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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-0) 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,¹² there is a need to establish longterm 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

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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.¹¹¹² 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 peerreviewed 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 authors 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 Instr	ument 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		>			>		>		>
	WHOQOL-BREF	>	>	>	>	>	>	>		>
Older adults	ASCOT				>	>	>	>		
	ICECAP-O		>		>		>	>		
	Inter-RAI (LTCF)		>		>	>	>	>		
	LTC-QoL		>		>	>	>			
	JoLS		>		>	>	>		>	
	NHVQOL	>	>		>	>	>	>		
	OPQOL		>		>	>	>	>		>
	PGCMS		>	>	>		>	>		>
	WHOQOL-AGE	>	>		>	>	>	>		>
	WHOQOL-OLD	>	>		>		>	>		
										Continued



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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 ves/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 influence¹⁵ $^{25-45}$ (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

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 Visionrelated 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 (Joyof-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 Sumn	nary of QoL instrument	psychometric prol	perties and adn	ninistration chara	acteristics						
		Psychometric prope	rties*		Administration	ı characteristics					
Instrument acronym	Developmental history and theoretical influence	Validity	Reliability	Responsiveness	Items (length)	Intended administration†	Translations	Fee	Registration	User guide	Website‡
15-D (1992) ²⁷	WHO ²⁷	Good ⁸⁸	Good ⁸⁸	Good ⁸⁸	15 (5 mins)	_	32	None	Yes	Yes	Yes
ADRQOL (1997) ²⁵	Concepts of QoL ⁸⁹	Poor ⁷⁰	Poor ⁷⁰	1	40 (10–15 mins)	٩	9	Dependent on use	Yes	Yes	Yes
A-QoL-8D (2011) ⁹⁰	WHO ^{90 91}	Good ^{26 90}	Good ⁹²	1	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	ю	Dependent on use	Yes	Yes	Yes
CAD-EOLD (2001) ⁹⁹	Not stated ³⁹	Fair ¹⁰⁰	Fair ¹⁰⁰	1	14 (N/A)	٩.	-	Unknown	Unknown	Yes	N/A
COMQOL (1991) ²⁸	WHO ²⁸	Fair ^{101 102}	Fair ^{101 102}	1	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}	1	29 (less than 10 mins)	_	σ	Not stated	Recommended	Yes	Yes
DUKE (1990) ³⁰	МНО	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	1	29 (10 mins)	_	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)	۰.	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	1	50 (40–60 mins)	_	1	Yes	Recommended	Yes	Yes
JoLS (2019) ³⁵	Salutogenesis ⁵² , well-being theory ⁵²⁻⁵⁶	Good ¹¹⁹	Good ¹¹⁹	1	13 (N/A)	_		Not stated	Not stated	No	N/A
MANSA (1999) ³⁶	Lehman ⁵⁷	Fair ³⁶ 120 121	Fair ¹²⁰	1	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)	_	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)	_	N/A	Not stated	Not stated	Yes	N/A
OHIP (1993) ³⁷	Locker ⁶⁵ , WHO ⁶⁶	Good ¹³³	Good ¹³³	I	49 (17 mins)	_	8	Not stated	Not stated	Yes	N/A
OPQOL (2009) ³⁸⁻⁴⁰	WHO, Gap theory ^{58 60 134}	Good ^{135 136}	Good ¹³⁵ 1 ³⁶		13 (N/A)	_	3	Not stated	Not stated	No	N/A
PGCMS ⁴¹ (1975)	Lawton ^{41 104}	Good ^{137–139}	Good ^{137–139}	I	17 (10 mins)	_	5	None	Recommended	Yes	N/A
QOL-AD (1999) ⁴²	Lawton ¹⁰⁴	Fair ⁷⁰	Poor ⁷⁰	I	26 (10–15 mins)	I; P	o	Dependent on use	Recommended	Yes	Yes
LTC-QOL (2005) ¹⁴⁰	Not stated	Good ^{141 142}	Good ^{141 142}	I	6 (N/A)	Ь	N/A	Not stated	Not stated	No	Yes
QUALID (2000) ¹⁴³	Not stated	Poor-Fair ⁷⁰	Poor-Fair ⁷⁰	Poor ⁷⁰	11 (5 mins)	٩	e	Dependent on use	Recommended	No	Yes
										Ō	ontinued

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Table 2 Cont	tinued										
		Psychometric prop	erties*		Administratio	n characteristics					
Instrument acronym	Developmental history and theoretical influence	Validity	Reliability	Responsiveness	Items (length)	Intended administration†	Translations	Fee	Registration	User guide	Websit
QUALIDEM (2007) ⁴³	Adaptation-coping model ⁶¹ 62	Poor-Excellent ⁷⁰	Fair ⁷⁰	1	40 (10 mins)	۵.	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}	I	7 (1–3 mins)	S	33	None	Recommended	Yes	Yes
WHOQOL-AGE 2013 ⁴⁵	WHO ⁴⁵	Good ^{155 156}	Good ¹⁵⁵ 156	1	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	1	24 (N/A	S	N/A	None	Yes	Yes	Yes
*Psychometric prope construct), reliability of possible, psychometi instrument for older s	raties were defined according to the t (commonly known as test-retest) and ric properties are recorded according samples are summarised.	erminology from the CC d responsiveness (defin g to the most recent sys	insensus-based Stan ad as the ability of a n tematic review of the	dards for the selection of neasure to detect clinica instrument's psychomet	f health status Me Ily important chan ric properties, and	asurement INstrument iges following an inten d if this was not applic	:s taxonomy ⁶⁸ of v vention. ¹¹⁴ Propert able then a search	alidity (which is fu ies can be defined of articles assess	rther defined as criteric d as excellent, good, fa sing the psychometric p	on, content lir or poor. V oroperties c	and Vhere f the

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

of available WHOQOL-100 translations, of which the WHOQOL-BREF is a shorter version. EuroQoL-5 Dimensions; LTC, long-term care; NA, not available; NHS, National Heatth Service; NHVQOL, Nursing Home Vision-Targeted Heatth-related QoL; SF-36, Short Form 36; WHOQOL-BREF, WHO Quality of Life-Bref.

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

-self-administered; l=interview-administered; p=proxy.

§Based c EQ-5D, E 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 Applic:	ation of Qo	oL instruments across count	try, conte	ext setting	and study desi	ign					
			Context c	of use							
Instrument	No of articles	Countries of use	Home care*	Support centre†	Residential aged care	Assisted living group facilities‡	Training facilities§	Primary care	Population total	Mean age (SI	Study) design¶
15D	e	Finland			>	>	>		227	83 (0.5)	O; R
ADRQOL	14	Denmark; Germany; Norway; USA; Spain	>		>	>			2544	83 (3.4)	N; O; R
AQoL	9	Australia; Malaysia			>	>		>	1136	76 (4.3)	O; R
ASCOT	თ	Australia; The Netherlands; UK; Japan; Germany	>	>					32 433	80 (3.4)	0; R
CAD-EOLD	5	Belgium			>				101	85(-)	O; R
COMQOL	-	Australia	>		>				187	78(-)	0
DEMQOL	13	Australia; The Netherlands; UK; USA		>	>				5537	85 (3.0)	N; O; R
DUKE	-	France			>				1306	85(-)	0
D-QoL	Ø	Australia; France; Japan; Norway; The Netherlands; UK; USA	>		>	>			1826	84 (1.7)	Ö; H
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)	я ç ž
HU12/3	7	Canada; Germany	>		>	>			572 411	82 (3.1)	O; R
ICECAP-O	Ω	Australia; Germany; The Netherlands; Spain	>		>				763	82 (3.4)	0
InterRAI	Q	Canada; Germany	>		>				566 885	79 (1.1)	O; R
JoLS	-	Norway			>				188	87.4(-)	0
MANSA	ი	The Netherlands	>		>			>	468	71 (2.9)	0
dHN	ω	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	-	Sweden			>				41	87 (-)	0
OPQOL	5	Australia; Italy; Philippines; Norway	>		>				706	79 (5.9)	0
											Continued

No of articles Countries 2 The Nethe 39 Australia; France; G Spain; Sw Netherlan 1 USA		Context c	of use							
No of articles Countries 2 The Neth 39 Australia: 7 Penmarks France; G Spain; Sw Netherlan 1 USA										
2 The Nethr 39 Australia; Penmark; France; G Spain; Sw Netherlan 1 Australia	s of use	Home care*	Support centre†	Residential aged care	Assisted living group facilities‡	Training facilities§	Primary care	Population tota	I Mean age (SI	Study) design¶
39 Australia; Denmark; France; G Spain; Sw Netherlan 1 Australia	erlands; Germany	>		>				364	84.3 (0)	0
1 Australia 1 USA	Brazil; Canada; ; Estonia; Finland; àermany; Norway; veden; Switzerland; The nds; UK; USA	>		>	>	>		10 576	84 (3.2)	ы С Х
1 USA				>				28	86(-)	0
				>				62	82(-)	0
22 Australia; Sweden;	Italy; Norway; Spain; The Netherlands		>	>			>	6061	85 (1.2)	O; R
19 Germany: The Nethe	; Japan; Switzerland; erlands			>	>			3526	84 (2.0)	N; O; R
5 Japan; Ut	SA	>		>	>			910	81 (5.2)	N; O
24 China; Ge China; Ja Netherlan	ermany; Hong Kong; pan; Sweden; The ids; USA	>		>	>			5460	81 (4.4)	0; R
47 Australia; Ghina; Ge Nepal; Mi Norway; 5 Sweden; Taiwan; Tu	Belgium; Canada; armany; Iran, Italy; alaysia; New Zealand; South Africa; Spain; The Netherlands; ürkey; UK; USA	>	>		>	>	>	11 333	79 (5.7)	N; O; R
6 Canada; I Netherlan	Italy; Hong Kong; The ids; USA	>		>	>			4379	82 (2.8)	N; O
2 China; Ira	Ľ			>				297	85 (5.2)	0; R
E 1 Poland		>						176	75(-)	0
EF 23 Brazil; Cn Finland; C Hungary; Jordan; P Sri Lanka, Turkey	oatia; Czech Republic; Bermany; Hong Kong; Indonesia, Italy; oland; Portugal; Spain; t; The Netherlands;			>	>			6624	78 (6.1)	N; O; R
D 4 Brazil; Cz	ech Republic; Turkey	>	>	>				581	78 (5.5)	0

Open access

			Context c	of use					
Instrument	No of articles	Countries of use	Home care*	Support centre†	Residential aged care	Assisted living group facilities‡	Training facilities§	Primary care	Study Population total Mean age (SD) design¶
"Services offered at home TA place providing care at #Includes group living hon \$includes cognitive trainin "IStudy designs types incl ADRADCI, Abrheimer's Dise Comprehensive Quality of Health Profile; NHVQDL, N Health Profile; NHVQQL, Br in Alzheimer's Disease; OL	and in the c and recreation mes, suppor mes, suppor g facilities, r ude observe asse-Relate Life Scale; CAPability Jurish Horr JALID, Qual 3EF, WHO C	i facilities for older adults who cannot be the housing units, sheltered housing unit five housing units, sheltered housing unit tifor studies (D), non-randomised trials (f d Quality of Life, AQL-BD, Assessment to 15-D, 15-Dimensional instrument; DEMQ masure for Older people, JoLS, Joy-orl- ne Vision-Targeted Health-related QOL; OI ity of Life In Late-Stage Dementita, QUAL uuality of Life-Bref; WHOQOL-OLD, World	the standard of the standard of the standard are special are und memory where and rands of Quality of QL. Dement QL. Dement Life Scale; L. Life Scale; L. Life Noral HIR, Oral Heith Org J Heatth Org J Heatth Org	andent. This incl ccommodation. ccommodation. clinic. mised control tr mised control tr is Quality of Life is Quality of Life atth Impact Prof antia Speect Prof antia Speect Prof anization Quality	udes senior centre, a ials (R). - 8D Version; ASCOT * measure; DQOL, De are; LC-OOL, Long are; Life, Order Pe ialty of Life Instrume / of Life Scale - OLD.	dult day centre and day r, Adult Social Care Out mentia Quality of Life In Tem Care Quality of Life; P eoples Quality Of Life; P eoples Quality Of Life; P	centre. comes Toolkit; CA istrument; DUKE, e assessment soc GCMS, Philadelpi SWLS, Satisfacti	D-EOLD, Comfort Aro Duke Health Profile; E ale, MANSA, Manches ale, MANSA, Manches hia Geriatric Centre M on With Life Scale; WI-	und Dying-End of Life in Dementia; COMQOL, Q-5D, EuroQoL-5 Dimensions; HUI, Heatth Utility er Short Assessment of quality of life, NDP, Nottingham oral Scale; QoL, quality of life, QOL-AD, Quality of Life OQOL- AGE, World Heatth Organization Quality of Life

and are therefore amenable for economic evaluation in addition to quality assessment. Generic non-preferencebased 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 OoL 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

Continued

Table 3

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 validated⁶⁹⁷³ 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 organisations4 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

Siette J, et al. BMJ Open 2021;11:e050892. doi:10.1136/bmjopen-2021-050892

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 OoL-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 OoL-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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