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REVIEW ARTICLE

Therapeutic itinerary of children with special healthcare needs: integrative review

Itinerário terapêutico de crianças com necessidades especiais de saúde: revisão integrativa

Itinerario terapéutico de niños con necesidades especiales de atención en salud: revisión integradora

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ABSTRACT

Objective: to analyze the scientific production of therapeutic itineraries established for children with special healthcare needs (CSHCN) in the Brazilian Unified Health System. **Methods:** integrative review of the literature in the databases MEDLINE, LILACS, CINAHL, SciELO, BDENF, and Web of Science, covering the period from January 2012 to January 2024. The PICo strategy was used to prepare the guiding question and descriptors. The studies were exported to the Rayyan QCRI application and analyzed based on the Care System in the Folk, Individual, and Professional dimensions. **Results:** nine studies were selected. They highlighted the leading role of families/caregivers of CSHCN in the construction of the therapeutic itinerary, the need for improvements in the professional care system, and the strengthening of the support network with aid from popular and folk care systems. **Conclusion:** there are deficits in achieving the constitutional principles of the right to health, universality, equity, and comprehensiveness in actions aimed at CSHCN, highlighting an incipient, weakened, and fragmented care network.

Descriptors: Disabled Children; Child Health; Therapeutic Itinerary; Delivery of Health Care.

RESUMO

Objetivo: *analisar a produção científica sobre os itinerários terapêuticos estabelecidos para crianças com necessidades especiais de saúde no Sistema Único de Saúde brasileiro.* ***Métodos:*** *revisão integrativa da literatura nas bases de dados MEDLINE, LILACS, CINAHL, SciELO, BDENF,* Web of Science, *referente ao período de janeiro de 2012 a janeiro de 2024. A questão norteadora e os descritores foram elaborados a partir da estratégia PICo. Os estudos foram exportados para o aplicativo* Rayyan QCRI *e analisados baseados no Sistema de Cuidados nas dimensões Folclórica, Individual e Profissional.* ***Resultados:*** *foram selecionados nove estudos, nos quais evidenciaram-se o protagonismo das famílias/cuidadores de crianças com necessidades especiais de saúde (CRIANES) na construção do itinerário terapêutico, a necessidade de melhorias no sistema de cuidados profissional, o fortalecimento da rede de apoio e suporte dos sistemas de cuidados popular e folclórico.* ***Conclusão:*** *há déficits no alcance dos princípios constitucionais de Direito à saúde, universalidade, equidade e integralidade nas ações voltadas para as crianças com necessidades especiais de saúde, evidenciando uma rede de atenção fragilizada, fragmentada e incipiente.*

Descritores: *Crianças com Deficiência; Saúde da Criança; Itinerário Terapêutico; Atenção à Saúde.*

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RESUMEN

Objetivo: *analizar la producción científica sobre itinerarios terapéuticos establecidos para niños, niñas y adolescentes con necesidades especiales de atención en salud en el Sistema Único de Salud de Brasil.* ***Métodos:*** *revisión integradora de la literatura en las bases de datos MEDLINE, LILACS, CINAHL, SciELO, BDENF, Web of Science, abarcando el período de enero de 2012 a enero de 2024. La pregunta orientadora y los descriptores se elaboraron con base en la estrategia PICo. Los estudios fueron exportados a la aplicación Rayyan QCRI y analizados con base en el Sistema de Atención en las dimensiones Tradicional, Individual y Profesional.* ***Resultados:*** *se seleccionaron nueve estudios. Ellos destacaron el papel protagónico de las familias/cuidadores de niños, niñas y adolescentes con necesidades especiales de atención en salud (NANEAS) en la construcción del itinerario terapéutico, la necesidad de mejoras en el sistema de atención profesional y del fortalecimiento de la red de apoyo con el apoyo de los sistemas de atención popular y tradicional.* ***Conclusión:*** *existen déficits en el logro de los principios constitucionales del Derecho a la salud, universalidad, equidad e integralidad en las acciones dirigidas a los NANEAS, evidenciando una red de atención debilitada, fragmentada e incipiente.*

Descriptores: *Niños con Discapacidad; Salud Infantil; Ruta Terapéutica; Atención a la salud.*

INTRODUCTION

The concept of Children with Special Healthcare Needs (CSHCN) refers to clinically frail children and/or adolescents (0–18 years) at high risk or in conditions dependent on specialized care beyond the scheduled/expected demands in this age group(1).

In most cases, CSHCN may have limitations or weaknesses that make them dependent on technology or long-term assistance, characterizing a chronic health condition(2). In this context, caring for CSHCN represents a challenge for family members due to the need to access knowledge and practices previously outside the context of their lives(3).

Similarly, when considering the demands and singularities of the care provided by professionals to CSHCN, challenges and weaknesses have been observed. They indicate the unpreparedness of professionals, the need for training, difficulties in accessing health services for both diagnosis and follow-up treatment for an indefinite period, the lack of clinical care protocols and lines of care, in addition to the lack of a well-established support network for this population in the Healthcare Network (in Portuguese *Rede de Atenção à saúde*, RAS) of the Unified Health System (SUS)(4). This scenario compromises access and qualified, comprehensive, and continuous care for these children, including in the basic healthcare context(5), a situation that may be worse in Brazilian border regions(6).

With the implementation of advances in technology and professional training and qualifications for the care of CSHCN in the SUS, family members/caregivers began to experience improvements in care and support(7), even though healthcare is still fragmented, incipient(6,7) and fragile from a clinical point of view. It does not meet the different care needs of this vulnerable population (individual and social), which presents several care demands and in practice, experiences limitations and barriers in the conditions offered by health services(1,8).

In this sense, the paths taken to end up becoming a pilgrimage and the challenges faced by families/caregivers in search of well-established coordination within the RAS highlight the discontinuity of care and denounce the absence of referral and counter-referral flows(9). The fragile care relationships at different healthcare points in the SUS combined with the individual and social vulnerability of families signal the need to strengthen therapeutic itineraries, lines of care, and care protocols to guarantee comprehensive care for this population(7,9).

The therapeutic itinerary is a central term in health that indicates the choices of treatments and paths taken by users in search of healthcare. In a broad scope, it covers the clinical-care trajectory under cultural influence, which is guided by choices and translated into care pathways(10).

Considering the relevance of strengthening and facilitating the paths taken by families in search of care for their children, this study aimed to analyze the scientific production of the therapeutic itineraries established for CSHCN in the Brazilian SUS.

METHODS

This is an integrative review of the literature. It was carried out in databases of the Medical Literature Analysis and Retrieval System Online (Medline) of the National Library of Medicine of the United States of America using the search engine PubMed, Latin American and Caribbean Health Sciences Literature (LILACS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scientific Electronic Library Online (SciELO), Nursing Database (BDENF) and Web of Science.

Six steps were followed in the organization of this integrative review:

1. Establishment of hypothesis or research question;
2. Sampling or literature search;
3. Categorization of studies;
4. Assessment of studies included in the review;
5. Interpretation of results; and
6. Synthesis of knowledge or presentation of the review(11).

In the first step, the PICo strategy was used to prepare the guiding question, in which P (Population — CSHCN), I (Interest — Therapeutic Itinerary), and Co (Context — Healthcare Network of the Brazilian Health System). The following question was generated: "*What is the therapeutic itinerary for Children with Special Healthcare Needs in search of care in the Healthcare Network of the Brazilian Unified Health System?*".

The second step, search in databases, was carried out in June 2023 and updated in April 2024 by two collaborators independently, using two search strategies: the Boolean operator "AND" between the strategies, and "OR" between the Health Descriptors (DECS). **Table 1** describes the databases, the respective search strategies, and the number of articles found.

Primary, complete, and original studies were included, as well as case studies conducted in Brazil, available online free of charge, published from January 2012 to January 2024 in English, Portuguese, and Spanish, in which CSHCN was the studied population. In this sense, the definition of children according to the National Policy for Comprehensive Child Healthcare (acronym in Portuguese, PNAISC) and the World Health Organization (WHO) was adopted; children are people aged 0–9 years(12). Theses, dissertations, review articles, and editorials were excluded.

The beginning of the time frame established for the search was the year 2012, chosen by taking into account the emergence, implementation, and advances of Public Health Policies that propose Comprehensive Care for Children, in which Ordinance No. 1,459 of June 24, 2011, referring to the *Rede Cegonha* (Brazilian public health policy of antenatal and birth care) stands out(13).

The search results in the respective databases were exported in "RIS" format to the Rayyan QCRI ap-

Table 1. Number of articles found according to the search strategy in each database until January 2024

Database	Strategy used	Articles
Medline	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	136
Web of Science	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	47
LILACS	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	17
SciELO	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	15
CINAHL	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	40
BDENF	*(child* OR "infant premature" OR "disabled children") AND ("Delivery of Health Care" OR "Comprehensive Health Care" OR "Child Health" OR "Child Care" OR "Maternal-Child Health Services" OR "Continuity of Patient Care" OR "Child Health Services") AND (therapeutic itinerary OR clinical* protocol*)*	05

Note: Medline: Medical Literature Analysis and Retrieval System Online of the National Library of Medicine of the United States of America (USA); LILACS: Latin American and Caribbean Health Sciences Literature; CINAHL: Cumulative Index to Nursing and Allied Health Literature; SciELO: Scientific Electronic Library Online; BDENF: Nursing Database.

plication[14] (free version, 2022, Qatar Foundation, Qatar). Duplicate articles were excluded and the titles and abstracts of the remaining articles were read by two researchers independently to check suitability for inclusion criteria. Differences in opinions were resolved after analysis by two other evaluators, also independently.

The articles included in this review were coded to better present the results, complying with the following criteria: S (study) followed by an Arabic number according to the chronological sequence in which the articles were published (for example, S1, S2...).

A data collection instrument was prepared to organize the results. It included the following variables: study code, year of publication, place of study, title, methodological design, description of the therapeutic itinerary, and the main findings.

Furthermore, the articles were classified according to the level of evidence as follows:

Level I: systematic review studies, meta-analysis of randomized controlled clinical trials, and clinical guidelines;
Level II: well-structured randomized controlled clinical trials;
Level III: well-designed but non-randomized clinical trials;
Level IV: case-control or well-structured cohort studies;
Level V: systematic review of qualitative and descriptive studies;
Level VI: descriptive or qualitative studies;
Level VII: opinion from authorities or expert reports.
In this classification:
Levels I and II are considered as strong evidence;
Levels III and IV as moderate; and
Levels V to VII as weak(15).

Data were analyzed based on the theoretical framework of the Care System in three dimensions: Folk (traditional), Popular (family), and Professional(10). This reference allowed the categorization of information and a better understanding of the results, taking into account the diversities, singularities, and particularities involved in the care of CSHCN.

In this context, folk care corresponds to alternative care without official regulation with a strong relationship to beliefs, values, and culture (healers, among others); popular (family) care, corresponds to the attention and care offered by family members, caregivers, friends who live with or are in some way close to the patient; professional care is represented by those with professional regulations at different points of healthcare(10).

RESULTS

Of the 258 articles selected in the initial search, 249 were excluded because they did not meet the inclusion criteria. Nine articles remained and they comprised the sample for this review. The search results are presented in the flowchart in **Figure 1**, prepared according to the proposal of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA Group)(16).

Of the nine articles selected, six (67%) are qualitative studies, in which family members have a protagonist role in the care of CSHCN and the construction of the therapeutic itinerary. The results of these studies reiterate the need to strengthen professional(3,6,7,17-22) and folk(6,22) care systems in the national territory. Regarding the level of scientific evidence, six articles (S1, S2, S3, S5, S6, and S8) have level VI (weak), and three (S4, S7, and S9) have level IV, that is, moderate evidence. **Table 2** presents a summary of the articles included in this study.

The largest number of publications on the therapeutic itinerary concentrated in the years 2020 and 2022 (55.5%)(3,6,20-22) suggests a growing current interest and the need for more studies on this topic(3,6,7,20-22).

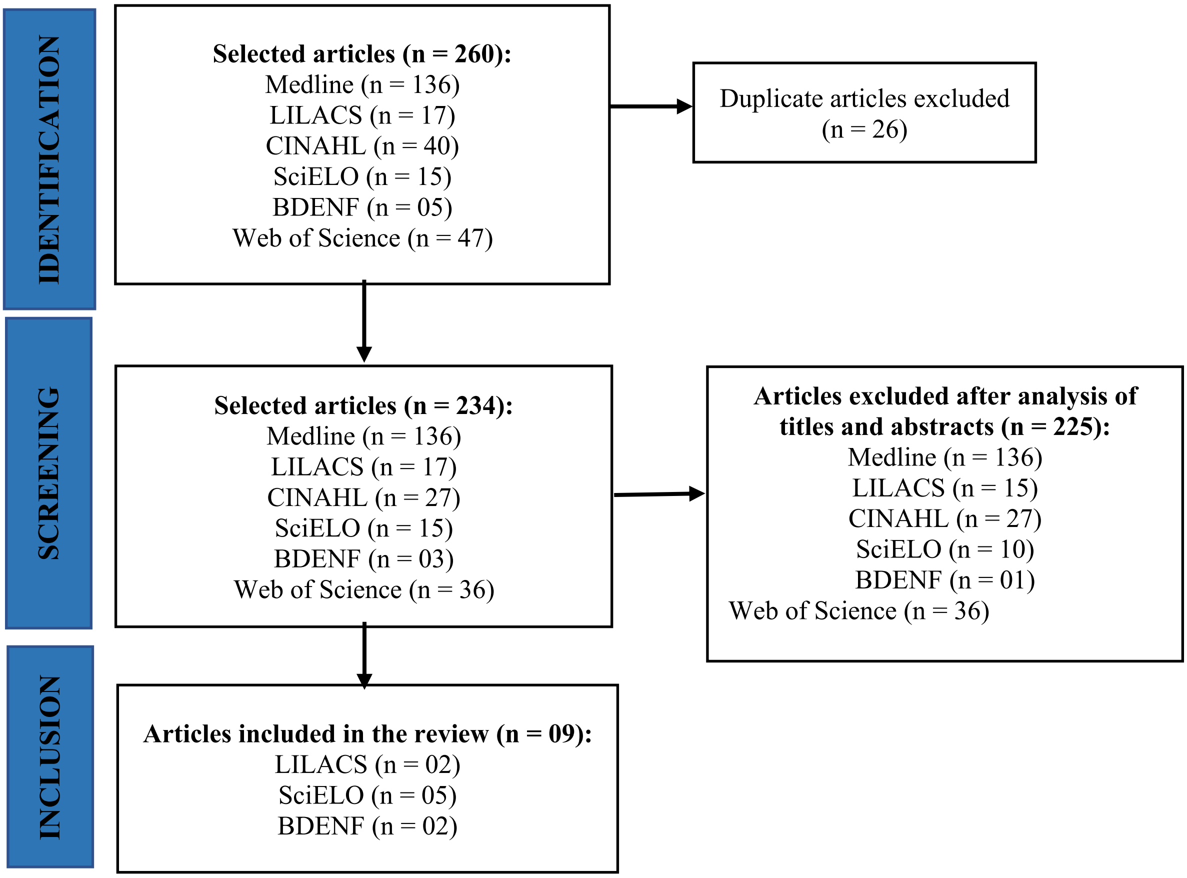
In the search for assistance and care for their children, family members/caregivers travel paths full of challenges, weaknesses, difficulties, affections, and hostility. These conditions are very present in therapeutic itineraries, especially concerning the professional care system, which was the most evident aspect in the studies included in the present review(6,17-22).

Among the obstacles, difficulties, and challenges faced, the incipience of RAS expressed uniquely in public health services, stands out(6,17-22).

Many studies indicate that most families exclusively use the Unified Health System for the healthcare of CSHCN. However, given the slowness of scheduling and doing some urgent exams, family members sometimes seek care in the private network to speed up the process(17). They count on the support of religious communities(17) or other family members to cover the costs or hire supplementary health insurance for care in the private health network(6,20).

The slowness and difficulty of accessing health services at different points in the RAS are well portrayed in studies, from diagnosis to continuity and effectiveness of care(6,17-22). Therefore, families of CSHCNs travel different paths and equipment within the SUS service network in search of assistance and care for their children(6,18,20).

Concerning the care system offered to this population, the care provided by professionals was the most discussed in the articles(3,6,7,17-22) and normally in



Note: Prepared following the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA Group)(16). Medline: Medical Literature Analysis and Retrieval System Online of the National Library of Medicine of the United States of America (USA); LILACS: Latin American and Caribbean Health Sciences Literature; CINAHL: Cumulative Index to Nursing and Allied Health Literature; SciELO: Scientific Electronic Library Online; BDENF: Nursing Database.

Figure 1. Study search and selection flowchart, January 2024

conjunction with the individual care system(3,17-19,22). In turn, folk care was mentioned in only one study(6), indicating the demand for religious and social groups.

DISCUSSION

Since 1995, there has been a growing increase in the theme of CSHCN internationally whereas, from 2000 onwards, this topic has been mentioned in the literature in the Brazilian scenario, showing the existence of a real population with demands for expressive and unique care resources(2,23) that sometimes involve a certain complexity of care, especially in cases of multiple pathologies, neurological diseases and disabilities(1).

In general, the therapeutic itineraries of families of CSHCN were full of challenges, and difficulties, marked by overload of care, continuous search for support, and healthcare, including in the private sector, although they are socially vulnerable. In cases where living conditions do not offer minimum financial resources, these families wait for care in long queues, according to the schedule of the specialized level in the SUS(6,17-22). The cases of disability and chronic neurological conditions presented the greatest challenges for care and construction of the therapeutic itinerary, especially in the professional system(3,22). This panorama is corroborated by other studies that indicate a lack of access and continuity of care; lack of physical structure at points of care and unpreparedness of health professionals in the face of different conditions and needs(24-26).

These findings signal deficits in the constitutional principles of the Right to Health; universality, equity, and comprehensiveness of health actions. The guarantee of fundamental health rights must promote professional training, so that CSHCNs can be assisted in a dignified, comprehensive, and coherent way with their demands, and a safe flow can be organized for the care and home care of CSHCNs in the context of RAS.

Although in theory, the National Policy for Comprehensive Child Healthcare within the scope of the SUS points to accessible, continuous, democratic, supportive care guided by the principles of the SUS(12), a challenging reality is experienced. Primary healthcare professionals face adverse conditions, such as varied re-

Table 2. Distribution of articles according to year of publication, location of study, title, theme and methodological design, therapeutic itineraries and main results, 2024

Reference and state	Theme and design	Therapeutic itineraries	Main results
Nepomuceno et al.(17) Mato Grosso	Ways of weaving networks for the care by families experiencing the chronic condition of adrenoleukodystrophy. Qualitative, descriptive-exploratory case study.	Lack of protocol and outlined flow; difficulty of access; professional negligence; little effectiveness of professional care in meeting the many needs of children living with a chronic condition; right to health.	Families develop the care network under their own logic, which is guided by the complexity of the situation, need, and lack of effectiveness of care. Families face difficulties in accessing and providing healthcare and obtaining effective responses to their needs, as well as neglect, indifference, and fragmentation of care.
Morais et al.(18) Bahia	Therapeutic itinerary of mothers of children who have undergone kangaroo care. Qualitative approach.	Care plan; Therapeutic itinerary of premature newborns.	The therapeutic itinerary is a path. In this path, the informal system is often sought by the family, whereas in the professional system, in addition to structuring care, there is a need to share it with the family, as the outlined itinerary is different.
Souza et al.(19) Bahia	Therapeutic itinerary for families of children with microcephaly. Qualitative, descriptive-exploratory study.	The itinerary highlighted the professional system and included the difficulty in diagnosis, social network, and spirituality.	It presents the itinerary for diagnosis and follow-up, showing difficulties mainly with the early diagnosis. The family is the first care unit in which the mother assumes the main role.
Dias et al.(3) Paraná	Organizational flowchart of home care for children with special healthcare needs. Quantitative, descriptive-exploratory, multiple case study.	Construction of a flow organization protocol for children with special healthcare needs in-home care services.	Need to develop a normative flowchart for home care of children with disabilities organizing the flow of care.
Vianna et al.(20) São Paulo	Therapeutic itinerary for deaf children in the healthcare network Qualitative case study	Protocol; Reconstruction of the therapeutic itinerary.	The hospital takes on a unique role in screening and using the clinical protocol to detect deafness, but it is flawed. Primary Health Care presented a problem with care coordination; another difficulty was the availability of rehabilitation centers in the municipalities of origin and the fulfillment of their role, moving towards a new methodology of care, promoting the coordination and comprehensiveness of actions for people with disabilities.
Petri et al.(21) Espírito Santo	The therapeutic itinerary of children with sickle cell disease. Qualitative, descriptive-exploratory study.	Screening (heel prick test), followed by centralized and specialized care.	The itinerary begins with the diagnosis. Participants reported satisfaction with the care offered in the Healthcare Network, although centralized. The secondary level of care was mainly accessed.
Farias et al.(22) Ceará	Construction of therapeutic itineraries for children with disabilities in the professional healthcare subsystem. Quantitative, descriptive-exploratory study.	Care flow.	It presents five paths: related to faith, support structures, medical and professional procedures, and health services. The professional system was recognized as deficient and fragmented.

Continue...

Table 2. Continuation.

Reference and state	Theme and design	Therapeutic itineraries	Main results
Casacio et al.(6) Paraná	Therapeutic itinerary for children with special healthcare needs: analysis guided by care systems. Exploratory qualitative study.	A delimited flow, protocols, or support for parents are not presented on this path (diagnosis, follow-up, and treatment).	The deconstruction of the therapeutic itinerary of CSHCNs was evidenced by barriers such as difficulty in accessing and resolving the health needs of CSHCNs and their families. Added to this is the burden on the caregiver, who is mostly the child's mother, as well as the fragility and fragmentation of the Healthcare Network for the care of CSHCN.
Rossetto et al.(7) Mato Grosso do Sul	Children and adolescents with special healthcare needs: care in-home, care services. Qualitative and quantitative, descriptive-exploratory study.	The flow or protocol are not organized.	Most cases are children/adolescents with cerebral palsy with medium complexity care needs. However, there are no flows or protocols for organizing care. Professionals develop educational activities, training, procedures, and case evaluations with families.

Note: CSHCN: Children with Special Healthcare Needs.

source deficits, work overload, and high demands from this population(27-29).

These situations and the fragmentation of care harm the continuity of care(30,31). One of the RAS bottlenecks for this public is access, followed by uncoordinated services, lack of comprehensiveness, resolution, and continuity of care(6,17-22), added to lack of coordination and fragmentation of care(6,20-22).

Family members sometimes weave laborious therapeutic itineraries affected by weaknesses of the health system. These produce a cascading effect on patients' care processes, resulting in care demands that overload family members/caregivers, forcing them to readapt by reorganizing their families and routines to provide care to their children(6,7,19).

Another point to highlight is the late and slow movement towards the construction/design of therapeutic itineraries for CSHCNs, the scarcity of studies on the topic, as evidenced in this review, and the lack of updating of public policies in the maternal and child area(12,30). The latest initiative in this area was Ordinance No. 1.130 of August 5, 2015, establishing the National Policy for Comprehensive Child Healthcare that features among its strategic axes: healthcare for children with disabilities or in specific and vulnerable situations(12).

Most therapeutic itineraries have been constructed essentially by family members in search of healthcare and assistance for CSHCNs, with a view to the weaknesses of the Care System in the professional component(5,6,8,17-19). In the pilgrimage experienced by families, there is an attempt to access different care systems(18,19,32,33). These itineraries were constructed based on the knowledge of family members/caregivers according to their socioeconomic and cultural conditions(1,32).

In the studies presented in this review, there were initiatives of some sectors of the professional care system to build the care flow by developing protocols that establish the path for the care of CSHCN, formalizing and institutionalizing these paths aimed at the comprehensive care of these children(3,19), and by validating home care protocols and flows(7).

In general, the health conditions and care needs of CSHCN require efforts from family members/caregivers in search of access to the professional care system, comprehensiveness, and effectiveness of actions(6,17-22), even though this care is not always efficient.

In addition to fragmentation, lack of flows, protocols or referral and counter-referral, other difficulties found in the professional system were the negligence and indifference demonstrated by health professionals and reported by family members/caregivers in one of the studies(17). However, the results of another study indicate satisfaction with the care received at some points of the RAS(21).

This scenario demonstrates there are different degrees of commitment in the professional system distributed across the different levels of healthcare in the RAS. They expose the difficulties in achieving the SUS principles of comprehensiveness, effectiveness, accessibility, and variability in the limitations in these aspects according to the uniqueness of the case. For example, in one of the studies, the lack of effectiveness of care due to the difficulty in early diagnosis of the child's special healthcare needs resulted from the professional's lack of ability to identify the problem(19).

This shows that not all professionals are properly qualified to care for CSHCNs, indicating gaps in training and continuing education, including specialized services(19). When the planning of the therapeutic itinerary is postponed, the start of the treatment and the stimulation of the child's neuropsychomotor development will be impaired(6,19), preventing the child from developing their full potential.

Among the strategies for expanding screening and the early identification of diseases that lead to special health conditions, the Brazilian Ministry of Health implemented the National Neonatal Screening Program regulated by Ordinance No. 822 of June 6, 2001, which was a major advance in the identification of CSHCNs. However, flaws in its implementation process still exist, as reported in one of the studies in this review. Regarding hearing screening(20), it warns that this situation may also be present in other types of screening proposed by the program.

Regarding the organization of health services, most were uncoordinated, except for one study(3), confirming flaws in the RAS and consequently, non-compliance with the principles of comprehensiveness, equity, and universality of the SUS(9,30).

The centralization of services(21) and the pilgrimage of families/caregivers at its various points due to lack of adequate guidance on the path to follow or the flows for care were other important aspects that weakened the RAS. This was the reality of most of the families included in the samples of the studies analyzed.

Decentralization of care is a principle of the SUS(34). Although it was established more than three decades ago, it has not yet been implemented in all areas of care, as seen in the case of care for patients with sickle cell disease(21).

Although people with this type of condition generally access the secondary level of care directly, instead of PHC, they should preferably be assisted by the Family Health Strategy (FHS) in PHC, since this is the priority gateway to the entire health system(32,33). This reinforces the importance of decentralizing these services and achieving greater resolution in PHC(21). Furthermore, the problems are intensified, considering the distance of reference and rehabilitation centers with the patient's city of origin(6,20), since financial assistance for family displacement is not always available(6).

Another relevant issue was that as the mother is the child's main caregiver(6,18,19), similar to the findings of another study(1), she is generally unable to engage in paid work. Although the purpose of this family arrangement is to minimize the risks of the child's health vulnerability, it can increase the social vulnerability of the family, as members need to organize themselves, especially from a financial point of view. This may contribute to families seeking different alternatives in care systems, and popular and informal systems are sometimes the first option(17,18).

These findings were also described in other studies, in which families sought alternative coping measures to deal with social vulnerability, and the therapeutic itinerary was constructed according to the family's living conditions, habits, and knowledge(1,35).

In this process, the family is impacted by obstacles, by not having their needs met, or by a lack of access and comprehensiveness of health actions or healthcare for their children. The stress this causes on the family goes beyond the difficulties of continuous care for the child, as depending on the therapeutic itinerary, it can become exhausting. In addition, the constant mobility of family members in search of support, and decisive, comprehensive, and continuous care creates tensions that harm relationships between families and professionals and, consequently, weaken the bond(36,37).

Thus, the care for family members and the caregiver is considered important, and social and emotional support is a strength for coping with care journeys(6), ensuring comprehensive, resolute, and timely care with well-delimited and clear care flows(38).

The folkloric medicine was used by participants in a small part of the studies(6,21), corroborating the literature, since there are few citations about this type of care(10). This is a recurrent fact, and the professional and individual (popular) systems are generally more debated(39). Anyhow, the folk system is a significant and extremely important element for care(6,39). It is expressed in the search for religious and social groups during the therapeutic itinerary(40), and the expectations of the professional health system must be aligned with the culture and values of people in their individuality(40).

For some special health conditions in certain regions, there is a more structured care process with a support network, covering professional, individual, and folk care systems(21). However, this reality is a utopia for most caregivers, family members, and parents of CSHCN, especially in border regions(6).

In border regions, these CSHCNs and their families/caregivers are affected by logistics and distance from large centers, delays in care, and consultations, especially from specialists. Other bottlenecks also prevent the continuity and comprehensiveness of care, still focused on the professional care system. In this sense, the PHC's role as the organizer of the network stands out in this context from the care provided by professionals and the formalization of bonds(6).

Publications classified as evidence level VI (weak), followed by level IV studies (moderate) predominated in this review. Although the development of studies with better levels of evidence is important(15), the object of study addressed here was to describe the paths taken by families of CSHCNs in search of care, directing, in a way, towards the descriptive or qualitative method in studies, which is justified by the research topic.

Families build their therapeutic itineraries according to their worldview, knowledge, and culture. Their choices are outlined by these conceptions in different care systems(10). This may justify the absence of a therapeutic possibility in the itineraries identified in this review within the scope of professional care systems. Although complementary therapies are beneficial for the comprehensive care of CSHCNs, they were not reported in the studies under analysis. Note that these constitute the scope of actions for the care of certain health conditions and contribute substantially to the treatment and quality of life of CSHCNs(41-44).

Studies carried out in Brazil on the therapeutic itinerary of CSHCNs are published in the country and abroad in journals with different types of access. The option to only include articles with open and free access may have been a limiting aspect of the present review. However, the studies analyzed allowed us to uncover important aspects of the topic, which can guide public policymakers and managers of health institutions linked to the SUS.

CONCLUSION

Important evidence was identified for the therapeutic itinerary experienced by families of CSHCN in search of healthcare in the Brazilian territory, especially concerning weaknesses in the professional component of the Care System, highlighted by difficulties in access, low resolution, and continuity (or lack thereof) of health actions. Different scenarios and paths were taken by family members to meet their needs, often autonomously and alone, characterizing a popular dimension in the exercise of care.

Cultural influence, although rarely reported, should be emphasized in the care system, as families have the right to choose/design their child's care path/plan based on their cultural experiences.

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Conflict of interests

None.

Author's contributions - CRediT

RBC: conceptualization; formal analysis; investigation; methodology; visualization; writing – original draft and writing – review & editing.

GA: conceptualization; formal analysis; investigation; methodology; visualization; writing – original draft and writing – review & editing.

RMMS: conceptualization; data curation; formal analysis; funding acquisition; methodology; project administration; resources; supervision; validation; visualization; writing – original draft and writing – review & editing.

AZ: conceptualization; data curation; formal analysis; funding acquisition; methodology; project administration; resources; supervision; validation; visualization; writing – original draft and writing – review & editing.

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