https://doi.org/10.23925/2176-2724.2021v33i1p124-140

Assessment of the Quality of Life of People with Disabilities: a systematic review of the literature

Avaliação da Qualidade de Vida da Pessoa com Deficiência: revisão sistemática da literatura

Evaluación de la calidad de vida de las personas con discapacidad: una revisión sistemática de la literatura

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Abstract

Introduction: The concept of quality of life (QOL) is a central reference when producing comprehensive health care for people with disabilities (PWD). **Objective:** To conduct a systematic review of the scientific production on the QOL of PWD from 2009 to 2019. **Method**: Identification of articles through simple and Boolean search with the descriptors: *deficiência/pessoa com deficiência*/disabled persons /persons with disabilities; *avaliação*/assessment/evaluation; *qualidade de vida*/quality of life; *avaliação da qualidade de vida*/assessment of the quality of life, in LILACS, SciELO, Cochrane Library, PubMed/MEDLINE, and Google Scholar. **Results:** A total of 19 studies met the selection criteria and were submitted to content analysis. Of these, 13 used instruments created by WHO: two used WHOQOL-100, and seven, its abbreviated version, WHOQOL-BREF; one, WHOQOL-OLD – add-on module to assess older adults; one, the Stroke-Specific Quality of Life Scale – SS-QOL – specific for people with a stroke;

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This article was produced as part of the project: Health for the population with disabilities in the Freguesia do Ó and Brasilândia neighborhoods: Dialogue with the services and the meanings given by the population to health care and the access to it – financed by the National Program of Support to the Health Care of People with Disabilities (PRONAS/PCD) of the Ministry of Health.

Authors' contributions:
ACP: Conceptualization of the study; Methodology; Data collection; Draft of the article; Critical revision; Supervision.
KVA: Conceptualization of the study; Methodology; Data collection.
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Received: 29/06/2020
Accepted: 11/11/2020

one, WHOQOL-DIS – specific for people with motor and intellectual disability; and one, WHODAS 2.0. Of the others, one study used the SF-36**;** one, Kidscreen; one, GENCAT; one QOL- Q; and one, PedsQL 4.0. **Conclusion:** The generic instruments are the most used. They allow for the comparison of QOL of PWD with that of other populations, though more in-depth observation of their specificities is not made possible. If the research aims to obtain information on dimensions to be recommended in the health care of PWD, they should use specific instruments, which highlight the physical, psychological/ emotional, social relationships, and environmental dimensions, besides the autonomy, self-determination, inclusion, and rights of the PWD.

Keywords: Quality of life; Disabilities; Disability Assessment; Systematic Review; World Health Organization.

Resumo

Introdução: O conceito de Qualidade de Vida (QV) é referência central na produção do cuidado integral à saúde da Pessoa com Deficiência (PcD). **Objetivo:** Realizar a revisão sistemática da produção científica sobre QV de PcD, no período de 2009 a 2019. **Método**: Identificação de artigos mediante buscas simples e booleana pelos descritores - deficiência/pessoa com deficiência/*disabled persons /persons with disabilities*; avaliação/a*ssessment/evaluation*; qualidade de vida/*quality of life*; avaliação da qualidade de vida/*assessment of quality of life*, nas bases LILACS, SciELO, Cochrane *Library*, PubMed/MedLine e Google Acadêmico. **Resultados:** Atenderam aos critérios de seleção e foram submetidos à análise de conteúdo 19 estudos. Desses, 13 utilizaram os instrumentos criados pela OMS: dois WHOQOL-100 e sete sua versão abreviada o WHOQOL-*bref*; um WHOQOL-OLD – módulo complementar para avaliação de pessoas idosas; uma versão *Stroke-Specific Quality of Life Scale* - SSQOL – específica para pessoas com acidente vascular cerebral; um o WHOQOL-DIS – específico para PcD motora e intelectual e um estudo o WHODAS 2.0. Entre os restantes um estudo usou o SF-36**;** um Kidscreen; um GENCAT; um QoL-Q (QQV em português) e um PedsQL versão 4.0. **Conclusão:** Os instrumentos genéricos são os mais utilizados. Eles permitem comparações da QV da PcD com outras populações, mas não permitem a observação mais aprofundada de suas especificidades. Se o objetivo da pesquisa for obter informações sobre dimensões a serem preconizadas no cuidado em saúde da PcDs é recomendável que sejam utilizados instrumentos específicos, que destacam as dimensões física, psicológica/emocional, relações sociais e meio ambiente, além dos aspectos autonomia, autodeterminação, inclusão, direitos da PcD.

Palavras-chave: Qualidade de vida; Deficiência; Avaliação da Deficiência; Revisão Sistemática; Organização Mundial da Saúde.

Resumen

Introducción: El concepto de calidad de vida (QOL) es una referencia central en la producción de atención integral de salud para Personas con Discapacidad (PcD). **Objetivo**: llevar a cabo una revisión sistemática de la producción científica sobre la calidad de vida de las personas con discapacidad, en el período de 2009 a 2019. **Método**: identificación de artículos mediante búsquedas simples y booleanas por los descriptores - discapacidad/personas con discapacidad/personas con discapacidad; evaluación; qalidad de vida/qalidad de vida/evaluación de calidad de vida/ evaluación de qalidad de vida basada en LILACS, SciELO, Cochrane Library-, PubMed/MedLine y Google Scholar. **Resultados:** cumplieron con los criterios de selección y fueron enviados análisis de contenido 19 estudios. De estos, 13 utilizaron los instrumentos creados por la OMS: dos WHOQOL-100 y siete su versión abreviada WHOQOL-bref; uno WHOQOL-OLD - módulo complementario para evaluar a las personas mayores; uno la versión de la Escala de calidad de vida específica para el accidente cerebrovascular - SSQOL - específica para personas con accidente cerebrovascular; uno WHOQOL-DIS - específico para PwD motor e intelectual y uno WHODAS 2.0. Entre el resto se utilizaron: uno SF-36; uno pantalla para niños; uno GENCAT; uno QoL-Q (QQV en portugués) y uno PedsQL versión 4. **Conclusión:** Los instrumentos genéricos son los **más** utilizados. Permiten comparaciones de QoL de PcD con otras poblaciones, pero no permiten una observación **más** detallada de sus especificidades. Si el objetivo del estudio es obtener información sobre las dimensiones

que se promoverán en la atención de la salud de las personas con discapacidad, se recomienda utilizar instrumentos específicos que resalten las dimensiones físicas, psicológicas / emocionales, de las relaciones sociales y del entorno, además de los aspectos de autonomía, autodeterminación , inclusión, derechos de PcD.

Palabras clave: Calidad de vida; Discapacidad; Evaluación de discapacidad; Revision Sistematica; Organización Mundial de la Salud.

Introduction

The International Convention on the Rights of Persons with Disabilities, approved on December 13, 2006, by the General Assembly of the United Nations, triggered profound changes in the concept of and approach to disability, treating under the perspective of the human rights and the social model, highlighting the importance of political actions and State intervention[1].

> "People with disabilities are those with long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various barriers, can hinder their full and effective participation in the society under equal conditions with the other people"[2].

The change in how disability is perceived and, consequently, in its conceptual model was based on the need to restructure the society and the theoretical bases in which the interventions in this field were grounded. Hence, it is considered an evolving, multidimensional concept, which is not limited to biological features, personal or individual condition, nor is it exclusively related to biomedical knowledge. It is the result of the interaction between the person with a disability (PWD) and the elements that either block or facilitate their full social participation.

The medical model, anchored on the normal/pathological binomial and on an idealized view of the human being, developed a clinical mindset guided by the notion of normality, proposing rehabilitation to normalize the PWD, using procedures aimed almost exclusively to improve or increase their functional performance. Thus, the fields of rehabilitation came to be seen as specialties in themselves. Contrary to this model, the Convention considers diversity as a feature of humankind, and disability as a consequence of social arrangements little sensitive to body diversity, thus preventing the expression of the PWD's capacities (potentialities). Therefore, it highlights the importance of well-being and social justice policies.

By adopting the social model, the Convention opposes the concept of disability described by the hegemonic medical model, as an individual problem directly caused by a disease, trauma, or health conditions, and responsible for the incapacities and disadvantages the PWD may have. Likewise, it disagrees with clinical and therapeutical conducts that give priority to body changes and lesions and disregard other determinants (social, cultural, economic, etc.), distancing from the person and their needs[2].

The social model of disability was developed by social movements struggling for human rights and respect for diversity, particularly the Union of the Physically Impaired Against Segregation (UPIAS)[3], the first political organization ran by people with disabilities, created in Great Britain in 1976. In a sociological approach, they understand that the problem does not lie in the person or their disability, but in the hegemonic social view of disability that leads to exclusion. They emphasize that the problem is not on the PWD or on the disability itself, but on how the society is organized. As it disregards human diversity, it imposes institutional and attitudinal accessibility barriers, to those who do not fit the established normality standards, excluding people who do not meet these standards – which is the case of the disabilities – hindering their active social and political participation.

Included in the restructuring, the activist movements demanded the revision of the instrument used to typify the disabilities – developed by the World Health Organization (WHO) in 1976, named International Classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease (ICIDH)[4]. It reinforced the biomedical perspective in the comprehension of disability, establishing a conceptual scheme with a causal and unidirectional relationship between its components: disease/lesion; disability; incapacity; disadvantage. The ICIDH was replaced with

the International Classification of Functioning, Disability, and Health (ICF)[5] – known in Brazil as *Classificação Internacional de Funcionalidade, Incapacidade e Saúde* (CIF) – also developed in a biopsychosocial approach including the health components at the body (structure and function) and contextual (social) levels.

Almost two decades before the International Convention on the Rights of Persons with Disabilities, the Brazilian constitution of 1988 secured every Brazilian the right to health, providing to the PWD access to services at different health care levels in the *Sistema Único de Saúde* (SUS, the Brazilian public health care system).

The SUS assistance model is grounded on the broadened and multidimensional concept of health, related to education, work, income, housing, mobility, ecosystem, and so forth, and adopts the biopsychosocial paradigm that encompasses health production, care, humanization, interpersonal relationship training, and symbolic/emotional productions that make up the life experiences[6].

Under the principles of universality, comprehensiveness, and equity, the health care of the PWD at SUS is no longer a responsibility of the specialized rehabilitation services alone, but also of the health care network, whose services must cooperate. The health care network with its various assignments must contribute to the development of unique therapeutic projects, encompassing both the general and specific needs. Hence, the professionals at the comprehensive PWD health care network need to be attentive to biopsychosocial health determinants, no longer having normality (which is a statistical criterion of the biomedical model) as their reference, but the quality of life (QOL) of the PWD.

The International Convention on the Rights of Persons with Disabilities[2] brought about radical changes in the conceptual and social bases regarding the PWD and their rights, with emphasis on the following aspects:

> "[...] The respect for the inherent dignity, the person's independence, including the freedom to make their own choices, the individual autonomy, the nondiscrimination, the full and effective participation and inclusion in the society, the respect for differences, the equal opportunities, the accessibility, the equality between men and women, and the respect for the developing capacities of children with a disability".

All of these are related to the concept of QOL, which has increasingly become the central reference in health care, in the sense of being useful to establishing priorities and projecting, implementing, monitoring, and assessing the effectiveness of prevention, attention, and rehabilitation programs and projects, besides being important guidelines for public policies[7].

Since the 1960s, WHO has been dealing with this issue. In 1994, it established the World Health Organization Quality of Life (WHOQOL), which 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 and in relation to their goals, expectations, standards, and concerns"[8]. Due to its complexity, there is no consensus on this concept, as QOL can be seen from different perspectives and defined in different ways in different contexts. Nonetheless, its multidimensional character is a consensus.

Some authors[9] consider that the concept of QOL must meet the principles of multidimensionality; have ethical/universal properties; be connected to the culture; have objective and subjective components; and be influenced by personal and environmental factors.

Other authors[10] emphasize the polysemic nature of the term QOL, which is related to the lifestyle, conditions, and mode, as well as the ideas of sustainable development and human ecology, and secured human and social rights.

The understanding of how QOL differs and manifests in the population with disabilities can help the social and health policies to meet their needs specifically, adequately, concretely, and comprehensively. Various generic and specific instruments to assess QOL have been developed also for people with disabilities, given the great impact they have on these people's life. WHO noticed the need to adjust the QOL assessment instruments to the PWD. WHOQOL developed QOL assessment scales specifically aimed at people with physical and intellectual disabilities, which is named WHOQOL-DIS. This literature review may aid not only to choose instruments but, above all, understand the importance of QOL assessment as a tool to take health promotion measures for the PWD, as well as the quality of the health care.

Objective

To identify studies on instruments used to assess QOL of PWD in their various age groups, with a systematic literature review, to recommend their use in health services.

Method

The investigation was guided by the following question: "What instruments have been used to assess the QOL of the PWD in their various age groups?".

Eligibility criteria

The criteria to review national and international articles that used QOL assessment instruments with PWD (children, adolescents, adults, and older adults) were: a) Participants/target population – People with any disability in the various age groups; b) Intervention: QOL assessment; c) Measure outcome – QOL assessment instruments for the PWD; d) Time – publications from the previous 10 years (from 2009 to 2019); e) language: articles written in Portuguese and English.

Duplicated articles, systematic review articles, technical reports, comments or editorials, and case reports were excluded.

Search strategies

The following databases were used for the review: LILACS, SciELO, Cochrane Library, PubMed/MEDLINE, CAPES Portal, and Google Scholar. A manual search was also conducted to find bibliographical references that were not retrieved from the databases.

The search strategies used combined Health Sciences Descriptors (DecS) and keywords (mostly synonyms of the descriptors) in both Portuguese and English (*deficiência/pessoa com deficiência*/ disabled persons /persons with disabilities; *avaliação*/assessment/evaluation; qualidade de *vida*/ quality of life; *avaliação da qualidade de vida*/ assessment of quality of life [Chart 1]. All the descriptors were employed in groups, considering the combination of the population being studied (people with a disability) and the use of questionnaires to assess QOL. When combining these items, the words were interconnected with the Boolean operators "OR" (to expand the results using synonyms or other terms) and "AND" (to intersect two sets), as follows: ("quality of life" OR "assessment of quality of life") AND ("persons with disabilities" OR "persons with disadvantages" OR "persons with incapacities"); ("quality of life" OR "HRQOL" OR "health-related quality of life" OR "Impact of the disease on the quality of life" OR "International Classification of Functioning, Disability, and Health" OR "ICF") AND ("persons with disabilities" OR "persons with incapacities" OR "persons with a visual disability" OR "persons with a hearing disability" OR "persons with a physical disability" OR "persons with an intellectual disability").

Chart 1. Descriptors and/or keywords in Portuguese and English

Descriptors and/or keywords in Portuguese	Descriptors and/or keywords in English
Qualidade de Vida Avaliação da qualidade de vida Qualidade de Vida Relacionada à Saúde- QVRS Impacto da Doença na Qualidade de Vida Avaliação da Deficiência Classificação Internacional de Funcionalidade Incapacidade e Saúde; CIF	Quality of Life Evaluation of Quality of Life/ Assessment of Quality of life Health-related quality of life - HRQOL Disability`s evaluation International Classification of Functioning Disability and Health; ICF
Pessoas com Deficiência Pessoas com Desvantagem Pessoas com Incapacidade Pessoas com Incapacidade Física Pessoa com Limitação Física Pessoas com incapacidade visual; cegas. Pessoas com deficiência auditiva; surdas. Pessoas com deficiência intelectual	Disabled Persons; Disabled individuals Persons with disabilities Handicapped persons People with disabilities Persons with reduced mobility Persons with visual disabilities; blind. Hearing-impaired persons; deaf. Persons with Intellectual Disabilities

Data analysis

The studies were selected by the three authors in three stages, in all of which the abovementioned eligibility criteria were used. The first stage consisted of the analysis of the title of the articles found with the combination of descriptors and keywords in all the databases. Those that initially met the eligibility criteria were selected. In this stage, a manual search was also conducted. In the following stage, the abstracts were analyzed; those with information on the use of QOL instruments for the PWD were selected. In the third stage, after reading the texts in full, the incomplete ones were excluded, and only those which met the eligibility criteria of the study were selected.

Results

The flowchart with the selected articles [Figure 1] shows that 7,461 articles were found. Attention is called to the greater concentration of articles in LILACS and Google Scholar in relation to the other databases. Of these 7,461 articles, after reading the titles, 72 were selected to have their abstracts read – after which, 29 articles were excluded. Thus, 43 were selected to be read in full, of which another 24 were excluded for not meeting the eligibility criteria. Hence, 19 articles were left based on the established criteria.

In the reading of the titles, the excluded articles approached themes unrelated to the study, or they were repeated ones, literature reviews, on specific pathologies, technical reports, whose objectives did not deal with the use of QOL instruments for PWD. In the analysis of the abstracts and full texts, similar articles that approached sports, forms to ensure social inclusion, health care networks for PWD, systematic/integrative review articles, articles on hearing accessibility, professionals/caregivers, technical reports, on older adults without a disability/limitation, development, adaptation, and validation of questionnaires, and some articles that did not assess PWD, but diseases such as HIV, Hansen's disease, and others, were excluded.

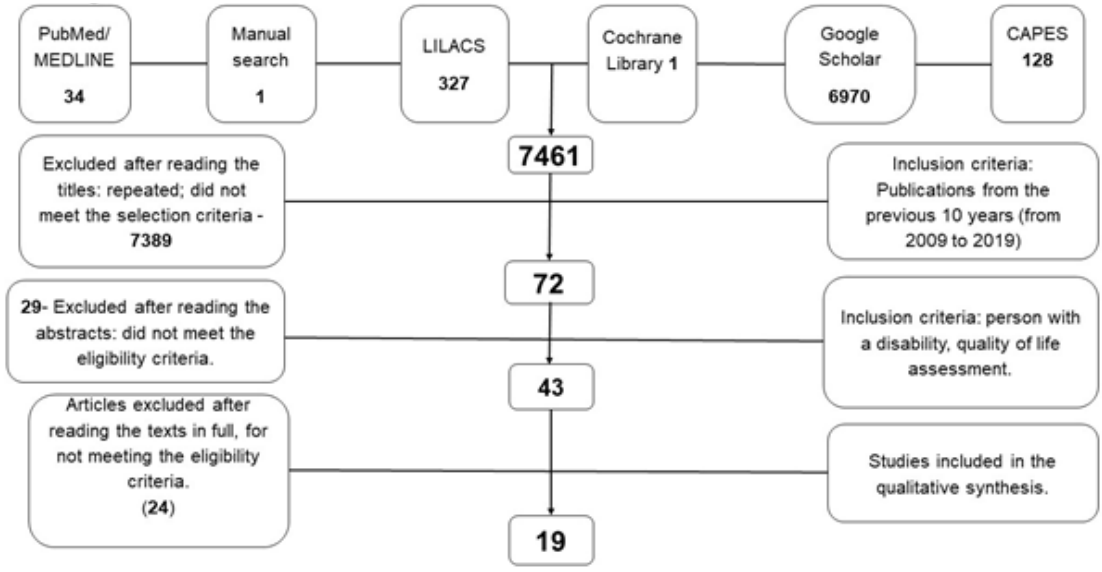

Figure 1. Flowchart of the selected articles

Chart 2. Characteristics of the selected studies according to authors, year of publication, type of study, sample, age group, instrument, administration method, type of disability, and results.

Study	Author(s) Year	Type of study	Sample/age group	Disability	Instrument and administration method	Results
A	Rebouças CBA, Araújo MM, Braga FC et al, 2016[11]	Exploratory, Descriptive; Quantitative.	20 youth/ Adults 18 - 55 years old	Visual	WHOQOL-100 individual interview	Most self-assessed as good QOL (68.75%). Domains with higher indexes: personal relationships (74.06%), sexual activity (66.88%), and spirituality/religion/personal beliefs (65%). With lower indexes: financial resources (43.44%), physical environment: pollution/noise/traffic/ weather (46.88%), physical safety and protection (37.19%), transport (35.63%), and dependence on medications or treatments (8.25%).
B	Custódio MIS, Santos ASPG, 2011[12]	Exploratory, Descriptive; Quantitative.	63 youth/ Adults 16 - 52 years old	Intellectual	WHOQOL-100 interviewer	Assessments with higher indexes referred to independence (F = 70.44% and M = 66.64%), and with lower ones, to social relationships (F = 64.24% and M = 62.05%).
C	Gomes JMPA, Araújo CAC, Soares MLSR 2013 [13]	Exploratory, Descriptive; Quantitative.	10 Adults/ older adults 41 - 77 years old	Motor	WHOQOL--BREF (26) individual interview	The highest QOL values were on the psychological and social relationships domains, whereas the worse ones were on the physical and general domains.
D	Sereno, ACN 2011 [14]	Exploratory, Descriptive; Quantitative.	22 Adolescents 11 - 19 years old	Motor	KIDSCREEN Self-administered	The family/family environment/neighborhood dimension has the highest mean value of all dimensions (M = 24.95; SD = 5.42). The provoking dimension has the lowest mean value of the ten dimensions (M = 5,68; SD = 2.58).
E	Barbosa, R 2012 [15]	Exploratory, Descriptive; Quantitative.	60 youth and adults 16 - 59 years old	Mental (mild and moderate)	WHOQOL--BREF (26) Interviewer	Higher mean scores in the physical domain (M = 73.12; SD = 17.02), followed by the domain associated with the environment (M = 69.44; SD = 13.47), general domain (M = 67.58; SD = 13.95), social relationships domain (M = 67.42; SD = 19.59), and psychological domain (M = 66.88; SD = 15.44).
F	França ISX, Coura AS, França EG et al 2011 [16]	Descriptive; Quantitative.	47 Adults, older adults 41 - 95 years old	Motor (medullary lesion)	WHOQOL--BREF (26) Self-administered	The score of the domains: physical (58.59%), psychological (63.82%), social (68.79%), and environmental (55.20%).
G	Maestro-Gonzalez A, Bilbao-Leon C, Fernandez-Carreira M et al 2018 [17]	Descriptive; Cross-sectional.	75 Adults 18 years old or above.	Motor Cerebral palsy	GENCAT Self-administered	The individuals perceive their QOL as equivalent to that of healthy adults. "Interpersonal relationships", "personal development", and "social inclusion" were the most important factors for QOL, while " material well-being" and "physical well-being" were the lowest ones. The data highlight that high QOL is related to having a sexual relationship.
H	Livramento, MS, 2017[18]	Exploratory, Descriptive, Cross-sectional	122 aged 17 to 78 years	Visual	WHODAS Online, in--person, or phone interviews	41% of the general functioning could be explained by factors involving social issues and services and resources access issues. Only two identified factors were more directly related to body elements: type of visual disability (blindness or poor eyesight) and having diseases or hindrances other than the visual.
I	Marinho CLA, Vieira SCM. 2015 [19]	Descriptive, Cross-sectional.	72 Adolescents 10 - 19 years old	Physical, Visual, and hearing	WHOQOL--BREF (26) Administered observing each disability's limitations	It was observed that the overall QOL was perceived as higher by those with a visual disability (65.62 ± 22.49) and lower by those with a physical disability (57.36 ± 20.67). The domains with the lowest scores were the social relationship among those with a physical (60.41 ± 7.30), visual (55.84 ± 13.34), and hearing disability (55.00 ± 20.33). Schoolers who attended special classrooms and younger adolescents had a lower perception of their QOL.
J	Bahia MM, Chun RY S.2014[20]	Prospective, Quantitative, Cross-sectional.	11 Adults/ older adults 37 - 67 years old	Aphasic	SS-QOL Head researcher	For the non-fluent aphasic people, the most impaired domains due to stroke were language, social relationships, and mindset. For the fluent ones, they were the behavior, social relationships, and mindset.
K	Shublaq M, Orsini M, Puccioni-Sohler M. 2011 [21]	Prospective, Quantitative, Cross-sectional.	30 Adults/ older adults 37 - 77 years old	Motor	SF-36 Not specified	The domains with the lowest scores were the physical, emotional, and social ones.

Study	Author(s) Year	Type of study	Sample/age group	Disability	Instrument and administration method	Results
L	Torres GV, Reis LA, Fernandes MH et al 2009 [22]	Analytical, Cross-sectional.	117 older adults 60 - 106 years old	Dependents for the activities of daily living; Barthel index	WHOQOL-OLD Not specified	The QOL is most impaired in the domains of social participation (32.03 points) and sensory functioning (40.76 points).
M	González S, Tello J, Silva P et al 2012 [23]	Descriptive	42 Adults/ older adults – 18 - 65 years old	Motor	SF-36 Interview	Significant results between people with changed mental health (Goldberg ≥ 5) and those with some degree of dependence in the Barthel Index (Fisher's test = 0.34). There was a 10-point difference in the physical component between people with and without a change in mental health (statistically nonsignificant), and lower QOL in the physical component as the educational level increased (statistically significant).
N	Pereira JRT 2009 [24]	Descriptive	15 Adults over 18 years old	Intellectual	QOL-Q Self-administered	The highest mean percentage was reached on the scale of satisfaction (73.6), followed by social participation (52.8) and productivity (43.73). Independence (12.8) was the domain with the lowest performance.
O	Lucas-Carrasco R, Pascual-Sedano B, Galán I et al 2011 [25]	Descriptive	149 Adults and older adults	Physical Neurodegenerative diseases	WHOQOL--BREF WHO-QOL-DIS Interview	WHOQOL-BREF and WHOQOL-DIS significantly discriminated depressed and non-depressed and those who perceived the most serious impacts of the disability on their lives.
P	Funes CJ, Mace RA, Macklin EA et al 2019 [26]	Cross-sectional, Descriptive.	41 Adults	Hearing due to neurofibromatosis	WHOQOL--BREF Self-administered	The deaf participants (d3RP-NF2) had significantly greater improvement in the baseline for post-treatment physical QOL (14.79, 95% CI 5.41–24.18; p ≤ 0.001), psychological QOL (18.77, 95% CI 7.09–30.44, p ≤ 0.001), and environmental QOL (13.25, 95% CI 1.10–25.39, p = 0.03) when compared with the "placebo" (dHEP-NF2). The social QOL also increased significantly in the d3RP-NF2 (16.32, 95% CI 6.66–25.97, p = 0.001). The improvement did not go beyond the dHEP-NF2. The gains in QOL were clinically significant and maintained in the 6-month follow-up for the participants of the d3RP-NF2 in all the QOL domains. There was more response to the treatment in the d3RP-NF2 when compared with the dHEP-NF2.
Q	Angelo TCS, Morete ALM, Costa AO et al 2016 [27]	Descriptive, Cross-sectional	70 Adults and older adults 23 - 75 years old	Hearing and control group	WHOQOL--BREF Self-administered	There was no statistically significant difference between the Study group (SG) and the Control Group (CG), except for domain 4 (environment), which correlated with socioeconomic level and schooling. No statistically significant correlation was found in the comparison of the mean QOL scores of the SG subjects with speech recognition performance, age when assessed, time of hearing sensory deprivation, and time of CI use.
R	Rajendran V, Roy FG. 2010 [28]	Cross-sectional, Prospective	100 Children 6 - 11 years old	Hearing with and without motor change, and control group (with normal hearing)	PedsQL 4.0 Self--administered or interview, depending on the child's literacy	Children with hearing loss and no motor impairment achieved significantly lower scores in the domains of emotional health and school functioning than children with normal hearing. There was, though, no significant difference in the scores in the domains of social and physical health. Children with hearing loss and motor disability had significantly lower scores in all the domains when compared with children with normal hearing. The children with hearing loss, with and without motor impairment, had lower QOL.
S	Kim ES, Kim JW, Kang HJ et al 2018 [29]	Longitudinal/ Prospective	288 aged 30 - 87 years	Stroke sequelae	WHOQOL--BREF Self-administered	The WHOQOL-BREF scores were significantly and persistently lower one year after the stroke in patients with post-stroke depression (PSD) at the beginning of the study in comparison with those without PSD at the beginning of the study, regardless of the demographic and clinical characteristics, including the severity of the stroke.

Legend: WHOQOL-100 - World Health Organization Quality of Life-100; WHOQOL-BREF - World Health Organization Quality of Life, abbreviated version; SF-36 - Short-Form 36; QOL – the quality of life; WHOQOL-DIS - World Health Organization Quality of Life-Disabilities; WHODAS 2.0 - World Health Organization Disability Assessment Schedule; QOL-Q - Quality of Life Questionnaire; PedsQL – Pediatrics Quality of Life Inventory; M - male; F - female; PSD - post-stroke depression..

Chart 3. Instruments used in the selected studies

Developed by/year	Generic versions	Specific versions	Validated in Brazilian Portuguese	Number of articles found	Studies	Disabilities assessed	Domains	Field of knowledge of the professional of the study	Place of the study
Developed by/year	Generic versions	Specific versions	Validated in Brazilian Portuguese	Number of articles found	Studies	Disabilities assessed	Domains	Field of knowledge of the professional of the study	Place of the study
WHO, 1998[8]	WHOQOL-100		Yes	2	A, B	Visual (A); Intellectual (B)	6: physical; Psychological; degree of Independence; social relationships; environment; spirituality/ Religiosity/ personal beliefs	Nursing (A), Education (B)	Brazil (A) Portugal (B)
WHO, 1998[8]	WHOQOL-BREF (26)		Yes	7	C, E, F, I, P, Q, S	Motor (C); Mental (E); Motor (F); Physical, Visual and Hearing (I, P, Q) stroke sequelae (S)	4: physical; psychological; social relationships; environment	Nursing (C, F) Psychology (E), Education (I), Medicine (S, P), Medicine (Q)	Brazil: Paraíba (F); Pernambuco (I); Bauru (Q) Portugal (C, E) South Korea (S); USA (P)
WHO, 2005[31]		WHOQOL-OLD	Yes	1	L	Motor-dependents for activities of daily living – Barthel Index	6: functioning of the senses; autonomy; past, present, and future activities; social participation; death and dying; intimacy	Nursing and Physical Therapy	Brazil: Bahia
WHO, 2011[32]		WHOQOL-DIS	Yes	1	O	Motor	3: discrimination; autonomy; Inclusion	Psychology and Medicine	Spain
WHO, 2010[30]	WHODAS 2.0		Yes	1	H	Visual	6: cognition, mobility, self-care, interpersonal relationships, activities of living, participation	Psychology	Brazil: Santa Catarina
Williams LS, Wienberger M, Harris LE, Clark DO, Biller J, 1999; WHO[33]		SS-QOL	Yes	1	J	Aphasic	12: energy; disposition; mindset; behavior; social relationships; family relationships; personal care; eyesight; language; work/ productivity; functioning of the upper limbs.	Speech-Language-Hearing Pathology	Brazil: São Paulo
Benard, B, 1995[34]	KIDSCREEN		Portugal	1	D	Motor	10: health and physical activity; feelings; overall mood; about themselves; autonomy/free time; family, and family environment; economic issues; friends; school environment and learning; provoking.	Education	Portugal
Shalock and Keith, 1993[35]	QoL-Q		Yes	1	N	Intellectual	4: satisfaction; productivity; independence; social participation.	Psychology	Spain
Ware, Gandek, IQOLA Project Group, 1994[36]	SF-36		Yes	2	K, M	Motor (K) and (M)	8: physical functioning; the role of physical functioning; physical pain; overall health; vitality; social functioning; emotional function; mental health. PS: 1 comparative question between current health and that of the year before.	Medicine (K) and (M)	Brazil: Rio de Janeiro (K) Chile (M)

Developed by/year	Generic versions	Specific versions	Validated in Brazilian Portuguese	Number of articles found	Studies	Disabilities assessed	Domains	Field of knowledge of the professional of the study	Place of the study
Schalock and Verdugo, 2007[9]	GENCAT		Portugal	1	G	Motor Cerebral palsy	8: emotional well-being; interpersonal relationships; material well-being; personal development; physical well-being; self-determination; social inclusion; rights	Nursing	Spain
Varni JW, Seid M, Kurtin. 2001[37]	PedsQL™ 4.0		Yes	1	R	Hearing	4: physical (eight items), emotional, social, and school functioning.	Speech-Language-Hearing Pathology	India

Discussion

This study conducted a systematic literature review on the instruments used to assess the QOL of PWD. The results of the research showed that, of the 19 selected articles, 13 used the instruments created by WHO to assess the QOL of PWD. Two studies (A and B) used the WHOQOL-100[39]; seven (C, E, F, I, P, Q, S) used the WHOQOL-BREF[8], an abbreviated version of the WHOQOL-100; one (L) used the WHOQOL-OLD[31], an add-on module created to assess older adults; one (J) used the Stroke Specific Quality of Life Scale – SSQOL[33], specific for people with a stroke; one (O) used the WHOQOL-DIS[32], specific for PWD with motor and intellectual disability; and one (H) used the WHODAS 2.0[30].

As for the other six, two (K, M) used the SF-36[36]; one (D) used the Kidscreen[34]; one (G) used the GENCAT[9]; one (N) used the QOL-Q[35]; and one (R) used the PedsQL, version 4[37].

As mentioned in the Introduction, the lack of tools to assess the QOL from a transcultural perspective led WHO to establish, in the 1990s, a group to study the QOL and develop for it a measurement applicable and valid to be used in various cultures. The collective project was developed in 15 centers. The first instrument developed was the WHOQOL-100. This generic instrument, which has a transcultural character and values the person's individual perception, can assess the QOL in various groups and situations[38].

This research reveals that the most used instruments to assess QOL in PWD are the generic ones (WHOQOL-100 and its abbreviated version, WHOQOL-BREF). These instruments assess various aspects of the QOL and health status of young and adult people and can be used regardless of the people's type of impairment/problem or condition, and even to assess healthy people. They make it possible to compare QOL of people with the same disease/health problem, in different situations, and with the general population. The WHOQOL-100 has 100 questions – 24 general ones on QOL, and the others equally approaching six domains: physical, psychological, level of independence, social relationships, environment, and spirituality/religiosity/personal beliefs. WHOQOL-BREF, its abbreviated version, comprises 26 questions – the first one generally on QOL, and the second on satisfaction with their own health; the other 24 are divided into the physical, psychological, social relationships, and environment domains. This instrument appears in this research as the most used one. The WHOQOL-OLD is an add-on module to the WHOQOL-100, encompassing specific older adult characteristics. It is made up of 24 items divided into six facets: functioning of the senses, autonomy, past, present, and future activities, social participation, death and dying, and intimacy. It assesses their perception of the impact the diseases have on their lives and it can be used as a complement to WHOQOL-100 or WHOQOL-BREF. The Brazilian Portuguese versions of the instruments (the cited WHOQOL) were validated with satisfactory psychometric characteristics[39].

There is a consensus in the literature that generic assessments may be less sensitive to changes in the disease/disability or treatment and that, regarding the PWD, they may not reach specific domains in these people's lives. Nevertheless, in this research, of the WHO instruments, only three studies (L, J, O) used specific ones, despite their being the ones that most effectively assess QOL in PWD.

Three WHOQOL-BREF versions were developed for people with disabilities: WHOQOL-DIS-PD, for people with physical disabilities; WHOQOL-DIS-ID, for people with intellectual disabilities; WHOQOL-DIS-ID-Proxy for parents/guardians/caregivers of people with intellectual disabilities. The three versions were validated for Brazilian Portuguese[40]. Besides these versions, there is also the WHOQOL-BREF and WHOQOL-DIS ones in Brazilian Sign Language[41].

In Study J, the stroke-specific quality of life scale (SS-QOL) was used, which is specifically for people with cerebrovascular diseases. Translated to Portuguese and validated as "*Questionário Específico de Avaliação da Qualidade de Vida para Doença Cerebrovascular*", it is frequently used in people with aphasia following a stroke[42]. The questionnaire has 49 items subdivided into 12 domains and two parts. One investigates the person's degree of mobility, upper limb function, work/productivity, personal care, language, and eyesight. The other one, subdivided into 12 domains, assesses each domain in the relationship between the present moment and before the disease (Table 3). In comparison with other generic QOL assessment instruments, it offers the greatest coverage on the functions typically affected by the stroke. Generic instruments, such as the SF-36 and WHOQOL, have no questions on language, hand function, cognition, and eyesight – which are covered in the SS-QOL, one of the few specific questionnaires with a translation and cultural adaptation study for the Brazilian population[43].

Study H used the World Health Organization Disability Assessment Schedule (WHODAS 2.0), also developed by WHO. Conceptually, the QOL and functioning constructs are often seen as interchangeable. Although WHODAS 2.0 is not categorized as a QOL instrument, it is a generic health condition and disability assessment instrument (i.e., it measures functioning – the objective performance in a given domain in life). WHOQOL measures subjective well-being – the person's satisfaction with their performance in a given domain in life. The same domains used to assess functioning should correspond to domains used to assess QOL. WHODAS 2.0 and WHOQOL should be complementarily used – the first one investigates what a person "does" in a particular domain, while the second investigates what the person "feels" in this domain. Originally published in 1988 as an instrument to assess functioning in psychiatric patients, it underwent various revisions before reaching the current version, WHODAS 2.0. After the ICF was published, the scale was modified to include the health aspects approached in the ICF in terms of functioning and disability[5;44]. It comprises 36 items divided into six domains directly related to the ICF Activity and Participation components. There are several other published disability measuring instruments, also known as the health condition or functioning measures; however, WHODAS 2.0 is currently recommended because it provides a standardized health and disability measurement model based on the ICF and the biopsychosocial health model.

Studies K and M used the SF-36 (Short Form 36) to assess the QOL index. This scale – which goes from 0 (worst) to 100 (best) – has 36 items arranged in eight domains: four related to physical health and four, to mental health (Table 3), allowing for the analysis of the impact of the disease and its treatment, instead of the disability alone from the patient's standpoint. It was validated in Portuguese for other conditions, such as multiple sclerosis, HIV infection, Parkinson's disease, and so forth. The questionnaire is versatile, as it is filled in five to 10 minutes and it can be self-administered, or applied in interviews or phone calls, with people over 14 years old. The SF-36 and the WHOQOL versions, besides being validated and having attested psychometric qualities, stand out for enabling the comparison with other instruments[45].

Study D used the Kidscreen questionnaire in children with motor difficulties. It is a generic instrument used to measure, monitor, and assess the subjective health associated with QOL of children and adolescents. Used in hospitals, schools, public and private health services, it was created in the context of the European project named Screening and Promotion for Health-Related Quality of Life in Children and Adolescents – A European Public Health Perspective. It can be administered to children and adolescents eight to 18 years old and their parents. This self-administered questionnaire has 52 items, divided into 10 dimensions (Table 3).

Study N used the first Brazilian version of the Quality of Life Questionnaire (QOL-Q), translated as "*Questionário de Qualidade de Vida*" (QQV)[24]. It comprises four scales referring to four QOL domains: Satisfaction (with life); Productivity (occupations and labor activities); Independence (con-

trol of their own life and decision-making power); Social Participation (in the community or neighborhood). The authors report that they chose this instrument because the population of the research comprised people with an intellectual disability. According to them, this is the main instrument to assess QOL in this population. The QOL-Q was developed in the United States[35] and is intended to: a) assess the needs of individual services/programs; b) assess the results of a specific event or circumstance; c) assess programs or services; d) research, for instance, the effects of intervention programs or such that aim to identify transcultural QOL components. The questionnaire has 40 items divided into four QOL domains (Table 3).

Study G used the GENCAT scale[9], meant to assess QOL of adults with a disability. According to the authors, QOL is a multidimensional concept, with culture-related ethical/universal properties. Its objective and subjective components are influenced by personal and environmental factors, as well as the interaction between them. Hence, the authors structured the QOL assessment in eight domains: Emotional Well-Being – satisfaction, self-concept, and absence of stress or negative feelings; Interpersonal Relationships – positive social, family relationships, having friends; relationships with peers and sexuality; Material Well-Being – house, work, income, material possessions, the possibility of having their wishes satisfied; Personal Development – limitations/capacities, new technologies, learning opportunities, working and functioning abilities; Physical well-Being – primary health care, activities of daily living, access to technical assistance; Self-determination – personal goals and preferences, decisions, and autonomy; Social Inclusion – integration, participation, accessibility, and support; Rights – privacy, respect, knowledge, and exercise of their rights. When developing this instrument, the authors[9] understand that QOL is related to the social constitution with cultural relativity; it involves people's satisfaction with their life in various fields; it is related to the existential aesthetics and with what is understood as comfort and well-being in defined spaces and time. It is further related to health and encompasses eating, housing, sanitation, work, education, culture, leisure, lifestyles, and care. The authors point to the importance of implementing QOL programs that make the institutions collect, analyze, and assess information for their activities to be planned and carried out to result in truly effective improvements. The QOL program helps the services promote actions centered on aspects of the patients' life, increasing their self-determination, decision-making opportunities, and social inclusion. The services must also provide support in their patients' various QOL domains and create environments to welcome and include people with disabilities, diminishing their segregation, consolidating political health care options in terms of prevention, rehabilitation, and equal opportunities.

Study R used the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™), validated in 2002, which is a generic scale for children and youth from two to 18 years old that helps differ healthy children from child patients with chronic or acute diseases. It has 23 items divided into four domains: Physical functioning (eight items); emotional functioning (five items); social functioning (five items); and school functioning (five items), in a five-point scale: "never" (0), "almost never" (1), "sometimes" (2), "often" (3), and "almost always" (4).

Most of the articles analyzed were based on cross-sectional studies. However, constructs such as QOL, which are multifactorial and undergo individual changes in time/context, have greater quality and methodological rigor in longitudinal studies. One such article and one randomized clinical trial were found, comparing interventions, whose assessment instrument used was the WHOQOL-BREF.

Regarding the characteristics of the samples, the number of subjects ranged widely (from 11 to 288), which hinders the comparison of results between the groups. Of the 19 articles, only five studies (L, H, S, R, O) had more than 100 participants. As for the disabilities studied, there was a prevalence of the physical/motor disabilities (eight studies), followed by the intellectual (three), visual (two), and hearing ones (two studies). Besides these, there was one study on people with aphasia, another one on people with stroke sequelae, and another two that assessed QOL of people with multiple disabilities – one on visual, hearing, and physical disabilities, and the other on hearing and motor disabilities.

The National Health Survey (PNS-2013, in Portuguese)[46] estimated that 6.2% of the 200.6 million people living in permanent private households had at least one of the four disabilities. The estimated prevalence of intellectual disability was

0.8%; physical disability, 1.3%; hearing disability, 1.1%; visual disability, 3.6%. The PNS also showed who attended some type of rehabilitation service: 18.4% of those with physical disabilities; 8.4% of those with hearing disabilities; 4.8% of those with visual disabilities; and 30.4% of those with intellectual disabilities attended some health rehabilitation service. These data reveal quite precarious accessibility to rehabilitation services, which should be necessarily coordinated with the health promotion and aggravation prevention actions, and present at every health care level. This perspective, which seeks to combine rehabilitation and QOL is relatively recent within the public health care services.

The Family Health Care Support Center, currently called Extended Family Health Care Center (NASF, in Portuguese), was in theory conceived as an essential component to help coordinate health care and potentialize comprehensive care and the solvability of primary health care and SUS. However, it has been facing countless barriers to play its role. Among other obstacles, what stands out is the fragmented work processes, the fragmented relationship between the different professional training, and the precarious training of the various categories that oftentimes remain distant from the training for SUS[46].

Despite the various positive aspects that took place in the field of health assistance in the last decades (creation of SUS, implementation of the National Health Policy for People with Disabilities, ratification of the International Convention of Persons with Disabilities, implementation of the Health Care Network for People with Disabilities, Law on Inclusion), what still prevails in the assistance offered to the PWD in Brazil is the biomedical model, which is focused on the organic and individual aspects of the disability[6]. Many health practices do not incorporate postulates of the comprehensive health care policy for people with disabilities and still do not include the values, knowledge, and needs of the PWD.

Nevertheless, although it is not a reference to institutional and individual planning of the health services, the QOL assessment is conceived in practically all the studies analyzed as an agent of change to overcome traditional perceptions, putting in the first place the demands and needs identified by the very people with disabilities in their living circumstances. Highlighted in the different instruments analyzed, the clinical listening to the PWD regarding their QOL self-assessment makes room for embracing other demands, not always related to the severity of the organic or functional impairment[6], but that imply in actions to promote their active participation, as well as their family's and community's, in producing health and a greater protagonism regarding personal and social aspects[8 9 12 15].

It was observed in this study that QOL of PWD is being studied by professionals of the following health specialties: Nursing (four), Medicine (four), Psychology (two), Speech-Language-Hearing Pathology (one), Social Work (one), Education (three). Nursing/Physical Therapy (one), Medicine and Psychology (one), Medicine and Speech-Language-Hearing Pathology (one), Physical Therapy, and Speech-Language-Hearing Pathology (one) (Table 3). Only two studies had a multiprofessional approach with two fields of knowledge in health, which may be related to the ongoing change in the technical/assistive model adopted by SUS, as well as the few papers that deal with PWD health promotion, for whom interventions restricted to professional or specialty fields are not fitting. It can also be because the significant advancements achieved with inclusion policies in Brazil have not yet unfolded with the same strength in the routine of the institutions. For QOL of PWD to become a reference in planning actions in the health services, changes must take place at different levels, particularly in the implementation of means to promote the PWD's self-determination, decision-making, and social inclusion; development of programs aimed at the PWD, offering support in the various QOL domains; actions developed by the community to include the PWD, diminishing their segregation; implementation of policies to furnish the prevention, rehabilitation, and equal opportunities[48].

Another point to be highlighted is the importance of professional training and the perspective of working in interdisciplinary teams, which can be observed in Brazil especially in primary health care, which has been an entry point to SUS and the redirecting of the assistive model.

Regarding the place of origin where the publications were developed, nine studies were Brazilian (A, F, H, I, J, K, L, N, Q); four, Portuguese (B, C, D, E); two, Spanish (G, O); one, Chilean (M); one, American (P); one, Indian (R); and one, South Korean (S). Noticeably, most articles on QOL assessment of PWD are Brazilian studies grounded on

the SUS assistive model, which advocates comprehensive health care and considers biopsychosocial determinants in its actions.

Various studies were found on the validation and adaptation of instruments (which did not meet the eligibility criteria), and few ones on the applicability of the instruments. Concerning the authorship of publications, Table 2 shows that no group of authors was repeated – i.e., the studies were conducted isolated. It was also noticed that few researchers approach in depth the outcomes regarding the advancements in their investigations. Considering the diversity encompassed in this segment of the population, this reveals that the number of groups and/or research lines dealing with the health and QOL of PWD needs to be broadened to become a reference to the work and training of future professionals.

It was observed in the articles selected for this review that the most mentioned domains in the generic instruments were the physical, psychological, social, and environmental ones. The specific instruments bring up other dimensions related to the disadvantages that need to be observed regarding autonomy, self-determination, social inclusion/participation, rights (education, work, leisure, privacy, etc.). The results show the multidimensional character of the concept of QOL.

The studies on QOL furnish information and indicators to assess the efficacy, effectiveness, and impact of certain treatments on groups with impairments; compare procedures; assess the cost-benefit of services; assess decision-making and adherence or not to treatments; define action strategies; and monitor and maintain the QOL of patients who attend health services, complementing other indicators of the impact of diseases on people (mortality, morbidity)[49].

Conclusion

The results of this research point to the existence of various instruments that allow for the assessment of QOL of PWD in different age groups. The studies analyzed highlight that their use provides a broadened profile of the functional and psychosocial conditions of the PWD, making it possible to understand their health needs, other than the disability-related ones. Considering the person's life expectations, their applications provide more active participation of the PWD in planning promotion, prevention, and rehabilitation actions and consequently more effective care.

The review of the studies selected for this research revealed a great variability of instruments, of which a large part is already validated in Brazil. The generic ones are the most used, which allow for comparisons with other populations, though they may not make it possible to observe specificities of people with disabilities. In this study, the use of the WHOQOL prevailed, especially its abbreviated version, WHOQOL- BREF, in their adapted forms in Brazil, Latin America, and Europe. Among the specificities of the instruments meant to assess PWD, in addition to the physical, psychological/emotional, social relationships, and environmental dimensions, items such as autonomy, self-determination, inclusion, and rights (education, work, leisure, privacy, etc.) are highlighted – which may indicate dimensions to be recommended to the institutions to implement QOL promotion policies for the PWD.

All the analyzed QOL assessment instruments encompassed this broad range of life domains, providing a look beyond the organic and individual aspects of the disabilities, thus opening the possibility of reflection on how the psychosocial determinants both influence and are influenced by the PWD's health condition and QOL.

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