Participants' Bias in Disability Research on Family Quality of Life During the 0-6 Years Stage

Carmen Tania Francisco Mora , Alba Ibáñez-García * , Anna Balcells-Balcells

Posted Date: 28 July 2023

doi: 10.20944/preprints202307.1972.v1

Keywords: Family Quality of Life; Conceptualization; Participants; Research Ethics; Disability; Family

Article

Participants' Bias in Disability Research on Family Quality of Life during the 0-6 Years Stage

Carmen T. Francisco Mora [1], Alba Ibáñez García [2] and Anna Balcells-Balcells [3]

[1] Faculty of Psychology, Education and Sports Sciences, Ramon Llull University, 08022 Barcelona, Spain; carmenrm@blanquerna.url.edu
[2] Faculty of Education, University of Cantabria, 39005 Santander, Spain. alba.ibanez@unican.es. Group of Research on Quality of Life, Health and Supports in Socioeducative Contexts (EDU-QoL), 39012 Santander, Spain
[3] Faculty of Psychology, Education and Sports Sciences, Ramon Llull University, 08022 Barcelona, Spain; annabb0@blanquerna.url.edu
* Correspondence: alba.ibanez@unican.es

Abstract: Background: Over the past two decades, various research teams have designed and applied instruments to measure the quality of life of families with a member who has a disability. A recent systematic review on the state of art of Family Quality of Life in early care identified that many of these studies collected data only from the mothers. The present study aimed to investigate whether there is a bias in participant selection in these types of studies. Method: A systematic review of the scientific literature was conducted in the 3 databases from the year 2000 to 2022. A total of 72 empirical studies have been identified. Results: The findings indicated that most studies examining the family quality of life were based on the information of a single informant per family unit. The profiles of participants according to the research objective is quite similar. In one third of studies the authors report that family members who participate cannot be represented by only mothers or one participant per household. Conclusions: Given the dynamic and collective nature of the construct, the application of a systemic approach is necessary.

Keywords family quality of life; conceptualization; participants; research ethics; disability; family

1. Introduction

In the context of the systemic and ecological theoretical framework and the principle of integrality, family research must be understood from a holistic perspective rather than focusing on individual subsystems [1]. The authors argued that families "have qualities and characteristics that cannot be understood by narrowly focusing on one or two family members" (p. 7). Other scholars have similarly emphasized a transformative paradigm that prioritizes listening to the voice of the family [2]. This approach is characteristic of the inclusive movement [3–5]; and what Bruner called the "narrative turn" in the social sciences [6–9], which highlight the importance of the representativeness of the participating subjects in the field of epistemology and research ethics without solely depending on external sources of information.

Scabini and Iafrate [10] found that family research presents a challenge associated with "the need to obtain information both at the level of the family group and in relation to the subsystems that compose it" (p. 230). Similarly, participatory family research studies [11,12] emphasize the active role of family members as subjects of research. In this study, we adhered to the first and sixth principles of Citizen Science: "Citizen science projects actively involve citizens in scientific tasks that generate new knowledge or a better understanding" and "Citizen science represents a type of research like any other, with its limitations and biases that must be considered and controlled" [13] (p. 1) .

Family Quality of Life (FQoL) research is characterized by a plurality of approaches that focus on different aspects of research among families (narrative, participatory, and inclusive). The conceptualization of FQoL requires a specific theoretical framework [14,15], a distinct definition, and assessment methods, which are distinct from Individual Quality of Life (QoL). Specially Gardiner

 doi:10.20944/preprints202307.1972.v1

et Iarocci [16] and Fernandez et al. [17], propose to consider the principles of systems theories to investigate in the research of FQoL.

Francisco et al. [18] suggested in a systematic review the need for future research "to understand the ethical requirement that the methods used to address FQoL respect the holistic nature of the research" (p. 16). Although some studies have highlighted ethical implications in FQoL research [19,20], there is a need for further development in the area to ensure that the research methods take into account the family and its subsystems as a unit to avoid biases in information and address crucial epistemological and ethical implications.

Given the importance of considering all family members in research focused on the family as a unit of analysis, this study aims to identify the extent of participation of family members in QoL studies of families with children with disabilities aged between 0 to 6 years. To achieve this objective, the following research questions will be answered:

Q1: What is the profile of participants in FQoL research during the 0-6 years stage?

Q2: Are there differences in the profiles of participants according to the research objective, such as (a) development of conceptualization, (b) development of assessment instruments for FQoL, or (c) applied research?

Q3: If any biases or limitations are identified, what perspectives do researchers provide in response?

2. Methods

This study draws on a systematic review conducted by Francisco et al. [18], which examined the scientific literature on QoL research for families with children with disabilities aged 0 to 6 years. A total of 63 articles were selected and analyzed from the perspective of the construct of FQoL.

In this study, based on the results obtained in the systematic review until August 2019, the bibliographic search in the Scopus, Web of Science, and Eric databases was extended until August 2022 using the same keywords "Family quality of life" or "Quality of family life". We also decided to exclude the term ‘disability’ to maintain the same criteria and arguments as in the previous SR (i.e., to enrich our understanding on FQoL, to cover any type or diagnosis of disability and to improve our current measurements on disability related FQoL). The keywords have been searched for using the criterion: title, abstract and keyword.

The inclusion criteria for this study were: a) reporting empirical work that included families of children aged 0 to 6 years with disabilities and/or developmental concerns, b) published after 1999, c) written in English or Spanish, and d) published in peer-reviewed journals or book chapters. In terms of exclusion criteria, studies that: a) considered disability as a disease, b) examined FQoL from an individual rather than a holistic perspective, and c) conceptualized FQoL from a medical-rehabilitative perspective, were excluded from the analysis.

The present study extends the systematic review by Francisco et al. [18], removing theoretical articles, and includes studies published between 2019 and 2022. A total of 1498 studies were identified, and after eliminating duplicates and applying the exclusion criteria (Figure 1), 72 articles were finally selected for the current systematic review.

Preprints (www.preprints.org) | NOT PEER-REVIEWED | Posted: 28 July 2023 doi:10.20944/preprints202307.1972.v1

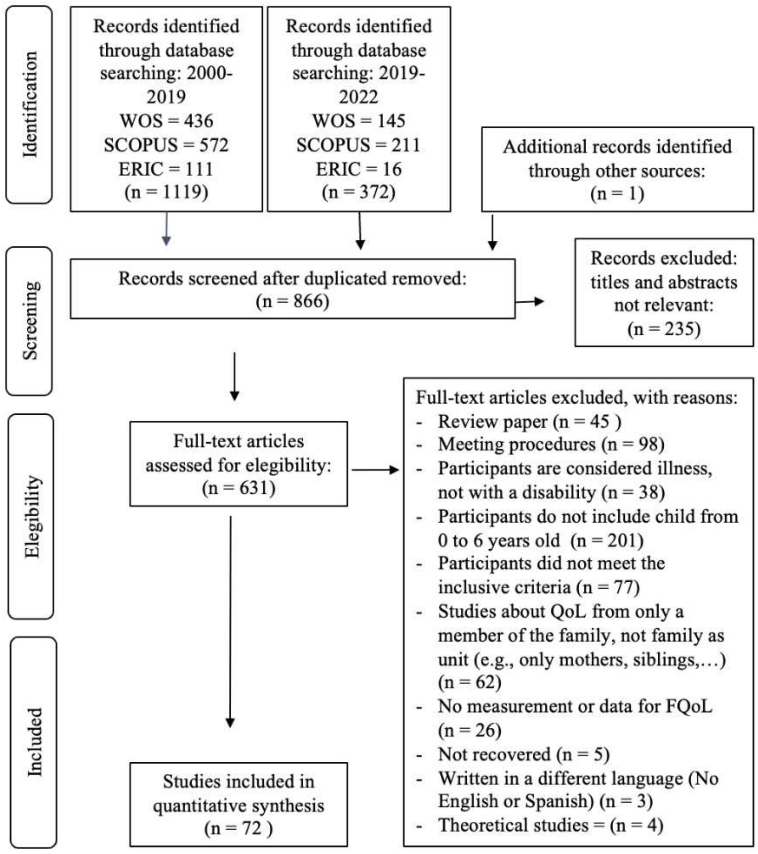

Figure 1. Flowchart of the selection process according to the recommendations of the Prisma statement [21]. Source: Own elaboration.

A total of 72 articles were analyzed in this study, with 59 articles from the systematic review by Francisco et al. [18] and 13 from the updated search. The breakdown of these publications is as follows: a) 71 empirical studies found in the data bases; b) The Family Quality of Life Survey (FQOLS-2006) is identified through other sources [22].

3. Results

The 72 selected empirical studies were classified and analyzed following each research question.

3.1. What is the profile of participants in FQoL research during the 0-6 years stage?

The articles were evaluated based on those following a "traditional approach," which according to Wang et al. [23], are studies that only relied on the perspective of a single family member to assess FQoL, and those that follow an approach that is consistent with the systemic theory.

As shown in Table 1, 65 out of the 72 selected articles followed the traditional approach, which indicates that each family unit surveyed or interviewed was represented by a single member or main caregiver. These studies are grouped in column (1) of Table 1 under the formula nF = nP, where n represents the number, F the families, and P the participants. The remaining seven studies are included under the formula nF < nP, suggesting that for each family, there were more participants from families surveyed or interviewed. Within this second group, distinctions included the study by Vanderkerken et al. [24] which presents a systemic approach by focusing on the family as a unit rather than information provided by a single participant. In addition, four studies focused on the parental subsystem, with one study on the sibling subsystem and another study comparing the QoL of fathers and mothers.

Preprints (www.preprints.org) | NOT PEER-REVIEWED | Posted: 28 July 2023 doi:10.20944/preprints202307.1972.v1

Table 1. Articles classified according to participant profile.

Approach	Participants	Number of studies	Authors
Traditional Approach (nF = nP)	50%-69% mothers	7	Rivard et al. [25]; Feng et al. [26]; Huang et al. [27]; Mas et al. [28]; Levinger et al. [29]; Schlebusch et al. [30]; Schlebusch et al. [31].
	70%-89% mothers	22	Svavarsdottir and Tryggvadottir [32]; Córdoba et al [33]; Verdugo et al. [34]; Chiu et al., [35]; Waschl et al. [36]; Escorcia et al. [37]; Giné et al. [38]; Balcells-Balcells et al. [39]; Balcells-Balcells et al. [40]; Bhopti et al. [41]; Chiu et al. [42]; Hoffman et al. [43]; Algood and Davis [44]; Barnard et al. [45]; Balcells-Balcells et al. [46]; Eskow et al. [47]; Hsiao et al. [48]; Hsiao et al. [49]; Boehm y Carter [50]; Samuel et al. [51]; Schertz et al. [52]; Rillotta et al. [53].
	90%-99% mothers	12	Kyzar et al. [54]; Kyzar et al. [55]; Jackson et al. [56]; Taub y Werner [57]; Samuel et al. [58]; Susanto et al. [59]; Samuel et al. [60]; Steel et al. [61]; Epley et al. [62]; Davis y Gavidia Payne [63]; Summers et al. [64]; Clark et al. [65]
	Mothers only	6	Cohen et al. [66]; Holloway et al. [67]; McStay et al. [68]; Meral et al. [69]; Rodrigues et al. [70]; Valverde y Jurdi [71]
	Not specified	18	Bello-Escamilla et al. [72]; Brown et al. [22]; Brown et al. [73]; García Grau et al. [74]; García Grau et al. [75]; García Grau et al. [76]; Giné et al. [77]; Hielkema et al. [78]; Leadbitter et al. [79]; Lei et al. [80]; Liu et al. [81]; Lee et al. [82]; Neikrug et al. [83]; Perry e Isaacs [84]; Tait and Husain [85]; Tejada-Ortigosa et al. [86]; Verger et al., [87]; Wang et al. [88].
	Systemic	1	Vanderkerken et al. [24].

 doi:10.20944/preprints202307.1972.v1

New approaches (nF < nP)	Dyads fathers / mothers	5	Wang et al., [23]; McStay et al., [89]; Mello et al. [90]; Vanderkerken et al. [91]; Demchick et al. [92]
	Siblings	1	Moyson et Royers [93].

Source: Own elaboration.

Studies adopting a traditional approach were classified based on the profile of the single participant, typically specifying their gender and relationship to the child with a disability. To facilitate the analysis of the results, these studies were grouped into five categories: 1) mothers constituted 50% - 69% of participants; 2) mothers constituted 70% - 89% of participants; 3) mothers constituted 90% - 99% of participants; 4) only mothers participated; and 5) no informant profile was specified. In cases where only mothers were involved or no information on gender or relationship was specified, the studies were sorted alphabetically.

The percentages of the five groups of studies are stated below in descending order. The largest group (33% of the total studies) comprised 22 studies with the participation of mothers ranging from 70% to 89%. The second group, comprising 24% of the total studies, was represented by 16 studies that did not specify the profile of the participant. The third group, consisting of 23% of the total studies, was represented by 15 studies with 90% to 99% participation of mothers. The fourth group comprised 11% of the total studies and corresponded to 11 studies with 50% to 69% of mothers participating. Finally, 9% of the total studies were represented by six studies where only mothers participated. In five of the six studies, the researchers explicitly invited only mothers to participate, while in the remaining study [71] the authors invited a member representing their respective families to participate, but only 10 mothers agreed to participate.

The studies employing new approaches (n=7) were organized into three groups:

1. The first group comprised a single study by Vanderkerken et al. [24], which stands out for having utilized a systemic design representing all three subsystems: spousal, parental, and sibling. This study included 49 parental dyads, one father, 12 mothers, 10 children with disabilities, and 14 siblings, with a total of 135 participants from a sample of 63 family units (nF 63 < nP 135). The authors stated, “In addition, we went beyond parents' perceptions by also taking into account the views of children (with and without disability) on FQoL and by comparing parents' and children's views on FQoL” (p. 782).
2. The second group consisted of five studies that investigated FQoL from the perspective of both fathers and mothers. These studies were grouped together because the number of families was smaller than the number of participating relatives (nF < nP). Four of these studies adopted a parental subsystemic approach. Vanderkerken et al. [91] examined 34 parental dyads and argued that "members of the same family had different opinions regarding FQoL, which supports the idea of including every family member's opinion when evaluating the complex reality of quality of life in families" (p. 13). This systemic approach examines FQoL from the standpoint of the members of the parental subsystem. Similar approaches can be found in the studies by McStay et al. [89], Demchick et al. [92], and Mello et al. [90]. The fifth study in this group was by Wang et al. [23], which compared the individual perspectives of fathers and mothers. While providing information on the parental subsystem, the purpose of the study was to "test whether mothers and fathers similarly view the conceptual model" (p. 977).
3. The third group comprised a study by Moyson and Roeyers [93], which approached the assessment of QoL from the experiences of siblings, concluding that siblings may define their QoL differently from their parents. Based on the data analysis, only 5.47 % of the reviewed studies adopted a systemic or sub-systemic approach. These approaches were characterized by a detailed profiling of each participant’s position within the family system and an assessment of their respective perceptions in relation to those of other family members. Rather than assessing their knowledge, these studies focused on their roles as fathers or mothers, sons or daughters, brothers or sisters, grandfathers or grandmothers, or other family members. Participants’ gender identity and their dynamic interactions with other members of the family unit were considered key

Preprints (www.preprints.org) | NOT PEER-REVIEWED | Posted: 28 July 2023 doi:10.20944/preprints202307.1972.v1

elements. Vanderkerken et al. [24] pointed out the primary strength of the systemic approach by stating, "Discussing and examining differences of opinion can be a valuable approach to generate a nuanced picture of life in a family" (p. 750).

3.2. Are there differences in the profiles of participants according to the research objective?

To address the second research question, the 72 studies were categorized into four groups based on their research objectives (see Appendix Table): 1) Seven studies aimed at developing instruments for assessing FQoL, including two international scales – the FQoL Scale [43]) and the FQoL Survey [22] for all age groups, as well as five specific instruments designed to assess the QoL of families with children with disabilities aged 0-6 years; 2) 10 studies aimed at the validation of the instruments; 3) 32 studies either compared or described FQoL; and 4) 23 studies examined the predictors of FQoL.

Figure 2 illustrates a graph linking the participant profile data (Table 1) with the four types of studies based on their research objectives.

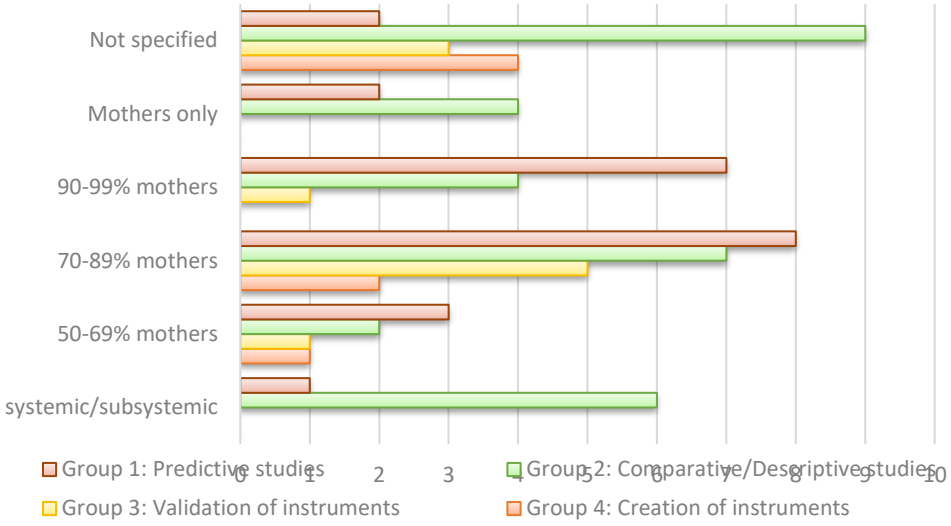

Figure 2. Participant profile data by types of studies.

The studies in groups 1 and 2 are characterized by the traditional approach and have minimally taken into account the perspectives of various family members. A significant difference was observed in the "unspecified" variable, where four studies that focused on the development of instruments for measuring FQoL did not identify the personal and family characteristics of the participants. For instance, the FQoL Survey was administered to the main caregiver of the person with a disability to report on the family's QoL [22]. Other studies, such as those conducted by García-Grau [76], Giné [77], and Leadbitter et al. [79] omitted references to participant profiles for selection purposes.

Among the 32 studies in the third group, which had a comparative or descriptive nature of FQoL, six studies stood out for utilizing a subsystemic approach with a focus on siblings of children with disabilities [4] or the parental dyad [22,89–92].

Finally, in the group of predictive studies on FQoL, only the study by Vanderkerken et al. [24] followed a systemic approach. Most studies in this group had a higher percentage of participating mothers (between 70% and 99%).

3.3. If any biases or limitations are identified, what perspectives do researchers provide in response?

To answer this question, the limitations identified by the authors in their respective studies were analyzed. Regarding coherence between the conceptualization of the construct and the methodological design, Boehm and Carter [50] explicitly stated that they initially relied on only one

parent's perceptions of FQoL. The definition of FQoL involves ''a dynamic sense of well-being of the family collectively and subjectively defined and informed by its members, in which individual and family-level needs interact'' [15] (p. 262). Therefore, one parent's perception of FQoL may not reflect the collective view of all members of the family (p. 111).

However, the mentioned limitation was not observed in the 11 studies that incorporated the definition of Zuna et al. [15] in their theoretical framework [27,28,35,39,42,47,52,54,55,57,66,73]. This indicated a significant gap between the stated intentions of the researchers to study the family unit and the methods adopted to conduct the research [26,30].

While the authors of the selected studies did not expressly identify any reporting bias, the study by Wang et al. [23] revealed that fathers did not differ significantly from mothers in assessing their overall FQoL. However, this study relied on other authors [36,64,69] to justify their preference for the opinion of a single family member.

Nonetheless, 25 out of the 72 selected studies acknowledged a limitation in their research due to the involvement of only mothers or one participant per household, which can be implicitly understood as an information bias. There are several studies in which metaphors based on photography are used, where the image was expected to correspond to the photographed object, that is, be truthful. However, articles highlighting the limitations of FQoL instruments that relied solely on mothers' involvement without participation from the rest of the family, reported that the truthfulness of the image would be compromised [39], the image would be unfocused [61], it would capture only half the picture [88],or in any case, it would be a 'snapshot' unable to reflect the dynamic nature of family life [24,30,57,83].

Another metaphor used by the authors was that of a choir to emphasize the necessity of acknowledging the diversity of familial voices, as a choir is composed of multiple voices. This concept was specifically highlighted in three studies that adopted a systemic or sub-systemic approach [24,91,93]. Tait and Hussain [85] identified "the integrity, uniqueness, and complexity of individual experiences and perceptions of FQoL in their mixed methods study" (p. 12).

To summarize the recognition of implicit reporting biases, six quotes were identified from studies that analyzed the family as the unit of analysis [23,26,30] and studies positing that the opinions and perceptions of other family members cannot be taken for granted [57,62,88,95]. The definition of FQoL entails a methodology that reflects collective information [24], and therefore, family members who did not participate cannot be represented by the informant. If the number of participants and family units were the same, the research would be compromised by information bias. The use of metaphors such as the image or the chorus of voices also highlights the need for a systemic approach that considers both the number of informants and their position or role in the family for examining a collective construct such as the family.

4. Discussion

In the following sections, the results are discussed in line with a holistic view that contextualizes the problems explored in relation to different theories, as well as the historical and cultural context in which research on FQoL has been conducted.

A relevant difference between systemic approaches and traditional models is that traditional models often struggle to achieve a balance between assigning importance to a qualified profile, typically the mother, while downplaying the role and gender of the sole participant by leaving it unspecified.

The selection bias among participants becomes evident when examined in relation to the theoretical framework, the definition of FQoL, and the need to avoid assuming the perceptions and views of family members who were not involved in the research. A significant milestone in the conceptualization of FQoL was the definition of the construct by Zuna and colleagues [15], which identifies two essential characteristics of the FQoL construct: (1) the dynamicity of family relationships, and (2) that it is collectively and subjectively defined.

Regarding the first characteristic, none of the selected articles explicitly address the relationship between the dynamicity of the FQoL construct and the bias resulting from a single informant's

 doi:10.20944/preprints202307.1972.v1

participation, which compromises the conceptualization of FQoL. However, this relationship may be implicitly conveyed through the image metaphor used by the aforementioned authors to refer to the FQoL construct.

Regarding the second characteristic of the definition of FQoL, only Boehm and Carter [50] examined the relationship between the limitation of the participation of one family member and the need for the FQoL construct to be defined subjectively and collectively.

However, none of the scales or questionnaires developed to measure FQoL have been designed following the epistemological requirement of representing the diverse subsystems that integrate the family unit. It is generally considered sufficient to obtain information from those who know the child best, whether with or without a disability (i.e. their primary caregivers, usually their mothers). However, this issue is not unique to FQoL research but is also present in other scientific fields. Shah et al. [94] found that individual bias in the design and use of instruments to measure the QoL of both the family unit and its individual members is a widespread limitation, even when referring to the inclusion of the family as a whole.

To obtain significant information from a systemic standpoint, it is necessary to encourage the participation of representatives from each sub-system of the family, which is not evident in existing instruments, especially those where the role of informants is not specified. The only exception is the 2019 revision of the CdVF-ER user manual, which invited various family members to participate in the research. It was noted that "the scale should be answered by fathers, mothers, siblings, or legal guardians of persons with intellectual or developmental disabilities (IDD). In any case, it should always reflect family opinion" [95] (p. 6). Therefore, the CdVF-ER for children below 18 years of age was designed using a systemic approach by considering the role of children within the family unit.

While studies examining the quality of family life attempt to conceptualize this systemic construct, the use of "traditional" instruments that rely on information from a single participant can limit the representation of the entire family unit or other family members.

The selected studies demonstrate an increasing tendency to consider the opinions of various family members beyond just the parents. Rillotta et al. [53] and Schlebusch et al. [31] suggest that future research should consider assessing FQoL from multiple perspectives, such as those of parents, siblings, grandparents, and individuals with disabilities. Vanderkerken et al. [24] also highlight that "future research can explore strategies to also include the views of children under 12 (with or without disability) on FQoL, for example, by simplifying the instruments, adding pictures, etc." (p. 801). Their study is pioneering in this respect.

An epistemological perspective allows for a better understanding of the systemic dynamics of the family [24], emphasizing the transformation of reality wherein disadvantaged people are placed at the center. Rodríguez-Cley et al. [96] aimed to "demonstrate how other epistemologies, coming from the experience of disability, can nurture participatory methodologies and design research" (p. 26). This is in line with the ongoing "narrative turn" observed in various areas of research, which aims to empower people to exercise greater control over aspects of their own lives [97].

Zuna and colleagues [15] indicate that FQoL is not only collectively but also "subjectively" defined. While this plurality of “nuances” is positive, the subjective nature of its definition can pose challenges for researchers. In the field of QoL research, Brown and Schippers [98] caution against the traditional approach in that "the results of qualitative research often carry less weight because of the strong influence of a traditionally positivist approach that considers qualitative data as subjective" (p. 8). In addition, the authors highlight the importance of "the scientifically recorded experiences and views of people with life problems and their families" (p. 8) and insist that data itself is never subjective, but rather "it is the interpretation that risks being subjective" (p. 7).

Furthermore, the development of the ten principles of citizen science may contribute to a shift toward involving people as "contributors, collaborators, or as leaders in research projects" [13].

Culturally, families have been mere observers of the work done with their children with functional diversity. It is essential to break this idea of passive work, so that the family becomes an active part of the process. Only from this perspective, the family will feel able to develop the model (p. 19).

 doi:10.20944/preprints202307.1972.v1

Another significant aspect of citizen science is the democratization of scientific research and knowledge. In the context of FQoL research, it is important for family members to establish a deep and existential connection with the research topic, which may encourage them to participate responsibly.

The limitations observed in the conceptualization of FQoL not only manifest in the epistemological and methodological aspects but also indicate the existence of ethical considerations. First, the ethical dimension emphasizes the importance of inclusive research that amplifies the voices of the most vulnerable people within the family unit, such as minors and people with disabilities [99–102].

Second, the ethical need to represent vulnerable individuals may lead researchers to explore suitable methods to enable them to be active participants in the research. For instance, the photovoice methodology has been examined as a means of providing visibility to vulnerable members of society while respecting their privacy [100,103,104]. In photovoice research, participants are informed of the ethical aspects of the use of images [105], and the informed consent of the individuals appearing in the photographs is requested. In FQoL research, it may also be ethically advisable to obtain informed consent or assent from family - so that participants can speak on their behalf.

In addition, recognizing individuals as active subjects in their own lives and striving to capture the authentic voices of families may encourage researchers to involve as many family members as possible in the research process, ensuring that the different family sub-systems are adequately represented.

Regarding future research directions, researchers in the field of FQoL should embrace its conceptualization as a family unit with unique methodological and temporal needs, as opposed to understanding QoL solely from the perspective of individual family members. Egaña and Barría [106] highlight the need to "be rigorous with the idea that the family as a unit of analysis is different from the individuals who, as family members, compose it" (p. 15). Each researcher should, therefore, establish a theoretical framework relevant to the specific objects of their study, whether it be the entire family, individual family members, or subsystems, to ensure consistency in the methodological design.

Longitudinal studies have also been recommended for FQoL research [41,89]. In particular, Gardiner and Iarocci [16] point out the need for longitudinal research when examining the dynamic interactions between individual and family needs. This approach may also apply to research on family routines, considering their dynamic nature in the context of FQoL [31].

In addition, FQoL research may benefit from the epistemological and ethical approaches that are being applied in the field of social sciences, such as the inclusion of persons with disabilities, citizen participation, and respect for the privacy of those being studied.

5. Conclusion

Based on the systematic review of FQoL research, it can be concluded that, with the exception of the study by Boehm and Carter [50], the remaining 71 articles reviewed did not consider the epistemological need inherent in the FQoL construct for the participation of all family members. This inference is drawn from the observation that the epistemological limitation was not taken into account either because of the lack of a theoretical framework or definition of FQoL, or inconsistency with the requirements of the integrated definition in their respective theoretical frameworks. In addition, the relationship between this limitation and the dynamic nature of the construct has not been examined.

The findings of the current research suggest that only a few reviewed studies have adopted a systemic or subsystemic approach (8.2%) compared to the traditional approach, where only one member per family unit participates, which was employed by the majority (91.8%) of the reviewed studies. Approximately one-third of the selected studies identified the potential for possible reporting biases due to the participation of only one family member.

On evaluating the "limitations" section of some of the selected studies, it was noted that potential participants' bias may affect the validity of the results from assuming that the opinions and

knowledge of the different members of the family are accurately represented by one family member. Recognizing and addressing these considerations is crucial for upholding the ethics of scientific research.

In summary, this research holds significant implications in the field of FQoL in social, health, and education research. The findings highlight the importance of ensuring the participation of the family as a collective unit, recognizing the unique perspectives and contributions of each individual member.

Author Contributions: Conceptualization, C.F.M., A.I. and A.B.-B.; methodology, C.F.M., A.I. and A.B.-B.; formal analysis, C.F.M., A.I. and A.B.-B.; investigation, C.F.M., A.I. and A.B.-B.; writing—original draft preparation, C.F.M.; writing—review and editing, A.I., A.B.-B. and C.F.M; visualization, A.I. and C.F.M. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Informed Consent Statement: Not applicable.

Data Availability Statement: Data sharing is not applicable.

Conflicts of Interest: The authors declare no conflict of interest.

Appendix A

Study objective	Authors
Creation of instruments	Barnard et al. [45]; Brown et al. [22]; García Grau et al. [76]; Giné et al. [77]; Hoffman et al. [43]; Huang et al. [27]; Leadbitter et al. [79]
Validation of instruments	Chiu et al., [35]; Chiu et al., [42]; Garcia Grau et al. [75]; Lei et al. [80]; Perry e Isaacs [84]; Rivard et al. [25]; Samuel et al. [61]; Samuel et al. [51]; Verdugo et al. [34]; Waschl et al. [36]
Comparative/ Descriptive	Algood and Davis [44]; Balcells-Balcells et al. [46]; Bello-Escamilla et al. [72]; Brown et al. [73]; Clark et al. [66]; Córdoba et al. [33]; Demchick et al. [92]; Escorcia Mora et al. [37]; García Grau et al. [74]; Giné et al. [38]; Holloway et al. [67]; Jackson et al., [57]; Lee et al. [82]; Mas et al., [28]; McStay et al. [68]; McStay et al. [89]; Mello et al. [90]; Moyson et Roeyers [93]; Neikrug et al. [83]; Rillotta et al. [54]; Rodrigues et al. [70]; Schertz et al. [53]; Schlebusch et al. [31]; Steel et al. [61]; Tait and Husain [85]; Tejada-Ortigosa et al. [86]; Valverde y Jurdi [70]; Vanderkerken et al. [91]; Verger et al. [87]; Wang et al. [23]
Predictive	Balcells-Balcells et al. [39]; Balcells-Balcells et al., [40]; Bhopti et al. [41]; Boehm y Carter [50]; Cohen et al. [66]; Davis y Gavidia Payne [63]; Epley et al. [62]; Eskow et al. [47]; Feng et al. [26]; Hielkema et al. [78]; Hsiao et al. [48]; Hsiao et al. [49]; Kyzar et al. [55]; Kyzar et al. [56]; Levinger et al. [29]; Liu et al. [81]; Meral et al. [69]; Samuel et al. [58]; Schlebusch et al. [30]; Summers et al. [64]; Susanto et al. [59]; Svavarsdottir and Tryggvadottir [32]; Taub y Werner [58]; Vanderkerken et al. [24]; Wang et al. [88]

Source: own elaboration.

References

1. Mandak, K., O'Neill, T., Light J., y Fosco, G. Bridging the gap from values to actions: a family systems framework for family-centered AAC services. *Augmentative And Alternative Communication* **2017**. http://dx.doi.org/10.1080/07434618.2016.1271453
2. Verger, S., Riquelme, I., Bagur, S., & Paz-Lourido, B. Satisfaction and Quality of Life of Families Participating in Two Different Early Intervention Models in the Same Context: A Mixed Methods Study. *Frontiers in Psychology 2021*, *12*. https://doi.org/10.3389/fpsyg.2021.650736
3. Parrilla, A. Ética para una investigación inclusiva. *Revista Educación Inclusiva* ***2010*** *3(1),* 165-174. https://revistaeducacioninclusiva.es/index.php/REI/article/view/218
4. Nind, M. Participatory Data Analysis: A Step Too Far? *Qualitative Research* ***2011*** *11(4),* 349-363. https://doi.org/10.1177/1468794111404310
5. Passmore, S., Kisicki, A., Gilmore-Bykovskyi, A., Green-Harris, A. and Edwards, D. "There's not much we can do…" researcher-level barriers to the inclusion of underrepresented participants in translational research, *Journal of Clinical and Translational Science* **2021** 1-9. https://doi.org/10.1017/cts.2021.876
6. Denzin, N. Foreword: narrative's moment, en M. Andrew - S. Sclater -C. Squire - A. Treacher (Eds.), *Lines of narrative*, Routledge, London, 2003.
7. Esteban-Guitart, M. Bruner's Narrative Turn: The Impact of Cultural Psychology in Catalonia. In Marsico, G. (ed). *Jerome S. Bruner beyond 100. Cultivating posibilities,* Salerno, 2015, 117-112. https://doi.org/10.1007/978-3-319-25536-1
8. González Monteagudo, J. Jerome Bruner and the challenges of the narrative turn. *Narrative Inquiry* **2011** *21*(2), 295–302. https://doi.org/10.1075/ni.21.2.07gon
9. González-Monteagudo, J. y Ochoa Palomo, C. El giro narrativo en España. Investigación y formación con enfoques autobiográficos. *Revista Mexicana de Investigación Educativa* **2014** *19/62*, 809-829. https://core.ac.uk/reader/157763950
10. Scabini, E., & Iafrate, R. *Psicologia dei legami familiari.* Il Mulino: Bologna, 2019.
11. Llorente, C., Revuelta, G. y Carrió, M. Characteristics of Spanish citizen participation practices in science. *Journal of Science Communication* **2020**, 20(04), 1-28. https://doi.org/10.22323/2.20040205
12. Quiroga, V., Parra, B., Durán, P., & Magaña-González, C.R. [Re]pensemos la participación de las familias: Diagnóstico y propuestas de intervención en los servicios de atención básica a las personas en la ciudad de Barcelona. *Pedagogia y Treball Social. Revista de Ciències Socials Aplicades* **2021**, *3-20.*
13. ECSA (European Citizen Science Association). Ten Principles of Citizen Science. Berlin, 2015. http://doi.org/10.17605/OSF.IO/XPR2N
14. Turnbull, A. P.; Summers, J. A.; Lee, S.-H.; Kyzar, K. Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Ment. Retard. Dev. Disabil. Res. Rev*. **2007**, *13 (4)*, 346–356. https://doi.org/10.1002/mrdd.20174
15. Zuna, N.; Summers, J. A.; Turnbull, A. P.; Hu, X.; Xu, S. Theorizing about family quality of life. In *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice;* Kober, R., Ed., 2010; Vol. 41, pp 241–278.
16. Gardiner, E.; Iarocci, G. Family Quality of Life and ASD: The role of child adaptive functioning and behavior problems. *Autism Res.* **2015**, *8 (2),* 199–213. https://doi.org/10.1002/aur.1442.
17. Fernández González, A.; Montero Centeno, D.; Martínez Rueda, N.; Orcasitas García, J. R.; Villaescusa Peral, M. Calidad de Vida Familiar: marco de referencia, evaluación e intervención, Siglo Cero, vol. 46 (2), 254, 2015, abril-junio, pp. 7-29 http://dx.doi.org/10.14201/scero2015462729
18. Francisco Mora, C., Ibáñez, A., Balcells-Balcells, A. State of the Art of Family Quality of Life in Early Care and Disability: A Systematic Review. *International Journal of Environmental Research and Public Health* **2020**, *17*, 7220. https://doi.org/10.3390/ijerph17197220
19. Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. Family Quality of Life: A Qualitative Inquiry. *Mental Retardation* **2003,** *41*(5), 313–328. https://doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2 .
20. Roth, D., & Brown, I. Social and Cultural Considerations in Family Quality of Life: Jewish and Arab Israeli Families' Child-Raising Experiences. *Journal of Policy and Practice in Intellectual Disabilities*, **2017,** *14*(1), 68-77. https://doi.org/10.1111/jppi.12208

21. Moher, E. y Liberati, A. Revisiones Sistemáticas y Metaanálisis: La responsabilidad de Los Autores, Revisores, Editores y Patrocinadores. *Medicina Clínica* **2010,** 135, 505–506. https;//doi.org/10.1016/J.MEDCLI.2010.02.016
22. Brown, I., Brown, R.I., Baum, N.T., Isaacs, B.J., Myerscough, T., Neikrug, S., & Wang, M. Family Quality Life Survey: Main Caregivers of People with Intellectual or Development Disabilities, Toronto, Canadá: Surrey Place Centre. 2006. http://www.surreyplace.ca/documents/FQLS%20Files/FQOLS-2006%20General%20Version%20Aug%2009.pdf
23. Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D., & Mannan, H. Perspectives of fathers and mothers of children in early intervention programs in assessing family quality of life. *Journal of Intellectual Disability Research* **2006**, *50*(12), 977–988. https://doi.org/10.1111/j.1365-2788.2006.00932.x
24. Vanderkerken, L., Heyvaert, M., Onghena, P., & Maes, B. Quality of Life in Flemish Families with a Child with an Intellectual Disability: a Multilevel Study on Opinions of Family Members and the Impact of Family Member and Family Characteristics. *Applied Research in Quality of Life* **2018**, *13*(3), 779–802. https://doi.org/10.1111/jppi.12134
25. Rivard, M., Mercier, C., Mestari, Z., Terroux, A., Mello, C., & Bégin, J. Psychometric properties of the Beach Center Family Quality of Life in French-speaking families with a preschool-aged child diagnosed with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities* **2017**, *122*(5), 439–452. https://doi.org/10.1352/1944-7558-122.5.439
26. Feng, Y., Zhou, X., Qin, X., Cai, G., Lin, Y., Pang, Y., … Zhang, L. Parental self-efficacy and family quality of life in parents of children with autism spectrum disorder in China: The possible mediating role of social support. *Journal of Pediatric Nursing* **2021,** *63,* 159–167. https://doi.org/10.1016/j.pedn.2021.10.014
27. Huang, R., Shen, R. y Su, S., (2020) The factor structure and psychometric properties of the Family Quality of Life for Children with Disabilities in China. *Front. Psychol*. **2020**, 11, 1585. https://doi.org/10.3389/fpsyg.2020.01585
28. Mas, J. M., Baqués, N., Balcells-Balcells, A., Dalmau, M., Giné, C., Gràcia, M., & Vilaseca, R. Family Quality of Life for Families in Early Intervention in Spain. *Journal of Early Intervention* **2016,** *38*(1), 59–74. https://doi.org/10.1177/1053815116636885
29. Levinger, M.; Alhuzail, N. A. Bedouin hearing parents of children with hearing loss: Stress, coping, and Quality of Life. *Am. Ann. Deaf* **2018**, *163 (3),* 328–355. https://doi.org/10.1353/aad.2018.0022.
30. Schlebusch, L.; Samuels, A. E.; Dada, S. South african families raising children with Autism Spectrum Disorders: Relationship between family routines, cognitive appraisal and Family Quality of Life. *J. Intellect. Disabil. Res.* **2016**, *60 (5),* 412–423. https://doi.org/10.1111/jir.12292.
31. Schlebusch, L.; Dada, S.; Samuels, A. E. Family Quality of Life of south african families raising children with autism spectrum disorder. *J. Autism Dev. Disord.* **2017**, *47 (7),* 1966–1977. https://doi.org/10.1007/s10803-017-3102-8.
32. Svavarsdottir, E. K.; Tryggvadottir, G. B. Predictors of Quality of Life for families of children and adolescents with severe physical illnesses who are receiving hospital-based care. *Scand. J. Caring Sci.* **2019**. *33 (3), 698-705* https://doi.org/10.1111/scs.12665
33. Córdoba-Andrade, L.; Gómez-Benito, J.; Verdugo-Alonso, M. A. Family Quality of Life of people with disability: A comparative analyses. *Univ. Psychol*. **2008**, *7 (2),* 369–383.
34. Verdugo, M. A.; Cordoba, L.; Gomez, J. Spanish Adaptation and Validation of the Family Quality of Life Survey. *J. Intellect. Disabil. Res.* **2005**, *49,* 794–798. https://doi.org/10.1111/j.1365-2788.2005.00754.x.
35. Chiu, C. Y.; Seo, H.; Turnbull, A. P.; Summers, J. A. Confirmatory Factor Analysis of a family quality of life scale for taiwanese families of children with intellectual disability/developmental delay. *Intellect. Dev. Disabil.* **2017**, *55* (2), 57–71. https://doi.org/10.1352/1934-9556-55.2.57.
36. Waschl, N.; Xie, H.; Chen, M.; Poon, K. K. Construct, Convergent, and Discriminant Validity of the Beach Center Family Quality of Life Scale for Singapore. *Infants Young Child.* **2019**, *32 (3),* 201–214. https://doi.org/10.1097/IYC.0000000000000145.
37. Escorcia Mora, C.T.; García-Sánchez, F.A., Sánchez-López, M.C., Orcajada, N y Hernández-Pérez, E. Prácticas de intervención en la primera infancia en el sureste de España: Perspectiva de profesionales y familias. *Anales de psicología/ annals of psychology* **2018**, vol. 34, nº 3, 500-509. http://dx.doi.org/10.6018/analesps.34.3.311221

38. Giné, C., Gràcia, M., Vilaseca, R., Salvador Beltran, F., Balcells-Balcells, A., Dalmau Montalà, M., et al. Family Quality of Life for people with intellectual disabilities in Catalonia. *J. Policy Pract. Intellect. Disabil.,* **2015**, *12 (4),* 244–254. https://doi.org/10.1111/jppi.12134
39. Balcells-Balcells, A.; Giné, C.; Guàrdia-Olmos, J.; Summers, J. A. Family Quality of Life: Adaptation to spanish population of several family support questionnaires. *J. Intellect. Disabil. Res.* **2011**, *55 (12),* 1151–1163. https://doi.org/10.1111/j.1365-2788.2010.01350.x.
40. Balcells-Balcells, A.; Gine, C.; Guardia-Olmos, J.; Summers, J. A.; Mas, J. M. Impact of supports and partnership on Family Quality of Life. *Res. Dev. Disabil.* **2019**, *85,* 50–60. https://doi.org/10.1016/j.ridd.2018.10.006
41. Bhopti, A.; Brown, T.; Lentin, P. Family Quality of Life: A Key Outcome in Early Childhood Intervention ServicesA Scoping Review. *J. Early Interv.* **2016**, *38 (4),* 191–211. https://doi.org/10.1177/1053815116673182.
42. Chiu, S.-J.; Chen, P.-T.; Chou, Y.-T.; Chien, L.-Y. The mandarin chinese version of the Beach Centre Family Quality of Life Scale: Development and psychometric properties in taiwanese families of children with developmental delay. *J. Intellect. Disabil. Res.* **2017**, *61 (4),* 373–384. https://doi.org/10.1111/jir.12356.
43. Hoffman, L.; Marquis, J.; Poston, D.; Summers, J. A.; Turnbull, A. Assessing Family Outcomes: Psychometric Evaluation of the Beach Center Family Quality of Life Scale. *J. Marriage Fam*. **2006**, *68 (4),* 1069–1083. https://doi.org/10.1111/j.1741-3737.2006.00314.x.
44. Algood, C.; Davis, A. M. Inequities in family quality of life for african-american families raising children with disabilities. *Soc. Work Public Health* **2019**, *34 (1),* 102–112. https://doi.org/10.1080/19371918.2018.1562399.
45. Barnard, D.; Woloski, M.; Feeny, D.; McCusker, P.; Wu, J.; David, M.; Bussel, J.; Lusher, J.; Wakefield, C.; Henriques, S.; et al. Development of disease-specific health-related quality-of-life instruments for children with immune thrombocytopenic purpura and their parents. *J. Pediatr. Hematol. Oncol.* **2003**, *25* (1), 56–62. https://doi.org/10.1097/00043426-200301000-00011.
46. Balcells-Balcells, A., Mas, J. M., Baqués, N., Simón, C., & García-Ventura, S. The spanish family quality of life scales under and over 18 years old: Psychometric properties and families' perceptions. *International Journal of Environmental Research and Public Health* **2020**, *17*(21), 1-19. https://doi.org/10.3390/ijerph17217808
47. Eskow, K.; Pineles, L.; Summers, J. A. Exploring the effect of autism waiver services on family outcomes. *J. Policy Pract. Intellect. Disabil.* **2011**, *8 (1),* 28–35. https://doi.org/10.1111/j.1741-1130.2011.00284.x.
48. Hsiao, Y.-J.; Higgins, K.; Pierce, T.; Whitby, P. J. S.; Tandy, R. D. Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Res. Dev. Disabil,* **2017**, *70,* 152–162. https://doi.org/10.1016/j.ridd.2017.08.013
49. Hsiao, Y.-J. Autism Spectrum Disorders: Family demographics, parental stress, and Family Quality of Life. *J. Policy Pract. Intellect. Disabil.* **2018**, *15 (1),* 70–79. https://doi.org/10.1111/jppi.12232
50. Boehm, T. L.; Carter, E. W. Family Quality of Life and its correlates among parents of children and adults with intellectual disability. *Am. J. Intellect. Dev. Disabil.* **2019**, *124 (2),* 99–115. https://doi.org/10.1352/1944-7558-124.2.99.
51. Samuel, P. S.; Tarraf, W.; Marsack, C. Family Quality of Life Survey (FQOLS-2006): Evaluation of internal consistency, construct, and criterion validity for socioeconomically disadvantaged families. *Phys. Occup. Ther. Pediatr.* **2018**, *38 (1),* 46–63. https://doi.org/10.1080/01942638.2017.1311393
52. Schertz, M.; Karni-Visel, Y.; Tamir, A.; Genizi, J.; Roth, D. Family Quality of Life among families with a child who has a severe neurodevelopmental disability: impact of family and child socio-demographic factors. *Res. Dev. Disabil.* **2016**, *53–54,* 95–106. https://doi.org/10.1016/j.ridd.2015.11.028.
53. Rillotta, F.; Kirby, N.; Shearer, J.; Nettelbeck, T. Family Quality of Life of Australian Families with a Member with an Intellectual/Developmental Disability. *J. Intellect. Disabil. Res*. **2012**, *56 (1),* 71–86. https://doi.org/10.1111/j.1365-2788.2011.01462.x.
54. Kyzar, K. B.; Brady, S. E.; Summers, J. A.; Haines, S. J.; Turnbull, A. P. Services and supports, partnership, and Family Quality of Life: Focus on deaf-blindness. *Except. Child.* **2016**, *83 (1),* 77–91. https://doi.org/10.1177/0014402916655432.
55. Kyzar, K.; Brady, S.; Summers, J.A.; Turnbull, A. Family Quality of Life and partnership for families of students with deaf-blindness. *Remedial and Special Education*. **2018**, 1–13. https://doi.org/10.1177/0741932518781946

56. Jackson, C. W.; Wegner, J. R.; Turnbull, A. P. Family Quality of Life following early identification of deafness. *Lang. Speech Hear. Serv. Sch.* **2010**, *41 (2),* 194–205. https://doi.org/10.1044/0161-1461(2009/07-0093).
57. Taub, T.; Werner, S. What support resources contribute to family quality of life among religious and secular jewish families of children with developmental disability? *J. Intellect. Dev. Disabil.* **2016**, *41 (4),* 348–359. https://doi.org/10.3109/13668250.2016.1228859.
58. Samuel, P. S.; Hobden, K. L.; LeRoy, B. W. Families of children with autism and developmental disabilities: A description of their community interaction. *Res. Soc. Science and Disabil.* **2011**, 6, 49-83. https://doi.org/10.1108/S1479-3547(2011)0000006006
59. Susanto, T., Rasni, H., & Susumaningrum, L. A. Prevalence of malnutrition and stunting among under-five children: A cross-sectional study family of quality of life in agricultural areas of Indonesia. *Mediterranean Journal of Nutrition and Metabolism* **2021**, *14*(2), 147–161. https://doi.org/10.3233/MNM-200492
60. Samuel, P. S.; Pociask, F. D.; Dizazzo-Miller, R.; Carrellas, A.; LeRoy, B. W. Concurrent validity of the International Family Quality of Life Survey. *Occup. Ther. Health Care* **2016**, *30 (2),* 187–201. https://doi.org/10.3109/07380577.2015.1116129.
61. Steel, R.; Poppe, L.; Vandevelde, S.; Van Hove, G.; Claes, C. Family Quality of Life in 25 belgian families: quantitative and qualitative exploration of social and professional support domains. *J. Intellect. Disabil. Res.* **2011**, *55*, 1123–1135. https://doi.org/10.1111/j.1365-2788.2011.01433.x.
62. Epley, P. H.; Summers, J. A.; Turnbull, A. P. Family Outcomes of early intervention: families' perceptions of need, services, and outcomes. *J. Early Interv.* **2011**, *33 (3),* 201–219. https://doi.org/10.1177/1053815111425929.
63. Davis, K.; Gavidia-Payne, S. The impact of child, family, and professional support characteristics on the Quality of Life in families of young children with disabilities. *J. Intellect. Dev. Disabil.* **2009**, *34 (2),* 153–162. https://doi.org/10.1080/13668250902874608.
64. Summers, J. A.; Marquis, J.; Mannan, H.; Turnbull, A. P.; Fleming, K.; Poston, D. J.; Wang, M.; Kupzyk, K. Relationship of perceived adequacy of services, family-professional partnerships, and Family Quality of Life in early childhood service programmes. *Int. J. Disabil. Dev. Educ.* **2007**, *54 (3),* 319-338. https://doi.org/10.1080/10349120701488848.
65. Clark, M.; Brown, R.; Karrapaya, R. An Initial look at the quality of life of malaysian families that include children with disabilities. *J. Intellect. Disabil. Res.* **2012**, *56 (1),* 45–60. https://doi.org/10.1111/j.1365-2788.2011.01408.x
66. Cohen, S. R.; Holloway, S. D.; Domínguez-Pareto, I.; Kuppermann, M. Receiving or believing in family Support? Contributors to the life quality of latino and non-latino families of children with intellectual disability. *J. Intellect. Disabil. Res.* **2014**, *58 (4),* 333–345. https://doi.org/10.1111/jir.12016.
67. Holloway, S. D.; Dominguez-Pareto, I.; Cohen, S. R.; Kuppermann, M. Whose job is it? Everyday routines and quality of life in latino and non-latino families of children with intellectual disabilities. *J. Ment. Health Res. Intellect. Disabil.* **2014**, *7 (2),* 104–125. https://doi.org/10.100/19315864.2013.785617 .
68. McStay, R. L.; Trembath, D.; Dissanayake, C. Maternal stress and Family Quality of Life in response to raising a child with autism: From preschool to adolescence. *Res. Dev. Disabil.* **2014**, *35 (11),* 3119–3130. https://doi.org/10.1016/j.ridd.2014.07.043.
69. Meral, B. F.; Cavkaytar, A.; Turnbull, A. P.; Wang, M. Family Quality of Life of turkish families who have children with intellectual disabilities and autism. *Res. Pract. Pers. Sev. Disabil.* **2013**, *38 (4),* 233–246. https://doi.org/10.1177/154079691303800403.
70. Rodrigues, S. A.; Fontanella, B. J. B.; de Avó, L. R. S.; Germano, C. M. R.; Melo, D. G. A Qualitative study about quality of life in brazilian families with children who have severe or profound intellectual disability. *J. Appl. Res. Intellect. Disabil.* **2019**, *32 (2),* 413–426. https://doi.org/10.1111/jar.12539.
71. Valverde, B. B. R., & Jurdi, A. P. S. Analysis of the relationship between early intervention and family quality of life. *Revista Brasileira de Educacao Especial* **2020**, *26*(2), 171–186. https://doi.org/10.1590/1980-54702020v26e0116
72. Bello-Escamilla, N.; Rivadeneira, J.; Concha-Toro, M.; Soto-Caro, A.; Diaz-Martinez, X. Family Quality of Life Scale (FQLS): validation and analysis in a chilean population. *Univ. Psychol.* **2017**, *16 (4), 20-29.* https://doi.org/10.11144/Javeriana.upsy16-4.ecvf.
73. Brown, R. I.; MacAdam-Crisp, J.; Wang, M.; Iaroci, G. Family Quality of Life when there is a child with a developmental disability. *J. Policy Pract. Intellect. Disabil.* **2006**, *3 (4),* 238–245. https://doi.org/10.1111/j.1741-1130.2006.00085.x

74. García-Grau, P.; McWilliam, R.A.; Martínez-Rico, G.; Grau-Sevilla, M.D. Factor structure and internal consistency of a spanish version of the family quality of life (FaQoL). *Applied Research in Quality of Life* **2017,** *13*, 385–398. https://doi.org/10.1007/s11482-017-9530-y
75. Garcia-Grau, P., McWilliam, R. A., Martinez-Rico, G., Morales-Murillo, C. P., García-Grau, P., McWilliam, R. A., ... Morales-Murillo, C. P. Child, Family, and Early Intervention Characteristics Related to Family Quality of Life in Spain. *Journal of Early Intervention* **2019**, *41*(1), 44–61. https://doi.org/10.1177/1053815118803772
76. García-Grau, P., McWilliam, R. A., Martínez-Rico, G., & Morales-Murillo, C. P. Rasch Analysis of the Families in Early Intervention Quality of Life (FEIQoL) Scale. *Applied Research in Quality of Life* **2021**, *16*(1), 383-399. Scopus. https://doi.org/10.1007/s11482-019-09761-w
77. Giné, C.; Vilaseca, R.; Gràcia, M.; Mora, J.; Orcasitas, J. R.; Simón, C.; Torrecillas, A. M.; Beltran, F. S.; Dalmau, M.; Pro, M. T.; et al. Spanish Family Quality of Life Scales: Under and over 18 Years Old. J. *Intellect. Dev. Disabil.* **2013**, *38 (2)*, 141–148. https://doi.org/10.3109/13668250.2013.774324.
78. Hielkema, T.; Boxum, A. G.; Hamer, E. G.; La Bastide-Van Gemert, S.; Dirks, T.; Reinders-Messelink, H. A.; Maathuis, C. G. B.; Verheijden, J.; Geertzen, J. H. B.; Hadders-Algra, M. LEARN2MOVE 0–2 years, a randomized early intervention trial for infants at very high risk of cerebral palsy: Family outcome and infant's functional outcome. *Disabil. Rehabil.* **2019**, *41*, 1-9. https://doi.org/10.1080/09638288.2019.1610509.
79. Leadbiter, K.; Aldred, C.; McConachie, H.; Le Couteur, A.; Kapadia, D.; Charman T.; Mcdonald, W.; Salomone, E.; Emsley, R.; Green, J. The Autism Family Experience Questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. *J. Autism Dev. Disord.* **2018**, 1042–1062.
80. Lei, X., & Kantor, J. (2020). Social support and family quality of life in Chinese families of children with autism spectrum disorder: The mediating role of family cohesion and adaptability. *International Journal of Developmental Disabilities* **2021**. https://doi.org/10.1080/20473869.2020.1803706
81. Liu, H., Song, Q., Zhu, L., Chen, D., Xie, J., Hu, S., … Tan, L. Family Management Style Improves Family Quality of Life in Children With Epilepsy: A Randomized Controlled Trial. *Journal of Neuroscience Nursing* **2020**, *52(2)*, 84–90. https://doi.org/10.1097/JNN.0000000000000497
82. Lee, J. S., · Cinanni, N., Di Cristofaro, N., Lee, N · Dillenburg, R., ·. Adamo, K. B., · T. Mondal, T., · Barrowman, T. . Shanmugam, G,·. Timmons, B. W ·Longmuir, P. W. Parents of Very Young Children with Congenital Heart Defects Report Good Quality of Life for Their Children and Families Regardless of Defect Severity, *Pediatric Cardiology* **2020**, 41, 46–53. https://doi.org/10.1007/s00246-019-02220-1
83. Neikrug, S.; Roth, D.; Judes, J. Lives of Quality in the face of challenge in Israel. *J. Intellect. Disabil. Res.* **2011**, *55*, 1176–1184. https://doi.org/10.1111/j.1365-2788.2011.01475.x.
84. Perry, A.; Isaacs, B. Validity of the Family Quality of Life Survey-2006. *J. Appl. Res. Intellect. Disabil.* **2015**, *28 (6)*, 584–588. https://doi.org/10.1111/jar.12141.
85. Tait, K.; Fung, F.; Hu, A.; Sweller, N.; Wang, W. Understanding Hong Kong chinese families' experiences of an autism/ASD diagnosis. *J. Autism Dev. Disord.* **2016**, *46 (4)*, 1164–1183. https://doi.org/10.1007/s10803-015-2650-z.
86. Tejada-Ortigosa, E. M.; Flores-Rojas, K.; Moreno-Quintana, L.; Muñoz-Villanueva, M. C.; Pérez-Navero, J. L.; Gil-Campos, M. Health and socio-educational needs of the families and children with rare metabolic diseases: qualitative study in a tertiary hospital. *An. Pediatr.* **2019**, *90 (1)*, 42–50. https://doi.org/10.1016/j.anpedi.2018.03.003
87. Verger, S., Riquelme, I., Bagur, S., & Paz-Lourido, B. Satisfaction and Quality of Life of Families Participating in Two Different Early Intervention Models in the Same Context: A Mixed Methods Study. *Frontiers in Psychology* **2021**, *12*. https://doi.org/10.3389/fpsyg.2021.650736
88. Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities* **2004**, *29*(2), 144–155. https://doi.org/10.1111/j.1365-2788.2006.00932.x
89. McStay, R. L.; Trembath, D.; Dissanayake, C. Stress and Family Quality of Life in Parents of Children with Autism Spectrum Disorder: Parent Gender and the Double ABCX Model. *J. Autism Dev. Disord.* **2014**, *44 (12)*, 3101–3118. https://doi.org/10.1007/s10803-014-2178-7.
90. Mello, C., Rivard, M., Terroux, A., & Mercier, C. Quality of Life in Families of Young Children With Autism Spectrum Disorder. *American Journal On Intellectual and Disabilities* **2019**, *124*(6), 535–548. https://doi.org/10.1352/1944-7558-124.6.535

91. Vanderkerken, L., Heyvaert, M., Onghena, P., & Maes, B. The Relation Between Family Quality of Life and the Family-Centered Approach in Families With Children With an Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities* **2019**, *16*(4), 296-311. https://doi.org/10.1111/jppi.12317
92. Demchick, B. B.; Ehler, J.; Marramar, S.; Mills, A.; Nuneviller, A. Family quality of life when raising a child with pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS). *J. Occup. Ther. Sch. Early Interv.* **2019**, *12 (2),* 182–199. https://doi.org/10.1080/19411243.2019.1592052
93. Moyson, T.; Roeyers, H. The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of Life of siblings of children with intellectual disability: The siblings' perspectives. *J. Intellect. Disabil. Res.* **2012**, *56 (1),* 87–101. https://doi.org/10.1111/j.1365-2788.2011.01393.x .
94. Shah, R., Ali, F. M., Finlay, A. Y., & Salek, M. S. Family reported outcomes, an unmet need in the management of a patient's disease: Appraisal of the literature. *Health and Quality of Life Outcomes* **2021**, *19*(1). https://doi.org/10.1186/s12955-021-01819-4
95. Giné, C., Mas, J., Balcells-Balcells, A., Baqués, N. & Simón, C. Escala de Calidad de Vida Familiar con hijos/as con hijos menores de 18 años con discapacidad intelectual y/o en el desarrollo, Versión Revisada 2019, CdVF-ER (<18) Madrid: Plena Inclusión. 2019
96. Rodríguez-Cely, D. y Espina-Salazar, A. Epistemologías otras en la investigación en diseño: Transformaciones para el diseño inclusivo. *Bitácora Urbano Territorial* **2020**, *30*(II), 25-34. https://doi.org/10.15446/bitacora.v30n2.81509
97. Bruner, J. Life as narrative. J. Bruner. *In search of pedagogy. The selected works of Jerome Bruner.*. Routledge: New York, 2006, *Vol. 2*, 129–140: https://doi.org/10.4324/9780203088609
98. Brown, R., & Schippers, A. The background and development of Quality of Life and Family Quality of Life: applying research, policy, and practice to individual and family living. *International Journal of Child Youth & Family Studies* **2018**, *9*(4), 1-11. https://doi.org/10.18357/ijcyfs94201818637
99. Aldersey, H. M., Francis, G. L., Haines, S. J., & Chiu, C. Y. Family Quality of Life in the Democratic Republic of the Congo. *Journal of Policy and Practice in Intellectual Disabilities* **2016**, *14*(1), 78-86. https://doi.org/10.1111/jppi.12189
100. Van Heumen, L., & Schippers, A. Quality of life for young adults with intellectual disability following individualised support: Individual and family responses†. *Journal of Intellectual and Developmental Disability* , *41*(4), 299–310. https://doi.org/10.3109/13668250.2016.1213797
101. Correia, R. A., Seabra-Santos, M. J., Campos Pinto, P., & Brown, I. (2017). Giving Voice to Persons With Intellectual Disabilities About Family Quality of Life. *Journal of Policy and Practice in Intellectual Disabilities, 14(1)*, 59–67. https://doi.org/10.1111/jppi.12226
102. Jhul, P. Preverbal children as co-researchers: Exploring subjectivity in everyday living, in *Theory & Psychology* **2018**, 1–20. https://doi.org/10.1177/0959354318820158
103. Arestedt, L., Benzein, B., Persson, C. & Rämgard, M. A shared respite—The meaning of place for family well-being in families living with chronic illness. *International Journal of Qualitative Studies on Health and Well-being* **2016**, *11*(1), 30308. https://doi.org/10.3402/qhw.v11.30308
104. Noyek, S., Davies, T., Batorowicz, B., Delarosa, E. y Fayed, N. The "Recreated Experiences" Approach: Exploring the Experiences of Persons Previously Excluded in *Research, International Journal of Qualitative Methods* **2022**, 21, 1–17. http://doi.org/ 10.1177/16094069221086733
105. Creighton, G.; Oliffe, J. L.; Ferlatte, O.; Bottorff, J.; Broom, A.,; Jenkins, E.K. Photovoice ethics: Critical reflections from men's mental health research. *Qual. Health Res.* **2018**, *28 (3)* 446–455. https://doi.org/10.1177/104973231772
106. Egaña, D. y Barría, S. La familia como categoría difusa en la atención primaria del sistema de salud chileno, *Revista Cubana de Medicina General Integral* **2015**, *11, 3,* 1-15.