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The experience of children and family in pediatric home hospitalization: A systematic review of qualitative evidence

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ABSTRACT

Objective: To synthesize the experiences of children and parents/caregivers in the process of pediatric home hospitalization (PHH).

Introduction: The practice of home hospitalization (HH), while not a new concept has expanded in recent years. This model of care consists of continuous care at home for children with acute illness or acute chronic disease and presents itself as an alternative to conventional hospitalization (Middel, 2007; Parab et al., 2013). Excellence in pediatric healthcare is fundamental and this review provides a necessary understanding towards the experiences of children and their families in HH.

Methods: Research was carried out in three phases and included both published and grey literature in the CINAHL, MEDLINE, MedLatina, PubMed, *Cochrane Library*, *Psychology and Behavioral Sciences Collection*, and OpenAIRE databases to find relevant articles. Studies published in Portuguese, English, Spanish, and French with no time limit were considered.

Results: Findings were aggregated into five categories: communication and care experiences, parental dynamics and role carers, benefits and challenges for parents and children, relationship between parents, children's, and healthcare professionals and enhancing continuity of care and family support. According to ConQual the confidence level of the results was moderate in all articles.

Conclusions: Through PHH, it is possible to avoid the impact of a conventional hospitalization since it promotes family union, increases the affective bond, the feeling of security, comfort, tranquillity, relief, confidence, and autonomy, reducing stressors such as anxiety, fear, nervousness, uncertainty, and fear.

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Background

One of the biggest challenges in healthcare is the achievement of quality and excellence in the care provided. According to the [European Association for Children in Hospital \(2022\)](#), children's rights to improved care must be given priority, regardless of the context in which they are practiced. However, it is recognized that this care should be provided at home, in the child's familiar environment, or, when this

is not possible, as part of outpatient consultation or at a day-care hospital ([European Association for Children in Hospital, 2022](#)).

One of the first crises in pediatric patients is related to disease and hospitalization due to the lack of coping mechanisms to deal with stress. By changing the environment, the child becomes more vulnerable ([Bsiri-Moghaddam et al., 2011](#)). Therefore, keeping children, as much as possible, in their family context is preferable to conventional hospitalization ([Cabrera López et al., 2022](#)).

Processes of transition experiences influence people's daily lives and environment. According to [Meleis \(2010\)](#), a transition is the move from one stage in life to another, a process triggered by change. This can potentiate striking changes in those who experience them, with significant health and welfare repercussions ([Meleis, 2010](#)). The transitions can be developmental, situational, health-illness, and organizational. Since the transitions are unique and complex, preparation and knowledge are

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needed, and the response to a transition process can be impacted by contextual, situational, and biological factors (Chick & Meleis, 1986; Meleis et al., 2000).

Changes in the environment and the child's health can trigger a transition (Meleis, 2010). In conventional hospitalization, the environment is different, so through the implementation of PHH, the feelings of anxiety and fear can be controlled. Given that theory and conceptual frameworks guide professional practice (Rice, 2001), the authors considered it crucial to resort to Afaf Meleis' Transitions Theory to sustain this process and better understand the various transition processes that exist and how nurses can operate to reduce the impact of each transition experienced by the child and their family (Meleis, 2010).

Human growth and development involve multiple transitions, often triggered by health-disease processes, and hospitalization urges a transitional process (Meleis, 2010). Therefore, this literature review will focus on the hospital-to-home transition. In conventional hospitalization, the trauma of separation of the child from their physical and affective environment causes a transition that could lead to a family crisis (Jorge, 2004; Pian & Klig, 2020). In these situations, the family frequently resorts to internal and external coping strategies and relies on the social support provided by the nursing team (Jorge, 2004).

Home care emerged in the late 17th century, with the Boston Dispensary in 1796, one of the first to provide home healthcare to alleviate and treat the sick without needing to distance themselves from their family. Florence Nightingale appointed neighborhood nurses who dedicated themselves to this practice (Rice, 2001).

In 1947, Martin Cherkasky, president of Montefiore Hospital, signed a contract with a healthcare organization to build home care with hospital care, thus creating the concept of "hospital-based home care." Cherkasky advocated that it was inhuman and unjust to divide people into independent areas and that knowing patients' families, environment, and daily life routine was essential to understanding them (Barondess, 1999). Home care supported by the hospital model was primarily aimed at the elderly. However, in 1973, this concept introduced specific procedures, including a younger age group (Mendes, 2001).

The search for more humane, personalized, and individualized care within the family and the need to reduce hospital admission fees and costs through early discharge led to greater interest and need for research on the home hospitalization (HH) modality (Parab et al., 2013). Families faced with the need for continuous child care reported that nurses' interventions were crucial (Sobotka et al., 2023). Thus arose the concept of pediatric home hospitalization (PHH), defined as constant care to children at home, as an alternative to conventional hospitalization in the advent of an acute disease or agudization of chronic disease (Middel, 2007; Parab et al., 2013). This 24/7, continuous monitoring at home can be performed through face-to-face visits, video, or telephone calls by a multidisciplinary team. Moreover, the development of telemedicine allowed continuous non-invasive monitoring at home and early detection of complications (Cabrera López et al., 2022).

The safety and success of this practice required a definition of inclusion criteria and a team to provide that care with specialized training. It also required compliance with clinical, social, and geographical principles (Cabrera López et al., 2022).

HH is intended to ensure a safe and timely response and continuity of care focused on patient's needs, allowing the articulation between the different levels of care to promote patients' wellbeing and recovery (Pian & Klig, 2020). The intervention of the healthcare team should guide and support the provision of childcare by parents in such a process, detecting and responding to the specific needs of each family (Pettersson et al., 2023). Every transition generates emotional responses reflecting the difficulties inherent to this process. Thus, it is essential to understand families' experiences during a hospital-to-home transition in an acute phase of the child's disease (Meleis, 2010).

To explore this topic, the authors assessed that no previous review has addressed the experience of children and families in PHH. No papers

were found in a preliminary search of this topic in PROSPERO, Open Science Framework (OSF), MEDLINE, CINAHL, Cochrane Database of Systematic Reviews, INPLASY, Zenodo, and Joanna Brings Evidence Synthesis.

Therefore, this study aimed to synthesize the experiences of children and parents/caregivers in PHH. This will contribute to constructing a body of knowledge that will inform the practice and achieve future health gains in PHH.

Material and methods

Design

This review of evidence from qualitative studies, was conducted in line with the Joanna Briggs Institute (JBI) guidelines for systematic reviews of qualitative studies, according to the PICO mnemonic (Munn & Aromataris, 2021). The main review question was: What are the experiences of children and families in the context of PHH?

The protocol for this study was previously registered in Open Science Framework on 9 January 2024 (doi:10.17605/OSF.IO/QRD6A).

Sample

Inclusion criteria were as follows: Studies with samples of parents, informal caregivers, and children going through experiences of PHH; Children under the age of 18 with acute or agudization of chronic disease; families of children and or any person identified by the child as a family (regardless of bloodline relation).

Qualitative studies exploring the experiences of children, parents, and informal caregivers who underwent a process of PHH were under analysis (expressions, behaviors, attitudes, and feelings generated in children, parents, and informal caregivers who go through this process); Papers following the concept of PHH: care provided at home, to the child and family at a stage of acute illness or acute chronic illness, by a multidisciplinary team ensuring 24/7 assistance, always safeguarding the safety of the patient and enabling the provision of individual and personalized care of quality and excellence. Mixed studies were also considered; however, only qualitative data were extracted. Additionally, grey literature, including theses and dissertations, were analyzed to maintain academic rigor. Studies published in English, Portuguese, Spanish, and French, without any time limitation, in all geographical areas were included to analyze and understand the phenomenon under study in depth.

Articles not accessible in full text and articles not related to the topic under study; Studies describing and evaluating the experiences and thoughts of the adult population in home hospitalization, health professionals, or other formal caregivers who provide care in the context of PHH were excluded, to focus on the experiences provided by the child and family. Studies that included the child in the context of institutionalization or end-of-life care were not considered. Purely quantitative studies were excluded.

Design

Two independent reviewers carried out the research in three phases and adapted it to each database chosen, with the primary objective of finding published and unpublished studies (Munn & Aromataris, 2021). Initially, exploratory and limited research was conducted, using PubMed and CINAHL to ensure that there were well-founded scientific studies for further analysis. In the second phase, a more careful selection was performed based on the inclusion and exclusion criteria. Subsequently, an analysis of each article that was considered relevant was carried out.

Each database was chosen with meticulous consideration of its relevance to the study area, ensuring a comprehensive coverage of the

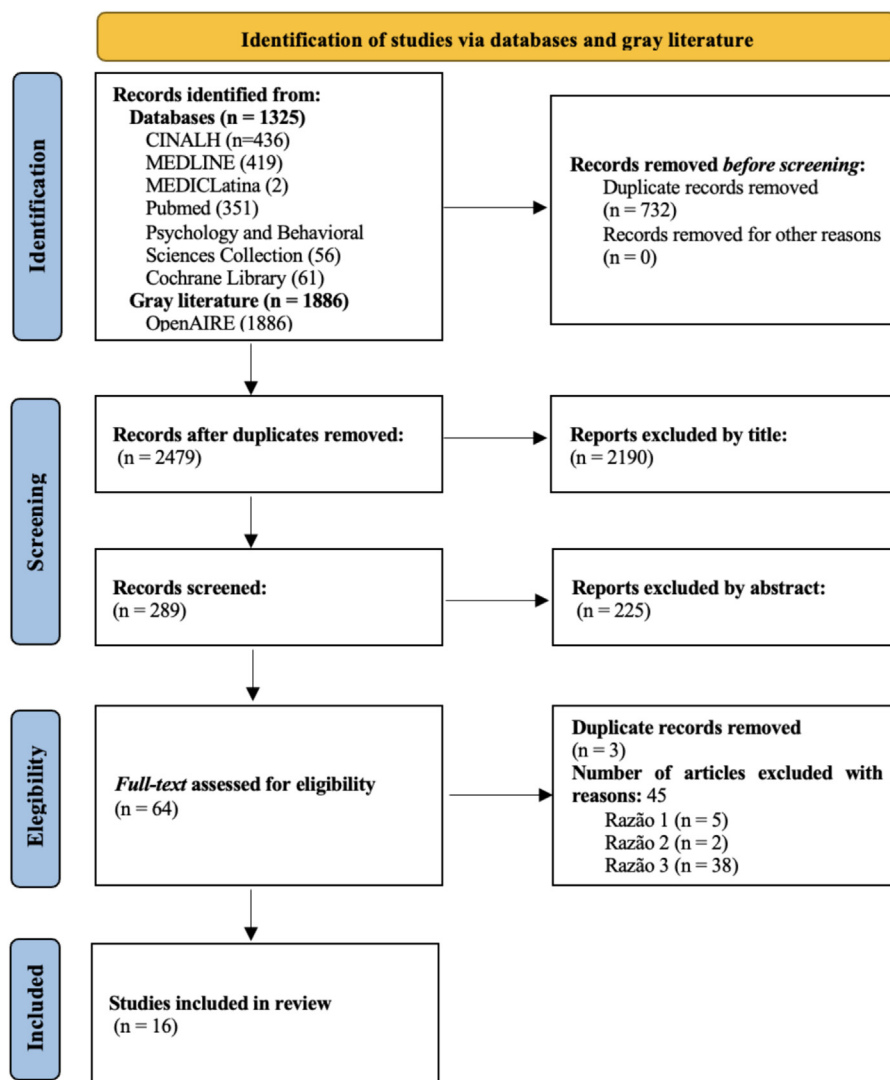
literature. Experts in database research sought guidance to improve the research. The following databases were searched: CINAHL Complete, MEDLINE Complete, MediciLatina, PubMed, Cochrane Library, and the *Psychology and Behavioral Sciences Collection*. Free/natural terms were used in all databases. As for controlled vocabulary, in CINAHL, the CINAHL Subject Headings were used, and in the remaining databases, the MeSH (Medical Subject Headings), except for the *Psychology and Behavioral Sciences Collection* database, where controlled and specific vocabulary was used, namely the subject terms. Grey literature was also included to expand the understanding of the phenomenon under study through OpenAIRE, using free/natural terms, and two research equations were created since the database does not permit the formulation of very complex equations. Boolean indicators AND and OR were used. The search strategies for each database mentioned above are detailed (Supplementary File 1).

In the third and final phase of the research, the bibliographic references of the articles selected to evaluate methodological quality were analyzed to maximize the identification of additional studies (Munn & Aromataris, 2021).

Study selection

As a guiding tool for this selection process, the Rayyan program was used to ensure an anonymous review by the two principal researchers of this review. Duplicate articles were initially excluded. Later, some articles were excluded by title, others by analyzed abstract, and content considered inappropriate or less relevant to the topic. After these selections, the studies were recovered in a complete analysis of the selected articles, and the reasons for exclusion were performed, as they did not fit the inclusion criteria defined a priori. Most disagreements were resolved by reaching a consensus in the first phase (selection by title), but a third reviewer was later included in the process, which determined the remaining disagreements. Then, eligible studies were carefully evaluated by two independent reviewers and didn't need a third reviewer.

The results obtained through the research were reported in whole and presented in the systematic review of qualitative studies using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow chart (Moher et al., 2015) (Fig. 1).



Reason 1: Methodology; Reason 2: Population; Reason 3: Phenomena of interest

Fig. 1. PRISMA flow chart of study selection.

At last, all studies that met the predefined inclusion criteria were assigned to evaluate methodological quality. The authors established as a prerequisite including at least seven “yes” answers in the ten questions and that question number eight, regarding the representation of participants and their voices, be answered in the affirmative, accordingly with a checklist provided by JBI was used for qualitative research.

Data extraction and management

Data were extracted from the studies based on a tool designed by JBI after being adapted to optimize data extraction. Thus, the extracted data included crucial details about geographic location, context, objective(s), methodology/method, participants, phenomena of interest, and main results.

Assessing the risk of bias compilations

The results of the confidence assessment were based on the guidelines given by JBI, using ConQual (Munn & Aromataris, 2021).

As for reliability, all articles were classified high since all articles were qualitative, except for one with a mixed methodology. At a later stage, considering the first five checklist questions of the methodological quality assessment, all received the answer “yes” except one that did not apply to a question, so we assume that the high rating continues.

As for credibility, all articles were classified as credible, which lowered a level as per JBI standards. Consequently, the final evaluation of all articles was determined to be moderate.

Data synthesis

The results of qualitative research were gathered and presented whenever possible, using the meta-aggregation approach. This will include the aggregation or synthesis of the results to originate a set of statements representing this meta-aggregation by grouping the results according to the classification of their quality and categorizing the results supported by the similarity of meaning. These categories are subject to a synthesis to generate a broad set of summarized results (Munn & Aromataris, 2021) and support for evidence-based practice in child and pediatric health nursing, mainly related to PHH. Only unambiguous and credible results were included. Where it was impossible to aggregate categories, the results will be presented in narrative form (Munn & Aromataris, 2021).

Results

An exhaustive search of the literature in the databases allowed us to obtain 3211 potential titles, of which 732 were removed due to duplication. Subsequently, 2190 were released after reading the title, and 225 were excluded after reading the abstract. There remained 64 articles that were fully recoverable and evaluated considering the a priori inclusion criteria, while three were removed due to duplication and 45 for not meeting the inclusion criteria. The latter were excluded for three reasons: five for not complying with the intended methodology, two for not specifying the desired population, and 38 for not including any phenomena of interest, PHH, and experiences. Of the 16 that were not excluded, all their bibliographic references of all included articles in the sample were analyzed, and seven articles appeared to meet the inclusion criteria after reading the abstract. Still, none were integrated into the review after reading the full text. Finally, 16 articles were included in this review (Aasen et al., 2019; Aasen et al., 2022; Angelhoff et al., 2015; Batlle et al., 2022; Castor et al., 2018; de Flon et al., 2021; Hägi-Pedersen et al., 2021; Hansson et al., 2012; Holm et al., 2019; Jennings, 1994; Jerntorp et al., 2021; Jönsson and Fridlund, 2003; Leite et al., 2022; Mougél, 2021; Sartain et al., 2001; Young et al., 2006).

Quality of included studies

All studies that met the predefined inclusion criteria were assigned for evaluation of methodological quality, and the checklist provided by JBI was used for qualitative research.

Before the evaluation, including at least seven “yes” answers in the ten questions defined by JBI was established as a prerequisite. However, it was considered a mandatory requirement that question number eight, regarding the representation of participants and their voices, be answered in the affirmative, the opposite being a criterion for exclusion. Careful evaluation of the methodological quality led to the exclusion of some of the studies. The methodological quality evaluation results will be presented in narrative format and as a table (Table 1).

Two studies were excluded because they did not meet the previously defined methodological quality criteria.

Characteristics of included studies

The characteristics of the included studies are presented in Table 2 according to the timeline and PICo mnemonic.

Characteristics of methodology and methods are found in Table 3.

Further characteristics of the included studies are found in Supplementary File 2.

Experiences of children and family in PHH

Understanding the experiences of the child and family is crucial for planning and providing care that meets the needs of families (Hansson et al., 2012). The environment of care changes, and

Table 1
Results of the evaluation of methodological quality.

Study	1	2	3	4	5	6	7	8	9	10
Aasen et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Aasen et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Angelhoff et al. (2015)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Batlle et al. (2022)	Y	Y	Y	Y	Y	U	Y	Y	Y	N
Castor et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
de Flon et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Hägi-Pedersen et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hansson et al. (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Holm et al. (2019)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Jennings (1994)	Y	U	Y	Y	U	Y	N	U	N	N
Jerntorp et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jönsson and Fridlund (2003)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Leite et al. (2022) - C	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Mougél, 2021 - C	Y	NA	Y	Y	Y	Y	Y	Y	Y	U
Sartain et al. (2001)	Y	U	Y	Y	Y	N	N	Y	N	N
Young et al. (2006)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
%	100	88	100	100	94	81	75	94	81	75

Y, Yes; N, No; U, Unclear; NA, Not Applicable.

JBI Critical Appraisal Checklist for Qualitative Research.

1 = Is there congruity between the stated philosophical perspective and the research methodology?

2 = Is there congruity between the research methodology and the research question or objectives?

3 = Is there congruity between the research methodology and the methods used to collect data?

4 = Is there congruity between the research methodology and the representation and analysis of data?

5 = Is there congruity between the research methodology and the interpretation of results?

6 = Is there a statement locating the researcher culturally or theoretically?

7 = Is the influence of the researcher on the research, and vice-versa, addressed?

8 = Are participants, and their voices, adequately represented?

9 = Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?

10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Table 2
Characteristics of the included studies: Time line and PICO mnemonic.

Time line	Between 2003 and 2022			
Participants	Type	Characteristics	Sample	
	Child Caregivers	Between 0 and 18 years Parents and informal caregivers	Interviewees Between 7 and 49	Questionnaire One sample of 532
Phenomena of interest	Experiences of the child and/or parents/caregivers	Hospital at home; home hospital care; hospital care at home; hospital-at-home with telemedicine; home care service; early neonatal home care; telehomecare; home care in NICU; home hospitalization; internação domiciliar; community home care; hospital services using monitors		

		Model of care	Number of studies
Context	Home	Pediatric clinic of a hospital	1
		Hospital	4
		Pediatric hospital	1
		Home care service	1
		Home hospital care project	1
		Neonatal ward	1
		Oncology ward	1
		Neonatal Intensive Care Unit	1
		Home Hospitalization Unit	1
		Private homecare company	1
			Continent
Geographic location	Europe	Barcelona	1
		França	1
		Norway	2
		Sweden	5
		Denmark	3
	America	Canada	1
		São Paulo	1

professionals enter a space that is not their own – the home – but it is here that they can make a difference in the lives of the children and families they care for (Mougel, 2021).

It is crucial to understand the resources available to each individual and the coping strategies that each person uses to deal with the stressors triggered by hospitalization based on physical, psychological, social, and economic variables. In the absence of resources and energy on the parents' part, stress can significantly and detrimentally impact the experience, even if at home. It is, therefore, essential to understand parents' experiences before PHH to mitigate these negative effects and achieve excellent care (Aasen et al., 2019).

PHH, in addition to enabling home care in situations of acute illness or acute, chronic disease, allows the early discharge of premature babies who have had a previous hospitalization in the NICU. From the perspective of Forsyth et al., (1998), the main stressors of parents of premature babies include financial constraints, stress associated with the child's condition, separation from the child, feelings of guilt, and sometimes mourning for the loss of a child they had idealized as perfect (Forsyth et al., 1998 cited by Jönsson & Fridlund, 2003).

The interconnection between the family and the pediatric department, PHH, and community teams should be constant and timely. Only in this way is it possible to reduce the impact of the transition from hospital to home in this home care regime to avoid feelings of insecurity and abandonment (Castor et al., 2018).

Table 3
Characteristics of the included studies: Methodology and methods.

	Type of studies	Theoretical framework	Number of studies
Methodology	Qualitative	phenomenology, participatory design, and ethnography	15
	Mixed		1
	Data collection		Number of studies
Methods	Open and semi-structured interviews		14
	Questionnaires		1
	Observation		1

When hospitalizations were very prolonged, parents mentioned that it felt unreal to be at home, noting that they were experiencing a dream. However, they identified that the challenges were even more significant and the degree of confidence lower at the time of the child's birth compared to early discharge (Hägi-Pedersen et al., 2021).

The decision to hospitalize a child with PHH is often driven by the strong desire to stay at home, as this is where the family meets (Aasen et al., 2022; Hägi-Pedersen et al., 2021). As Young et al. (2006) found in their study, parents often describe the feeling of returning home as an indescribable experience. Families reported decreased frequency and length of stay as beneficial (Hansson et al., 2012).

To synthesize the results found in the included studies, the results were aggregated into five main categories, presented below. (See Fig. 2).

Communication and care experiences

Mougel (2021) found parental dominance in communication because the parents take the lead on treatment and act as spokespersons for their children, and the child's voice tends to disappear due to the urgency of the information handled by adults. The length of interaction with the child becomes secondary, given the priority established by nurses in responding to caregivers' requests.

Nurses use therapeutic play and communication techniques, namely humor, to draw the child's attention, encouraging communication, autonomy, and participation in treatment. Therefore, nurses use to engage children techniques to establish a good and solid relationship, gain their trust, and praise their voice (Aasen et al., 2019; Castor et al., 2018; de Flon et al., 2021; Mougel, 2021).

Hansson et al. (2012) report the experiences and perceptions of children and parents of care children at home. Children feel a greater sense of security and wellbeing at home, where the environment promotes relaxation and recovery (Castor et al., 2018; Hansson et al., 2012; Young et al., 2006).

The positive home environment contributes to reducing negative feelings associated with the hospital. Children find comfort in their familiar surroundings, including the presence of pets, which are beneficial to their recovery (Castor et al., 2018; de Flon et al., 2021).

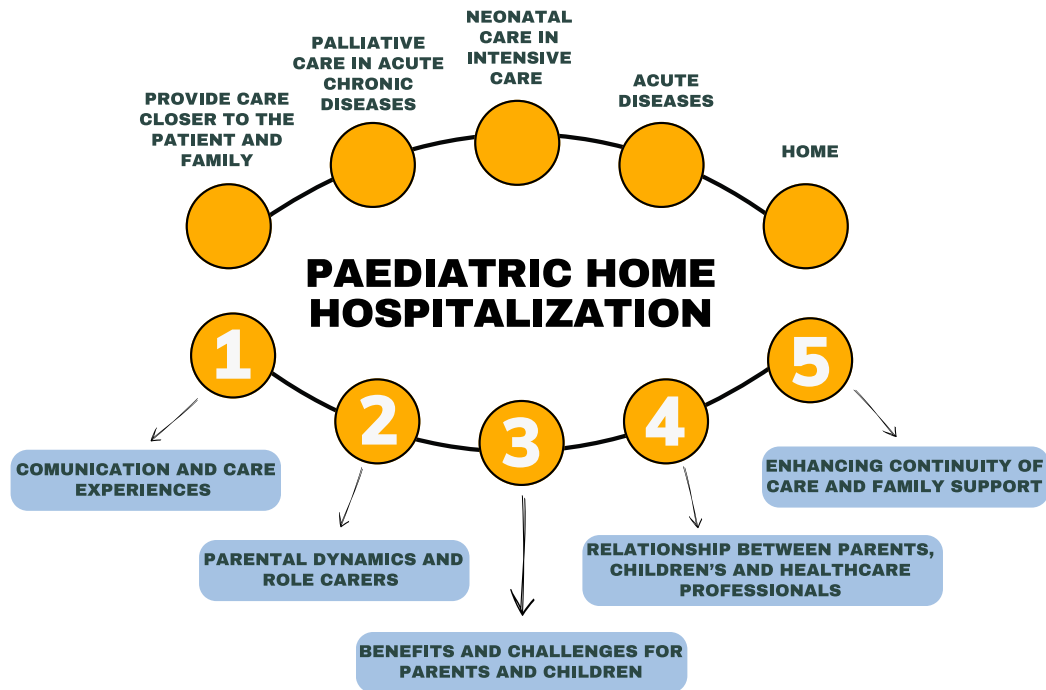


Fig. 2. Summary of results of included studies

Home care can improve various aspects of life, such as appetite due to homemade food, stable sleeping patterns, and overall satisfaction from the ability to customize the treatment environment. These factors contribute to a better quality of life and wellbeing for the child (Angelhoff et al., 2015; Castor et al., 2018; Hansson et al., 2012).

Parental dynamics and role carers

Parents' progressive familiarity with the procedures performed at home emerged, which generated a feeling of greater power, relaxation, and comfort. This results in greater parental responsibility and involvement in the child's care plan (Aasen et al., 2022; Castor et al., 2019; Hägi-Pedersen et al., 2021; Holm et al., 2019; Young et al., 2006). Thus, a risk of exhaustion on the part of the caregiver was reported due to work overload (Batlle et al., 2022; Young et al., 2006). The increased responsibility can lead to caregiver exhaustion due to work overload (Batlle et al., 2022; Young et al., 2006).

In some cases, especially in premature babies with early discharge, the team provided support tools like scales for monitoring weight and digital applications for recording health data to provide comfort and reassurance to parents, reducing anxiety and promoting a sense of security (Hägi-Pedersen et al., 2021; Holm et al., 2019). The concern and anguish of the parents arose from the greater vulnerability inherent in prematurity and the uncertainty of the baby's future. Economic pressures and lack of support can exacerbate these feelings, particularly for mothers (Jerntorp et al., 2021).

Fathers were concerned about the health of the baby and the mother's wellbeing because they knew that the mother had a greater responsibility for the child and that she sometimes felt unaided by professionals. They experience guilt for perceived inadequacies in supporting their partner and feel excluded or overlooked in caregiving process (Jerntorp et al., 2021).

Home care promotes more significant involvement of both parents, particularly fathers, which enhances the tranquillity of mothers and integrates both parents into the care process (Hägi-Pedersen et al., 2021; Holm et al., 2019; Jerntorp et al., 2021). This involvement leads to increased parental confidence and happiness.

Parents rely on professionals and social networks for support, comfort, and reflection, which are crucial for managing the emotional challenges of caregiving (Hägi-Pedersen et al., 2021). Caregiving challenges, including anxiety and economic stress, negatively impact parents' sleep patterns, leading to exhaustion and decreased overall well-being. Support from the health system and engaging in physical and leisure activities are associated with improved wellbeing and better sleep quality (Angelhoff et al., 2015).

Benefits and challenges for parents and children

Families often choose PHH for its comfort, better balance between work and family life, and reduced economic burden. Negative experiences in hospitals, such as anxiety and previous traumatic events, also influence this choice (Aasen et al., 2019; Batlle et al., 2022; de Flon et al., 2021).

PHH helps maintain family routines, strengthens relationships with extended family and friends, and allows for social interactions, often restricted in hospital settings (Castor et al., 2019; de Flon et al., 2021; Young et al., 2006).

Despite the advantages of PHH, parents reported some drawbacks, namely the lack of relationships with other families who also experience processes of health-disease transition, play activities at hospitals, the involvement of child entertainers, and the support provided by different professionals, particularly psychologists and social workers (de Flon et al., 2021). However, parents of children with cancer prefer limited contact with other affected families and reduced stress and tension associated with hospital visits and higher risk of cross-infection (Hansson et al., 2012).

PHH allows parents to feel more like a family, particularly after experiences in NICUs, where they often feel detached. At home, they feel relief and a sense of normalcy, which helps in strengthening family bonds (Aasen et al., 2019; Holm et al., 2019; Jerntorp et al., 2021; Jönsson & Fridlund, 2003) like maintaining daily routines and managing time better without the constraints of hospital policies; avoiding disruptions to siblings' education and family life (Angelhoff et al., 2015; Batlle et al., 2022; Castor et al., 2019; de Flon et al., 2021; Hägi-Pedersen et al., 2021; Hansson et al., 2012).

factors, and promoted better sleep patterns (Angelhoff et al., 2015; Batlle et al., 2022).

Through this training, new challenges have arisen through the implementation of PHH, with greater responsibility, trust, and active participation, something that promoted the parental role and enabled the partnership of care between parents and health professionals (Aasen et al., 2022; Hägi-Pedersen et al., 2021; Holm et al., 2019; Jerntorp et al., 2021).

A child's illness process causes an imbalance in the family, which must be addressed. PHH promotes greater acceptance of the process since it maintains family unity and proximity to all its elements and normalizes daily life. The family, therefore, experiences better time management, greater peace of mind, and a sense of relief (Aasen et al., 2019; Hansson et al., 2012; Leite et al., 2022).

Health professionals should always value each family's adaptation process, considering the coping factors, personal resources, and needs of each family (Angelhoff et al., 2015; Jönsson & Fridlund, 2003). Empowering families to provide care for their children and access specialized care, especially nursing, is crucial to allowing a successful and safe transition (Young et al., 2006).

Establishing a therapeutic relationship between professionals and the family led to greater confidence and security since the team was available to clarify any doubts that would arise during the hospitalization at home. Professional training and team cohesion were factors highlighted by parents in achieving quality care (de Flon et al., 2021; Leite et al., 2022).

Telemedicine enabled children to be cared for at home, uniting and making the family responsible for care (Holm et al., 2019). The emergence of these programs allowed early discharge and enabled the connection between the hospital and the home, improving family resources, promoting the child's wellbeing, and restoring the child's health (Young et al., 2006).

Through its implementation, it is possible to promote a safe transition to the home, where the assumptions of family-centered care are even more evident (Holm et al., 2019). Telemedicine ensures round-the-clock monitoring of families, promoting safety, autonomy, and accessibility (Hägi-Pedersen et al., 2021; Holm et al., 2019; Young et al., 2006).

From the reported experiences, the caregivers made suggestions for improvement, namely prior contact with primary healthcare, greater readiness in telephone care, transportation to the hospital where needed, the inclusion of a wireless telemonitoring device integrated into the caregiver's mobile phone, and reduction of noise associated with some medical devices, such as the nebulizer (Batlle et al., 2022). Nevertheless, overall experiences with these programs were positive (Hägi-Pedersen et al., 2021).

Through the analysis of the word cloud, it is evident that the positive feelings and experiences caused by PHH outweigh the negatives, demonstrating a high level of satisfaction in families who accept this model of care.

Limitations

This study has limitations; for instance, all studies analyzed the parents' discourse as primary caregivers of children. No studies presented other types of informal caregivers. Another area for improvement is related to the concept of PHH, which was found to vary in the international literature and could have led to the exclusion of studies during the analysis of the complete texts.

Recommendations for practice

The literature highlighted the need for health professionals, especially nurses, to become more sensitive to the child and family's needs. As such, more studies are needed shortly related to children's experiences in PHH. There is also an urgent need for researchers to conduct

studies in the field of telemedicine in toddlers, school-aged children, and adolescents since the studies focused mainly on neonatology.

The authors also aspire, in the future, to apply the knowledge acquired during their clinical practice and respective professional contexts. These consider PHH an innovative contribution to improving the quality of specialized nursing care in children and pediatric health, increasing the proximity of the child and family to the surrounding environment.

Conclusions

The health-to-disease transition is a process considered arduous by parents. The analysis of qualitative studies allowed us to verify many experiences before the PHH phenomenon. Through it, it was possible to reduce the impact of conventional hospitalization since it promotes family unity and increases the affective bond, the sense of security, comfort, tranquility, relief, confidence, and autonomy, reducing stressors such as anxiety, fear, nervousness, uncertainty, and fear. This enables a balance between the child's hospitalization and family life. From the reports of children and primary caregivers, it was noted that the experience of the disease at home eased this transition process since it made it smoother and less traumatic for the child. Negative experiences are described in both models of care but are preponderant in conventional hospitalization. It was shown that home care by a specialized team was essential for maintaining parents' trust in health professionals, which nurses significantly reported.

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CRediT authorship contribution statement

Catarina Pinheiro: Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Cláudia Pires:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Joana Romeiro:** Writing – review & editing, Visualization, Validation, Investigation. **Sílvia Ramos:** Writing – review & editing, Visualization, Validation, Investigation. **Zaida Charepe:** Writing – review & editing, Visualization, Validation, Investigation.

Declaration of competing interest

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2024.06.027>.

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