CA: Academic Press, 1991: 3–23.
- 65 Locker D. Measuring oral health: a conceptual framework. *Community Dent Health* 1988;5:3–18.
- 66 World Health Organization. *International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease, published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976*. World Health Organization: Geneva, 1980.
- 67 Boyle MH, Torrance GW, Sinclair JC, *et al.* Economic evaluation of neonatal intensive care of very-low-birth-weight infants. *N Engl J Med* 1983;308:1330–7.
- 68 Amsterdam Public Health. *Guideline for systematic reviews of outcome measurement instruments*, 2021. Available: <https://www.cosmin.nl/tools/guideline-conducting-systematic-review-outcome-measures/?portfolioCats=19>

- 69 Bulamu NB, Kaambwa B, Ratcliffe J. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. *Health Qual Life Outcomes* 2015;13:179.
- 70 Hughes LJ, Farina N, Page TE, et al. Psychometric properties and feasibility of use of dementia specific quality of life instruments for use in care settings: a systematic review. *Int Psychogeriatr* 2021;33:917–31.
- 71 Haywood KL, Brett J, Tutton E, et al. Patient-Reported outcome measures in older people with hip fracture: a systematic review of quality and acceptability. *Qual Life Res* 2017;26:799–812.
- 72 Cleland J, Hutchinson C, Khadka J, et al. A review of the development and application of generic Preference-Based instruments with the older population. *Appl Health Econ Health Policy* 2019;17:781–801.
- 73 Bulamu NB, Kaambwa B, Ratcliffe J. A systematic review of instruments for measuring outcomes in economic evaluation within aged care. *Health Qual Life Outcomes* 2015;13:1–23.
- 74 Department of Health. *Transparency in outcomes: a framework for quality in adult social care: the 2012/13 adult social care outcomes framework*. Leeds, 2012.
- 75 Grewal I, Lewis J, Flynn T, et al. Developing attributes for a generic quality of life measure for older people: preferences or capabilities? *Soc Sci Med* 2006;62:1891–901.
- 76 Bowling A, Hankins M, Windle G, et al. A short measure of quality of life in older age: the performance of the brief older people's quality of life questionnaire (OPQOL-brief). *Arch Gerontol Geriatr* 2013;56:181–7.
- 77 Brownie S, Horstmanhof L. Creating the conditions for self-fulfilment for aged care residents. *Nurs Ethics* 2012;19:777–86.
- 78 Baxter R, Sandman P-O, Björk S, et al. Illuminating meanings of thriving for persons living in nursing homes. *Gerontologist* 2020;60:859–67.
- 79 Leading Aged Services Australia. *Lasa taking the lead on quality indicators, 2019*. Available: <https://lasa.asn.au/wp-content/uploads/2019/10/LASA-taking-the-lead-on-quality-indicators.pdf>
- 80 van Leeuwen KM, Bosmans JE, Jansen APD, et al. Comparing measurement properties of the EQ-5D-3L, ICECAP-O, and Ascot in frail older adults. *Value Health* 2015;18:35–43.
- 81 Chua K-C, Brown A, Little R, et al. Quality-Of-Life assessment in dementia: the use of DEMQOL and DEMQOL-Proxy total scores. *Qual Life Res* 2016;25:3107–18.
- 82 Comans TA, Nguyen K-H, Ratcliffe J, et al. Valuing the AD-5D dementia utility instrument: an estimation of a general population tariff. *Pharmacoeconomics* 2020;38:871–81.
- 83 Mulhern B, Rowen D, Brazier J, et al. Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technol Assess* 2013;17:1–140.
- 84 Smith Ket al. *Good spirit, good life: a quality of life tool and framework for older Aboriginal peoples*. Gerontologist, 2020.
- 85 Ratcliffe J, Cameron I, Lancsar E, et al. Developing a new quality of life instrument with older people for economic evaluation in aged care: study protocol. *BMJ Open* 2019;9:e028647.
- 86 Siette J, Georgiou A, Jorgensen M, et al. Integrating social engagement instruments into Australian community aged care assessments to enhance service provision. *Health Soc Care Community* 2018;26:810–8.
- 87 Cardona B, Fine M, Stebbing A, et al. Measuring consumer outcomes: development and testing of the Australian community care outcomes measure. *Australas J Ageing* 2017;36:69–71.
- 88 Sintonen H. The 15D instrument of health-related quality of life: properties and applications. *Ann Med* 2001;33:328–36.
- 89 Rabins PV, Kasper JD, Kleinman L, et al. Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's Disease. *Journal of Mental Health and Aging* 1999;5:33–48.
- 90 Richardson J, Iezzi A, Khan MA, et al. Validity and reliability of the Assessment of Quality of Life (AQoL)-8D multi-attribute utility instrument. *Patient* 2014;7:85–96.
- 91 Hawthorne G, Richardson J, Osborne R. The assessment of quality of life (AQoL) instrument: a psychometric measure of health-related quality of life. *Qual Life Res* 1999;8:209–24.
- 92 Richardson Jet al. *Modelling the utility of health states with the assessment of quality of life (AQoL) 8D instrument: overview and utility scoring algorithm*. Victoria, Australia: Centre for Health Economics, Monash University, 2011.
- 93 Nocon A, Qureshi H. *Outcomes of community care for users and carers: A social services perspective*. Vol. 3. Portland, Or: Taylor & Francis, 1996.
- 94 Nocon A, Qureshi H, Thornton P. *Outcomes in community care practice. The perspectives of users' and carers' organisations*. Vol. 4. University of York: Social Policy Research Unit, 1997.
- 95 Qureshi Het al. *Outcomes in community care practice. Outcomes of social care for older people and carers*. Vol. 5. University of York: Social Policy Research Unit, 1998.
- 96 Bamford Cet al. *Outcomes in community care practice. Outcomes for disabled people and carers*. Vol. 6. University of York: Social Policy Research unit, 1999.
- 97 Department of Health and Social Care. *Adult social care outcomes framework: Handbook of definitions, 2017*. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/629812/ASCOF_handbook_definitions.pdf
- 98 Malley JN, Towers A-M, Netten AP, et al. An assessment of the construct validity of the Ascot measure of social care-related quality of life with older people. *Health Qual Life Outcomes* 2012;10:21.
- 99 Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord* 2001;15:194–200.
- 100 van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res* 2012;21:671–84.
- 101 Gullone E, Cummins RA. The comprehensive quality of life scale: a psychometric evaluation with an adolescent sample. *Behaviour Change* 1999;16:127–39.
- 102 Cummins RA, McCabe MP, Romeo Y, et al. Validity studies the comprehensive quality of life scale (Comqol): instrument development and psychometric evaluation on College staff and students. *Educ Psychol Meas* 1994;54:372–82.
- 103 Lawton MP. Environment and other determinants of well-being in older people. *Gerontologist* 1983;23:349–57.
- 104 Lawton MP. Quality of life in Alzheimer disease. *Alzheimer Dis Assoc Disord* 1994;8 Suppl 3: :138–50.
- 105 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA* 1995;273:59–65.
- 106 Rapin A, Dramé M, Jolly D. Psychometric properties of the Duke health profile in a neuromuscular disease population. *Eur J Phys Rehabil Med* 2016;52:57–64.
- 107 Parkerson GR, Willke RJ, Hays RD. An international comparison of the reliability and responsiveness of the Duke health profile for measuring health-related quality of life of patients treated with alprostadil for erectile dysfunction. *Med Care* 1999;37:56–67.
- 108 Krueger R. Group dynamics and focus groups. In: *Quality of life and pharmacoeconomics in clinical trials*. New York: Lippencott-Raven, 1996: 397–402.
- 109 Devlin NJ, Brooks R. EQ-5D and the EuroQol group: past, present and future. *Appl Health Econ Health Policy* 2017;15:127–37.
- 110 Feng Y-S, Kohlmann T, Janssen MF, et al. Psychometric properties of the EQ-5D-5L: a systematic review of the literature. *Qual Life Res* 2021;30:647–73.
- 111 von Neumann J, Morgenstern O, Rubinstein A. *Theory of games and economic behavior (60th anniversary Commemorative edition)*. Princeton University Press, 1944.
- 112 Saiguay W, Sakthong P. The psychometric testing of the Thai version of the health Utilities index in patients with ischemic heart disease. *Qual Life Res* 2013;22:1753–9.
- 113 Mpundu-Kaambwa C, Chen G, Huynh E, et al. A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy. *Qual Life Res* 2018;27:1781–99.
- 114 Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. *J Chronic Dis* 1987;40:171–8.
- 115 Hirdes JP, Ljunggren G, Morris JN, et al. Reliability of the interRAI suite of assessment instruments: a 12-country study of an integrated health information system. *BMC Health Serv Res* 2008;8:277.
- 116 Mor V, Finne-Soveri H, Hirdes JP, et al. *Long term care quality monitoring using the interRAI common clinical assessment language, in Performance measurement for health system improvement : experiences, challenges and prospects*. Cambridge: Cambridge University Press, 2010: 472–505.
- 117 Kim H, Jung Y-I, Sung M, et al. Reliability of the interRAI long term care facilities (LTCF) and interRAI home care (HC). *Geriatr Gerontol Int* 2015;15:220–8.
- 118 Hirdes JP, van Everdingen C, Ferris J, et al. The interRAI suite of mental health assessment instruments: an integrated system for the continuum of care. *Front Psychiatry* 2019;10:926.

- 119 Haugan G, Rinnan E, Espnes GA, *et al.* Development and psychometric properties of the Joy-of-Life scale in cognitively intact nursing home patients. *Scand J Caring Sci* 2019;33:801–14.
- 120 Eklund M, Sandqvist G. Psychometric properties of the satisfaction with daily occupations (SDO) instrument and the Manchester short assessment of quality of life (MANSA) in women with scleroderma and without known illness. *Scand J Occup Ther* 2006;13:23–30.
- 121 Petkari E, Giacco D, Priebe S. Factorial structure of the Manchester short assessment of quality of life in patients with schizophrenia-spectrum disorders. *Qual Life Res* 2020;29:833–41.
- 122 Hunt SM, McKenna SP, McEwen J, *et al.* A quantitative approach to perceived health status: a validation study. *J Epidemiol Community Health* 1980;34:281–6.
- 123 Hinz A, Klaiberg A, Schumacher J, *et al.* [The psychometric quality of the Nottingham Health Profile (NHP) in the general population]. *Psychother Psychosom Med Psychol* 2003;53:353–8.
- 124 Sharples LD, Todd CJ, Caine N, *et al.* Measurement properties of the Nottingham health profile and short form 36 health status measures in a population sample of elderly people living at home: results from ELPHS. *Br J Health Psychol* 2000;5:217–33.
- 125 Wiklund I, Romanus B, Hunt SM. Self-assessed disability in patients with arthrosis of the hip joint. reliability of the Swedish version of the Nottingham health profile. *Int Disabil Stud* 1988;10:159–63.
- 126 Carlsson E, Olsson SB, Hertervig E. The role of the nurse in enhancing quality of life in patients with an implantable cardioverter-defibrillator: the Swedish experience. *Prog Cardiovasc Nurs* 2002;17:18–25.
- 127 Kjeldsen BJ, Thorsen H, Whalley D, *et al.* Influence of follow-up on health-related quality of life after radical surgery for colorectal cancer. *Scand J Gastroenterol* 1999;34:509–15.
- 128 Klevsgård R, Hallberg IR, Risberg B, *et al.* The effects of successful intervention on quality of life in patients with varying degrees of lower-limb ischaemia. *Eur J Vasc Endovasc Surg* 2000;19:238–45.
- 129 Klevsgård R, Risberg BO, Thomsen MB, *et al.* A 1-year follow-up quality of life study after hemodynamically successful or unsuccessful surgical revascularization of lower limb ischemia. *J Vasc Surg* 2001;33:114–22.
- 130 Dreer LE, McGwin G, Scilley K, *et al.* Development of a nursing home vision-targeted health-related quality of life questionnaire for older adults. *Aging Ment Health* 2007;11:722–33.
- 131 Owsley C, McGwin G, Scilley K, *et al.* Impact of cataract surgery on health-related quality of life in nursing home residents. *Br J Ophthalmol* 2007;91:1359–63.
- 132 Owsley C, McGwin G, Scilley K, *et al.* Effect of refractive error correction on health-related quality of life and depression in older nursing home residents. *Arch Ophthalmol* 2007;125:1471–7.
- 133 Zucoloto ML, Maroco J, Campos JADB. Psychometric properties of the oral health impact profile and new methodological approach. *J Dent Res* 2014;93:645–50.
- 134 Garratt AM, Ruta DA. The patient generated index. In: Joyce CRB, O'Boyle CA, McGee H, eds. *Individual quality of life approaches to conceptualisation and assessment*. Amsterdam: Harwood Academic Publishers, 1999.
- 135 Bowling A. *The psychometric properties of the Older People's Quality Of Life questionnaire, compared with the CASP-19 and the WHOQOL-OLD*. *Current Gerontology and Geriatrics Research*, 2009.
- 136 Haugan G. Meaning-in-life in nursing-home patients: a correlate with physical and emotional symptoms. *J Clin Nurs* 2014;23:1030–43.
- 137 Wong E, Woo J, Hui E, *et al.* Examination of the Philadelphia geriatric morale scale as a subjective quality-of-life measure in elderly Hong Kong Chinese. *Gerontologist* 2004;44:408–17.
- 138 Pinar R, Oz H. Validity and reliability of the Philadelphia geriatric center morale scale among Turkish elderly people. *Qual Life Res* 2011;20:9–18.
- 139 Niklasson J, Conradsson M, Hörnsten C, *et al.* Psychometric properties and feasibility of the Swedish version of the Philadelphia geriatric center morale scale. *Qual Life Res* 2015;24:2795–805.
- 140 McDonald T. Measurement features of a long-term care quality of life (LTC-QoL) assessment scale. *J Care Serv Manag* 2013;7:76–86.
- 141 McDonald T, Russell F. Long-Term care quality-of-life scale utility in community home care. *Nurs Health Sci* 2019;21:494–500.
- 142 McDonald T. Measurement features of a long-term care quality of life (LTC-QoL) assessment scale. *J Care Serv Manag* 2020;7:76–86.
- 143 Weiner DK, Hanlon JT. Pain in nursing home residents: management strategies. *Drugs Aging* 2001;18:13–29.
- 144 Butterworth P, Crosier T. The validity of the SF-36 in an Australian National household survey: demonstrating the applicability of the household income and labour dynamics in Australia (HILDA) survey to examination of health inequalities. *BMC Public Health* 2004;4:44.
- 145 Bunevicius A. Reliability and validity of the SF-36 health survey questionnaire in patients with brain tumors: a cross-sectional study. *Health Qual Life Outcomes* 2017;15:92.
- 146 LoMartire R, Ång BO, Gerdle B, *et al.* Psychometric properties of short Form-36 health survey, EuroQol 5-dimensions, and hospital anxiety and depression scale in patients with chronic pain. *Pain* 2020;161:83–95.
- 147 Gandek B, Sinclair SJ, Kosinski M, *et al.* Psychometric evaluation of the SF-36 health survey in Medicare managed care. *Health Care Financ Rev* 2004;25:5–25.
- 148 Cameron JI, Herridge MS, Tansey CM, *et al.* Well-Being in informal caregivers of survivors of acute respiratory distress syndrome. *Crit Care Med* 2006;34:81–6.
- 149 Supino PG, Borer JS, Franciosa JA, *et al.* Acceptability and psychometric properties of the Minnesota living with heart failure questionnaire among patients undergoing heart valve surgery: validation and comparison with SF-36. *J Card Fail* 2009;15:267–77.
- 150 Wittink H, Turk DC, Carr DB, *et al.* Comparison of the redundancy, reliability, and responsiveness to change among SF-36, Oswestry disability index, and multidimensional pain inventory. *Clin J Pain* 2004;20:133–42.
- 151 Haywood KL, Garratt AM, Fitzpatrick R. Quality of life in older people: a structured review of generic self-assessed health instruments. *Qual Life Res* 2005;14:1651–68.
- 152 Diener E, Emmons RA, Larsen RJ, *et al.* The satisfaction with life scale. *J Pers Assess* 1985;49:71–5.
- 153 López-Ortega M, Torres-Castro S, Rosas-Carrasco O. Psychometric properties of the satisfaction with life scale (SWLS): secondary analysis of the Mexican health and aging study. *Health Qual Life Outcomes* 2016;14:170.
- 154 Swami V, Chamorro-Premuzic T. Psychometric evaluation of the Malay satisfaction with life scale. *Soc Indic Res* 2009;92:25–33.
- 155 Caballero FF, Miret M, Power M, *et al.* Validation of an instrument to evaluate quality of life in the aging population: WHOQOL-AGE. *Health Qual Life Outcomes* 2013;11:177.
- 156 Santos D, Abad FJ, Miret M, *et al.* Measurement invariance of the WHOQOL-AGE questionnaire across three European countries. *Qual Life Res* 2018;27:1015–25.
- 157 Skevington SM, Lotfy M, O'Connell KA, *et al.* The world Health organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the International field trial. A report from the WHOQOL group. *Qual Life Res* 2004;13:299–310.
- 158 von Steinbüchel N, Lischetzke T, Gurny M, *et al.* Assessing quality of life in older people: psychometric properties of the WHOQOL-BREF. *Eur J Ageing* 2006;3:116–22.
- 159 Skevington SM, Epton T. How will the sustainable development goals deliver changes in well-being? A systematic review and meta-analysis to investigate whether WHOQOL-BREF scores respond to change. *BMJ Glob Health* 2018;3:e000609.