

Family quality of life: an integrative review on the family of people with disabilities

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Abstract *The objective of this integrative revision is to understand the Brazilian scientific production of the thematic focus on the family quality of life (FQoL) of people with disabilities, as well as the participating population, referential theory, and instruments used in the studies. The data survey was done in the BVS, Scielo, and PubMed databases, and in the Capes' Periodic portal, whose inclusion criteria were articles published from 2007 to 2018, available fully online, in Portuguese or English. These articles portrayed the theme of life quality of families of people with disabilities and articles from research done in Brazilian contexts. The results showed that only three of the 19 selected articles to the study analyzed the theme of FQoL directly including the aspects related to the construct. They also pointed out that WHOQOL-Bref was the most used instrument to evaluate the FQoL (n=11), followed by semi structured interviews (n=5) and that only 10,5%, i.e., two articles used the appropriated definition of the FQoL. The research determined that the thematic research is still in the beginning stage in the scientific national production, large use of individual constructs of life quality, and sparse presence of specific measures instruments to measure FQoL.*

Key words *Quality of life, family, People with disabilities*

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Introduction

Understanding the quality of life of families (FQoL) brings the challenge of thinking about the family beyond the individual demands of its members. It is the conception of the family as a unit that is the focus of attention and intervention; it is the art of replacing a vision limited to individual needs by understanding collective needs to provide tools that can help the whole family experience a positive sense of well-being.

FQoL has become an area of considerable international interest with advances in family-centered practices, being a natural extension of studies developed within the scope of the individual quality of life of people with disabilities¹.

The increasing interest and scientific investigations on FQoL in the early 2000s led researchers in the area to direct their attention to the development of FQoL measurement instruments. Initially qualitative, these studies were the first steps in defining the construct².

FQoL conceptualization aroused interest in two lines of investigation: 1) The growing recognition of the capacity to adapt, and the strengths and positive points of families with a member with disabilities; and 2) The change in the understanding of disability from a view of limitations and deficits exclusive to the person with disabilities and their family to a view that considers the influences of contexts and environments, resources they offer, and support needed by families of people with disabilities in conducting the lives of all its members, including the disabled one³.

Zuna et al.⁴ (p. 262) defined FQoL after an extensive review of theoretical and empirical studies on the subject as *a dynamic perception of family well-being, collectively and subjectively defined and informed by its members, in which individual and family needs interact*.

This definition brings the combination of objective and subjective elements that work as a guideline for assessing the concept of FQoL, being a reference for the development of practices as it presents subjective components linked to the impressions and individual needs of family members without losing the focus on a family unit with characteristics that cannot be described by meeting only individual needs. It is a dynamic concept that changes over time according to the growth and development of the person with disabilities and their family^{2,5}.

Zuna et al.⁴ conducted a literature review on FQoL in disabilities, analyzing the findings and relating them to the components of a possible

theory (definitions, concepts, variables, and relationships between variables) for the theme, the Unified Family Quality Life Theory (UFQoLT)^{2,4}. This theory has related components that directly or indirectly influence FQoL, including (a) factors related to the family as a unit, (b) factors related to each family member, (c) factors related to the action, and (d) systemic elements.

In 2013, Caya Chiu et al.³ reviewed and updated the UFQoLT by expanding, redefining, and establishing new factors that influence FQoL. The authors incorporated elements such as factors referring to inputs and outcomes into the original theory, and rewrote the ones related to the action, naming them as family support and individual support level factors. The new proposal by Caya Chiu et al.³ defined the UFQoLT using six factors (Figure 1).

The graphic representation of the conceptual structure of the UFQoLT (Figure 1) is constituted by a network of overlapping circles in which system variables interact in a complex way with one another to produce satisfactory or unsatisfactory FQoL results.

Chart 1 briefly presents the definitions of the variables included in the revised and updated conceptual structure of the UFQoLT.

The emphasis of the model is the QoL of each member of the family and the family as a whole, bringing the philosophy of empowerment with the target point of *achieving the active participation of the family, enabling it to recognize its needs by itself, identifying its priorities, and developing strategies to achieve its goals*⁵.

FQoL is established when its members struggle and get what they want, feel satisfied with what they achieve, feel empowered to live the life they want, have their needs met, and enjoy life together planning and achieving goals that are meaningful to everyone^{6,7}.

Considering the above, the objective of this study is to know the national scientific production on the FQoL of people with disabilities published between 2007 and 2018, and also to describe who the study participants are, its theoretical framework, and the instruments used to measure FQoL, discussing them in the light of the UFQoLT.

Based on the aforementioned objectives, the hypothesis that guided this study was that investigations on the FQoL of people with disabilities in Brazil focus only on one of the family members, especially the member who plays the role of primary caregiver and is not in the family group as a unit.

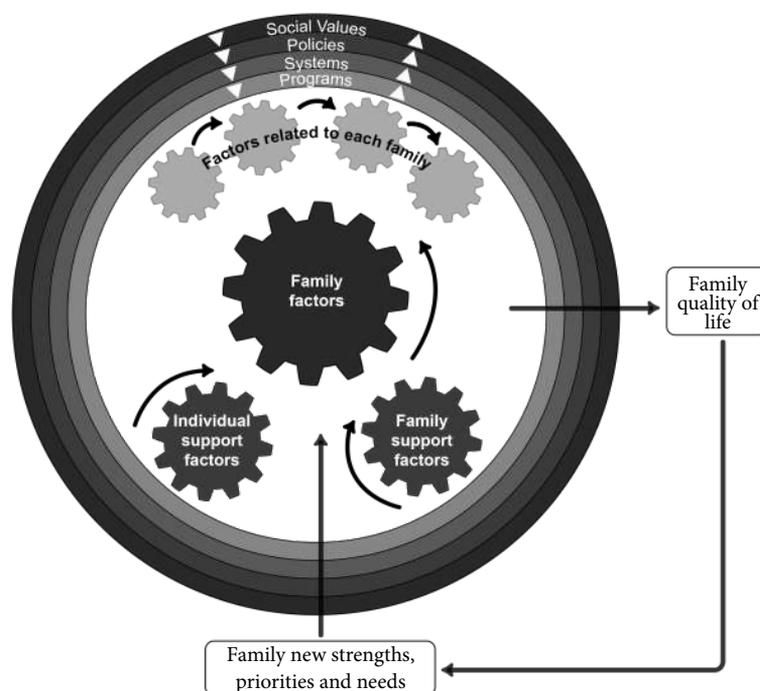


Figure 1. Revised and updated conceptual structure of the Unified Family Quality of Life Theory.

Source: CHIU C et al.³.

Chart 1. FQoL variables according to Zuna NI et al.^{2,4} and Chiu C et al.³

Family Quality of Life Components	
Variables	Definition
Family unit factors	They refer to the forms in which a family can be described as a unit. It considers aspects inherent to family interactions and the ongoing relationships between its members.
Individual factors of each family member	They include the demographic data, characteristics, and individual beliefs of each individual within a family. They consider basic characteristics such as age, sex and ethnicity, disability type and severity, educational level of parents, and employment status of family members in working age.
Family Support Level and Individual Support Level Factors	These include the formal (professional rehabilitation and special education services, for example) and informal support (extended family, friends, neighbors, etc.) received by the families of people with disabilities.
Systemic factors	They represent the macro environment in which people with disabilities and their families live. They refer to the constitutional and ethical principles that govern a society at the federal, state, and local levels in the areas of education, social protection, and health care.
Outcome-related factors	These are the outcomes of the interaction between factors related to each member of the family and/or related to the family unit individually, or factors related to individual and/or family unit support.
Input-related factors	These include new strengths, priorities, and needs of the family that reenter the system in a feedback loop.

Source: Zuna et al.^{2,4} e Chiu C et al.³

This study considers a person with disabilities as a person **with** a long-term impediment of physical, mental, intellectual, or sensory nature, which, when interacting with one or more barriers, can obstruct their full and effective participation in society on equal terms with other people⁸.

Methods

This study is an integrative literature review, i.e., a construction of a broad analysis of the literature, contributing to discussions about research methods and results, as well as about reflections for future studies⁹.

The study considered the following steps: research question selection and hypothesis formulation; establishment of the inclusion and exclusion criteria; database selection; definition of keywords and search strategies; definition of the information to be extracted from the selected studies; study identification and selection; study categorization and evaluation; result interpretation; and presentation of knowledge review/synthesis⁹.

The guiding question of this research was “How has the Brazilian scientific literature addressed the issue of FQoL of people with disabilities?”

The inclusion criteria were studies on the theme of FQoL (of any family member or caregiver) of people with disabilities; conducted in the Brazilian context; published from January 2007 to December 2018; available in full and online; published in Portuguese or English; and indexed in the BVS, Scielo, and PubMed databases and in the Capes Periodicals portal.

The exclusion criteria were the theme of QoL not focused on the family of people with disabilities, i.e., QoL studies aimed exclusively at the person with disabilities. Literature review articles and articles not performed in the Brazilian context were also excluded.

The search strategy included as main descriptors “Qualidade de Vida Familiar,” in Portuguese, and “Family Quality of Life,” in English. Searches were also conducted using the descriptors with a Boolean operator, including “Qualidade de Vida” and “Família” and “Deficiências,” in Portuguese, and “Quality of Life” and “Family” and “Disability,” in English.

All findings were compared to eliminate duplications. Then, titles and abstracts were read using the following criteria: a) title with at least one of the descriptors in Boolean operation or with the main descriptor; b) abstract with the inclusion

criteria theme of FQoL of people with disabilities and study conducted in Brazilian contexts.

Finally, the selected articles were read in full. Review articles and those that did not address the proposed theme were excluded.

Results

A total of 4,758 articles were found from the descriptors, of which 4,730 were excluded after applying the search filters (year of publication, availability of the full article online, and language) and the inclusion and exclusion criteria, with 28 articles selected for full reading.

After the full reading, seven articles were excluded for not addressing the issue of FQoL of people with disabilities or for not being conducted in a Brazilian context, and two studies were excluded for not specifying the target population in the sample, thus leaving 19 articles for analysis and discussion.

Chart 2 shows the main data found in the articles included in the sample (authors, objective, study participants, method/instrument or technique used to assess FQoL, theoretical framework or theme of theoretical deepening/QoL definition used, and main results).

Analysis and discussion

Although there has been an increased interest in studies on the QoL of people with disabilities in the last decades, thereby arousing interest in the FQoL and increasing international scientific production on this topic, the results of the studies reviewed here (Chart 1) confirm the hypothesis that guided this literature review, since 17 of the 19 articles analyzed the QoL of primary caregivers or of one of the family members of people with disabilities (parents or siblings). In addition, data on the characteristics of the instruments and the theoretical framework used in the studies corroborated the guiding hypothesis of the present review.

The results presented in Table 1 show a predominance of studies with a quantitative approach (n = 13) and articles published in journals in the health area, with a predominance of journals in the area of public health, speech therapy, and nursing.

The year with the highest number of selected studies published was 2016 (n = 4). There was a uniform distribution of publications in 2008,

2010, 2011, 2014, and 2015, with one publication on the theme per year, and in 2009, 2012, 2013, 2017, and 2018, with two publications per year. No study published in 2007 was found.

Target subjects, theoretical framework, and instruments used in the studies

Of the 19 studies selected for analysis, eight included family members/caregivers of children/adolescents with disabilities^{11,12,16-18,23-25}; three included family caregivers of people with disabilities with a mixed profile (sample composed of caregivers of children/adolescents, adults, and older people)^{13,26,27}; six did not present information on the age of the subject of care (only the type of disability)^{10,15,20-22,28}; one study included

family caregivers of older people¹⁹; and one study included caregivers of adults with disabilities¹⁴.

The analysis of the theoretical framework or theme of theoretical deepening used in the introductions and discussions showed that the most used themes, alone or in sets with other themes, were Clinical and sociodemographic data; impact of disabilities on family dynamics; and/or the family as a protector, provider of care and development (42.10%, n = 8)^{12,14,18,20-22,25,26}; caregiver health and burden (21.05%, n = 4)^{15,19,24,28}; and health-related QoL (21.05%, n = 4)^{10,16,17,23}. Only three articles (15.79%) directly explored the theme of FQoL, including aspects related to the construct (support needs, emotional, physical and material well-being, family interaction, demographic, and economic data as positive or negative predictors

Chart 2. Description of the main data found in the articles included in the final sample of the review.

Authors	Objective	Study participants	Method/instrument or technique used to assess FQoL	Theoretical framework or theme of theoretical deepening/QoL definition used	Main results
Costa et al. (2016) ¹⁰	To investigate the association between QoL domains related to the health of family caregivers and the sociodemographic characteristics of individuals with stroke sequelae.	136 caregivers.	Quantitative/ Short-Form-36 instrument (SF-36).	Health-related QoL/ QoL according to the WHO	QoL related to the health of family caregivers was compromised in almost all domains assessed. QoL differences linked to sociodemographic aspects of people with stroke sequelae (age, marital status, and education).
Jorge et al. (2015) ¹¹	To adapt the Family Quality of Life Scale (FQOLS) culturally for the Brazilian Portuguese (BP) version to evaluate instrument reliability of the QoL of families that have children with hearing impairment.	41 Parents.	Quantitative/ FQOLS.	FQoL aspects without specifying a theory/none	The FQOLS proved to be an easy to administer instrument with satisfactory reliability. The assessed families indicated satisfactory FQoL. The instrument helps health professionals understand the dynamics, weaknesses, and singularities of each family better.
Nascimento et al. (2016) ¹²	To investigate the relationship between socioeconomic classification and the perception of QoL of people who have a family member with hearing impairment.	20 family members.	Quantitative/ WHOQOL-Bref.	Family as a promoter of child development (ecological influences on child development)/QoL according to the WHO	Directly proportional relationship between socioeconomic classification and the FQoL perceptions in all domains assessed in the survey, except for the environmental domain.

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Authors	Objective	Study participants	Method/ instrument or technique used to assess FQoL	Theoretical framework or theme of theoretical deepening/QoL definition used	Main results
Tomaz et al. (2017) ¹³	To investigate the impact of moderate intellectual disability on family dynamics and QoL.	15 mothers.	Qualitative/ Semistructured interview.	Systemic model and FQoL (not mentioning a theory)/FQoL according to the UFQoLT	Care for the disabled child centered on the mother; interference in the quality of the marital relationship; greater burden of responsibility in maintaining family harmony for the mother; intense symbiosis between mother and child with disabilities and interference in the relationship with other children; schools, the main community institution for children and adolescents, were considered inadequate, with a negative impact on FQoL; difficulties in obtaining information and accessing health and education services and the perception that the quality of care provided is unsatisfactory represent a major source of family stress; family impoverishment and financial difficulties as a result of mothers leaving the labor market; and difficulties in coordinating the schedules of different family members were aspects identified as family leisure complicators.
Ponte; Fedosse (2016) ¹⁴	To correlate the impact of an ABI on the work of people in working age with their QoL, as well as that of their family members.	48 people with ABI and 27 family members.	Qualitative-quantitative/ WHOQOL-Bref.	Clinical and demographic data and the impact of ABI on the subjects' lives/QoL according to the WHO	The sudden onset of an ABI causes disabling sequels, disorganizing the subjects and their family, affecting their QoL in all aspects.

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of QoL, and support services and policies for the family and the person with disabilities, leisure, and community relations)^{11,13,27}.

It was also noted that 68.4% (n = 13) of the studies used the World Health Organization (WHO) definition of QoL^{10,12,14-18,21-23,25,26,28}; 21%

of the articles (n = 4) presented no definition of QoL^{11,19,24,27}; and only 10.5% (n = 2) used the definition of FQoL^{13,20}.

The WHOQOL-Bref was the most used instrument to assess QoL (n = 11)^{12,14,15,18,19,21-25}, followed by semi structured interviews (n =

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Bracciali et al (2012) ¹⁵	To analyze and compare the QoL of caregivers working with people with special needs in a rehabilitation institution.	90 Caregivers.	Quantitative/ WHOQOL-Bref.	Caregiver health and overload/QoL according to the WHO	QoL was classified as good, and the environmental domain received the lowest score.
Oliveira et al. (2008) ¹⁶	To understand the quality of life of caregivers working with children with cerebral palsy.	8 Mothers.	Qualitative/ Semistructured interview.	Health-related QoL/ QoL according to the WHO	Difficulties in transportation, financial resources, health, social life (leisure), life projects and coping (religiosity); the caregivers' QoL was considered unsatisfactory.
Moretti et al, (2012) ¹⁷	To evaluate the quality of life of caregivers of children with cerebral palsy treated at the Association of Parents and Friends of Disabled People (Associação dos Pais e Amigos dos Excepcionais - APAE) in Rio Branco, AC, South Western Amazon, Brazil.	12 Caregivers.	Qualitative/ Semistructured interview.	Health-related QoL; Caregiver health and burden/QoL according to the WHO	The QoL of caregivers was considered unsatisfactory, especially regarding the psychological domain and independence level.
Favero-Nunes; Santos, (2010) ¹⁸	To assess the prevalence of dysphoria/depression symptoms in mothers of children with autistic disorder and to identify possible relationships with QoL and sociodemographic characteristics.	20 Mothers.	Quantitative/ WHOQOL-Bref.	Clinical and sociodemographic data of people with PDD; maternal mental health; health-related QoL/ QoL according to the WHO	Most participants positively assessed their QoL; mothers with a higher level of education were less vulnerable to the criteria for dysphoria/ depression and had higher scores in the psychological, environmental, and physical QoL domains.
Reis et al. (2013) ¹⁹	To assess the QoL and associated factors of caregivers working with older people with functional disabilities to help plan and implement multidisciplinary measures to improve the caregivers' QoL.	40 Caregivers.	Quantitative/ WHOQOL-Bref.	Caregiver health and burden/None	QoL is affected more in the physical and environmental domains and is less impaired in the psychological domain; high prevalence of health problems in caregivers and QoL affected by the work burden.

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Authors	Objective	Study participants	Method/ instrument or technique used to assess FQoL	Theoretical framework or theme of theoretical deepening/QoL definition used	Main results
Silva; Fedosse, 2018. ²⁰	To define the sociodemographic profile and QoL of caregivers working with people with intellectual disabilities in a small city in RS, Brazil.	75 caregivers; 71 family members, and four formal caregivers.	Quantitative/ WHOQOL-Bref.	Family as a protector/caregiver health burden/ FQoL according to the UFQoLT	The higher mean scores were in the social domain, followed by the physical, psychological, and environmental domains, with few differences between men and women. They experience difficult situations and economic, physical and/or emotional changes. Abdication of leisure activities to dedicate to work; social isolation, decreased interpersonal relationships with focus on household and religious environments.
Bittencourt; Hoehne, (2009) ²¹	To evaluate the QoL of parents of deaf people in a health Rehabilitation service.	15 family members of deaf people.	Quantitative/ WHOQOL-Bref.	Impact of deafness/ QoL in health and QoL according to the WHO	A total of 80.0% of the interviewed parents reported having “good” or “very good” QoL; 80.0% of respondents reported being “satisfied” or “very satisfied” with their health; and lower perception of QoL in the environmental and psychological domains.
Lima et al. (2014) ²²	To describe and compare the QoL of stroke patients and their caregivers.	210 participants, divided into four groups: stroke with caregivers (44); stroke without caregivers (39); caregivers (44); and control group (83).	Quantitative/ WHOQOL-Bref.	Sociodemographic Stroke/QoL data according to the WHO	In all domains, the mean scores for the group of stroke patients with caregivers and stroke patients without caregivers were lower than the mean scores of the group of caregivers, which had a mean score lower than that of the control group; the physical domain was the most affected for the group of stroke patients with caregivers and the least affected for the group of caregivers and the control group.
Oliveira; Limongi, (2011) ²³	To evaluate the QoL of parents/caregivers of children and adolescents with Down Syndrome (DS) and the influence of sociodemographic aspects on the results obtained.	31 parents/ caregivers.	Quantitative/ WHOQOL-Bref.	Health-related quality of life; family dynamics in DS. QoL according to the WHO	Most parents/caregivers rated their QoL as “good”; the environmental domain was the most affected; statistically significant positive correlations were found between the environmental domain and the sociodemographic variables socioeconomic and education levels.

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Authors	Objective	Study participants	Method/ instrument or technique used to assess FQoL	Theoretical framework or theme of theoretical deepening/QoL definition used	Main results
Barbosa; Fernandes (2009) ²⁴	To evaluate the QoL of caregivers of children with autistic spectrum disorders (ASD) and determine if there is a relationship between the different domains and demographic aspects of the parents' education and social class.	150 caregivers.	Quantitative/ WHOQOL- Bref.	ASD caregiver health and burden/ None	The statistical analysis showed that the aspects included in the physical, psychological, and social relations domains of WHOQOL-Bref, and sociodemographic issues were decisive in the characterization of the subjects' QoL; factors related to the environmental domain, such as difficulties in accessing health services, increased the stress level of caregivers of ASD children and adolescents.
Vieira; Fernandes (2013) ²⁵	To evaluate the self-reported QoL of older siblings of autistic children using the WHOQOL-Bref.	21 older siblings.	Quantitative/ WHOQOL- Bref.	Dynamics and difficulties of families of children with ASD/QoL according to the WHO	The most affected domain was the environment; both the caregivers of autistic children and their siblings notice QoL difficulties, mainly related to access to health and transportation services, housing conditions, security, leisure, financial resources, and opportunities to acquire information and skills; the siblings who answered the questionnaire reported no significantly impaired QoL.

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5)^{13,16,17,26,27}. One article used the Short-form Health Survey (SF-36)¹⁰, one used a questionnaire prepared by the researchers themselves²⁸, and one addressed the process of adaptation and validation of the FQOLS¹¹.

Family quality of life or quality of life of family members?

The comparison between QoL studies from different countries^{3,29,30} that included theoretical references and specific FQoL measurement instruments and the studies found and selected in

the present literature review shows discrepancies between the results obtained in the two scenarios, confirming the hypothesis formulated for the present study.

This comparison points to a distinction between what can be called studies on the FQoL (according to the UFQoLT) and studies on the QoL of family members of people with disabilities. The first identifies and works with variables that affect the well-being and QoL of the whole family (such as individual factors of each family member, factors at the level of family support, factors at the level of individual support, and systemic factors); and the second focuses on variables that interfere

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Moreira et al. (2016) ²⁶	To analyze the QoL perception of parents/caregivers of people with DS.	10 caregivers.	Qualitative/ semi structured interview.	Clinical and sociodemographic data of DS/QoL according to the WHO	60% of respondents participate in regular leisure activities, but the desire for more leisure moments is present, being at the same time a limiting factor for the QoL of parents/caregivers; evidencing that the absence of health problems interferes with QoL, which is influenced by the availability of health services; FQoL is seen by parents/caregivers as a need to be closer to their children.
Rodrigues et al., 2018 ²⁷	To analyze the impact of severe or profound intellectual disabilities in FQoL dimensions in a sample of Brazilian families to identify a series of aspects that could be modified.	15 mothers	Qualitative/ semi structured interview.	FQoL/ Sociodemographic data of the Brazilian population/does not present a concept of QoL but uses the Family Quality of Life Survey 2006 (FQOLS-2006) as a base and reference for FQoL.	Impact of aspects related to health management issues in FQoL, how the Unified Health System and its professionals are perceived as inadequate/mothers' perceptions that their children have less access to health services than they think necessary/difficulties in obtaining information and access to health services, as well as the perception that the quality of care was poor/decreased leisure and recreation activities owing to the lack of public services and adequate transport/impaired interaction with the community owing to the mothers' view on the social stigma related to disabled child.

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with the QoL of only one of the family members, usually the one directly affected by the impact caused by the presence of a person requiring special care (such as the impact of care, burden, and the presence of depression in the caregiver's life and health, as shown in Chart 2).

Although there is a lack of dissociation between the QoL of each family member and the

FQoL¹, because what affects one family member has an impact on all other members³¹, there is a contrast between what is meant by the QoL of a member of the family of people with disabilities, therefore individual QoL, and FQoL. Unlike individual QoL, which focuses on personal characteristics and environmental variables influencing the quality of life of only one member, FQoL

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Authors	Objective	Study participants	Method/ instrument or technique used to assess FQoL	Theoretical framework or theme of theoretical deepening/QoL definition used	Main results
Kantorski et al., 2017 ²⁸	To identify the prevalence of and factors associated with a poor FQoL assessment of psychosocial care center (CAP) users in the southern region of Brazil.	1,242 family members of CAP users	Quantitative/ Questionnaire prepared by the researchers.	Caregiver health and burden, and data on variables that influence QoL/QoL according to the WHO.	The factors associated with a poor assessment of QoL found in the research were education, easy access to CAPS, CAP effectiveness, CAP support to burden professionals, distribution of care activities, health problem, relationship with family, and feeling of burden.

Source: Author's elaboration.

considers the well-being of all family members in terms of what is necessary for everyone to have a good life together¹.

Based on elements such as QoL, theoretical framework (or theme of theoretical deepening), characteristics of the instruments, and QoL dimensions found in the selected studies, some characteristics that separate the two types of studies mentioned above can be defined.

The definition of QoL found in most selected articles define the first distinction between the two types of studies. The WHO definition of quality of life refers to QoL as an *individual perception of his position in life in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards, and concerns*³². This definition contrasts with the concept of FQoL from a collective view, with emphasis on examining the perceptions and dynamics of the family unit as a whole⁴, *a dynamic perception of family well-being, collectively and subjectively defined and informed by its members, in which individual and family needs interact*².

The characteristics of the instruments used in the selected articles and their own measurement instruments for FQoL are another difference between FQoL studies and study on the QoL of family members, as they have a direct influence on the type of results found in FQoL studies and in studies on the QoL of only one member of the family.

As previously mentioned, the standardized instruments and techniques used to assess QoL in the selected studies were the WHOQOL-Bref, the SF-36, the FQOLS, and interviews (semi structured or structured).

The WHOQOL-Bref contains 26 questions divided into four domains or dimensions (physical, psychological, social relations, and environment)³², and the SF-36 has 36 questions divided into eight dimensions (functional capacity, physical aspects, pain, general health status, vitality, social aspects, emotional aspects, and mental health) and a question to comparatively assess the current health conditions and those of a year ago³³.

The WHOQOL-Bref and the SF-36 are measurement instruments that assess QoL based on the respondent's individual perception, which, despite containing questions related to the environment and social relationships, focus on performance measurements or physical and psychological structures of the subject related to these contexts, allowing a self-assessment of objective and subjective aspects of QoL, but not allowing the expansion of responses to the family unit.

The results of the studies using these two tools to assess QoL showed that the health of the caregiver was affected in almost all domains assessed by the instrument, such as disabilities disorganizing the caregiver's daily life; abdication from pleasurable activities, social isolation, and

decreasing interpersonal relationships for almost exclusively dedicating to the task of care; the environment as a source of stress and conditions linked to the subject as a factor promoting or impeding a positive or negative perception of QoL. Some studies point to a positive QoL, although they indicate deficits in some areas evaluated by the instrument (usually psychological and environmental areas).

Theoretical frameworks or theoretical deepening themes focus on examining the relationship between QoL, health, and the burden of the care task from an individual perspective, directly or indirectly using a theoretical approach to QoL more focused on psychological aspects, which essentially seek *indicators that deal with individual subjective reactions to experiences, thus depending, firstly, on the direct experience of the person whose QoL is being assessed and indicates how people perceive their own lives, happiness, and satisfaction*³⁴, but that poorly explores family unit and environmental variables that directly interfere with the unsatisfactory perception of QoL, in the identification of the support needs of the caregiver, and in the existing support that could effectively include other family members in the care task, relieving stress, improving health conditions, and decreasing the burden of the study's target caregiver.

In contrast, as previously mentioned, investigations on FQoL analyze QoL collectively (family group). In this sense, different authors focused their research on the conceptualization, measurement, and applicability of the UFQoLT. These studies try to identify the support needs expressed by the families; understand the satisfaction of families regarding the support received from formal and informal sources; understand how disability severity and type and demographic and economic data are positive or negative predictors of QoL, or how spiritual beliefs and positive family interaction promote a feeling of emotional well-being^{1,3,29,30}, and other determinants.

In the context of the present literature review, only three studies included the dimensions present in the concept of FQoL, discussing their findings as variables that affect the whole family, including the study by Tomaz et al.¹³, who assessed the QoL of 15 families of people with moderate intellectual disabilities through semi structured interviews and classified their findings into categories based on the nine QoL dimensions identified by the Quality of Life Research Unit group. The results showed an imbalance between mothers and fathers in the attention and care given

to the child with disabilities; interference in the quality of the marital relationship; intense symbiosis between mother and child with disabilities and interference in the relationship with other children; difficulties in obtaining information and in accessing health and education services, added to the perception of unsatisfactory quality of care provided and of these services as a great source of family stress; family impoverishment and financial difficulties as a result of mothers leaving the labor market, and difficulties in coordinating the agendas and interests of different family members as family leisure complicators.

The study by Rodrigues et al.²⁷ evaluated the QoL of 15 families of people with severe intellectual disabilities using semi structured interviews and classifying their findings in categories based on the Family Quality of Life Survey 2006 (FQOLS-2006). The results of the study showed dissatisfaction with public health services and with the professionals working there; dissatisfaction with the quantity and quality of care; difficulties in obtaining information and access to health services; decreased leisure and recreation activities; and impaired interaction with the community.

Finally, the study by Jorge et al.¹¹ used a quantitative instrument based on the Beach Center FQOLS validation process for use in Brazil. The results show low satisfaction levels in areas such as emotional well-being, support to people with disabilities, physical and material well-being, and the relationship between parents and children. It also shows a high satisfaction level in the family interaction domain.

The results of the studies by Tomaz et al.¹³ and Rodrigues et al.²⁷ showed that a semi structured interview is an excellent tool to assess FQoL in contexts with little availability or absence of quantitative instruments suitable for this purpose, as in the case of Brazil. The technique also has the advantage of exploring the desired theme in depth in studies involving small groups of subjects.

The first studies on FQoL assessment studies were qualitative, through discussion groups and semi structured interviews². These studies were extremely important for the progression of the theme, as they allowed the construction of concepts and quantitative measures. Three instruments were developed from these studies³⁵, including a) the International Family Quality of Life Survey-2006 - FQoL-S-2006, which assesses QoL in nine dimensions (economic well-being, family relationships, support from other people, support from services that provide care to peo-

ple with disabilities, cultural and spiritual beliefs, educational level and preparation for studies, leisure and free time, and community involvement). It has already been translated and adapted into 12 languages, currently being used in 18 countries; b) The Beach Center FQOLS, which assesses FQoL in five dimensions (family interaction, parenting, emotional well-being, physical and material well-being, and support related to disabilities) and has already been adapted for use in countries such as China, Taiwan, Spain, Colombia, Brazil, and Puerto Rico; c) The Latin American Scale of Quality of Life, which has 42 items distributed into six dimensions (emotional well-being, personal strength and growth, living standards, physical and material well-being, family life, and social and community relations) and aims at being an adequate scale for the sociocultural and economic Latin American context.

All of these scales corroborate the UFQoLT, as they are centered on the family and seek to identify variables that positively or negatively influence the QoL of the whole family unit.

It is worth mentioning that the UFQoLT²⁻⁴ has been the compass of several investigations on FQoL in different cultural contexts, and despite being a new theory, it has been well accepted by researchers who have investigated the dimensions of FQoL in each of the theory units (family characteristics, characteristics of each family member, and the support and influence of systemic factors in the FQoL)³⁰.

Therefore, the dissemination of the UFQoLT and its implementation as a reference could improve the access to research instruments already developed for this purpose, the development of instruments suitable for the Brazilian context, and the consolidation of Brazilian scientific production in the international trend of current studies on the QoL of families of people with disabilities.

Final considerations

FQoL is an increasingly growing theme that has become stronger in international research guidelines on people with disabilities and their families in recent decades. Contrary to this reality, the results of this literature review show a national scientific production focused on the individual understanding of QoL regarding families of people with disabilities.

The results found here also indicate an incipient national production on the theme, with few studies, with the expressive use of individual QoL constructs, and with the scarce use of measurement instruments that help understand FQoL.

The few studies found analyze FQoL and show the need for formal and informal support for families with disabled members, which constitute barriers to achieving family well-being.

Collaborations

AC Nunes contributed to the conception, design methodological, search, analysis and interpretation data, and writing the article. EAM Luiz contributed to the conception, design methodology, search and writing of the article. PCSB Barba contributed to the conception, design methodology, writing of the article and approval of the final version to be published.

References

1. Poston D, Turnbull A, Park J, Mannan H, Marquis J, Wang M. Family quality of life: A qualitative inquiry. *Ment Retard* 2003; 41(5):313-328.
2. Zuna NI, Turnbull A, Summers JA. Family quality of life: Moving from measurement to application. *J Policy Pract Intellect Disabil* 2009; 6(1):25-31.
3. Chiu C, Kyza K, Zuna N, Turnbull A, Summers J A, Aya-Gomez V. Family quality of life. In: Wehmeyer ML, editor. *The Oxford handbook of positive psychology and disability*. Oxford: Oxford University Press; 2013; 365-392.
4. Zuna N I, Summers JA, Turnbull AP, Hu X, Xu S. Theorizing About Family Quality of Life. In: Kober R, editor. *Enhancing the Quality of Life of People with Intellectual Disability: From theory to practice*. Dordrecht: Springer; 2010. p. 241-278.
5. Verdugo MA, Rodriguez A, Sainz F. *Escala de calidad de vida familiar Manual de aplicación*. Salamanca: Publicaciones del INICO; 2012.
6. Brown I, Brown RI. Concepts for beginning study in family quality of life. In: Turnbull A, Brown I, Turnbull R, editores. *Families and people with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Mental Retardation; 2004. p. 25-49.
7. Turnbull AP, Summers JA, Lee SH, Kyzar K. Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Ment Retardation Dev Disabil Res Rev* 2007; 13(4):346-356.
8. Brasil. Lei nº 13.146, de 6 de julho de 2015. *Dispõe sobre a Lei Brasileira de Inclusão da Pessoa com Deficiência* [Internet]. 2015 [acessado 2019 jan 9]. Disponível em: http://www.planalto.gov.br/ccivil_03/_Ato2015-2018/2015/Lei/L13146.htm
9. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. *Texto Contexto* 2008; 17(4):758-764.
10. Costa TF, Gomes TM, Viana LRC, Martins KP, Costa KNFM. Acidente vascular encefálico: características do paciente e qualidade de vida de cuidadores. *Rev Bras Enferm* 2016; 69(5):933-939.
11. Jorge BM, Levy CCAC, Granato L. Adaptação Cultural da Escala de Qualidade de Vida Familiar (Family Quality of Life Scale) para o Português Brasileiro. *CoDAS*; 27(6):534-540.
12. Nascimento GB, Schiling NO, Ubal SR, Biaggio EPV, Kessler TM. Classificação socioeconômica e qualidade de vida de familiares de crianças e adolescentes com deficiência auditiva. *Rev CEFAC* 2016; 18(3):657-666.
13. Tomaz RVV, Santos VA, Silva ALR, Germano C MR, Melo DG. Impacto da deficiência intelectual moderada na dinâmica e na qualidade de vida familiar: um estudo clínico-qualitativo. *Cad Saude Publica* 2017; 33(11):e00096016.
14. Ponte AS, Fedosse E. Lesão Encefálica Adquirida: impacto na atividade laboral de sujeitos em idade produtiva e de seus familiares. *Cien Saude Coletiva* 2016; 21(10):3171-3182.
15. Braccialli LMP, Bagagi PDS, Sankako AN, Araújo RDCT. Qualidade de vida de cuidadores de pessoas com deficiência. *Rev Bras Educ Espec* 2012; 18(1):113-126.
16. Oliveira MFS, Silva MBM, Frota MA, Pinto JMS, Frota LMCP, Sá FP. Qualidade de vida do cuidador de crianças com paralisia cerebral. *Rev Bras Promoc Saude* 2008; 21(4):275-280.
17. Oliveira MFS, Silva MBM, Frota MA, Pinto JMS, Frota LMCP, Sá FP. Qualidade de vida do cuidador de crianças com paralisia cerebral. *Rev Bras Promoc Saude* 2008; 21(4):275-280.
18. Fávero-Nunes MA, Santos MA. Depressão e qualidade de vida em mães de crianças com transtornos invasivos do desenvolvimento. *Rev Latino-Am Enfermagem* 2010; 18(1):33-40.
19. Reis LA, Santos KT, Reis L A, Gomes NP. Quality of life and associated factors for caregivers of functionally impaired elderly people. *Braz J Phys Ther* 2013; 17(2):146-151.
20. Silva RS, Fedosse E. Perfil sociodemográfico e qualidade de vida de cuidadores de pessoas com deficiência intelectual. *Cad Bras Ter Ocup* 2018; 26(2):357-366.
21. Bittencourt ZZLC, Hoehne EL. Qualidade de vida de familiares de pessoas surdas atendidas em um centro de reabilitação. *Cien Saude Colet* 2009; 14(4):1235-1239.
22. Lima ML, Santos JLE, Sawada NO, Lima LAP. Qualidade de vida de indivíduos com acidente vascular encefálico e de seus cuidadores de um município do Triângulo Mineiro. *Rev Bras Epidemiol* 2014; 17(2):453-464.
23. Oliveira EF, Limongi SCO. Qualidade de vida de pais/cuidadores de crianças e adolescentes com síndrome de Down. *J Soc Bras Fonoaudiol* 2011; 23(4):321-327.
24. Barbosa MRP, Fernandes FDM. Qualidade de vida dos cuidadores de crianças com transtorno do espectro autístico. *Rev Soc Bras Fonoaudiol* 2009; 14(4):482-486.
25. Vieira CBM, Fernandes FDM. Qualidade de vida em irmãos de crianças incluídas no espectro do autismo. *CoDAS* 2013; 25(2): 120-127.
26. Moreira RM, Oliveira BG, Cruz DP, Bomfim E S, Camargo CL, Sales ZN. Qualidade de vida de cuidadores familiares de pessoas com Síndrome de Down. *Rev Pesqui Cuid Fundam* 2016; 8(3):4826-4832.
27. Rodrigues SA, Fontanella BJB, Avó LRS, Germano CMR, Melo DG. A qualitative study about quality of life in Brazilian families with children who have severe or profound intellectual disability. *J Appl Res Intellect Disabil* 2018; 32:413-426.
28. Kantorski LP, Jardim VMR, Treichel CAS, Mola CL, Alves PF, Ferreira RZ, Oliveira MM. Fatores associados a uma pior avaliação da qualidade de vida entre familiares cuidadores de usuários de Centros de Atenção Psicossocial. *Cad Saude Colet* 2017; 25(4):460-467.
29. Hu X, Wang M, Fei X. Family quality of life of Chinese families of children with intellectual disabilities. *J Intellect Disabil Res* 2012; 56(1):30-44.
30. Mas JM, Baqués N, Balcells-Balcells A, Dalmau M, Giné C, Gràcia M, Vilaseca R. Family quality of life for families in early intervention in Spain. *J Early Interv.* 2016; 38(1): 59-74.
31. McWilliam RA, editor. *Routines-based early interven-*

- tion - *Supporting Young Children and Their Families*. New York/ London; The Guilford Press; 2010.
32. Fleck MPA, Louzada S, Xavier M, Chachamovich E, Vieira G, Santos L, Pinzon V. Aplicação da versão em português do instrumento abreviado de avaliação da qualidade de vida "WHOQOL-bref". *Rev Saude Publica* 2000; 34(2):178-183.
 33. Ciconelli RM. *Tradução para o português e validação do questionário genérico de avaliação de qualidade de vida Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)* [tese]. São Paulo: Universidade Federal de São Paulo; 1997.
 34. Pereira EF, Teixeira CS, Santos A. Qualidade de vida: abordagens, conceitos e avaliação. *Rev Bras Educ Fis Esporte* 2012; 26(2):241-250.
 35. Giné C, Momplet RV, García MG, Rueda CS, Montalá MD, Beltran FS, Balcells AB, Hernández MTP, Pinatella DS, Alcocer ALA, Valdés AGY, Del Gredorio VC, Mas JM. Las escalas de calidad de vida familiar (cdvf-e): apoyo y orientación para la intervención. *Siglo Cero: Revista Española sobre Discapacidad Intelectual*; 44(247):21-36.

Article submitted 02/07/2018

Approved 27/08/2019

Final version submitted 29/08/2019

Chief editors: Romeu Gomes, Antônio Augusto Moura da Silva