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REVIEW

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Quality of life measurement tools for people with dementia and intellectual disabilities: A systematic review

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Abstract

Background: Adults with intellectual disabilities are an at-risk group of developing dementia. In the absence of a cure for dementia, emphasis on treatment is the promotion of Quality of life (QoL). The aim of this review is to identify and describe QoL tools for people with intellectual disabilities and dementia.

Method: A systematic review was carried out using 10 databases and papers from up to March year 2021.

Results: Two instruments were identified and examined. The QoL in late-stage dementia, which showed evidence of good levels of internal consistency, intra-rater reliability, test–retest reliability, and convergent validity. The Dementia Quality of Life – proxy was also used; however, its psychometric properties have yet to be studied within the intellectual disabilities population.

Conclusion: It is recommended instruments should be developed and psychometrically tested specifically for adults with intellectual disabilities and dementia to help inform policy makers, measure outcomes of interventions and personal outcomes.

KEYWORDS
dementia, Down's syndrome, intellectual disabilities, quality of life, systematic review

1 | INTRODUCTION

There is an established relationship between dementia and people with intellectual disabilities, including those with Down's Syndrome and previous estimates have found that the incidence of dementia in adults with intellectual disabilities is up to five times higher than adults in the general population (Strydom et al., 2013). In recent decades, the life expectancy of people with intellectual disabilities has increased, with more living into older age across developed countries. For example, on average, estimated median age at death of people with Down's Syndrome increased from 25 years in 1983 to 49 years in 1997 (Yang et al., 2002), and is now estimated the median age at death in 2021 was 61 for males and 60 for females (White et al., 2022) For adults with Down's Syndrome, dementia was found to be the second highest primary cause of death in a prospective cohort study (Oppewal et al., 2018). Age related complications continue to rise for this population, adding great importance to the intersections of aging and disability.

In the absence of a cure for dementia, the focus of treatment is to promote the life of the person with dementia holistically, including the person's medical symptoms and ensuring their comfort (Logsdon et al., 2007; Woods et al., 2014). Quality of life (QoL) has been seen to be increasingly important in recent years to ensure that not only the positive changes in biomedical markers are recognised, but the whole person's needs are assessed (Rabins & Black, 2007). This has led to increased recognition of psychosocial interventions, to be important in enabling adults with dementia, despite their deteriorating condition, rather than pharmacological managements, which have

shown issues with side effects, contra-indications (Prasher, 2004) and the mixed evidence base in the efficacy of using dementia medications (Mohan, Bennett, & Carpenter, 2009a; Mohan, Bennett, & Carpenter, 2009b; Mohan, Carpenter, & Bennett, 2009; Hanney et al., 2012; Eady et al., 2018). As a result, efforts have been towards defining, quantifying and systematically measuring QoL as part of capturing positive and negative aspects of end of life care and interventions which may not be detected by using standard clinical outcomes.

Many attempts have been made to define QoL and a 'gold standard' of the definition has yet to be agreed. The World Health Organisation (1995) broadly defined QoL as the 'individual's perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards, and concerns'. There are different approaches to studying QoL and a further definition, with health bias, suggests 'the value assigned to duration of life as modified by impairment, functional status, perception and opportunity influenced by disease, injury, treatment and policy' (Post, 2014, p. 174) Such differences reflect on the different approaches to studying QoL.

Many QoL measures in dementia refer to the model by Lawton (1997), who asserts that QoL encompasses two objective components: behavioural and environmental quality and two subjective components: perceived QoL and psychological well-being. Lawton stresses the importance to measure both objective and subjective components of QoL. Lawton's model of QoL has provided the foundation for subsequent models. For example, Brod et al. (1999) proposed 10 domains of QoL including: Physical Functioning, Daily Activities, Discretionary Activities, Mobility, Social Interaction, Interaction Capacity, Bodily Well-being, Sense of Well-being, Sense of Aesthetics and Overall Perceptions. Dementia affects all domains of QoL and it is said to be applicable to everyone with or without dementia.

The domains Aesthetics and Interaction Capacity are said to be dementia specific as they appear to be of particular importance to people with dementia (Brod et al., 1999). Aesthetics is the experience of appreciation and pleasure obtained from sensory awareness on either a verbal or nonverbal level, such as viewing or creating art, the sights and sounds of nature, and listening to music. Interventions using arts and music has been shown to improve QoL in people with dementia supports the importance of the QoL domain Aesthetics (Schneider, 2018; van der Steen et al., 2018). The domain of Interaction Capacity also reflects a disease-specific influence for people with dementia. This domain includes aspects of communication difficulties and difficulty in social interactions. This has a direct connection with dementia as even during the early signs of dementia, loss of linguistic abilities amongst people with dementia, such as word finding, may precede other aspects of cognitive decline (Banovic et al., 2018). Thus, often the most basic conversation may be difficult for people of all stages of dementia. Such difficulties in communication may prevent the individual with dementia expressing their QoL needs.

Models of QoL for intellectual disabilities are based on the normalisation principle, for people with intellectual disabilities to be able to live as part of society and moving from institutional care towards community-based services, bringing them closer to the legal and humans rights of all other citizens (Culham & Nind, 2003). In addition, the rise of consumer empowerment movement, which involves choice and self-determination, has led to the emphasis on person centred planning, maintaining personal dignity and integrity (Schalock, 2004). Such changes started in the 1960s–1970s when the disability rights movement challenged the medical model and advocated towards a social model of disability (Davidson et al., 2017), shifting the focus away from the medical view to understanding the complex combination in an individual's life. Thus, this allows a fuller assessment beyond physiology and considers the individual as a whole. For example, Schalock's model of disability considers personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and material well-being as vital components in influencing best practices for individualised support and services within the intellectual disabilities population (Verdugo et al., 2005).

Raphael et al. (1996) offers an alternative approach and suggested QoL should be separated from quality of personal care, but focusing upon the abilities rather than disabilities of the individual, ensuring the consideration of the perspectives of the person with intellectual disabilities. The model is multidimensional, holistic and encompasses the individuals' basic needs (food, shelter), the life opportunities, personal choice and control. Three life domains are identified in Raphael et al.'s model: Being (i.e., who one is) including the subdomains of Physical Being, Psychological Being and Spiritual Being; Belonging (i.e., the person's fit with their environment) including subdomains of Physical Belonging, Social Belonging and Community Belonging; Becoming (i.e., purposeful activity carried out to achieve personal goals, hopes and wishes) including subdomains of Practical Belonging, Leisure Becoming and Growth Becoming.

QoL can be explained by a variety of different ways from different disciplines of study. This consequently adds difficulty in deciding its subsequent measure in collecting QoL data. Bertelli et al. (2020) has offered a classification system of grouping QoL: (a) Shared QoL suggests the characteristics of the person's life and their environment which are common in people, (b) Personal QoL which takes into account individual differences. For example, one aspect in a person's life may be meaningful for one individual but may mean little for another individual and (c) Family QoL, considering the effects of disability on the family system as a whole. The approaches to QoL for both dementia and intellectual disabilities share similarities with QoL theory for intellectual disability in general, as they aim to understand the individual as a whole. However, such approaches have yet considered their applicability to both adults with intellectual disabilities and dementia.

Within the dementia literature, the perspectives of dementia are dominated by people within in the general population, whilst the perspectives of adults with dementia and intellectual disabilities remain largely unknown (Watchman et al., 2019). Moreover, the impact of aging in people with disabilities has been overlooked as the focus tends to be in the general population (Jönson & Larsson, 2009). This is unsurprising given that people with intellectual disabilities who have impaired social functioning and limited cognitive ability are likely to be

underrepresented in self-report studies because of additional research barriers including validity (i.e., operationalise concepts in an accessible format for people with intellectual disabilities); managing response bias, including acquiescence bias; and recruiting processes which are dependent on gatekeepers (Gjertsen, 2019; O'Keeffe et al., 2019). Nevertheless, people with intellectual disabilities should be directly involved in the measurement of their QoL and any tools should be able to adapt to their appropriate cognitive and linguistic abilities (Fellinger et al., 2020). Whether the framework of current QoL measures is applicable to adults with intellectual disabilities and dementia has yet to be established. Although adults with Intellectual disabilities are an at-risk group of developing dementia, the World Health Organisation (WHO) have reported that people with intellectual disabilities are generally disregarded and often marginalised when accessing social and health care services compared to the general population (WHO, 2000).

There are currently no systematic reviews that have identified and assessed the properties of current measures of QoL in adults of intellectual disabilities with dementia, despite QoL having increasingly been the focus of research in intellectual disabilities over the past few decades (Schalock, 2004). The aims of this systematic review are to (a) identify whether there are QoL measures available for people with dementia within the intellectual disabilities population and compare the psychometric properties and appropriateness of the measures, (b) to assess the scope and domains included in the QoL measures, theoretical and conceptual frameworks, and the extent of user or patient involvement in their development, by type of user, and (c) to suggest research implications and recommendations.

2 | METHOD

The present review complies with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) recommendations (Moher et al., 2009). The systematic review has been registered with the International Prospective Register of Systematic Reviewers (PROSPERO), registration number CRD42021252193.

2.1 | Search strategy

From the initial scoping searches, a small number of eligible studies was anticipated. The systematic literature search was undertaken using 10 electronic databases, in order to carry out a comprehensive search. The databases used: EBSCOhost research databases (Abstracts in social Gerontology, Academic Search Complete, CINAHL, Medline, PsycArticles, Psycinfo, socindex), Web of Science, Scopus and IBSS. In addition, reference lists of included articles were hand searched, and a Google Scholar search was performed. The databases were accessed in March 2021 and articles considered were from inception to March 2021 due to the scarcity of the current evidence base. As part of the review was to identify QoL measures for people with intellectual disabilities and dementia, a broad range of search terms and its synonyms for the domains for intellectual disability, dementia and measure of QoL were generated and agreed by the researchers, to retrieve all relevant studies The search terms were combined using the Boolean operators (AND, OR) and the truncation was indicated by an asterisk (*) for words with various endings (see Table 1 for the list of search terms used). The language was restricted to English; all available years were searched.

TABLE 1 List of search terms

	#1 intellectual disab*
	#2 intellectual delay*
	#3 intellectual disor*
	#4 intellectual limitation*
	#5 learning disab*
	#6 developmental disab*
	#7 developmental delay*
	#8 developmental disor*
	#9 developmental limitations*
	#10 intellectual impair*
	#11 cognitive disab*
	#12 down syndrome
	#13Mental retardation
	#14 mental disabil*
	#15 mental delay*
	#16 mental handicap*
	#17 pervasive developmental dis*
	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR '17)
AND	#18 Dement*
	#19 'Cognitive impairment'
	#20 'Vascular dementia'
	#21 Alzheimer*
	#22 Memory problem
	#23 mild cognitive impairment*
	(#18 OR #19 OR #20 OR #21 OR #22 OR #23)
AND	#24 'Quality of life'
	#25 QoL
	#26 QL
	#27 'Well being'
	#28 'Wellbeing'
	#29 'Life satisfaction'
	#30 HRQOl
	#31 'Health related quality of life'
	(#24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31)
AND	#32 Measure*
	#33 Valid*
	#34 Reliab*
	#35 Scale*
	#36 Tool*
	#37 Instrument*
	#38 Assessment*
	#39 Outcome *
	#40 Observation*
	#41 Psychometric*
	#42 Evaluate*
	#43 Rating*
	#44 Questionnaire*
	(#32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44)

2.2 | Selection criteria

2.2.1 | Inclusion criteria

- Participants with a diagnosis of an intellectual disability (IQ < 70) and suspected or confirmed diagnosis of dementia Suspected dementia defined as individuals who are currently in the process of receiving a diagnosis of dementia at the time of the study. Participants aged 40 years or above.
- Measures assessing QoL of the individual with dementia and intellectual disabilities.
- Measures based on a clear conceptual framework created to assess QoL in dementia.
- Measures assessing a specific part of QoL or QoL holistically.
- Measures assessing psychosocial domains such as life satisfaction and well-being, as they can be synonymous to a specific domain of QoL.
- Informant based instruments, self-reports and observational tools were included.

2.2.2 | Exclusion criteria

- QoL measures for people who do not have both intellectual disabilities and dementia.
- Instruments which measure family QoL.
- Instruments or studies measuring QoL of the primary carer.
- Studies which were primarily qualitative, without measuring QoL elements.
- Book chapters, editorial reports, study protocols, non-peer reviewed articles and dissertation/theses.

2.3 | Study selection and appraisal

Initial screening of titles and abstracts was done by one independent reviewer. Papers were exported to Mendeley Referencing Software, where the titles and abstracts were screened against the selection criteria. Articles that passed the initial screening were independently reviewed by two reviewers to assess their eligibility through full text screening. A third reviewer was involved in the discussion of any disagreements. These were resolved via a group discussion involving all three reviewers. Reasons for exclusion were noted. The following data of eligible articles were extracted including name of instrument, country, language of instrument, sample characteristics (i.e., age range, gender, dementia severity, number of participants), purpose the assessment was developed for, measurement domains, number of items, response format and psychometric properties (i.e., construct validity, content validity, internal consistency, inter-rater reliability, test–retest reliability and responsiveness).

Methodological quality ratings of eligible studies were performed by two independent reviewers using the Mixed Methods Appraisal Tool (MMAT) (Hong, Gonzalez-Reyes, & Pluye, 2018; Hong, Pluye, et al., 2018). The MMAT was chosen due to its inclusion of mixed methods studies, and it is a useful single appraisal tool in critical appraising different study designs. The MMAT was first published in 2009. It has been validated in several studies testing its inter-rater reliability, usability and content validity The latest version of the MMAT was updated in 2018 on the basis of findings from literature review of critical appraisal tools, interviews with MAT users and an e-delphi study with international experts (Hong, Gonzalez-Reyes, & Pluye, 2018, Hong, Pluye, et al., 2018). The MMAT includes specific set of criteria independently for qualitative studies, quantitative randomised controlled trials, quantitative nonrandomised studies, quantitative descriptive studies and mixed methods studies. Different criteria were judged dependent on the methodology design of the study and the criteria for quantitative descriptive studies was used. No studies were excluded from this review based on the overall quality rating to ensure a comprehensive review given the scarcity of the current literature in this area.

3 | RESULTS

3.1 | Study selection

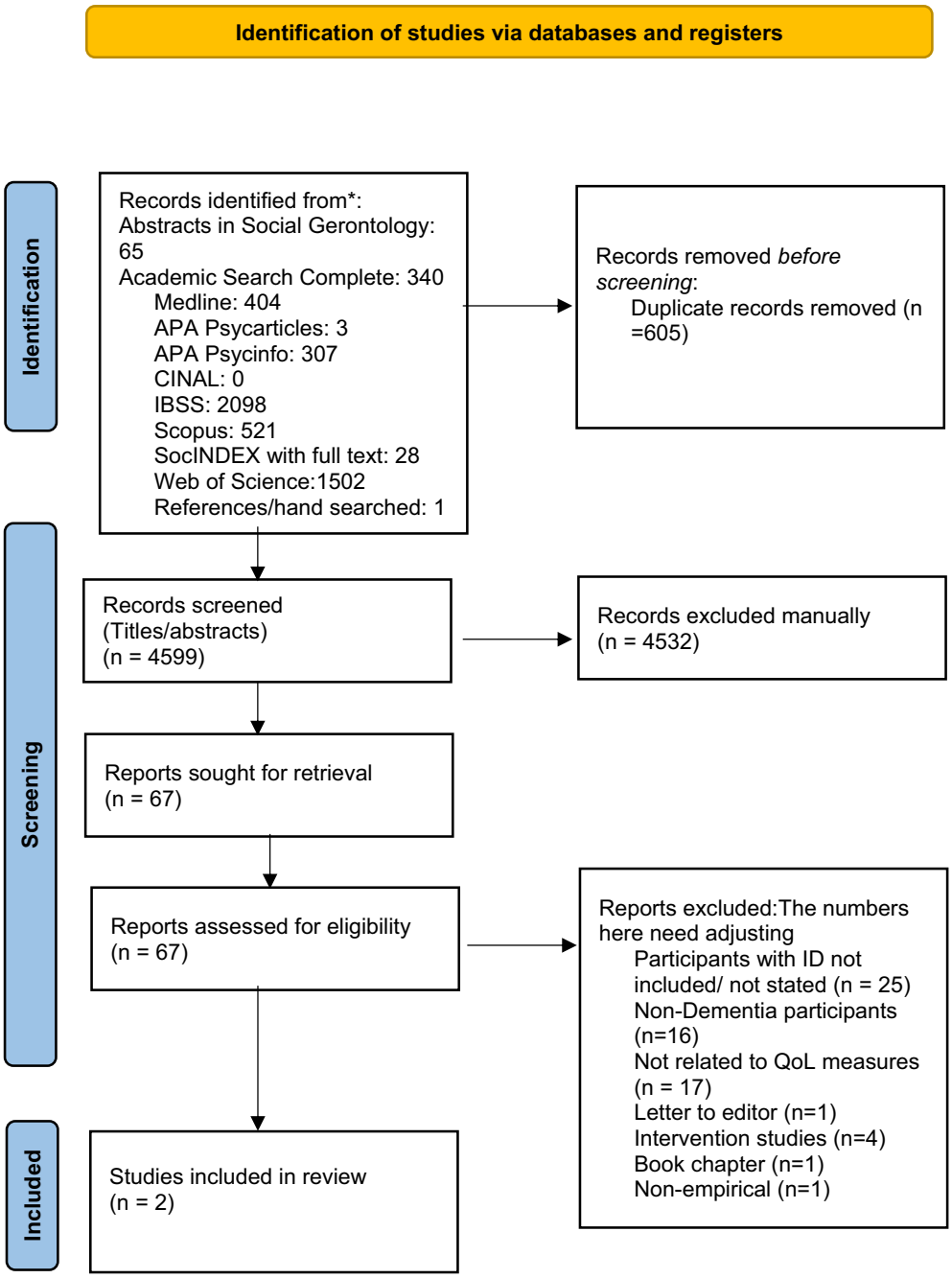
Figure 1 shows the study selection. 5204 hits were obtained and 605 of these records were duplicates and subsequently removed. 4599 articles were passed to the initial title and abstract screening and 4532 of those articles were excluded manually because they were completely irrelevant to the present study. A further 65 of these articles were excluded due to studies excluding participants with an intellectual disability ($n = 25$); studies included participants with intellectual disabilities but were not diagnosed or suspected of having dementia ($n = 15$); studies which did not look at QoL measures ($n = 17$); letter to editor ($n = 1$); intervention studies ($n = 4$); and book chapters ($n = 1$). One study was found through hand searching reference list of relevant studies, which met the selection criteria (De Vreese et al., 2012). 63 out of 67 studies were agreed between two reviewers (94% agreement) when assessing the final stage of eligibility.

3.2 | Study characteristics

Of the 67 papers considered for final eligibility, two papers fulfilled all the inclusion criteria (De Vreese et al., 2012; Forrester-Jones et al., 2017). Characteristics of the studies are shown in Table 2. No instruments designed to specifically measure QoL in adults of intellectual disabilities with dementia were found.

The study by De Vreese et al. (2012) used a quantitative cross-sectional design with 40 adults with a mean age of 56.5 years. $n = 24$ (60%) of participants were diagnosed with Down's Syndrome and $n = 16$ (40%) with other types of intellectual disabilities. Twenty participants, including $n = 17$ with Down's Syndrome (85%), had received a clinical diagnosis of Alzheimer's disease. The other study by

FIGURE 1 PRISMA flow diagram



Forrester-Jones et al. (2017) used a mixed methods approach, single instrumental care study design. Participants were residents with intellectual disabilities ($n = 9$) of a mean age of 53 years and 6 were diagnosed with dementia.

3.3 | Identified QoL measures psychometric properties and theoretical framework

The paper by De Vreese et al. (2012) was the only study that assessed and validated the use of a QoL measure for adults of intellectual disabilities with a proxy. The Quality of life in late-stage dementia (QUALID; Weiner et al., 2000) was found to show good levels of internal consistency, intra-rater reliability and test–retest reliability. Some evidence of convergent validity was found for QUALID which correlated, albeit weakly, with the Assessment for Adults with Developmental Disabilities (AADS), a proxy report rating the frequency, management, difficulty and effects on behavioural excess and deficits (Kalsy et al., 2002). However, the instrument had been translated to Italian for the purpose of the study, making this difficult to conclude whether the results would be generalisable in the UK setting.

QUALID is a proxy report used to assess clinical management and treatment effects on QoL in persons with late-stage dementia, who may experience more difficulty in communicating coherently and are

TABLE 2 Characteristics of eligible studies

First author (year)	Name of instrument	Country	Language of instrument	Age range	Gender	Diagnosis of dementia?	Number of participants with down syndrome	Purpose of assessment
De Vreese et al. (2012)	Quality of Life in Late-Stage Dementia	Italy	Translated to Italian from English	45–68 years	$n = 18$ (45%) males; $n = 22$ (55%) females	$n = 40$ (100%)	$n = 24$ (60%)	Investigates behavioural areas indicate of QoL
Forrester-Jones et al. (2017)	DEMQOL-Proxy	UK	English	24–68 years	$n = 2$ males (22%); $n = 7$ (78%) females	$n = 6$ (67%)	Not provided	Measures health related QoL

not involved in activities that may be considered as typical by people without dementia. It was developed by a group of clinicians with extensive experience in assessing persons with late-stage Alzheimer's disease. The QUALID comprises of 11 items rated by frequency on a five-point Likert scale with lowest scores indicative of better QoL. Observable behaviours include: smiles, appears sad, cries, has facial expression of discomfort, appears physically uncomfortable, verbalizations suggest discomfort, is irritable or aggressive, enjoys eating, enjoys touching/being touched, enjoys interacting with others and appears calm and comfortable (Weiner et al., 2000). As the measure relies on observable characteristics, it may be difficult to link some of the observed behaviours to specific domains of QoL. For example, the item 'appearing physically uncomfortable', where the assessment of being physically uncomfortable is unclear from observation alone, further measures may be needed to verify this. Furthermore, current QoL frameworks tend to reflect on domains that are relevant for those who still have the capacity to be involved in activities. In Lawton's Model (Lawton, 1997), the domain of behavioural competence includes aspects of Instrumental activities of daily living such as work and recreational activities. However, a patient with late stage of dementia would no longer have the capacity to complete such activities. Finally, the QUALID assumes those who have progressed to the late stages of dementia are not able to communicate coherently and to be involved in widely accepted activities. A person with an intellectual disability and early to moderate dementia, particularly those who possess high cognitive functioning prior to their dementia, may retain their communication abilities and to be able to talk about their QoL.

The study by Forrester-Jones et al. (2017) used the Dementia Quality of Life- proxy (DEMQOL-proxy). It was found that staff was able to differentiate participants' mood from a Likert scale of one to four. However, for items constituting participant's memory and everyday life, scores tend to cluster towards the maximum rating of four. We can attribute the results as being due to the small sample size of nine participants, as this could have provided less variance with the results. In addition, some items on the DEMQOL-proxy may be difficult for carers to rate. For example, depending on the stage of cognitive deterioration from dementia and limited cognitive functioning from their intellectual disabilities, the item 'forgetting things that happened a long time ago?' may have been difficult to assess for adults with intellectual disabilities and dementia, who may struggle to express this to their carers. Given that this study did not explore the psychometric properties of the DEMQOL-proxy, it is difficult to comment on the validity and reliability of this tool. Therefore, it is inconclusive whether DEMQOL-proxy is validated for adults of intellectual disabilities with dementia.

The DEMQOL-proxy is a 31-item interview administered questionnaire answered by caregivers. Drafted versions of the questionnaire were piloted and involved 12 people with dementia and their caregivers. Item reduction and preliminary field testing, further involved 130 people with diagnosis of dementia and 126 caregivers. From this evaluation, the DEMQOL-Proxy shows good acceptability and internal consistency and moderate evidence of validity in people with mild to moderate and severe dementia in the general population. (Smith et al., 2005). The development of the DEMQOL was based around a five-domain conceptual framework including daily activities, health and well-being, cognitive functioning, social relationships and self-concept (Mulhern et al., 2013), which are congruent to other established QoL frameworks for both dementia and intellectual disabilities. For example, in Lawton's framework (1997), DEMQOL-proxy's health and well-being domains overlap with Lawton's Psychological well-being domain; DEMQOL-Proxy's cognitive functioning domain overlaps with Lawton's Behavioural competence; and DEMQOL-Proxy's social relationships overlaps with Lawton's 'Objective environment' domain. The exception of the DEMQOL-proxy's self-concept includes aspects of one's appearance (i.e., Keeping him/herself looking nice) is a domain that is generally not reflected in previous QoL models in dementia and QoL models in intellectual disabilities.

3.4 | Quality assessment

Both studies by De Vreese et al. (2012) and Forrest-Jones et al. (2017) scored 100% on the MMAT quality rating scale indicating high methodological quality and both studies presented relevant sampling strategies to address the research questions, the sample was representative of the population understudy, the measures were appropriate due to previous psychometric testing indicating clear validity and

TABLE 3 Psychometric properties of eligible studies

First author (year)	Name of instrument	Measurement domains	Number of items	Administration	Internal consistency	Intra-rater reliability	Test–retest reliability	Convergent validity
De Vreese et al. (2012)	Quality of Life in Late-Stage Dementia	Behavioural symptoms of discomfort Behavioural symptoms of positive social interaction Behavioural symptoms	11	Interview via proxy	Cronbach's α for the total QUALID score = 0.80	Intraclass Correlation Coefficient (ICC) of the total QUALID scores obtained by the same rater at a two-week interval was 0.89 (95% CI = 0.795–0.941).	ICC = 0.89	Total QUALID score correlated weakly with Assessment for adults with development disabilities sub-scores of behavioural Excesses: Frequency (Spearman's rho = 0.30; $p = 0.031$); Management Difficulty (Spearman's rho = 0.34; $p = 0.017$) and Effect (Spearman's rho = 0.32; $p = 0.023$).
Forrester-Jones et al. (2017)	DEMQOL-Proxy	Feelings/mood Memory concerns Worries they had around aspects of their everyday lives	30	Interview via proxy	Not provided	Not provided	Not provided	Not provided

reliability in people with dementia within the general population and a response rate of at least 60% (see Table 3).

4 | DISCUSSION

4.1 | Overall findings

Within this review, two papers were found using QoL measures in people with both dementia and intellectual disabilities. Only the QUALID scale has been psychometrically validated in people with dementia within the intellectual disability population and deemed to show good levels of internal consistency, intra-rater reliability, test–retest reliability and convergent validity. However, the QUALID has been translated to Italian and yet to be validated in English speaking intellectual disabilities populations. Moreover, the QUALID was originally designed in people with late stages of dementia, specifically those who can no longer communicate clearly. Hence, this measure may not be appropriate for all levels of intellectual disability. For example, a person with a mild intellectual disability in the early stages of dementia may still have the ability to communicate their QoL. In addition, as QUALID assumes the person measured is currently in the late stages of dementia, QoL relating to activities of daily living are not considered because people with late stages of dementia can no longer complete such activities. In people with intellectual disabilities and dementia, particularly in the early to moderate stages, this may not be the case.

The DEMQOL-proxy has been used in one study measuring QoL for people with dementia and intellectual disabilities. The underlying theoretical framework of the DEMQOL-Proxy coincides with established models of QoL in people with dementia (e.g., Lawton, 1997) and models of QoL in people with intellectual disabilities (e.g., Schalock et al., 2002). However, no psychometric results have been provided for this population and warrants further evidence to see whether the DEMQOL-proxy is psychometrically valid for people with intellectual disabilities and dementia.

4.2 | Methodological issues in measuring QoL

Measuring QoL has been notoriously challenging to define as a result of varying concepts, logistical and measurement difficulties as individuals' perceptions of what is considered important in their life can vary significantly. In a clinical setting, the patient determines what is important in their life, where the emphasis of care is on the individual and this differs from patient to patient. However, in clinical research, it is the researcher and not the individual who determines which domains are to be assessed in order to obtain comparable scores in any outcome measures. In essence this is a normative approach of the concept of QOL and the important facets in QoL are determined by perceptions of the professionals (Etterma et al., 2005).

Due to the degenerative nature of dementia involving cognitive impairment such as memory and language difficulties, there can be significant barriers in capturing the subjective experience of QoL in a person with dementia. Therefore, it may not be possible to capture the patient's perceived QoL from self-report measures. Interpretation of concepts can be problematic, especially when life situation of the respondent is vastly different to that of a researcher. For example, Barlow and Kirby (1991) found that adults with intellectual disabilities frequently interpreted the meaning of 'friends' more generally including acquaintances who acted in a friendly manner towards them. When a concept can be interpreted either more generally or context specific, it can be problematic for participants to understand the construct defined by the researchers.

Acquiescence bias is a problem that has often been described in the literature of intellectual disabilities (Finlay & Lyons, 2001), and it is the tendency for such participants to say 'yes' to questions regardless of their content. It is likely to occur if the participant does not know the answer to the question, questions are too long, and the structure of the question is too complex so that participants may only focus on parts of the question and miss the rest of the phrasing and social desirability. To adjust the language accordingly, it is suggested to include reverse-worded questions to check for evidence of acquiescence bias, ensure wording is simple and avoid binary response, and using pictorial form to accommodate understanding with pictorial response options that are easy to differentiate and can help increase understanding (Finlay & Lyons, 2001).

Many proxy-rated tools have been created to compensate the methodological barriers of self-report tools. However, the validity of proxy reports can be questioned too. In previous research, there has been a tendency for proxy raters to underestimate the QoL of a person with dementia and their estimate is affected by their own personal perceptions of the person with dementia's QoL (Selai et al., 2001) Similarly, people with intellectual disabilities without dementia tend to rate their QoL higher compared to their proxies (Schmidt et al., 2010). This brings into the question of the degree of how much proxy responses actually reflect the perceptions of QoL for the person of interest. Researchers have advocated that patients can rate their own QoL until the late stages of dementia and caregiver ratings should not substitute for patient ratings. Patients' subjective rating should be the gold standard, but independent observational ratings are of benefit for patients with severe dementia (Schölzel-Dorenbos et al., 2007). However, self-report measures may be more difficult to utilise for adults of intellectual disabilities with dementia, in which their cognitive abilities and language may be already limited prior to their development of dementia. A significant challenge is how to ensure that people who experience such difficulties are not excluded from expressing their own subjective feelings and their perception of life. Such difficulties of using self-reported assessment have been reported in a variety of settings in psychiatric, psychological, health and service needs assessments (Doody & Bailey, 2017; Mileviciute & Hartley, 2015; Sandercock et al., 2020).

4.3 | Limitations

There are limitations to this systematic review. There is an obvious lack of studies published from peer reviewed journals. Although this helps to ensure that the quality of studies is high, studies from grey literature and open science databases could provide the review with additional knowledge into a clearly unknown area of study.

Another limitation is that existing QoL measures in measuring people of intellectual disabilities with dementia were created with a person of dementia from the general population in mind (Brod et al., 1999; Lawton, 1997; Logsdon et al., 2002; Rabins & Kasper., 1997; Ready et al., 2002; Volicer et al., 1999). A person with intellectual disabilities may have faced differences in their life to the general population, particularly as there may be profound inequalities in health and social care (Hughes, 2013) and whether existing QoL measures can capture such discrepancies remains unknown. Furthermore, the conceptualisation of QoL can vary in different stages of dementia in the general population. For example, in the early stages of dementia enjoyment of daily activities is a relevant domain for QoL (Brod et al., 1999), but may no longer seem to be applicable in severe or advanced dementia (Hurley et al., 1992). This can present a problem in choosing the right QoL measure for a person of intellectual disabilities with dementia. For example, if a QoL measure is used to measure QoL domains specifically for someone with moderate levels of dementia, it is unclear if it is possible to translate this for a person with intellectual disabilities and moderate dementia, given their limitations in cognitive and adaptive functioning prior to the onset of the disease. It is clear no instruments can be used across all stages of dementia, types of care and settings.

No self-reported measures have been psychometrically validated for r adults of intellectual disabilities with dementia. Evaluating QoL requires significant introspection, and self-report ratings are the ideal method for assessment. However, in both dementia and intellectual disabilities, the validity of self-report ratings can be questioned due to the cognitive deterioration even for people with early onset dementia. As a result, researchers highly depend on proxy reports to collect QoL data. The accuracy of proxy reports in measuring QoL, even for people with dementia within the general population can be questioned. When comparing QoL measures of proxy reports with self-rated reports, it was found that patients with early Alzheimer's disease

(AD) generally reported higher QoL than their informants (Vogel et al., 2006). Interestingly, Robertson et al. (2017) found that relatives and staff, rated QoL of care home residents with dementia similarly; more distressed staff rated the resident's QoL at a lower level; and relatives rated QoL lower when the resident had lived in the care home for longer, when relatives observed more restraint practices, or contributed more to fees. These results suggest that proxy rated QoL measures can be prone to bias and the person with dementia's QoL rating is affected by both the characteristics and mood of the carer. For QoL research and subsequent policy and interventions to be meaningful, it is essential that QoL measurements of residents with dementia are valid. Although patients can, to some extent, rate their QoL until late stages of dementia, caregivers' ratings should not substitute for patient ratings. Patients' subjective rating should be the gold standard, but independent observational ratings may also be of benefit for patients with severe dementia (Schölzel-Dorenbos et al., 2007). To evaluate the success of an intervention in improving QoL, especially for those who are more cognitively impaired, there may be dependence on proxy reports.

4.4 | Implications

To our knowledge, this is the first systematic review so far in synthesising the current evidence base of QoL measures for adults with intellectual disabilities and dementia. Although conceptualisation of QoL for people with intellectual disabilities has been established and increasingly focused on intellectual disabilities research, there is a clear lack of literature in its application and utility. Given that current QoL measures for people with dementia in the intellectual disabilities population are lacking, research efforts should be directed to develop and foster the use of developing QoL concepts to reflect on the objective and subjective experiences of people with intellectual disabilities and dementia. The inequities between people with an intellectual disability and people from the general population due may also influence QoL and the domains considered (Emerson, 2007). A conceptual framework to understand QoL in people with intellectual disabilities and dementia would enable the foundation to create a QoL measure specifically for this population. Due to the degenerative nature of dementia and the lack of curative treatment for this insidious disease, the main focus of treatment is to promote QoL with greater focus on the person's needs. As a result, reliable and valid QoL data can help inform potential personal outcomes, policies, service planning, assess efficacy of interventions and plan end of life care. A variety of instruments should reflect this, including the simultaneous use of proxy-reports, self-reports and observational measures to fully capture QoL.

CONFLICT OF INTEREST

No potential conflict of interest was reported by the authors.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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