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Review Article

Complex chronic health conditions in childhood and social vulnerability: a literature mapping review

Condições crônicas complexas de saúde na infância e vulnerabilidade social: uma revisão de mapeamento da literatura

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Abstract

Introduction: The definition of children with complex chronic health conditions (CCHCC) involves dependence on specialized care, rehabilitation, highly technological life support, and the involvement of multiple systems. Among the limitations imposed by the chronic condition, CCHCC and their families experience challenges arising from the vulnerable context in which many families find themselves, consequently leading to difficulties in accessing healthcare services, compromising the family's well-being. The influence of the social context on the lives of CCHCC is still rarely discussed. **Objective:** This study investigates what has been discussed in national and international literature regarding the influences of social vulnerability on the lives of CCHCC and their families. **Method:** This is a mapping literature review that used a descriptive analysis of the material found in the SciELO, Web of Science, PubMed, and Virtual Health Library databases, as well as Brazilian occupational therapy journals. **Results:** Eighteen studies were found that, although they did not examine CCHCC and social vulnerability together, contribute to the discussion on the importance of considering the social context in which these children and their families live. **Conclusion:** The mapping highlights the lack of materials linking CCHCC and vulnerability; however, it discusses the burden on mothers, the difficulties in accessing technological resources, and the influence of the context on the child's development and involvement in essential occupations, leading us to understand that social vulnerability can indeed impact the daily lives of these children and their families, underscoring the need to invest in more holistic approaches.

Keywords: Occupational Therapy, Child, Social Vulnerability, Chronic Disease.

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Resumo

Introdução: A definição de crianças com condições crônicas complexas de saúde (CCCCS) envolve a dependência de cuidados especializados, reabilitação, suporte de vida altamente tecnológico e comprometimento de múltiplos sistemas. Dentre as limitações impostas pela condição crônica, as CCCCS e suas famílias vivenciam desafios advindos do contexto vulnerável no qual muitas famílias estão inseridas, o que consequentemente acarreta dificuldades de acesso aos serviços de saúde, comprometendo o bem-estar da família. Ainda é pouco discutida a influência do contexto social na vida das CCCCS. **Objetivo:** Este estudo investiga o que tem sido discutido na literatura nacional e internacional sobre as influências da vulnerabilidade social na vida das CCCCS e de suas famílias. **Método:** Trata-se de uma revisão de mapeamento da literatura, que utilizou uma análise descritiva do material encontrado nas bases de dados *SciELO*, *Web of Science*, *Pub Med* e Biblioteca Virtual em Saúde, além de periódicos brasileiros de terapia ocupacional. **Resultados:** Foram encontrados 18 estudos que, apesar de não estudarem CCCCS e vulnerabilidade social em conjunto, contribuem para a discussão sobre a importância de olhar para o contexto social no qual essas crianças e suas famílias vivem. **Conclusão:** O mapeamento aponta a falta de materiais associando CCCCS e vulnerabilidade, contudo, discute a sobrecarga das mães, as dificuldades no acesso a recursos tecnológicos e as influências do contexto no desenvolvimento da criança e seu envolvimento em ocupações fundamentais, nos levando a compreender que, de fato, a vulnerabilidade social pode impactar o cotidiano dessas crianças e suas famílias, sendo preciso investir em abordagens mais integrais.

Palavras-chave: Terapia Ocupacional, Criança, Vulnerabilidade Social, Condição Crônica.

Introduction

Children with complex chronic health conditions (CCHCC) represent a group dependent on specialized care, rehabilitation, highly technological life support, and involvement of multiple systems (Fernandez et al., 2019). Understanding the degree of complexity highlights, according to the definition of the term, the presence of physical and cognitive limitations, as well as dependence on advanced technologies, continuous medication use, and the need for multiprofessional care (Moreira et al., 2017).

These children face restrictions in life experiences due to various barriers that can impact the acquisition of skills for development and social participation. Both the child and the family members face difficulties arising from the chronic health condition and the adversities resulting from the vulnerable context in which many families are situated.

The demands present in the daily lives of these families reflect the burden of tasks and activities related to caring for the child, affecting both the nuclear and extended family members (Trindade et al., 2020). The literature points to women-mothers as the primary caregivers, a role socially understood as a duty (Baleotti et al., 2015). This reality impacts family functioning, as the care required for the child demands significant changes to the caregiver's routine. In addition to changes in family relationships, many mothers leave the workforce, which impacts household income and makes it difficult to obtain the material resources necessary for the child's care.

Therefore, we can say that families with CCHCC are financially more vulnerable. In addition to expenses related to support materials, medications, therapies, and transportation, the caregiving demands resulting from the illness interfere with parents' ability to remain employed. This makes socioeconomic status a factor that impacts healthcare, with poverty linked to worse living conditions for those involved (Baltor & Dupas, 2013).

In the care provided to these children and their families, occupational therapists are essential professionals, as they not only assist in overcoming physical and cognitive challenges but also promote self-confidence, creative expression, and the development of healthy interpersonal relationships. They create an environment conducive to these children's full development, integrated with health, well-being, quality of life, and identity building, favoring the coordination of care for the entire family unit.

In this context, considering that families with CCHCC experience biopsychosocial challenges, this study identified and described how the topic has been addressed in international literature (investigating the simultaneous approach of “complex chronic condition in childhood” along with “social vulnerability”) and in national occupational therapy literature, also seeking the simultaneous presence of both topics.

Considering the importance of occupational therapists' practice in childhood and understanding that children with complex chronic health conditions and their families face adverse situations in their daily lives, it is crucial to seek insights from literature that allows identification of what has been studied regarding the daily lives of these families when, in addition to facing the challenge of caring for a CCHCC, they are also immersed in contexts of social vulnerability.

The knowledge produced in this mapping will help understand whether social vulnerability in the daily lives of children with complex chronic health conditions is a concern in the field, allowing us to comprehend how this integrated approach, considering context and daily life, has been described in recent literature. Such reflections enhance the practice of occupational therapists and care teams, promoting a comprehensive view of the child and their family, and avoiding reductionist thinking that does not account for the influences of the social context in people's daily lives. Therefore, this study is based on the hypothesis that the daily lives of these individuals are impacted by the context in which they live.

Method

Study characterization

This study, conducted within the context of research in a professional master's program in occupational therapy, can be described as a mapping literature review that uses a qualitative and descriptive approach to analyze the material found. It aims to identify how the literature of the past ten years in general publications and the past five years in Brazilian occupational therapy literature has addressed the topic of CCHCC and what knowledge has been produced, seeking studies that address both the themes of complex chronic conditions in childhood and social vulnerability.

Literature reviews consist of the analysis and synthesis of available information from relevant studies on a specific topic, summarizing part of the existing knowledge on that subject and highlighting key areas of interest (Mancini & Sampaio, 2006). Mapping reviews can synthesize data found, allowing the identification of gaps in the study's theme (Galvão & Pereira, 2022). By identifying what has been produced on the topic, a literature review on CCHCC and the social context contributes to improving the care provided to children and their families, as daily healthcare is intrinsically linked to the social context in which people live. Understanding the influences of social vulnerability in the daily lives of these families enables occupational therapists and other professionals involved to provide holistic and multidimensional care, involving the child, family, health context, and social context.

Strategies for mapping literature

In an attempt to identify whether studies focusing on CCHCC and social vulnerability are present in the literature, the databases SciELO, PubMed, Web of Science, and the Virtual Health Library (BVS) were used for an initial search. The terms used were "complex chronic conditions," "child," "infant," and "social vulnerability," combined with the Boolean operators "and" for joining the terms, and "or" for the terms "child" and "infant." The results of this first search yielded 33 studies, with only ten identified as potentially meeting the inclusion criteria (none were published in Brazilian journals or those specifically focused on occupational therapy).

A second search was conducted, focused solely on Brazilian literature, in occupational therapy journals (Cadernos Brasileiros de Terapia Ocupacional, Revista de Terapia Ocupacional da Universidade de São Paulo, and Revista Interinstitucional Brasileira de Terapia Ocupacional) using the terms separately: "condições crônicas," "complex chronic," "vulnerabilidade social," "social vulnerability," "infância," "infant," "criança," and "child." The terms were used separately because no studies with both topics were found in the first phase, nor were there any Brazilian studies in the field of occupational therapy.

In the first phase, studies were pre-selected based on their titles (presence of one or more of the search terms), indicating which might directly or tangentially address the topics of CCHCC and social vulnerability. Studies written in languages other than English, Portuguese, and Spanish were also excluded. Following the pre-selection, the studies were read in full and included according to the following criteria: (1) the central theme of the study focused on complex chronic conditions in childhood; (2) the study discussed topics related to managing chronic conditions; (3) it addressed issues related to identifying social vulnerability; (4) the texts were published between 2014 and 2024 (ten years).

In the second phase, using the isolated terms, 340 studies were found; however, only 29 were selected for analysis, and 15 studies were subsequently read in full and selected for discussion. In this phase, almost the same inclusion criteria were applied, with a filter of five years for publication (2019-2024).

Results

First step

The initial (general) search in the Scielo, PubMed, Web of Science and Virtual Health Library (VHL) databases using the descriptors “complex chronic conditions” AND (“child”

OR “infant”) AND “social vulnerability”, resulted in a total of 33 studies (Web of Science = 22; PubMed = 1; Scielo = 0; VHL = 10). After identification, only 13 were selected for analysis according to the reading of the title and, among them, two studies were excluded for not meeting the criteria for English, Portuguese and Spanish languages and one was excluded for not having free access (even though it was Virtual Private Network is used). After analysis carried out by reading in full, only three studies were included according to the mentioned criteria. Figure 1 describes the study selection process.

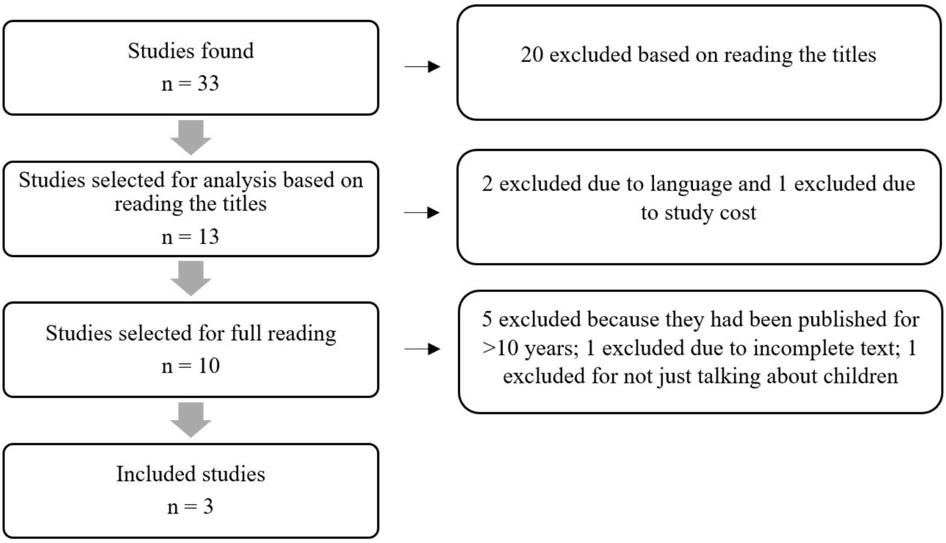

Figure 1. Study selection flow during the first stage.

Among the three selected studies (Table 1), none jointly addresses the CCHCC and social vulnerability themes. However, despite differences in approach, objectives and scenarios, the works promote important understandings about these children and their family members/informal caregivers, making it possible to highlight the importance of the families' life context.

Table 1. Studies included in the first stage

STUDY	AUTHORS/YEAR	JOURNAL
Health Care Providers’ Perspectives on COVID-19 and Medical Neglect in Children with Life-Threatening Complex Chronic Conditions	Cleveland et al. (2022)	Journal of Child & Adolescent Trauma
Psychosocial factors related with caregiver burden among families of children with chronic conditions	Toledano-Toledano & Domínguez-Guedea (2019)	BioPsychoSocial Medicine
Parental perceptions of child vulnerability in a community-based sample: Association with chronic illness and health-related quality of life	Houtzager et al. (2015)	Sage Journals

3.2 Second step

The search in Brazilian occupational therapy journals resulted in a total of 340 studies (Cadernos Brasileiros de Terapia Ocupacional = 162; Revista de Terapia Ocupacional da Universidade de São Paulo = 29; Revista Interinstitucional Brasileira de Terapia Ocupacional = 149). By reading the titles and descriptors, 29 were pre-selected for refinement and, according to the criteria, 15 were included for the mapping effort as shown in Figure 2.

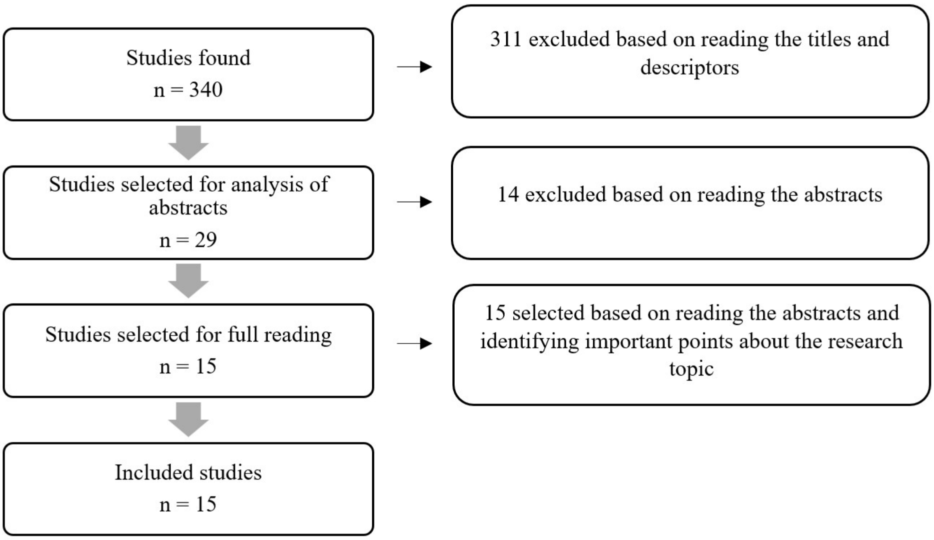

Figure 2. Study selection flow in Brazilian occupational therapy journals.

As in the first stage, after reading the studies, relevant aspects were selected to support the discussion following the theme of this review (Table 2). In general, eight studies had health services (hospital and outpatient clinic) as their setting; five, the home context of children and their families; and two, the educational context (school). The main chronic conditions that appear in the works are: meningitis, congenital clubfoot, cerebral palsy, cancer, microcephaly, sickle cell anemia, congenital heart disease associated with Down Syndrome and chronic renal failure.

The thematic analysis identified four major themes of interest in studies carried out in the context of occupational therapy: (1) Access to services and resources, (2) Stimuli for child development, (3) The mother as the main caregiver and (4) Social vulnerability.

Analysis of Results

The studies selected in the first phase bring different aspects regarding chronic conditions in childhood and highlight issues related to informal caregivers (who are almost always women-mothers) and the life context of families (Cleveland et al., 2022; Toledano-Toledano & Domínguez-Guedea, 2019; Houtzager et al., 2015).

Table 2. Studies included in the second stage

STUDY	AUTHORS/YEAR	JOURNAL
A experiência materna no cotidiano de cuidados dos bebês de risco no domicílio	Petrokas & Galheigo (2023)	Revista de Terapia Ocupacional da Universidade de São Paulo
Perfil das necessidades de Tecnologia Assistiva de pacientes pediátricos em hospital de alta complexidade: um estudo de caso	Vieira et al. (2023)	RevisbraTO
Relação entre o perfil sociodemográfico e a competência motora de crianças	Ferreira et al. (2023)	Cadernos Brasileiros de Terapia Ocupacional
A prática de terapeutas ocupacionais com mães acompanhantes em enfermarias pediátricas	Souza & Joaquim (2023)	Cadernos Brasileiros de Terapia Ocupacional
Effectiveness of a task-oriented training on occupational performance, functional independence, and fatigue in children with childhood cancer: a randomized-controlled trial	Kolit et al. (2021)	Cadernos Brasileiros de Terapia Ocupacional
O adoecimento crônico e o tratamento pelo olhar do adolescente: considerações com base em uma história de vida	Lino et al. (2021)	Cadernos Brasileiros de Terapia Ocupacional
Repercussões de doença renal crônica na rotina familiar de crianças em hemodiálise	Santos et al. (2020)	Revista de Terapia Ocupacional da Universidade de São Paulo
Intervenção com um sistema digitalizado de assento e encosto para cadeira de todas com adolescentes com paralisia cerebral grave: estudo de dois casos	Costa & Cruz (2020)	RevisbraTO
Perfil de independência no autocuidado da criança com Síndrome de Down e com cardiopatia congênita	Amaral et al. (2019)	Cadernos Brasileiros de Terapia Ocupacional
Perfil sociodemográfico e participação paterna nos cuidados diários de crianças com microcefalia	Cruz et al. (2019)	Cadernos Brasileiros de Terapia Ocupacional
O brincar de faz de conta como ferramenta na expressão do imaginário de crianças em tratamento quimioterápico hospitalizadas	Campos et al. (2019)	Revista de Terapia Ocupacional da Universidade de São Paulo
O cotidiano de crianças com insuficiência renal crônica em terapia renal substitutiva	Monteiro et al. (2019)	RevisbraTO
Crianças e adolescentes em vulnerabilidade social: bem-estar, saúde mental e participação em educação	Souza et al. (2019)	Cadernos Brasileiros de Terapia Ocupacional
Análise da acessibilidade no centro de tratamento da criança com câncer de um hospital universitário	Galvan et al. (2019)	Cadernos Brasileiros de Terapia Ocupacional
Crianças com microcefalia	Carvalho et al. (2019)	Revista de Terapia Ocupacional da Universidade de São Paulo

When healthcare professionals from intensive, complex, and palliative care teams are questioned about medical negligence in children with life-threatening complex chronic conditions (CCHCC), narratives reveal that the pandemic exposed the fragility of the medical and social systems supporting the families of CCHCC, emphasizing their vulnerability. The peculiarities of the pandemic period led to the distancing of families from support systems (medical and social), affecting the medical community's ability to engage and support the families (Cleveland et al., 2022).

The issue of care and support for CCHCC families is also present when the topic is caregiver burden: sociodemographic markers, family support, parental stress, anxiety, support networks, family functioning, and historical and sociocultural assumptions are prominent variables (Toledano-Toledano & Domínguez-Guedea, 2019). Findings indicate that variables included in the psychosocial and sociodemographic profile explain 40% of the variance in caregiver burden. Historical and sociocultural assumptions, stressors, and anxiety were identified as positive individual predictors, while education (high school completion), social support networks, family support, harmonious family functioning, and high well-being indices were identified as negative individual predictors of caregiver burden.

When it comes to parents' perceptions of their child's vulnerability (PPCV) with a chronic health condition, again the caregiver and family living conditions come to the forefront. Houtzager et al. (2015) discuss that the health status of these children can affect the psychosocial adjustment of parents, who perceive the child as more vulnerable, potentially impacting their overall development. In other words, the demands of the child's health condition can lead parents to act indulgently, controlling, protective, or intrusive. Study results show that the child's age and gender, their position in the family, the severity of the chronic condition, as well as the parents' gender, ethnicity, marital status, and educational level influence their perception of the child's vulnerability, highlighting a negative association between quality of life (QoL) and PPCV.

With different focuses (caregiver burden, vulnerability perceived by parents, and medical negligence) and research methods, the studies from the first phase highlight the role of the family and informal caregivers, placing them as the focus of attention and reaffirming the importance of considering the life context of these families. Issues such as communication with the caregiver (whether the caregiver receives appropriate guidance and understands the recommendations to the point of being able to follow them); social support for parents (as they perceive the care of CCHCC as difficult and exhausting); providing better support to families (Cleveland et al., 2022); gender stereotypes that make mothers the primary caregivers; adversities, risks, and vulnerabilities faced by families throughout the life of the CCHCC (Toledano-Toledano & Domínguez-Guedea, 2019); and the importance of intervening with these families, considering that how the child is cared for affects their development and quality of life (Houtzager et al., 2015), all highlight the vulnerability experienced by caregivers, not the so-called "social" vulnerability in the sense of poverty and lack of access to rights, but that resulting from the lack of support from social and healthcare systems to manage the complex task of caring for these children. Furthermore, these issues contribute to reaffirming the importance of considering sociodemographic and historical-cultural markers as crucial filters when the focus is caregiver burden.

The term “vulnerability” has been used with various meanings, linked to the challenge of caregiving and the perception of the fragilities of CCHCC. The studies highlight the caregiver/family member of these children in the face of the complexity of continuous care, which leads to greater burden depending on sociodemographic and cultural factors, with women/mothers as the primary caregivers. When discussing CCHCC, the studies address the needs of caregivers and identify socioeconomic vulnerabilities within families, but they do not discuss the impact on the child’s development or on the caregiver's daily life when these two conditions are associated.

In the second phase of the review, when mapping how the topic of children with complex chronic health conditions appears in Brazilian occupational therapy literature, no studies were found that intentionally focus on investigating CCHCC and social vulnerability together. The reading of the 15 selected studies aimed to identify and understand the influences of the socioeconomic context in which families with CCHCC live, grouping the analysis around major themes identified during the reading. The identification of major themes or categories allows for the discussion of the studies in such a way that the meaning attributed to the analysis contributes to the understanding of CCHCC and social vulnerability.

Access to services and resources

When it comes to the access of CCHCC and their families to healthcare services and resources, the importance of this access for the quality of life of all involved is a central aspect, which directs attention to a comprehensive approach to these situations, considering not only the restoration of health but also social aspects (Galvan et al., 2019). Furthermore, understanding that chronic illness in childhood implies the need for specialized care and access to Assistive Technology (AT) resources, the inaccessibility of equipment dispensing services, the high cost of resources, and the lack of professional training for assessment and prescription are factors that affect the quality of care and its comprehensiveness (Vieira et al., 2023). In this regard, human and material resources for adapting wheelchairs are pointed out as crucial in the context of some CCHCCs, such as Cerebral Palsy (Costa & Cruz, 2020). Authors discuss the development process of CCHCC and the need for continuous and specialized follow-up, making assistive technology resources essential, with barriers to accessing them being frequent in public healthcare contexts (Vieira et al., 2023).

Thus, it is important to recognize the role of the occupational therapist in the production of these resources and in coordinating actions aimed at the participation of these children (and their family caregivers) in meaningful daily occupations.

As AT is an indispensable resource for participation in occupations (Vieira et al., 2023; Costa & Cruz, 2020), it is possible to identify the harm to quality of life caused by a lack of access to these resources, which often occurs due to financial constraints, difficulty accessing healthcare services, and ineffective public policies. Given this, it is possible to think that families in social vulnerability contexts may have greater difficulty accessing the resources necessary for the care of the child.

In this sense, recognizing that the living conditions of these families affect the well-being and care of CCHCC is fundamental for structuring and ensuring the success of treatment: caregivers and children must have access to spaces for living and care that enhance their abilities and promote their quality of life. Therefore, it is important to understand whether CCHCC and their families truly have access to spaces that can provide comfort and dignity amidst the tasks inherent in caring for the child.

Stimuli for the child's development

In this major topic, the importance of an environment rich in stimuli is discussed, both for care at home - an aspect that is directly influenced by the family's socioeconomic conditions - and for periods of hospitalization. In this sense, it is important to be aware of the multiple demands of children with chronic conditions, such as postural changes, provision of sensory stimulation and toys, as well as opportunities to participate in daily activities (Carvalho et al., 2020), aspects that continue to call attention to the importance of the context for the treatment and development of the child.

Long and recurrent periods of hospitalization are a concern regarding the stimuli present in the environment. In the hospital context, playing assumes central importance as it is a source of stimulus for development, in the face of yet another disruption in the child's daily life. However, playing is still seen as something secondary for the health services team and family, since the main focus during the hospitalization period is disease control (Campos et al., 2019).

Therefore, given the demands of daily care and an exhausting routine, CCHCC play can be neglected in the stressful environment of treating a chronic health condition, whether in a home or hospital context, which directly impacts the supply of stimuli. The authors point out that, in many of these situations, the person responsible for care is the mother: these mother-caregivers experience a routine in which care for CCHCC is combined with care for the home, other children and spouse, in addition to a series of other activities and financial concerns that compete with offering incentives to the child.

When a complex chronic condition in childhood intersects with vulnerable contexts, it is necessary to consider the difficulties in providing a stimulating environment, in a routine marked by the need to guarantee survival.

The child's interaction with the environment in which they live is fundamental to their development, and any elements that may impact this interaction can be understood as barriers to the acquisition and development of skills to participate in fundamental occupations throughout the development process (Amaral et al., 2019). In the context of CCHCC, the intersection of the demands of health conditions and social vulnerability can harm the child's interaction with the environment, which can also generate stressors linked to lack of access to material goods, difficulty in accessing services, and lack of stimuli, among other situations in the social, economic and cultural context.

Therefore, negative experiences linked to the context of life can directly affect the development of CCHCC, their participation in activities of daily living and their involvement in social activities (Kolit et al., 2021). Authors carry out this discussion in the context of children with cancer with the aim of developing strategies that improve their participation in daily occupations, allowing them to understand that the negative experiences resulting from social vulnerability bring limitations to the lives of CCHCC and aggravate the restrictions imposed by the chronic disease itself.

As already discussed here, through the approach to the themes of studies on CCHCC, chronic illness results in disabilities, meaning that children and their families also live with the limitations resulting from the illness. In this scenario, it is important that care helps build possibilities for a better life (Lino et al., 2021).

Chronic illness and treatment strongly influence daily life, quality of life and family and social life. In this way, a high level of stress and disorganization is generated in the child, which consequently impacts their involvement in fundamental occupations (Monteiro et al., 2019). Authors speak of a routine permeated by changes in lifestyle habits and their results point to deprivations in the main occupations expected for the age group. As in most works, the living conditions of the family and their functioning are also considered, which again leads us to the importance of an integral approach, that is, reductionist thoughts that do not look at children and their families will not be able to promote better conditions of life.

The Mother as the Primary Caregiver

The theme mobilized in this section brings important contributions that reinforce the need for a comprehensive approach to CCHCC cases, since those who provide care also need care. Furthermore, we are once again faced with the importance of context on the treatment and development of these children.

Any childhood illness presents peculiarities that generate structural and emotional difficulties, changing the routine of the entire family nucleus. The chronically ill child becomes the center of attention, altering family functioning. Furthermore, the treatment has a strong impact on daily life, with travel, moving to another city, leaving a job, usually by the mother, who accompanies the child during hospitalizations, exams, and returns to the health service. In general, the mother bears the responsibility of being the main caregiver (Campos et al., 2019; Santos et al., 2020). All of this strongly impacts the participation of everyone involved in meaningful occupations, as the focus becomes the treatment of the child.

It is worth mentioning that gender issues and the belief that women have a great responsibility for caring for their children, the home and their partners are aggravated in the presence of a CCHCC, as the responsibility for looking after the child's survival, accompanying consultations, treatments and organizing the entire arsenal of home maintenance and dedication to the child.

When occupational therapists are heard about interventions carried out with mothers in pediatric wards, the findings of Souza & Joaquim (2023) reinforce the role of mothers as main caregivers not only in the home environment, but also in hospitalization contexts, which contributes to the occurrence of overload, impacting the health of these women and the care provided to the child. Therefore, the mentioned study contributes with reflections that make it possible to understand the diverse impacts of the role of mothers in comprehensive care for children.

There is a lot of research on the daily lives of mothers of high-risk babies in a hospital context, but little about the period after hospital discharge, a time when the family fully assumes the care of the baby (Petrokas & Galheigo, 2023). In both situations, hospital or home, mothers assume the role of caring. The authors state that caring for a high-risk baby at home is a lonely experience, which creates the feeling that life revolves around caring for the baby, even though other household tasks also remain under your responsibility, leading to physical and emotional overload. mental. Thus, the daily life narrated by mothers caring for high-risk babies after hospital discharge is surrounded by insecurity. The precariousness of post-discharge care continuity programs leads these women to personally weave a care network.

Despite the sociocultural and economic transformations related to the roles attributed and expected of men and women, in most families, mothers are still the most engaged in caring for children, which ends up generating physical, emotional and social overload (Cruz et al. al., 2019). When investigating paternal participation in child care, what is clear is that this participation is perceived as "help", and not as a "duty": the idea that the father's responsibility is to support the family is still maintained, so the division of care tasks is never equitable. Authors discuss that the father needs to be more than an adjunct in care, actively participating in the care routine, and their results allow us to conclude that even with the identification of maternal burden, plus the fathers' small participation, they consider themselves to contribute enough to the routine of care (Cruz et al., 2019).

In general, studies whose theme is the mother as the main caregiver allow us to understand that the presence of a CCHCC impacts the daily life, dynamics and functioning of the entire family, but women-mothers receive the greatest burden of this impact, being physically and emotionally and ceasing to perform their other occupational roles to dedicate themselves exclusively to caring for the child. All of this reinforces the importance of a comprehensive approach and attention to the context.

Social vulnerability

The studies that address the theme of social vulnerability do not involve complex chronic conditions in children (CCHCC). They were included in this review because they are part of the context of occupational therapy in childhood and can contribute to reflections on the impact of social vulnerability on the lives of these families.

Ferreira et al. (2023) emphasize that the home environment serves as the main space for children to explore and receive a variety of stimuli. The authors investigate the relationship between individual and environmental factors in the motor development of children in situations of social risk, as these children are more likely to experience motor delays. Although the study does not specifically focus on CCHCC (it was conducted in a school setting), it is important to reiterate that the barriers imposed by social vulnerability directly affect the stimuli experienced by children with CCHCC.

In analyzing the living conditions of families in social vulnerability related to well-being, mental health, and school participation of children and adolescents, Souza et al. (2019) identified that social and economic conditions have a significant impact on the quality of life of individuals. Adverse situations caused by limited access to services, due to social and economic precariousness, result in physical, cognitive, emotional, and occupational impairments.

In line with what has been presented here, the authors discuss that the inability to reconcile work with household and childcare leads to overload for women. The caregiving role assigned to mothers, especially those in social vulnerability, directly impacts their daily lives, changing their habits, roles, routines, and affecting their well-being and health. Furthermore, vulnerability manifests in insufficient purchasing power: income is low and unable to meet all the family's needs.

Returning to the context of families with children with CCHCC, as the primary caregiver of the child, the mother often has to step back from other roles and occupations, including work, to care for the child, which reduces the family's income. In this sense, families experience difficulties in reconciling expenses with food, housing, supplies, medications, and transportation, which increases the likelihood of these families becoming socially vulnerable.

Final Considerations

This mapping review points to the lack of studies that connect children with complex chronic health conditions (CCHCC) and social vulnerability, reinforcing the hypothesis that the social context in which CCHCC and their family unit live is still not widely considered. The findings, even though they do not link the two conditions, suggest that chronic conditions in childhood constitute a broad topic still shaped by various understandings of the term, pathologies, and the lack of studies that consider complex chronic conditions as a definition that truly reflects the situation of many children.

The path followed in this work leads us to develop an understanding based on the combination of common findings, indicating that the daily lives of children with CCHCC and their families are already directly impacted by the chronic condition, which can be further exacerbated by social vulnerability. As noted, it is clear that these families face significant challenges, often dealing with living conditions marked by physical and emotional overload, as well as difficulties accessing services. Furthermore, in a scenario where social vulnerability is just one of many daily violations of rights, families face ineffective public policies that do not ensure a better quality of life for the entire family unit.

The discussion related to maternal overload, specifically the need to balance childcare with other social obligations imposed on women, is common and recurring. This highlights the importance of creating a support network for these mothers, preventing physical, emotional, and social harm.

Therefore, it is essential to discuss how difficulties in accessing material goods and services, among multiple factors, can be aggravated by families' placement in vulnerable contexts. This underscores the importance of social and health service teams being prepared to provide comprehensive care, beyond life-sustaining support, and expanding care networks to include the family, surrounding environment, and community. In this regard, the perspective of occupational therapists in this context is crucial, as the very essence of the profession comes from the biopsychosocial understanding of individuals, valuing the influence of context on participation in daily occupations.

Finally, it is evident that new studies on this topic are needed in order to expand the evidence base that can demonstrate the negative impacts of social vulnerability on the daily lives of CCHCC and their families.

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Grazielle Keile Xavier was responsible for designing the text, analyzing and organizing sources, writing the text, reviewing, formatting the text and final review. Lediane de Oliveira dos Santos collaborated in data collection and synthesis. Maria Paula Panúncio-Pinto supervised the work and was responsible for designing the text, analyzing and organizing sources, writing the text, reviewing and formatting the text. All authors approved the final version of the text.

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