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ORIGINAL ARTICLE

HOME CARE: POTENTIAL AND CHALLENGES FOR THE DEHOSPITALIZATION OF CHILDREN WITH COMPLEX CHRONIC CONDITIONS

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ABSTRACT

Objetivo: To review and analyze the scientific evidence on dehospitalization through home care for children with complex chronic conditions. **Method:** A survey of articles published between 2010 and 2023 in the databases Web of Science, PubMed and Scopus was carried out in April 2024, following the PRISMA guidelines. Of the 385 articles found, 41 were considered eligible and 17 were selected for analysis. **Results:** The articles analyzed addressed different aspects of home care, organized into five thematic axes: costs, caregivers, transition of care, quality of home care and planning of home care. They highlight the importance of this type of care, the gaps for availability of this service, the policies involved and future directions in home care. **Final thoughts:** The literature review highlights the need for an approach that focuses on integrality and equity in care for children with complex chronic conditions, highlighting the importance of family involvement and empowerment. The implementation of comprehensive policies, adequate financing and the organization of health care in networks are essential to ensure a qualified home care, favoring the growth and development of these children.

Palavras-chave: Complex Chronic Conditions. Children's health. Pediatric home care. Prolonged hospitalization. Dehospitalization.

INTRODUCTION

The scientific and technological advances of recent decades have affected significantly the treatment and evolution of diseases. These advances modified or attenuated the natural course of the diseases, minimizing risks and reducing sequelae, as well as improving survival and quality of life for patients. Despite these efforts and the better understanding of pathophysiology and treatment of diseases, many of them still evolve to chronicity and some have been called Complex Chronic Conditions (CCC), either by the absence of current curative treatment, due to unmodifiable genetic factors or the severity of the disease. In these situations, long courses of disease with prolonged and recurrent hospitalizations, high-cost treatments and the need for specialized and multidisciplinary care are expected. The group of chronic pediatric patients, when compared with healthy children and young people with normal development, needs many different types of actions and services(1).

In Brazil, the creation of public, social and health policies played a crucial role in coping with chronic diseases. The National Policy of Comprehensive Child Health Care (PNAISC - *Política Nacional de Atenção Integral à Saúde da Criança*) emphasizes comprehensive care for children with childhood illnesses and chronic diseases, with the promotion of home care and hospitalization whenever possible. These strategies, together with actions to prevent chronic diseases, reinforce the role of Home Care (HC)(2).

As a response to the need for a more integrated action to improve care, the National Policy on Specialized Health Care (PNAES - *Política Nacional de Atenção Especializada em Saúde*) was established in the Brazilian Unified Health System (UHS). This policy broadens and guarantees the population’s access to specialized services in a timely manner, with territorial reference and considering regional needs. Its objective is to ensure equity in care

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and quality of care, as well as comprehensiveness, effectiveness and efficiency in the application of financial resources(3). Within this structure, the Home Care Services (HCS) are a strategy for the dehospitalization of children with Complex Chronic Conditions (CCC), offering person-centered care. Its objective is to reduce the fragmentation of care and strengthen work in multiprofessional teams, with support from the Health Care Networks (HCN) at their different levels: primary, ambulatory and hospital.

Improving the dehospitalization process and quality of life of children with CCC is important for patients and their families, but also for managers and professionals involved in hospital care. Reviewing works published in the literature, analyzing the experiences of other services in the dehospitalization of children with CCC, can contribute to increase knowledge on the subject, with the improvement of the provided care. In this sense, the objective of this article was to analyze the production of knowledge about home care for children with CCC, its role in dehospitalization, its specificities, potentialities and barriers, through a review of works published in the literature.

METHODOLOGY

A qualitative integrative literature review was carried out, following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)(4). The research question for this review (How has the dehospitalization of children with complex chronic conditions occurred through home care and what are the specificities, potentialities and barriers of this process?) was structured according to the PICo(5) model, namely: P (population): children in complex chronic conditions, I (interest): home care and Co (context): hospitalized children.

The search covered articles published between 2010 and 2023 in the databases Web of Science (WOS), Pubmed and Scopus, and the strategy was built in English as shown in chart 1. The combination of keywords was inserted in the topic option (title, abstract and keywords) of the articles and the same strategy was used in all databases.

Chart 1. Search strategy

“Health care servic*” OR “home care servic*” OR “pediatric home health” OR “pediatric home care” OR “home health care” OR “pediatric home servic*” OR “home child* care”
AND
“Pediatric complex care” OR “child* with medical complexity” OR “child* with special health care needs” OR “child* with complex chronic conditions” OR “technology-dependent child*”

Source: Research Data.

The temporal delimitation occurred because the field of knowledge in question is still little explored, having been effectively consolidated as a study area only from 2000. In the Brazilian context, the first ministerial decree on home hospitalization was promulgated in 2006, repealed by the Ordinance no 2029 of 2011(6) and redefined in 2016 (ordinance 825)(7). Recently, a new MH ordinance (n. 3005/2024) was published updating the rules of the HCS and the Better at Home Program (PMeC - *Programa melhor em Casa*)(8). The inclusion criteria covered only complete original articles. Abstracts of congresses, literature reviews, guidelines for clinicians, letters, notes and those without access to the full version of the document were excluded.

The search strategy returned 385 articles and the final sample was composed of 17 articles as described in figure 1 (Flowchart). After the selection process, we started the content analysis, starting with the pre-analysis, in which the articles were read in full to identify the role of HC in the dehospitalization of children with CCC.

Two reviewers independently conducted the five steps of the process: selection, evaluation, extraction, analysis and categorization of results, without the use of software. Both conducted critical analysis of the articles, categorizing the results according to the objectives of the study, and resolving the contradictions by consensus. The levels of evidence were classified into different categories: evidence from randomized clinical trials, cohort, prospective, qualitative studies and finally evidence from dissertation studies(9). The data synthesis was also performed independently.

In a second moment (material exploration), all the material was organized from the data found, identifying the thematic areas, and finally the treatment and interpretation of the results were done(9).

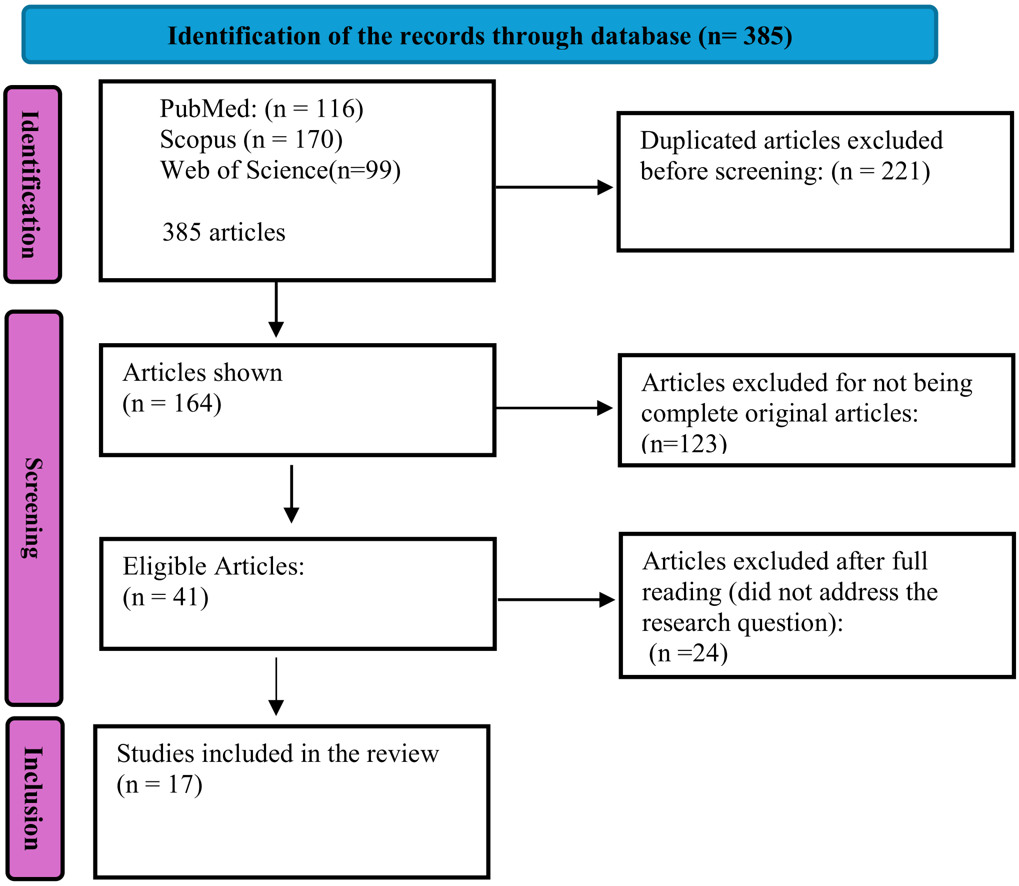

Figure 1. Flowchart of the selection process according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

RESULTS AND DISCUSSION

The information of the selected studies was extracted using a table prepared by the authors, which included the following sections: Authors/area of knowledge, Year, Country, Article Title, Study Design, Objectives and Results (Table 1). This organization allowed a qualitative and descriptive description of the data. In total, 17 articles met the criteria established in the methodology and were included in this review. Most articles analyzed were from the area of medicine (82%), followed by nursing (35%), psychology and physiotherapy (12%). Other areas, such as social service, epidemiology and biostatistics, accounted for only 1% of publications. These data show that this theme represents a research gap not only for nursing researchers, but also for professionals from other areas involved, considering the multidisciplinary nature in this field.

Table 1. Description of the studies analyzed and included in this review

Authors/area of knowledge	Year	Country	Title	Study design	Objectives	Results
Maynard R, Christensen E, et al. *Medicine* *Nursing*	2019	USA	Home Health Care Availability and Discharge Delays in Children with Medical Complexity	Multicenter prospective	To document causes, frequency, days and costs associated with delays in hospital discharge and readmissions	Discharge delays related to lack of nursing staff for new patients
Foster CC, Agrawal RK, Davis MM. *Medicine*	2019	USA	Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, and Future Directions	Dissertative	To analyze workforce gaps, payment models, and policy challenges in the care of complex children	Describes the main problems of pediatric home care
Notario PM, Gentile E, Amidon M, Angst D, et al. *Medicine* *Nursing*	2019	USA	Home-Based Telemedicine for Children with Medical Complexity	Randomized clinical trial	To assess the feasibility, usefulness and impact of a home telehealth device in the care of complex children.	Telemedicine device for home care providers
Nageswaran S, Easterling D, Ingram CW, et al. *Medicine* *Psychology* *Biostatistics*	2020	USA	Randomized controlled trial evaluating a collaborative model of care for transitioning children with medical complexity from hospital to home health care – Study protocol	Randomized clinical trial	To develop, implement and test a care delivery model that supports home care nurses	To provide strategies for reducing readmissions and other healthcare utilization metrics and reducing costs
Fratantoni K, Raisanen JC, Boss RD, Miller J, et al. *Medicine* *Nursing*	2019	USA	The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients	Qualitative	Better understanding of the pediatric home health care process	Process, barriers and facilitators of health care
Nageswaran S, Sebesta MR, Golden SL. *Medicine*	2020	USA	Transitioning Children with Medical Complexity from Hospital to home Health Care: Implications for Hospital-Based Clinicians	Qualitative	To describe issues related to the transition of children with medical complexity from hospital to home care	Domains for improving transition: health orders, communication, resources, preparation and caregiver
Sobotka SA, Dholakia A, Berry JG, et al. *Medicine* *Nursing*	2020	USA	Home nursing for Children with Home Mechanical Ventilation in the US: Informant perspectives	Qualitative, interviews	Experiences and opinions of home care providers for children on mechanical ventilation	Discrepancies between best practice and current reality of nursing hours
Leyenaar JK,	2018	USA	Importance and	Qualitative	To identify	Need for a high-

Rizzo PA, Khodyakov D, Leslie LK, et al. *Medicine*			feasibility of transitional care for children with medical complexity: results of a multi-stakeholder Delphi process		important and feasible interventions for transitioning care from hospital to home	quality, well-planned discharge program for complex children
Sobotka SA, Hall DE, et al. *Medicine*	2022	USA	Home Health Care Utilization in Children with Medicaid	Retrospective data analysis	To describe the landscape of home health care	To improve access to essential home care services
Foster C, Kaat AJ, Shaunfield, et al. *Medicine* *Psychology*	2022	USA	PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality	National multidisciplinary panel of experts	To measure the quality of home health care for complex children	Home health care measure for complex children to estimate quality deficits
Sobotka SA, Lynch E, Agrawal R. *Medicine* *Epidemiology*	2022	USA	The Role of Care Coordinators for Children with Respiratory Technologies and Home Nursing	Qualitative, interviews	To describe the perspective of care coordinators on their role in supporting families	Care coordinators for children with respiratory technologies require diverse skills
de Carvalho AJL, Ferreira HM, Borges EF, et al. *Medicine* *Physiotherapy*	2019	Brazil	Analyses of the effectiveness of Brazilian pediatric home care service: a preliminary study	Cross-sectional study, prospective data	To evaluate the effectiveness of the Home Care Service in relation to pediatric care	Children in home care had fewer infections, underwent fewer procedures, and had a lower readmission rate
Cohen E, Berry JG, Camacho X, Anderson G, et al. *Medicine*	2012	Canada	Patterns and. Costs of Health Care Use of Children with Medical Complexity	Retrospective cohort study	To assess health care utilization and costs in a population-based sample of complex children	Children with medical complexities are responsible for large costs
Tres DA, Martini RG, Toso BRGO, Zanatta EA *Nursing*	2022	Brazil	Characterization of Home Care Services and care for children with special health care needs	Qualitative, descriptive exploratory	To characterize the HCS in the state of Santa Catarina, knowing the main demands of children with special health needs	Care teams are critical in assisting and training family members and caregivers for children in HC
Babayan K, Keilty K, Esufali J, Grajales III FJ *Nursing*	2023	Canada	An After-Hours Virtual Care Service for Children with Medical Complexity and New Medical Technology: Mixed Methods Feasibility Study	Exploratory study, interviews	To establish the economic, operational and technical viability of a virtual care service expansion project	Virtual nurse consultation service is a useful tool for safe and positive care transitions
Thorburn-Winsor E, Doherty Met *Medicine* *Physiotherapy*	2022	Canada	Use of the interRAI PEDS HC in children receiving home care in	Cross-sectional study	To describe the beneficiaries of pediatric home care	Descriptive profile of beneficiaries of pediatric home care

			Ontario, Canada			
Mitchell TK, Bray L, Blake L, Dickinson A, Carter B. *Social Service*	2022	UK New Zeland	I feel like my house was taken away from me': Parents' experiences of having home adaptations for their medically complex, technology-dependent child	Qualitative	To identify the types of home adaptations that families need to care for their children at home	Differences in experiences and outcomes of home adaptations among parents receiving government subsidies

Regarding the country of origin of publications, the majority (65%) were from the United States (USA), followed by Canada (18%) and Brazil (12%). The analyzed articles addressed different aspects of health care and home care for children with CCC, HC and dehospitalization and, therefore, the following thematic areas were defined for analysis and discussion: costs, caregivers, transition of care, quality of home care and management of home care. The division by these axes shows that dehospitalization is a multifactorial process, which requires specific and integrated approaches that will be facilitated by the understanding of its potentialities, barriers and challenges for implantation and continuity of care, purpose of this article.

Costs

The USA is the country that most develops research on CCC and dehospitalization(10). Cost analyses in this country varied with respect to the evaluation model, and most focused on indirect costs of HC, especially those associated with hospitalization due to impossibility of home care. The costs of re-hospitalization of dehospitalized patients(11), delays in hospital discharge and the resulting increase in costs(12), the costs of private home care models with nurse support were evaluated(13) and the costs of using home telehealth devices(14). All the analyses show significant results, highlighting the importance of quality home care and the reduction of damage resulting from long hospital admissions, which increase costs and vulnerability to infections.

Children with CCC, despite being a numerically small group in relation to the general population, are responsible for a significant part of health costs. It was described that children with medical complexity hospitalized in Ontario corresponded to 0.67% of the total pediatric population of that province and represented 32.7% of the total costs in childhood health. Among those dependent on technology, the costs were 3.5 times higher than in children with CCC with only one organ affected by the disease(11), demonstrating the high cost of treatment in these situations.

In relation to adult or elderly patients with CCC, an analysis of the costs and benefits of HC was compared to hospital care, and it was found that the dehospitalization resulted in a decrease in the cost of food, supplies and equipment besides the release of hospital beds, reduction of readmissions and lower demand for emergencies, without considering the costs to families(15). A national study, also in the adult population, showed that the costs of the home system were lower compared to hospital, corroborating the viability and importance of HCS linked to the UHS(16). In a universal and equitable health system, it is important to plan and evaluate costs to optimize available resources. This is a challenge for HC, due to the complexity of the actions to be developed and the multiplicity of actors involved in care, where costs are still poorly defined, with a lack of publications, especially in Brazil. A national study that analyzed the direct cost of hospital care for children with CCC and technological dependence compared to non-chronic patients showed that the values are higher and increased according to the length of hospitalization(17). The current review did not find references on the costs of pediatric HC, highlighting the huge gap and the need for more studies in this field.

All costs of HC in the UHS are public, with funds intended directly for the payment of care teams, equipment and inputs released by a tripartite agreement – municipal, state and federal, as defined in the ordinance. From the perspective of hospital management, there is an impact on bed rotation, increased costs due to prolonged and unnecessary occupancy of beds by CCC, increased complications, risk of infections and high use of tests and procedures(10).

When patient care depends on electrical equipment (common in CCC), there is an increase in direct costs for family members. This has been an aggravating factor for low-income families, who lose formal jobs during long periods of hospitalization. One of the measures taken in Brazil to reduce the financial impact on families was the Electricity Social Tariff Ordinance, which established variable discounts in the energy bill of the residences for families with low income or who received the Continuous Benefit (BPC - *Benefício de Prestação Continuada*) from social assistance(18).

Caregivers

In the HC model, the caregiver is defined as the person with or without family ties, who is able to assist the user in their daily needs and activities, acting together with other family members. Its role is indispensable for the dehospitalization in the Brazilian public model of HC. This care is shared with the multidisciplinary team of HCS, which is responsible for the clinical follow-up of patients and the training of these caregivers. The involvement of family members should be ensured in all stages of dehospitalization, especially when it involves children with CCC. Caregivers and health care providers, at some points during the course of the disease evolution, must make decisions in a shared way, taking into account the clinical evidence and family preferences(19). This practice is still little used, especially when we talk about these children.

During the planning of HC, the various dimensions involved in care (psycho-affective, cognitive and moral) should be taken into account, reducing fatigue and aggravations in family dynamics(20). The health of the caregiver should be evaluated periodically, minimizing aggravations to him/her and consequent damage to the child's care. The guarantee of social benefits, through the BPC has been one of the ways in Brazil to ensure the minimum for the financial survival of these families, being sometimes the only source of income for the survival of the family. As this benefit is directed to the child and his/her needs, public policies should be considered that directly favor the caregiver. The 2024 National Care Policy was an important step in this direction, guaranteeing the right to be cared for, to care and self-care, without however mentioning the financial sustainability of the caregiver(21).

In private health care models in the USA, the presence of nurses at home for more complex patients is a common practice. The companies that provide this assistance consider the time worked by the caregiver with the patient when calculating the number of hours required for home nursing care(22). This does not happen in the Brazilian model of HC, since health professionals perform home visits and do not stay for prolonged periods in households, even in situations with dependence on invasive mechanical ventilation, that was incorporated in the scope of the UHS for patients with chronic respiratory failure(23).

Caregiver training, part of HC planning, is necessary to qualify the care initiated in the hospital environment and maintained by HCS teams during the HC period. A recent national study highlighted the importance of hospital training in the proper handling of technologies essential to children's well-being, such as tracheostomies and gastrostomies, evidencing its relationship with the improvement of the quality of life of these children(24). Caregivers who perceive themselves as capable have greater self-confidence, reducing emotional overload and fatigue. Ensuring the adequate technical preparation of caregivers is one of the success factors for home care(25,26). The need for caregiver training was rarely mentioned in the selected studies. In the North American model, there is specific training and capacity building for nursing developed by companies responsible for care, without mentioning the caretaker[20]. A Brazilian analysis on HCS reinforced the need for training of caregivers and highlighted the role of nurses as care coordinators, in addition to their role in education and training of parents and caregivers at home(27).

Care Transition

Care is a dimension of integrality in health, which transcends the curative practice, contemplating the individual at all levels of attention and social, family and cultural insertion. Care transition, understood as the transfer of patients between different levels of care, is an important part of the dehospitalization process and its success, avoiding discontinuity, interruption of treatment or exclusion of the user. It should be done in a planned and safe manner, with multidisciplinary and intersectoral involvement, within the concept of the HCN and integrality of care.

The pediatricians responsible for hospitalization are the basis for the beginning of the dehospitalization process and the care transition, especially in integrated and patient-centered health systems. They should multidisciplinary assess the needs of home care, map the HC services and networks available, contact the HCS of the child's living area, start training caregivers still in the hospital environment, ensure clarity in the information and provide information for other services, favoring the entire process of dehospitalization(28).

In the care transition, it is important to scale the effects of delay in the discharge of complex children, its causes, frequency and impact on hospital costs, in order to highlight the need for an available and easily accessible host network that ensures continuity of treatment according to the health demands of the user(12, 29).

In order to optimize the care transition, even in the hospital environment, the guidelines for the home must be well defined, there must be good communication between those involved in the various sectors, considering the opinions of providers of the home care(29). It is necessary to avoid the fragmentation of care(30), which can be reduced with effective coordination of the process, assisting children and families in seeking and integrating community health services and education necessary(28). The experience of health professionals who act as care coordinators is fundamental in the transition process, because they have more knowledge and are better able to support families, especially in situations where care teams have gaps and high turnover(30).

A current concern regarding dehospitalization involves security in the home and in the territories where patients are inserted, due to the violence present in large urban centers, with territories of difficult access and dwellings with inadequate conditions to receive patients. The involvement of the Social Service and the Public Agencies in the search for financing and solutions to improve housing conditions and safe alternatives for the care of teams should be a priority for HC.

Another important aspect in the transition is the need for better remuneration of professionals and the guarantee of maintenance of care teams, avoiding frequent turnover of professionals. This challenge of HC in Brazil is aggravated by municipal political changes and fragile employment links. To ensure the continuity of care and the permanence of children in their homes, HC should be structured as a state program, non-government.

Quality of Home Care

The quality of care provided at home depends on light technologies, which involve the relationships and bond between users and teams, the embracement and management of work processes, and hard technologies, related to the use of technological devices, apparatus and organizational structures(31). The main factor that defines HC as a new differentiated modality of care and determines its quality are light technologies. This includes the attitude of the health professional, who, in addition to technical training, must have relationship skills and maintain an active involvement with patients and their families.

The PNAES highlights key aspects to ensure the quality of work, such as encouraging the adoption of training strategies, lifelong education, valorization, provision and aiming at improving the attention and offering services with quality and in sufficient quantity to ensure access of the population, especially those from more vulnerable territories with assistance gaps(3). Service-based learning programs integrate teaching and learning activities into the daily lives of specialized care services and teams, promoting continuous improvement in the quality of care.

Due to the multidisciplinary nature of HC, it is important that all professionals are involved in the process. The pediatricians of the assistance are promoters of dehospitalization and therefore there should be a greater engagement and understanding of the process on their part(32). In the Brazilian model of HC, there is no description in published ordinances about the need and/or mandatory inclusion of pediatricians in multidisciplinary teams for the care of the most complex child (home care type 3-HC3)(8). Despite this, the absence of the pediatrician in the HCS teams may lead to delays in dehospitalization or be an impediment for it to occur. When the presence of a pediatrician in the team is not possible, alternatives should be sought such as the matriciation of teams for more specialized care or the availability of this professional for specific interventions whenever necessary. There is a complexity in pediatric care that needs to be included in the planning of HC, considering the focus on quality and effectiveness of this care.

Other determinants of the quality of care are the need for team cohesion, continuous training and adequate remuneration, strengthening the bond between staff and caregivers(20). There are regional variations in the provision of community and home health services in several countries, which are related to local administrative decision, the performance of care coordinators and available resources, and should be considered in this process. The search for quality involves individualization in planning, taking into account regional variations and the best ways and incentives to acquire and build support networks. Even in other countries with different socioeconomic realities from Brazil, there is concern about regional differences(25) and also about the social evaluation and the availability of family members for care(33).

In a country like Brazil, knowing the individual needs and political-social conditions of populations and regions allows the construction of individualized care plans. In a publication from Canada, using an assessment instrument - PEDS-HC by the agencies that provide HC, it was possible to standardize the assessment for pediatric HC beneficiaries, with data collection that reduced variability and promoted equity in care services, also allowing the comparison between regions(32). Comparing the access and quality of home care in different regions, wage differences, the training requirements that could affect the access or quality of service and parents' perception about improvements in care provided was the focus of a study to evaluate the quality of care provided(25). Other indirect measures of the quality of care are the favorable evolution of patients treated at home, in relation to the lower rate of readmission(34), the role of nursing at home as facilitator of hospital discharge(12) and the use of a telehealth device in home care to improve the care provided(14).

Effective communication between services, teams and families is a key point in this multidisciplinary work. The availability of an electronic medical record, which allows access to all professionals and families involved, improves the quality of care, ensuring the safe exchange of information and a better understanding of the patient’s illness process(28). Unfortunately, we do not yet have a unique electronic record to facilitate communication between health services in home care.

Telemedicine incorporated into the practice of HC has emerged as a safe alternative and auxiliary tool in this care, facilitating the control and supervision of patients, expanding the numerical capacity for patient care in specific and selected situations. Ensuring direct access of patients and families to the teams through online consultations is one of the factors that has transformed HC, enabling faster interventions, avoiding unnecessary displacements and reassuring families in situations of doubt, reducing the number of hospitalizations and consequently the cost(14). Telemedicine, regulated in Brazil by the Federal Council of Medicine (FCM) through resolution 2314/2022, has been useful in monitoring patients in their homes, as demonstrated in the covid-19 pandemic. Another example of the application of telemedicine was the creation of a virtual care program with caregivers of children with recent tracheostomies(35). Another key point for the quality of HC was the regulation of teleassistance in Brazil (resolution COFEN 696/2022), a nursing practice that uses communication and information technologies to promote health care, health education and supervision of nursing teams.

The creation of the Digital Information Department (SEIDIGI), responsible for formulating public policies to guide the management of digital health, was an important advance for the qualification of health care in Brazil. Established by Decree 11.358 of January 1, 2023, its objective is to support the Ministry of Health departments, managers, workers and users in planning, use and incorporation of information products and services and information technology in the field of health, as well as determining policies for the prospecting and incorporation of digital technologies and telehealth in the UHS.

Home Care Management

Care management is defined as the availability of health technologies, considering the unique needs of people at different moments of their lives, with the purpose of well-being, security and autonomy, being performed in six dimensions –individual, family, professional, organizational, systemic and societal(36). For the programming and organization of work processes, including HC, it is necessary to listen to each of the actors, identifying their potential and weaknesses, allowing autonomy and shared decision-making.

Some researchers in the review conducted after listening to parents and health professionals described five steps for planning pediatric home care: identification of needs, investigation of options, development of care plans, initialization of services and exploration of the needs involved(29). The personalized discharge for children with CCC is an important measure for the success of HC and should take into account the social evaluation and the availability of family members for home care, the need for a description of materials needed for care and the search for a coordination of this care(33). This is in consonance with the establishment of a Singular Therapeutic Project (STP)(37), an essential tool for the success of dehospitalization. It allows the identification of the problem situation and the sociofamily-psychological aspects involved; of the aspects of the disease itself that can modify the evolution and planning; the definition of goals in short, medium and long-term and the consequent division of responsibilities and professionals assigned to each activity and the reassessment of the goals defined at the beginning of the process. It should be used during the whole process of dehospitalization. Another important aspect for the management of care is related to health professionals who provide care. In the North American home care model, care is based on the continuous presence of nurses at home, as well as other professionals in a regular visiting system, based on available nursing agencies, who are hired for home care(13). In the Brazilian public model of HC, care is offered according to the patient's needs, without the continuous presence of professionals in the households. When there is stability of the patient's health condition and he/she needs less frequent visits, this care can be performed by the reference Primary Care. Cases of greater complexity, many with technological dependence and the need for more regular visits, are accompanied by the HCS Multiprofessional Home Care Teams (MHCT) and Multidisciplinary Support Teams (MST)(8).

Currently, maintaining more complex pediatric patients in HC has been a challenge for the health system, both from the point of view of the availability of equipment and supplies, as well as the need and maintenance of specialized teams. Social and housing factors play an important role in dehospitalization planning, as they involve necessary adaptations at home to receive technology-dependent patients. In addition to the issues of costs involved in reforms, which are a concern for low-income populations, it is necessary for the well-being of children and their families to create an aesthetic and functional domestic environment that optimizes health and brings home feeling for all(38). In Brazil, one of the great challenges imposed for the dehospitalization is the lack of adequate housing to receive these children, which does not present the minimum conditions of sanitation and infrastructure, aggravated by the impossibility of taking over these necessary reforms. The lack of a public housing policy for low-income families or the impossibility of government aid to improve housing for patients in HC directly affects planning, care transition and quality of care. It is necessary to develop public housing policies aimed at this population, favoring patients and their families with adequate and safe households as an important part of the HC process.

FINAL THOUGHTS

This review brought important contributions to the understanding and planning of HC in the care of patients with CCC, even in different health models. It highlights significant issues such as regional variations in the provision of care, the need to know the assisted populations, differentiated forms of payment, coverage of care, need for measurement of quality of care, the work force of caregivers and the involvement of parents in all stages of the process. It also highlights the barriers, potentialities and facilitators of HC, placing us in front of the main challenges for this care, which are interconnected, and calling us to propose changes to improve care. The need for public policies aimed at this population and caregivers also appears as an urgency for action planning.

The dehospitalization of children with CCC through HC has been shown to be a safe and viable alternative for the maintenance of care of these children in their homes, as well as for the optimization and provision of hospital beds. It enables the growth and development of these children, rescuing socialization, allowing reintegration of family members in the labor market and return to domestic activities essential for the maintenance of families. This is a challenge for managers and care teams, from their planning to the maintenance of this care, with the need for a defined flow that involves the actions and organization of the HCN, in the various levels of complexity.

Concerning future directions, it is crucial to continue the research, answering the knowledge gaps in this area and providing adequate support to families and health professionals involved to increase the use of technology in the monitoring of children to improve the provision of care. Comprehensive policy development, adequate funding and collaboration between health institutions and the various levels of the HCN, governments and communities can improve quality and access to home care for children with CCC.

ATENÇÃO DOMICILIAR: POTENCIALIDADES E DESAFIOS PARA A DESOSPITALIZAÇÃO DE CRIANÇAS COM CONDIÇÕES CRÔNICAS COMPLEXAS

RESUMO

Objetivo: revisar e analisar as evidências científicas sobre a desospitalização através da atenção domiciliar para crianças com Condições Crônicas Complexas. **Método:** Foi realizado, em abril de 2024, um levantamento de artigos publicados entre 2010 e 2023 nas bases de dados Web of Science, PubMed e Scopus, seguindo as diretrizes PRISMA. Dos 385 artigos encontrados, 41 foram considerados elegíveis e 17 foram selecionados para análise. **Resultados:** Os artigos analisados abordaram diferentes aspectos da atenção domiciliar, organizados em cinco eixos temáticos: custos, cuidadores, transição de cuidados, qualidade da atenção domiciliar e planejamento do cuidado domiciliar. Eles destacam a importância desse tipo de cuidado, as lacunas para disponibilidade deste atendimento, as políticas envolvidas e as direções futuras na assistência domiciliar. **Considerações finais:** A revisão da literatura evidencia a necessidade de uma abordagem centrada na integralidade e equidade do cuidado para crianças com Condições Crônicas Complexas, destacando a importância do envolvimento e capacitação dos familiares. A implementação de políticas abrangentes, o financiamento adequado e a organização da atenção à saúde em redes são essenciais para assegurar uma assistência domiciliar qualificada, favorecendo o crescimento e o desenvolvimento dessas crianças.

Palavras-chave: Condições Crônicas Complexas. Saúde da criança. Atenção domiciliar pediátrica. Internação hospitalar prolongada. Desospitalização.

ATENCIÓN DOMICILIARIA: POTENCIALIDADES Y DESAFÍOS PARA LA DESHOSPITALIZACIÓN DE NIÑOS CON CONDICIONES CRÓNICAS COMPLEJAS

RESUMEN

Objetivo: revisar y analizar las evidencias científicas sobre la deshospitalización a través de la atención domiciliaria para niños con Condiciones Crónicas Complejas. **Método**: se realizó, en abril de 2024, una recopilación de artículos publicados entre 2010 y 2023 en las bases de datos *Web of Science*, PubMed y Scopus, siguiendo las directrices PRISMA. De los 385 artículos encontrados, 41 fueron considerados elegibles y 17 fueron seleccionados para su análisis. **Resultados**: los artículos analizados trataron de diferentes aspectos de la atención domiciliaria, organizados en cinco ejes temáticos: costos, cuidadores, transición de cuidados, calidad de la atención domiciliaria y planificación de la atención domiciliaria. Ellos señalan la importancia de este tipo de cuidado, las lagunas para disponibilidad de esta atención, las políticas involucradas y las direcciones futuras en la asistencia domiciliaria. **Consideraciones finales**: la revisión de la literatura evidencia la necesidad de un enfoque centrado en la integralidad y equidad del cuidado para niños con Condiciones Crónicas Complejas, destacando la importancia del compromiso y la capacitación de los familiares. La implementación de políticas integrales, la financiación adecuada y la organización de la atención a la salud en redes son esenciales para asegurar una asistencia domiciliaria calificada, favoreciendo el crecimiento y el desarrollo de estos niños.

Palabras clave: Condiciones Crónicas Complejas. Salud del niño. Atención domiciliaria pediátrica. Internación hospitalaria prolongada. Deshospitalización.

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