

# Chronic Diseases of Childhood and the International Classification of Functioning, Disability, and Health: A Systematic Review

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## Abstract

The increase in chronic diseases in childhood highlights the need for a biopsychosocial approach to deal with the complexity of these health conditions. The International Classification of Functioning, Disability, and Health (ICF) results from the need to implement new explanatory evaluative and therapeutic models. Thus, the present systematic review aims to identify published studies on the use of the ICF in chronic childhood diseases. As a secondary objective, to map the themes that have already been studied in the area to support the discussion on the expansion of the use of this classification in health services. The systematic review followed the PRISMA protocol, and the model was the PICO acronym, where Population was children and adolescents with chronic diseases, Intervention/Exposure was evaluation based on ICF concepts, Comparator was any tool, instrument, or intervention, and outcome was direct or indirect use of the ICF. We selected eight articles, five of which used the ICF as a conceptual tool and three as a classification system, divided into the following themes: quality of life, evaluation of patients (without using coding) and mapping the inclusion of the activity's results and participation in clinical trials. Thus, use of the ICF in clinical practice is still incipient, although it has been recommended in guidelines. Further studies are necessary to expand the number of contributions by the ICF and to develop the necessary approaches for understanding the classification's use.

## Keywords

Chronic Diseases, International Classification of Functioning, Disability, and Health, Child, Adolescent, Disabled Children

## 1. Introduction

The health of children and adolescents in the 21st century is characterized by an epidemiological transition and a change in the morbidity and mortality profile, with a growing number of patients with chronic diseases [1]. In many cases, they are survivors of Intensive Care Units (ICU), such as premature infants and those born with congenital malformations and genetic diseases.

The definition of chronic disease according to the World Health Organization (WHO) [2]; includes prolonged or permanent conditions that require continuous care. The guidelines of the Brazilian National Policy for Children's Health [3] include comprehensive care for children with prevalent diseases of childhood and those with chronic diseases. The diseases listed in the document include allergies, obesity, diabetes, hypertension, neurological disorders, cancer, and mental health problems. Besides these diseases mentioned, there are other rare diseases, such as genetic and metabolic syndromes, which can be mild to severe and have simple to complex clinical presentations.

Children that present greater complexity in their chronic disease are defined as those with medical complexity or complex chronic health conditions [4] [5].

The following characteristics comprise the concept of complex chronic health condition in childhood: minimum duration of 12 months (except in the case of death as the outcome), severe impairment of an organ or body system or multi-system impairment, commonly with associated comorbidities; need for specialized and continuous follow-up, with hospitalization in some cases and extensive use of healthcare services and existence of functional limitations [4] [5].

The lack of well-established criteria for defining chronic illness in pediatrics makes it difficult to estimate the prevalence of this set of conditions which varies from 10% to 30% depending on the criteria and concepts used (1 - 9). In 2007, the WHO reported a global prevalence of 7% to 15% of adolescents with chronic diseases, depending on the definitions and quality of data [6]. However, when considering the various causes of chronic illness in adolescence, it can be estimated that 15% to 20% of young people are affected [7].

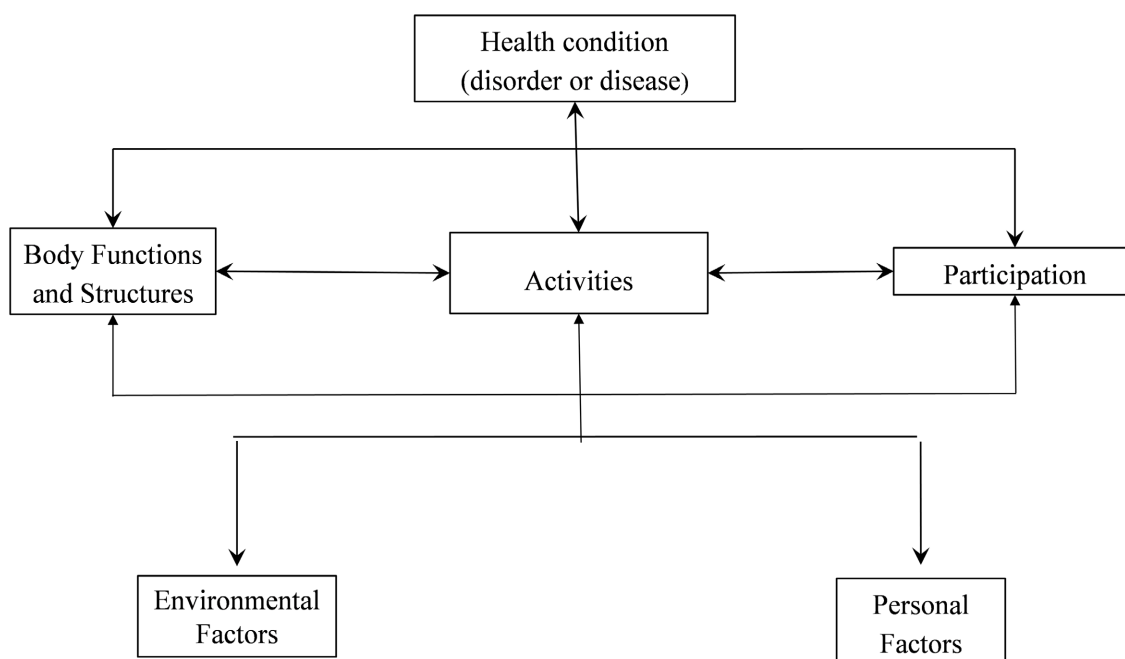
The group of children and adolescents with chronic health conditions is thus highly heterogeneous, including different age groups, varying levels of development, diseases and conditions with distinct etiologies, and variable severity and impact on life. Several chronic diseases, such as neurodevelopmental disorders, can be associated with the presence of disabilities, dependence on life support technologies, and the need for continuous healthcare, medicines, and rehabilitation. These multiple and complex health needs are challenges for formulating public healthcare policies [8].

The identification of children and adolescents with chronic conditions by health services and systems aims to improve the quality of their care, reduce health costs, improve outcomes for patients and their families [9]. It is often impossible to map all patient needs and identify the resources needed to meet them in a single outpatient visit. Such needs include, but are not limited to, diagnosis of

the disease. Thus, the description of the health situation based on disease classifications such as the International Classification of Diseases (ICD-10), whether at an individual or population level, is unable to identify the associated deficiencies in children with complex chronic conditions and, thus, understand gravity [9].

The publication of the International Classification of Functioning, Disability and Health (ICF) was a WHO response to the need to implement new models to explain the impact of health conditions on people's lives that include a biopsychosocial approach [10] [11]. This classification system made it possible to integrate the concepts of Functioning and Disability (**Figure 1**). In the ICF, functioning is the result of human experience related to health condition, body functions and structures, activity, participation and interaction with contextual factors, both personal and environmental. Disability represents the results of these interactions that cause damage, limitations and restrictions in the individual's life. The use of the ICF in chronic illness in childhood can help to understand and intervene in the complexities of the effects of diseases on people's lives [10] [11] [12].

This model can help establish care for the chronically ill, promoting a less fragmented way of visualizing and recording the impacts of the disease on functionality. In addition, it can promote less overlapping of practices, facilitate inter-professional communication, promote effective interdisciplinarity and include a broader view of the integrality of the health and life of children or adolescents. It can thus help establish decision-making goals and processes, follow-up of treatment results, and evaluation of the effectiveness of planned measures in these individuals' treatment plans [11].



**Figure 1.** Interactions between the components of ICF (adapted [10]).

According to the WHO proposal, the ICF can be used in various ways, as a conceptual model, a system of classification codes, or to assist the structuring of specific evaluations for the services' needs. However, it is still challenging to operationalize the ICF as a model in daily practice, since health training, services, networks, and information systems are still structured according to disease diagnoses and the associated procedures [13] [14].

The current systematic review thus aims to identify publications that use the ICF in situations of chronic childhood diseases. As a secondary objective, to map the themes already studied in the area to support the discussion on the expansion of the use of this classification in health services.

## 2. Methods

### 2.1. Study Design

We conducted a systematic literature review, aimed at meeting the recommendations of the PRISMA protocol [15].

We used the PICO acronym as the model, including population, intervention (or exposure), comparison, and outcome to define the research question [16]. The population was thus defined as children and adolescents with chronic disease. Intervention or exposure was any evaluation based on the ICF concepts. The comparator was any tool, instrument, or intervention, and the outcome was the direct or indirect use of ICF for discussion of chronic childhood illness.

### 2.2. Search Strategy

The electronic article search used databases, including the Virtual Health Library Research Portal (BVS), MEDLINE, Latin American and Caribbean Literature in Health Sciences (LILACS), and Google Scholar, from 2010 to 2020, using the keywords in Portuguese, English, and Spanish, “crianças com deficiência/disabled children/niños con discapacidad”; “doença crônica/chronic disease/enfermedad crónica”, “Classificação Internacional de Funcionamento/International Classification of Functioning, Disability, and Health (ICF)/Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud”. The data were collected from August to November 2020.

The initial search selected articles published on use of the ICF for children and adolescents with disabilities or chronic diseases. Next, we applied the eligibility criteria: publication in Portuguese, English, or Spanish, in original article format, and with a focus on chronic diseases of childhood. Refinement of the search was intended to identify studies that addressed chronic illness or conditions in childhood as a heterogeneous group of diseases with long duration. We thus excluded articles that discussed specific diseases or conditions such as cerebral palsy, autism spectrum disorder (ASD), attention deficit-hyperactivity disorder (ADHD), and others, those that focused exclusively on alterations of neurodevelopment or on children and adolescents with disability, and systematic reviews on ICF.

An article evaluation form was developed, and we proceeded to the data ex-

traction using Microsoft Office Excel to organize the information. We included the following characteristics of the articles: author, year, study objectives, study design, study population, sample size, ICF methodology (miscellaneous categories, checklist, or core set), qualifiers (original or adapted), use of additional instruments, methods, and results.

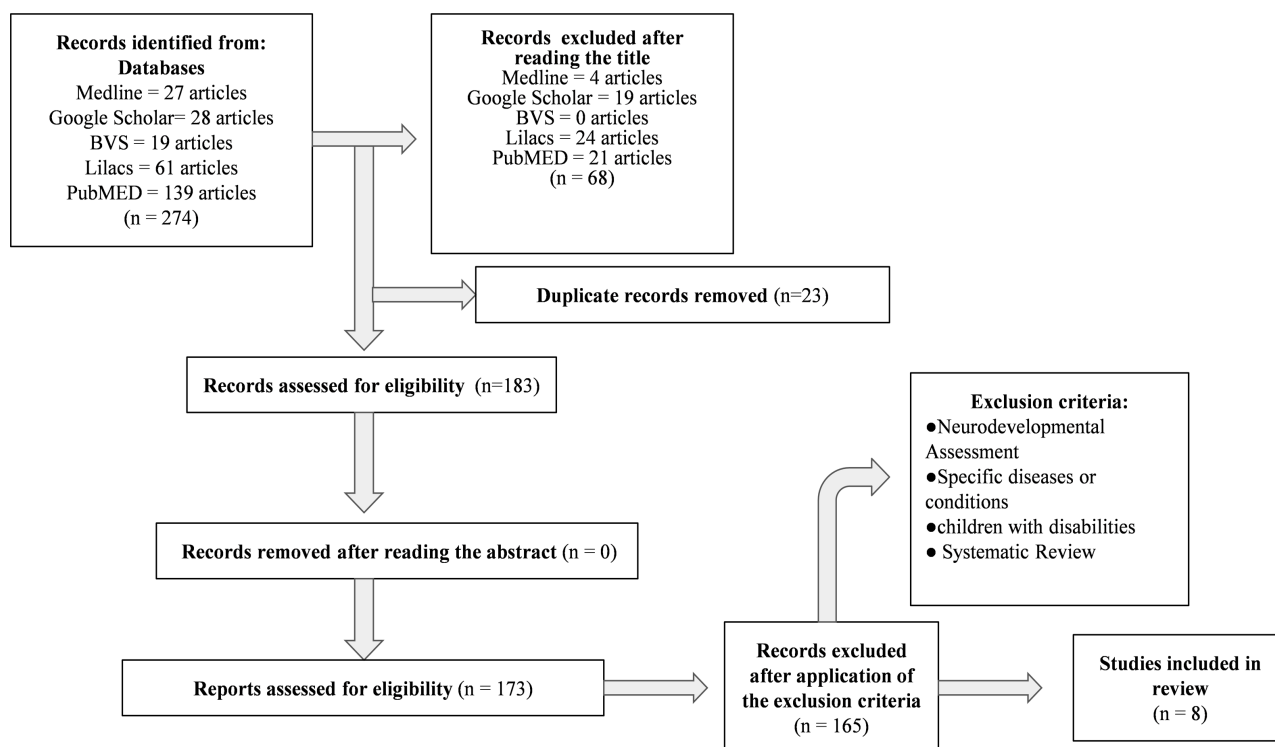
Qualitative methodology was used, with extensive reading of the selected articles and identification of the themes present, from the methodology of thematic analysis according to Brown and Clarke [17]. This procedure made it possible to identify, in the selected studies, the themes analyzed by the authors, on the use of the ICF and chronic childhood diseases. Such themes were discussed in the light of the current scientific literature, trying to point out the main results and gaps found.

### 3. Results

The initial search yielded 274 articles. Of these, 23 articles were duplicates and 68 did not deal with the theme “ICF and children and adolescents”. The abstracts of the other 183 articles were read, and 10 more articles were excluded that did not fit the theme.

The eligibility criteria were applied then, and eight articles were selected on chronic diseases in childhood and ICF for full reading and analysis, corresponding to 4.6% of eligible articles after reading titles and abstracts.

**Figure 2** shows the details of the selection process for eligible articles.



**Figure 2.** Flowchart for identification and selection of articles for the systematic review on ICF and children and adolescents with disability and chronic diseases.

## Characteristics of the Eligible Studies

**Table 1** presents the overall characteristics of the reviewed studies. Of these, six were cross-sectional and two were qualitative with a methodology linking the ICF to measurement instruments. Among the articles using a cross-sectional design, only one article did not use additional instruments for classification of functioning and disability.

The ICF was used conceptually in five articles and as a classification structure in three articles.

The studies' approach to quality of life in chronic illness was based on the evaluation of children and adolescents by the attending health professionals, as well as through the perceptions of the parents and patients themselves.

**Table 2** describes the principal results, conclusions, and limitations of the studies included in this systematic review.

## 4. Discussion

Use of the ICF in the international scenario has progressed continuously and consistently. However, daily use of the complete set of codes and application of the ICF with all its possibilities is impossible, due to its length and complexity. Thus, the World Health Organization has proposed the creation and implementation of ICF subsets, e.g., the use of concepts related to the ICF or the creation of applicable codes for a disease or condition [13].

In the scenario of chronic diseases of childhood, perhaps due to difficulties in identifying, classifying, and mapping this group of individuals [7] [8] [9], the ICF is frequently used for specific diseases or conditions, facilitating its applicability, which can be inferred from the small number of published studies on chronic diseases of childhood in general and ICF. The studies analyzed were produced in North America (Canada and USA) and Europe.

The use of thematic analysis made it possible to include the publications studied in one of three large groups: 1) Quality of life (related to the assessment of instruments; identification of contextual and functional factors related to quality of life in children and young people with chronic diseases); 2) Patient assessment (development of a list of rehabilitation priorities based on "mobility" (d4) and "self-care" (d5) activities in the ICF; identification of caregiver strategies to support participation at home; assessment of functionality and disability in children and adolescents in a vegetative or minimally conscious state and 3) Mapping the inclusion of activity results and participation in clinical trials.

The studies related to quality of life in children and adolescents with chronic diseases pointed to promising results from the use of ICF for conceptual discussion and as a classification tool in QoL indicators. The studies' target public included parents or caregivers and patients themselves through self-report in the questionnaires. Aspects of functioning, activity, participation, and environmental factors could also be addressed, both in the direct application of the ICF, as well as in cases of analysis of quality-of-life questionnaires.

**Table 1.** Characteristics of the studies included in the review.

| Author and year                          | Objectives   | Study design   | Characterization of the sample  | Use of ICF (conceptual structure or classification system) |
|--|--|--|---|--|
| Jarvis <i>et al.</i> , 2019 [18]         | Evaluate the most common type of strategy reported by caregivers to support their children's participation at home of after critical illness and identify themes in the compensatory strategies described.   | Cross-sectional  | children from PICU, 71% of whom had chronic health conditions                                     | conceptual   |
| McDougall, Bedell, and Wright, 2013 [19] | Evaluate the psychometric properties of a self-report version of the Child and Adolescent Scale of Participation (CASP) to further validate the parents' report and to compare the reports by parents to parents and children on the latter's activity and participation.                                  | Cross-sectional  | Children and adolescents 11 to 17 years of age with various conditions/disabilities               | conceptual   |
| Gandhi <i>et al.</i> , 2014 [20]         | Develop databases of items related to three quality-of-life instruments on pediatric health.   | Qualitative, with methodology linking ICF to measurement instruments | Parents of children 8 to 16 years of age  | conceptual   |
| McDougall <i>et al.</i> , 2014 [21]      | Explore the functional components based on the ICF and contextual factors associated with the perception of quality of life (QV) for young people with chronic conditions from the perspective of young people and their parents.  | Cross-sectional  | Children and adolescents 11 to 17 years of age with various chronic conditions, and their parents | conceptual   |
| Petersson <i>et al.</i> , 2013 [22]      | Compare the content dimensions of the HRQoL instruments for self-report by children, using the ICF-CJ structure.   | Qualitative, with methodology linking ICF to measurement instruments | Instruments for evaluation of quality of life   | classification system                                      |
| Rast and Labruyere, 2020 [23]            | Develop a detailed list of priority family-centered rehabilitation goals at the activity level in a pediatric population with a wide range of health conditions. Investigate the relationship between this list of priorities and the children's health status, level of functional independence, and age. | Cross-sectional  | Children admitted to a rehabilitation hospital  | classification system                                      |
| Fayed <i>et al.</i> , 2014 [24]          | Explore whether the results of activity and participation are included in clinical trials on chronic diseases of childhood and determine which characteristics of trials are associated with their use.  | Cross-sectional  | Registered clinical trials for children with chronic medical conditions                           | conceptual   |
| Leonardi <i>et al.</i> , 2012 [25]       | Describe the functioning and incapacity of children in vegetative state (VS) and minimally conscious state (MCS) using ICF-CY  | Cross-sectional  | Children in vegetative state (VS) and in minimally conscious state (MCS)                          | Classification system                                      |

**Table 2.** Results, conclusions, and limitations of the studies included in the review.

| Author and year                          | Results  | Conclusions/Recommendations  | Study limitations  |
|--|--|--|--|
| Jarvis <i>et al.</i> , 2019 [18]         | Most caregiver strategies were compensatory, more than half (60%) involving support for relationships. In contrast, strategies that address the child's natural environment (12%), services (3%), and attitudes of others at home (1%) were described less frequently. Similar issues were identified for caregivers whose children received (versus did not receive) rehabilitation services from the PICU.                 | The study's results show that caregivers can identify corrective and compensatory strategies to support their children's participation at home during the initial phase of recovery from a critical illness, but the compensatory strategies are limited. The results highlight the importance of educational activities for caregivers and suggest some potential areas for this action during PICU hospitalization for children with critical illnesses and near their discharge from the unit. Further studies are necessary to determine whether the results in functional recovery differ according to age and subgroups of diseases, e.g., history of prior chronic disease. | Absence of the caregivers' profile, limiting the results' generalization. Absence of information on the use of rehabilitation after discharge from the PICU. Use of print forms with limited space for detailed description of answers. Reductionist coding strategy for the environmental dimension, failing to adequately describe the support from caregivers.  |
| McDougall, Bedell, and Wright, 2013 [19] | Strong internal consistency and internal structure validity were demonstrated for the CASP report for patients and parents. The report's factor structure was similar to that of parents' report in this and other studies. Children reported slightly higher activity/participation compared to their parents. Significant differences in the CASP scores were found between various groups of conditions and disabilities. | The versions of the CASP for children and parents appear to measure activity and participation similarly enough to guarantee the use of the children's report alone when their perspectives are of primary interest.   | Use of a predominantly English-speaking sample of young people 11 to 17 years of age with chronic diseases and disabilities. Further studies are necessary to evaluate test-retest reliability, concurrent and convergent validity, and to examine in greater detail the discriminant validity and differences in reliability and mean values for young parents. The response capacity according to the youngsters' and parents' reports also needs to be studied. |
| Gandhi <i>et al.</i> , 2014 [20]         | The results of HRQoL in CSHN in seven of the eight domains (except personality) were significant compared to children without special health needs ( $p < 0.05$ ). This study shows a useful approach for comparing the concepts in the items of the three instruments and can generate item databases for a pediatric population.   | The ICF-CY serves as a useful structure for comparing the concepts of items in the three instruments from pediatric HRQoL and for generating item databases for a pediatric population.  | The study's findings cannot be generalized because it uses a cross-sectional design in a specific population. In addition, it only includes the researchers' perspective and does not include the parents' and children's perspectives, thus weakening the content validity. The response rate was only 30% of the interviewees, due mainly to the study's duration.   |



## Continued

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|--------------------------------------|---|--|--|
| McDougall <i>et al.</i> , 2014 [21]  | The authors identified factors negatively correlated with QoL, including pain and other physical and emotional symptoms, and positively correlated with QoL, such as scholastic performance, spirituality, social support for the family, and school belonging and safety. Family functioning was positively correlated and children's social anxiety, and environmental barriers were negatively correlated with the parents' perception of their children's QoL.  | The ICF structure and modified ICF model that was applied to study overall QoL of children with chronic conditions in this study extend far beyond the consideration of physical disabilities and functional limitations of individuals with chronic conditions, although pediatric rehabilitation services tend to focus on these aspects of children's and adolescents' life. The findings help justify the provision of services aimed at improving other dimensions of life, such as the child's or adolescent's emotional well-being and the family's well-being, as well as to provide additional support such as spiritual care for parents and their families and the defense of school and community environments in which the children and adolescents with chronic conditions can flourish and develop all their potential. | The study's findings cannot be generalized because it uses a cross-sectional design with data from a longitudinal study. Further studies are needed to unveil the complex interrelations between functioning, contextual factors, and self-rated quality of life over time, for example, relations between activity and participation and self-rated quality of life.  |
| Pettersson <i>et al.</i> , 2013 [22] | The authors identified 290 significant concepts linked to 88 categories in the ICF-CJ classification with 29 categories for the physical function components, 48 categories of activities and participation components, and 11 categories of environmental factor components. No concept was linked to the physical structure component. The comparison showed that the items in the HRQoL instrument corresponded mainly to the activity domain and less to environmental factors.   | The diversity of the various instruments becomes clear when the contents of the HRQoL instruments are coded by ICF. Comparison of the HRQoL instruments based on ICF-CY provides information that can help health professionals select an adequate instrument for measuring HRQoL.   | The study has various limitations. The instruments compared in this study measure health-related quality of life or HRQoL, which makes the comparison complicated. In addition, the instruments assess different dimensions, and the number of items varies between the instruments, from 6 to 87. Linkage revealed that the categories were addressed differently by the instruments, suggesting difficulty in use of the ICF for distinguishing some categories. A final limitation is that the instruments reviewed in this study only refer to the children's reports.   |
| Rast and Labruyere, 2020 [23]        | 93 females and 119 males were included in the study (mean age 10 years and 9 months, SD 4 years and 5 months, range 2 years and 1 month to 21 years and 5 months). The five most frequent rehabilitation goals were ICF codes d4500 'walking short distances' (11%), d4200 'moving in sitting position' (9%), d5400 'getting dressed' (7%), d451 'climbing up and down stairs' (6%), and d4153 'staying in sitting position' (5%). These principal goals varied between subgroups according to the underlying health condition, functional independence, and age. | The study recommends the incorporation of families' needs when designing future projects and developing new technologies. The study only evaluated the ICF chapters on mobility and selfcare.  | One limitation of this study is that the frequency of rehabilitation goals depends greatly on the specificity of the ICF categories, and the authors attempted to solve the problem by creating two sets of categories to increase the classification's precision. The linkage of rehabilitation goals to the corresponding ICF category was evaluator-dependent, and no preestablished or published linkage rules were used. For patients with prolonged hospitalization, the rehabilitation goals were modified over time and included in the analysis, adding more goals to this same category. The impact of the duration of rehabilitation was not evaluated in the list of priorities. |

## Continued

|                                    |  |   |   |
|------------------------------------|--|---|---|
| Fayed <i>et al.</i> , 2014 [24]    | <p>499 studies met the inclusion criteria, 495 of which had complete information on the hypothetical predictors. Only 36 of 495 studies included a result of activity and participation as part of the study's evaluation. Univariate and multivariate regression models showed that studies without drugs and the final trial phase (phase IV) had the highest likelihood of including a result of activity and participation.</p> <p>Most of the registered clinical trials for children with chronic medical conditions or trials underway did not include a comprehensive approach for the evaluation of health results, especially drug trials and trials in the initial phase. The measures of results of pediatric clinical trials are delayed in relation to the World Health Organization guidelines for comprehensive health evaluation.</p> | <p>The choice of a drug therapy rather than another therapy generally depends on the consequences for daily functioning, not only the signs and symptoms of the disease or biological outcomes.</p> <p>The study emphasizes the scarcity of clinical trials in children with chronic conditions that include the results of activity and participation in their evaluation.</p> | <p>Further and more in-depth studies are necessary to understand the reason for not including the results of activity and participation in pediatric clinical trials on chronic conditions.</p>   |
| Leonardi <i>et al.</i> , 2012 [25] | <p>A total of 36 children and adolescents (22 in VS, 25 males) were enrolled. The majority developed VS and MCS after a nontraumatic event; mean age was 114.8 months, and mean duration of the disease was 50.1 months. A total of 94 ICF-CJ categories were reported as relevant: 26 were bodily functions, especially mental functioning and mobility structures; nine were physical structures, 32 activities and participation, mainly chapters involving learning, mobility, and selfcare; and 27 environmental factors. Use of the ICF-CY allows obtaining a profile of specific functioning for each child that can be associated with known problems such as loss of brain functions and provision of life support interventions.</p>   | <p>Use of the ICF-CY allows obtaining a realistic and specific profile for each child's functioning.</p> <p>First report of information based on the ICF on physical disabilities, limitations in activities, and prevalence of environmental facilitators for children and adolescents in VS and MCS.</p>  | <p>Application of the ICF in this group may be questionable, since there is no personal involvement of these children in the respective activities. However, the authors contend that this reflects a real-life situation in which these activities cannot be performed, and a complete substitution is necessary.</p> <p>Another limitation was the use of some categories, especially D550-Eat and D560-Drink to describe eating and hydration. No ICF-CY category focuses clearly on this type of activity as performed by this group.</p> <p>Two main limitations may have produced a data collection and interpretation bias and need to be acknowledged. The first is associated with the heterogeneous composition of the researchers responsible for the data collection: common training based on ICF with detailed instructions was provided to limit possible differences in the administration of the ICF-CY questionnaires. The second is the sample's composition, particularly the limited number of cases and the heterogeneity between the two conditions, which does not allow generalization of the results.</p> |

Key: PICU (pediatric intensive care unit); CSHN (children with special health needs); ICF-CY (International Classification of Functioning, Disability, and Health for Children and Youth); HRQoL (health-related quality of life); QoL (quality of life); vegetative state (VS); minimally conscious state (MCS).

Further on QoL and chronic diseases of childhood, [20] identified the diversity of instruments and the inability to encompass all the situations for evaluation with a single model, and they thus recommend the continuous development of new QoL questionnaires in this area. They also point to the usefulness of ICF in choosing the most adequate instrument for each case.

As for use of the ICF for patients' evaluation, no study used the essential ICF coding system, as addressed in its manual. In addition, no author used the ICF in all its domains or in the full version.

In severely ill patients, both those from the PICU or those in vegetative state (VS) or minimally conscious state (MCS), the ICF was used to map the strategies reported by caregivers to support their children's participation at home after the critical disease in VS, as well as for evaluation of functioning and incapacity in MCS, thus reinforcing the extensive possibilities for the classification's use.

The study carried out with children from the PICU [18] aimed to identify themes among the compensatory strategies used by caregivers, as categorized by the environmental chapters of the ICF. The results showed that in 60% of cases, parents and caregivers were able to use compensatory strategies in interpersonal relationships. However, only 12% did so in relation to the environment, 3% in relation to services and 1% in relation to the attitudes of other people in the household. This may suggest that more educational strategies are needed to reduce the impact of environmental issues in the case of children coming from the PICU who develop sequelae and chronic health conditions.

The definition of rehabilitation goals for families for children with chronic conditions was primarily related to walking short distances (11%), although a large number of goals have been defined, due to the variety of clinical conditions presented by patients [23]. ICF codes were used to assess the most frequent rehabilitation goals, but not qualifiers or assessment of all domains and categories [23]. This is understandable, as the ICF has 1454 categories [24] [25] [26]. The applicability of the ICF is related to the conceptual use and development of simplified lists for specific diseases or conditions, the core sets, and for statistical purposes and epidemiological evaluation [27].

In the group of articles related to mapping the inclusion of activity results and participation in clinical trials, a single study of this sample analyzed 499 clinical trials in children with chronic medical conditions, showing the scarcity of studies that consider activities and participation in their scope, except some in phase IV and those that do not involve drug research. As a conclusion of this study, the authors proposed the creation of research guidelines that include the assessment of the impact of diseases on everyday life through measures of activity and participation [24].

Use of the ICF in clinical practice for chronic illness in childhood should be encouraged, as identified in various existing guidelines and core sets for specific diseases. In addition, such use reflects the global trend of adding an indicator of functioning to the usual morbidity and mortality indicators. In the scenario of

chronic health conditions in childhood, which (by definition) have the real possibility of affecting the individual's functioning, this practice may include, for example, new indicators and new ways of evaluating health policies and collaborating in the development of unique treatment plans and communication between teams, patients, and families. Besides, assisted by the classification, acknowledging patients' wishes in relation to their functioning helps promote the central role of the child or adolescent with a chronic health condition through a tool that can unify the language [27] [28] [29].

According to Nubilla and Buchalla [30], the processes related to a chronic health condition or disability in childhood become much more complex since they affect an individual in development. Often both the disability and the disease are viewed as the same problem, leading to incorrect assessments of the situation. The authors suggest that the use of the ICF can provide a common language needed to evaluate and document the children's disability more accurately, as well as to facilitate evaluation of the services offered to them.

The experience of chronicity amplifies the complexity of chronic diseases of childhood and requires adding measures or indicators to the ICF that can record and measure the duration of care over time and its impacts, as a contextual factor related to personal and environmental factors associated with chronicity of illness in childhood. The unique use of ICF, for example in the identification of environmental factors, can consider certain circumstances as facilitators or barriers, depending on the moment. In addition, the time at which the chronic illness occurs determines to some extent the impact of the illness on life. Moreira [31] reports that the absence of a life course break in the chronic health condition in childhood may have a normalizing aspect, of self-regulation and self-management of one's own health, since all the individual's growth and development were experienced in this situation. Such individual issues may thus not be experienced as barriers (contrary to onset at older ages) and impact QoL indicators.

When we consider the definition of complex chronic disease in childhood, there are four fundamental points: presence of one or more chronic conditions, which we can translate as the body's structure and function; the need for specific and continuous care, represented by environmental factors; the limitation in function, activity, and participation and heavy use of health services, also in contextual and environmental factors. However, we found that translating all the points encompassed in chronic illness without engaging with quality-of-life indicators is still a gap in publications on ICF.

## 5. Conclusions

There has been extensive research on the use of the ICF in pediatrics over the past 10 years. However, when analyzing the group of chronic patients, the quantity and scope of these studies are limited to the analysis of specific diseases or conditions, with the exception of a small number of studies.

Limitations of this study include publication bias, language, the risk of bias in primary studies, and the difficulty of performing comparisons in studies with very different populations. For this reason, an exploratory thematic analysis was chosen, in an attempt to map the state of the art on the subject, which we consider to be the main contribution of this study.

There is a need for more studies that expand the number of contributions and add new research approaches, allowing us to understand the use of the ICF in situations as heterogeneous as children and adolescents with chronic health conditions. We believe that such contributions can be useful to help structure public policies and emphasize the importance of including ICF dimensions in their proposals.

### Authors Contributions

Daniela Koeller Rodrigues Vieira and Carla Trevisan M. Ribeiro conceptualized and designed the study. Daniela Koeller Rodrigues Vieira, Roseane de Lima Ribeiro and Lara Carolina Januário Cabral conducted the preliminary data analysis and interpretation. Daniela Koeller Rodrigues Vieira and Carla Trevisan M. Ribeiro wrote and revised the manuscript. All authors approved the final content of the manuscript for publication.

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### Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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