




SCOPING REVIEW

Children's and parents' experiences of home care provided by hospital staff: A scoping review

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Abstract

Aims: To describe what is known from existing scientific literature on children's and parents' experiences of hospital-based home care and to identify future research areas.

Design: The scoping review design used adheres to the methodological framework of Arksey and O'Malley, and to the PRISMA-ScR checklist.

Review Methods: A systematic search was conducted, and peer-reviewed scientific papers were screened through the application of Rayyan software. Data were extracted and presented in table and synthesised thematically as narrative text.

Data Sources: Searches were carried out November 2021 and updated November 2022 in the CINAHL, MEDLINE, Embase, Cochrane, Scopus, Web of Science, Academic Search Elite, and Amed databases and Google Scholar.

Results: A total of 1950 studies were screened and assessed for eligibility. Eight studies met the inclusion criteria by reporting on parents' experiences, whereas five out of these eight studies also reported on the experiences of children. Parents of children with cancer and preterm children reported feeling more in control, being empowered, and being more connected to their children's care team when their children were receiving hospital-based home care. The family's own resources were activated, and they felt more involved in their children's care compared to being in an inpatient setting.

Children with cancer, acute infection, chronic disease, and/or a syndrome reported feeling safer and more comfortable in their home environment and experienced better interaction with their care providers. Some aspects of the children's health-related quality of life (HRQOL) were improved.

Conclusion: The identified studies indicate that hospital-based home care is a valued alternative to traditional inpatient care by both parents and children. The mode of care has no crucial negative effects. Future studies should encompass the experiences of children with different diagnoses and syndromes and compare patients treated in a traditional hospital setting with those in a hospital-based home-care programme.

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Relevance to Clinical Practice: Children's and parents' experiences of HBHC indicate that it offers a good solution if parents are well prepared and feel in control. In addition, certain structural conditions must be in place before this type of care can be established: there must be a certain number of patients and the hospital must not be too far away. In the field of neonatal home care, professionals should be more responsive to fathers' needs and tailor support by focusing on their individual experiences and needs. Our findings may guide and inform best practice for present and future providers of HBHC.

Implications for the Profession and/or Patient Care: Hospital-based home care can offer families a greater degree of autonomy, more flexible care options, improved family functioning, improved communication with care providers, and more control over the child's care. When certain structural conditions are met, such as a certain number of patients, the hospital not being too far away, and parents being well prepared and feeling in control, then hospital-based home care is valued as an alternative to traditional inpatient care. Specific aspects of children's HRQOL may improve, and the psychosocial burden on the family does not increase.

Impact: HBHC provides a valued alternative to traditional inpatient care and allows families to receive care in the comfort of their own home. Our findings may guide and inform best practice for present and future providers of hospital-based home care.

Reporting Method: In this scoping review, we have adhered to the Preferred Reporting Items for Systematic reviews and Meta Analyses Extension for Scoping Reviews checklist.

Patient or Public Contribution: There has been no direct patient or public contribution to the review.

Trial and Protocol Registration: Not required.

KEYWORDS

children, hospital-based home care, parents, scoping review, self-reported experiences

1 | INTRODUCTION

Preterm birth and acute or chronic illness in children of any age can require hospitalisation for the child and parents, and a long and demanding care pathway may be necessary. Medical treatment is a fundamental right of children, and the best interest of the child and the child's parents/caretakers should always be taken into consideration, whenever treatment and care are offered (European Association for Children in Hospital-for sick children, [n.d.](#)). A child must be admitted to hospital only when absolutely necessary and should be discharged as soon as possible (European Association for Children in Hospital-for sick children, [n.d.](#)). Patient- and family-centred care interventions are increasingly being implemented in various settings for improving the quality of health care (Park et al., [2018](#)), and there seems to be a shift towards care being provided closer to the patient, with more children receiving care in their homes. This mode of care can be a feasible alternative, as a hospital stay when a child is sick may lead to difficulties in maintaining everyday life for the family (Castor et al., [2017](#)).

What does this paper contribute to the wider global clinical community?

- This paper describes the existing scientific literature on children's and parents' experiences of hospital-based home care.
- This paper identifies future research areas that need to be explored within the field of children's and parents' experiences of hospital-based home care.

Paediatric home-care services (HCS) are defined as care that 'substitutes for acute hospital review and/or admission by providing clinical review, support, education and management of the acutely or chronically unwell child in their own home' (Parab et al., [2013](#)). There are different models for organising, delivering and financing home care for children internationally and within countries (Parab

et al., 2013; Spiers et al., 2012). Services may also be offered in the municipality, by community-based healthcare teams (Castor et al., 2017). These kinds of services have become more common internationally and within countries, as a hospital stay when a child is sick may lead to difficulties in maintaining everyday life for the family (Castor et al., 2017). Different tele- and e-health interventions have also been tested with regard to follow-up of children and their parents when they are leaving the hospital (Dol et al., 2017; Hylén et al., 2022).

A systematic Cochrane review published in 2006 (Cooper et al., 2006) found limited evidence of specialist home-care programmes for children, with few randomised controlled trials undertaken and heterogeneity amongst the trials that had been completed. However, there was evidence suggesting that home-care programmes may lead to greater parent satisfaction, improved quality of life, and reduced length of hospital stays. The cost-effectiveness of home-care programmes was still to be determined (Cooper et al., 2006).

Another Cochrane review published in 2013 showed that the current research did not provide supporting evidence of reduced access to hospital services or reduced hospital readmission rates for children with acute and chronic illnesses using specialist home-based nursing services; however, the only summary finding across the studies was of a significantly decreased length of hospitalisation (Parab et al., 2013). No adverse impact on physical health outcomes was shown, and several papers reported improved satisfaction with home-based care compared to in-hospital treatment. There was insufficient evidence to support the effectiveness of specialist paediatric nurse home visits for acute and chronic illnesses in terms of reducing hospital stays (Parab et al., 2013).

Studies reporting on the experiences of families receiving help offered by community-based healthcare teams in the municipality, where the children who received care were aged 0–14 years and had different diagnoses and care needs, show that the families experienced the treatment of their sick child at home as strengthening and normalising for family life, in addition to saving them time and energy (Castor et al., 2017, 2018). Good communication and the fact that the nurses from the home hospital took the time to build a relationship of trust with the family were described as necessary for a good experience. Some participants also described experiences where they felt overwhelmed and the nurses did not have sufficient competence or did not satisfy their need for information (Castor et al., 2018).

Hospital-based home care (HBHC) is defined as services provided by an ambulatory team managed by a hospital and offered by ambulatory teams staffed by specialised paediatric nurses and other multi-professional hospital staff (Parab et al., 2013; Parker et al., 2012). Accessibility varies, ranging from a few hours per day on weekdays to a 24-h service. As far as we know, no review exists that reports on children's and parents' experiences of HBHC. As there are multiple outcomes describing the perspective of the users, and

these are obviously not included in one single outcome, a scoping review approach has been chosen for this study.

2 | AIMS

The aims are to describe what is known from the existing scientific literature on children's and parents' experiences of HBHC and to identify research gaps within this area.

3 | METHODS

3.1 | Design

The methodological framework by Arksey and O'Malley was used in the conduct of this study and (Arksey & O'Malley, 2005) includes the following steps: (a) identification of the research question, (b) identification of relevant studies, (c) study selection, (d) charting the data, and (e) collating, summarising and reporting the results. Also applied were the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist and explanation (Tricco et al., 2018), consisting of 22 items relating to title, abstract, introduction, methods, results, discussion and funding (Data S1).

3.2 | Search methods

In the first stage, we developed a scoping review protocol. Our research question was refined by using the Population, Intervention, Comparison, Outcome, Study (PICOS) framework (Amir-Behghadami & Janati, 2020), whereas we applied the Population, Exposure, Outcome (PEO) version (Table 1). 'Population' was used to refer to children and parents, 'exposure' to hospital-based home care, and 'outcomes' to experiences. The planning of search terms and choice of databases were made and searches were conducted in collaboration with a health science librarian. A combination of medical subject terms and free text words were used, and the terms were combined with Boolean operators as shown in the documented search history (Data S2). Electronic searches were carried out in the CINAHL, MEDLINE, Embase, Cochrane, Scopus, Web of Science, Academic Search Elite and Amed databases using

TABLE 1 The population, exposition and outcome (PEO) model used to conduct the search.

Population	Exposition	Outcome
Children 0–18 years	Hospital based home care	Experiences
Parents/caregivers		

relevant keywords to capture evidence, which was limited to peer-reviewed scientific papers published between 2008 and January 2022, in a Nordic language or English. A grey literature search was performed in Google Scholar.

3.3 | Inclusion and/or exclusion criteria

The criteria for inclusion were that the studies assess children's and parents' experiences of HBHC, as delineated in the introduction. All kinds of study designs were accepted. Studies assessing community- or municipality-administered/-based home care or tele-/e-health/digital interventions were excluded.

3.4 | Search outcome and selection of sources of evidence

The initial searches in the electronic databases conducted in November 2021 identified 1880 articles. Following the removal of 240 duplicates, a total of 1640 articles were transferred to the software Rayyan. To ensure consistent application of inclusion and exclusion criteria, all of the authors (EGB, JD, MGB and AM) performed a blind pilot screening of titles and abstracts in 10 papers, followed by clarification and mutual understanding. Then, as two pairs, each pair of the researchers performed a blind screening of half of the remaining titles and abstracts. Disagreements were first resolved through discussion by the two authors constituting a pair, and thereafter through discussion involving all four authors. The same procedure of blind review followed by consensus was performed for the selection of full text articles. An updated search was conducted in November 2022, and a total of 377 new articles were identified, of which 67 duplicates were excluded, leaving 310 articles to be screened according to the eligibility criteria, first by title and abstract and then in full text. After the screening process was completed, eight studies were included for further analysis. Reasons were given for the exclusion of all papers screened in full text, as detailed in Figure 1 PRISMA flow chart (Page et al., 2021).

3.5 | Quality appraisal

No quality appraisal of the included articles was performed, as a scoping review method had been used (Arksey & O'Malley, 2005).

3.6 | Data abstraction and synthesis

Two of the authors (EGB and AM) read the included studies individually and extracted the following key information for inclusion in a table (Table 2): (1) author(s), year of publication, and country of origin (where the study was published or conducted); (2) methodology/design; (3) study population and sample size (if applicable); (4) aim(s);

(5) results/outcomes and details of these (e.g. how measured); and (6) conclusion/key findings related to the scoping review question(s). Study characteristics were described, and findings were thematically organised and presented narratively in accordance with Arksey and O'Malley (Arksey & O'Malley, 2005).

4 | RESULTS

4.1 | Selection of sources of evidence

Of the 1950 studies screened and assessed for eligibility, eight studies (Aasen et al., 2019; de Flon et al., 2021; De Zen et al., 2021; Hammarstrand et al., 2008; Hansson et al., 2012, 2013; Hemle Jerntorp et al., 2021; López et al., 2022) met the inclusion criterion of reporting on parents' experiences, and five of these eight studies (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013; López et al., 2022) met the criterion of reporting on children's experiences of HBHC. Reasons for exclusion at each stage are presented in the attached PRISMA flow chart (Figure 1).

4.2 | Characteristics of sources of evidence

Qualitative ($n=4$) (Aasen et al., 2019; de Flon et al., 2021; Hansson et al., 2012; Hemle Jerntorp et al., 2021), quantitative ($n=3$) (De Zen et al., 2021; Hansson et al., 2013; López et al., 2022), and mixed ($n=1$) (Hammarstrand et al., 2008) methods were used. Three of the studies were published in Sweden (de Flon et al., 2021; Hammarstrand et al., 2008; Hemle Jerntorp et al., 2021), two in Denmark (Hansson et al., 2012, 2013), one in Norway (Aasen et al., 2019), one in Italy (De Zen et al., 2021), and one in Spain (López et al., 2022) between the years of 2008 and 2022. Two studies report the results of parents of neonates (Hammarstrand et al., 2008; Hemle Jerntorp et al., 2021), the latter only of fathers. Four studies report the results of both children with cancer and their parents (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013), and two studies report on both children with different diagnoses and their parents (Aasen et al., 2019; López et al., 2022). The studies' sample sizes ranged from 5 to 217 children aged from 0 to 17 years, with a median age of 6 years (IQR 2.3–9.5) (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013; López et al., 2022), and from 7 to 217 parents (Aasen et al., 2019; de Flon et al., 2021; De Zen et al., 2021; Hammarstrand et al., 2008; Hansson et al., 2012, 2013; Hemle Jerntorp et al., 2021; López et al., 2022).

Hansson et al. (2012), Hemle Jerntorp et al. (2021), de Flon et al. (2021), and Aasen et al. (2019) all used a qualitative descriptive method with open qualitative interviews, and the analyses were performed by qualitative content analysis or Giorgi's outlines for phenomenological analysis.

A quantitative design was applied by Hansson et al. (2013) in an intervention study with an HBHC programme to assess its feasibility in terms of satisfaction, care preferences, safety, and cost. A controlled trial was conducted to assess children's health-related quality of life

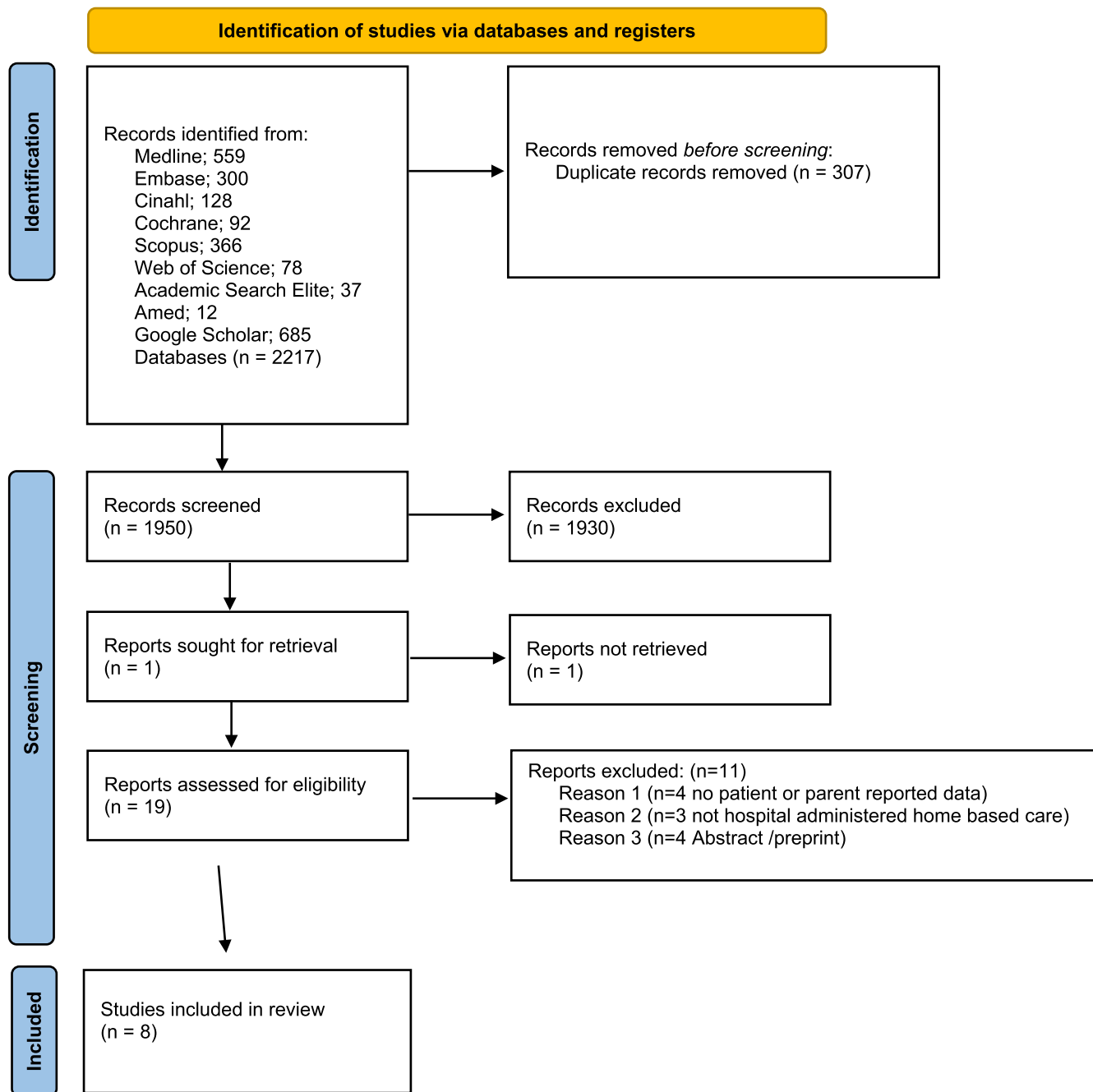


FIGURE 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only. Source: Page et al. (2021).

(HRQOL) by way of the parent-reported and self-reported Paediatric Quality of Life Inventory (PedsQL) Generic Core Scale and PedsQL Cancer Module (Varni et al., 2002), and the psychosocial impact on the family was assessed by the PedsQL Family Impact Module (Varni et al., 2004). De Zen et al. (2021) conducted a quantitative pilot study, where parental satisfaction was explored through an email survey of 32 Likert-type and short open questions. López et al. (2022) conducted a retrospective observational study (survey).

Hammarstrand et al. (2008) used a mixed methods approach with descriptive statistics when conducting a cost comparison analysis of HBHC and traditional hospital care. Furthermore, they

provided qualitative descriptions of parental experiences after the provision of HBHC.

4.3 | Results of individual sources of evidence

Data identified in the individual studies that relate to the review question are presented chronologically according to the year of publication, as in Table 2.

In a study of a neonatal home-care programme for neonatal infants who were physiologically stable but in need of further

TABLE 2 Overview of the included studies by author, year and country of origin, method/design, study population, aim, results and conclusion.

Author, year, and country	Method/design	Study population	Aim	Results	Conclusion
Hammarstrand, et al., (2008) Sweden <i>A neonatal home care program— an evaluation for the years 2002–2005</i>	Mixed methods Descriptive statistics, a cost comparison with traditional hospital care Qualitative descriptions of parental experiences after receiving hospital- based home-based care in 2005	Neonatal infants physiologically stable but in need of further special care (n = 390) and parents (n = 10) participated in the neonatal home-care programme during the years 2002–2005	To evaluate parental experiences of a neonatal home- care programme from a four-year perspective at Lund University's hospital in Sweden	On average, each infant spent 17 days in the programme and received a mean of 4.6 home visits When the costs of traditional hospital care were estimated, neonatal home care was found to be less expensive Interviews with 10 parents revealed that, in hospital, parents felt vulnerable and incompetent when caring for their child. At home, they felt comfortable and gradually became more confident	Neonatal home care with the support of staff from the neonatal unit is feasible and less expensive, activates the family's own resources, and normalises family life
Hansson, et al., (2012) Denmark <i>Hospital-based home care for children with cancer: A qualitative exploration of family members' experiences in Denmark</i>	A qualitative descriptive inductive method with open interviews was used Qualitative interviews were transcribed verbatim and analysed by qualitative content analysis	Parents (n = 14), representing 10 families, were interviewed about their experiences of a hospital-based home- care programme during a four-month period of 2009 at a university hospital in Denmark Children (n = 5) with a cancer diagnosis aged 4–15 participated in all or part of the interview	To describe the experiences of a hospital-based home-care programme of families of children with cancer	Hospital-based home care enabled the families to remain intact throughout the course of treatment, as it reduced the strain on the family and the ill child, maintained normality and an ordinary everyday life, and fulfilled the need for safety and security	According to family members of children with cancer, hospital- based home-care support enhanced their quality of life during the child's cancer trajectory The results highlight the importance of hospital-based home care being provided with consideration of the family members' needs for the sense of security that results from home care that is provided by experienced paediatric oncology nurses and regular contact with the doctor In future studies, interviews with children and siblings could be an important source of information for planning and delivering care suited to the families' perceived needs

TABLE 2 (Continued)

Author, year, and country	Method/design	Study population	Aim	Results	Conclusion
Hansson, et al., (2013) Denmark <i>Hospital-based home care for children with cancer: Feasibility and psychosocial impact on children and their families</i>	Intervention study A hospital-based home-care (HBHC) programme was carried out to assess its feasibility in terms of satisfaction, care preferences, safety, and cost A controlled trial was conducted to assess children's HRQOL by way of the parent-reported and self-reported PedsQL Generic Core Scale and PedsQL Cancer Module, and the psychosocial impact on the family was assessed by way of the PedsQL Family Impact Module	A subsample of children ($n = 28$) (age range 0–17, median 8) with cancer and parents ($n = 43$) in the home-care group, and children ($n = 47$) and parents ($n = 66$) receiving standard hospital care	To assess the feasibility and psychosocial impact (i.e. HRQOL) of a hospital-based home-care (HBHC) programme for children with cancer	The families received a mean of 10 home-care visits (range 1–75) All parents in the HBHC programme were satisfied and preferred home care. There were no serious adverse events associated with HBHC and costs did not increase When adjusting for age, gender, diagnosis, and time since diagnosis significantly higher HRQOL scores were found for parent-reported physical health ($p = 0.04$; 95% confidence interval (CI): 0.2–19.5) and worry ($p = 0.04$; 95% CI: 0.4–20.6) in the home-care group, indicating better physical health and less worry for children in the home-care group No significant difference was found in the Family Impact Module	This study indicates that HBHC is a feasible alternative to hospital care for children with cancer and that it is greatly preferred by parents Specific aspects of children's HRQOL may be improved with HBHC and the psychosocial burden on the family does not increase
Aasen et al., (2019) Norway <i>Being in control and striving for normalisation: A Norwegian pilot study on parents' perceptions of hospital-at-home</i>	Semi-structured qualitative interviews were performed and the data were analysed by qualitative content analysis	The sample included mothers ($n = 6$) and fathers ($n = 3$) aged 27–56 years (average age 39 years). Their children varied in age from new-born to 17 years and suffered from infection, cancer, chronic disease, and various syndromes	To explore how parents with a sick child experienced early hospital discharge and further care at home. The authors were especially concerned with identifying conditions that parents emphasised as important for mastering daily life at home	The results show that the parents experienced hospital-at-home as providing a calmer, more predictable family life as compared to hospitalisation. Good information and training in medical procedures prior to hospital discharge made hospital-at-home easier to master. The participants pointed out the importance of the professionals' competence and their ability to interact with the child and the parent. The certitude that they could return to hospital at any time made them feel safe and in control. The parents associated hospital-at-home with a kind of normalisation of family life. They had a strong need for normalisation, which probably motivated their agreeing to the hospital-at-home arrangement	The findings indicate that hospital-at-home for children is a good solution if the parents are well-prepared and feel in control. In addition, certain structural conditions must be in place before this type of health care can be established: there must be a certain number of patients and the distance to the hospital must be clearly limited. Norwegian policymakers should initiate more pilot testing of hospital-at-home for children. Users and clinicians should be involved in establishing and evaluating these services

(Continues)

TABLE 2 (Continued)

Author, year, and country	Method/design	Study population	Aim	Results	Conclusion
Hemle Jerntrorp et al., (2021) Sweden <i>Fathers' lived experiences of caring for their preterm infant at the neonatal unit and in neonatal home care after the introduction of a parental support programme: A phenomenological study</i>	A qualitative descriptive study, using Giorgi's outlines for phenomenological analysis.	Fathers (n = 7) from a larger study were included due to their rich narrative interviews about their experiences of neonatal home care. The interviews took place after their children's discharge from neonatal home care	To describe fathers' lived experiences of caring for their preterm infant at the neonatal unit and in hospital-based neonatal home care after the introduction of an individualised parental support programme	The general structure of the phenomenon can be described according to the following four themes: the partner was constantly present in the fathers' minds; the fathers were occupied by worries and concerns; the fathers felt that they were an active partner to the professionals; and the fathers were getting an opportunity to take responsibility. The fathers were satisfied with the support and treatment during their infant's hospitalisation. However, there were times when they felt excluded and not fully responsible for their infant. The fathers prioritised the mother, thus ignoring their own needs. Furthermore, they worried about their infant's health and the alteration of their parental role. Neonatal home care was experienced as an opportunity to regain control over family life	The general structure of the fathers' experiences highlights the importance of professionals being more responsive to fathers' needs and tailoring support to fathers by focusing on their individual experiences and needs
De Zen, et al., (2021) Italy <i>Safety and family satisfaction of a home-delivered chemotherapy program for children with cancer</i>	Pilot study Parental satisfaction was explored through an email survey of 32 Likert-type and short, open questions	Children (n=35), 22 male and 13 female, with a median age at diagnosis of 6 years (range 1–15 years, IQR 5 years) Main caregivers (21 mothers and 2 fathers) (n = 23) answered the anonymous questionnaire (dropout rate 8%)	To investigate the safety and feasibility of, along with parental satisfaction with a home chemotherapy programme implemented between 2011 and 2019 in a region of Italy	35 patients received 419 doses of intravenous chemotherapy at home (cytarabine, vincristine and vinblastine). The mean time spent on each home visit was 45 min. No adverse events were reported. 23 out of 25 eligible families completed the survey Most reported being 'very satisfied' with opportunity to maintain a work/domestic routine and reduce the time and financial burden of hospital access. Most were 'very satisfied' with the opportunity for their child to be less troubled by the treatment. Additionally, most reported being 'very satisfied' with the opportunity for healthy siblings to maintain their routine and cope with their brother's/sister's disease. Most perceived the programme as safe. All families recommended extending the programme to all children in the region	This first Italian study supports home chemotherapy as being safe and effective and positively influencing the quality of life for children and their families

TABLE 2 (Continued)

Author, year, and country	Method/design	Study population	Aim	Results	Conclusion
de Flon, et al., (2021) Sweden <i>The childhood cancer centre is coming home: Experiences of hospital-based home care</i>	Qualitative interviews Semi-structured interviews were performed, and the data were analysed by qualitative content analysis	Children (n = 6) with cancer aged 6–16 and parents (n = 8) participated	To describe how children with cancer and their parents experienced receiving care at home	Four main categories emerged: saving time and energy in the family; maintaining everyday life; trusting the healthcare professionals; mixed feelings about receiving treatment at home This hospital-based home-care project created good conditions for both children with cancer and their parents to feel secure. In addition, home care can be very child-centric, in that caregivers involve the children by taking their thoughts and utterances into account	By receiving care at home, children with cancer and their parents were able to save time and energy and maintain their family life. The children appreciated being close to their own things and staying in a safe home environment with their family. The children and the parents wanted to meet healthcare professionals they already knew because this was perceived as creating a sense of security. In addition, the parents wanted to be able to trust the healthcare professionals. It was desirable for the children that the healthcare professionals take the child's perspective, for example by involving them in their care.
López et al., (2022) Spain <i>Home-hospital care for children with acute illnesses: A 2-year follow-up study</i>	A retrospective, observational study (survey) conducted in the hospital-at-home programme of Niño Jesús Children's Hospital	833 children, median age 5 years (IQR 2.3–9.5), 290 of whose families were given an anonymous satisfaction survey, which was completed by 75% of those families (n = 217) The most frequent illnesses were acute infection (37%) (e.g. complicated appendicitis and ENT), and soft genitourinary, skin, and soft tissue infections) and acute respiratory disease (17.3%) (e.g. asthma, bronchiolitis, and pneumonia). 36% of admissions under-went nocturnal polysomnography	The aim of this study was to describe the procedures and the diseases treated in the first 2 years of a new paediatric hospital-at-home programme	90% of families reported a high level of satisfaction. Perceived safety, overall satisfaction, and degree of preference over conventional hospitalisation were evaluated on a 5-point Likert scale. A score of 4 or 5 was obtained in 98.5% of the responses measuring satisfaction, in 97.1% of responses measuring safety, and in 94.9% of responses measuring preference. Only one family gave a score of 2 for preference. The advantages highlighted by the families were greater comfort, privacy, ease of familial organisation, and perception of earlier recovery. The few families who reported disadvantages found that the patient's participation in the programme led to an increased workload and raised doubts as to whether they were conducting the procedures properly	Paediatric hospital-at-home programmes are a feasible, cost-effective alternative to hospital care. Further studies should compare the evolution of patients treated in the traditional hospital setting and the evolution of those in hospital-at-home

special care ($n=390$) during the years 2002–2005, Hammarstrand et al. (2008) made a cost comparison with traditional hospital care and found that, on average, each infant spent 17 days in the programme and received a mean of 4.6 home visits. When estimating the costs of traditional hospital care, neonatal home care was found to be less expensive. Interviews with 10 parents after the provision of HBHC during 2005 revealed that at hospital parents felt vulnerable and incompetent, when caring for their child. At home they felt comfortable and became gradually more confident. Hammarstrand et al. (2008) conclude that neonatal home care with the support of staff from the neonatal unit is feasible and less expensive, activates the family's own resources, and normalises family life.

In a qualitative exploration of family members' experiences of an HBHC programme during a 4-month period in 2009 at a university hospital in Denmark, Hansson et al. (2012) found, in descriptive interviews with 14 parents representing 10 families of children with cancer, that HBHC enabled them to remain intact families throughout the course of treatment, as HBHC decreased the strain on the family and the ill child, maintained normality and an ordinary everyday life, and fulfilled the need for safety and security. HBHC support enhanced the quality of life of the family members during the child's cancer trajectory. Hansson et al. (2012) conclude that the results highlight the importance of providing HBHC with consideration for the family members' need for the sense of security achieved through the provision of home care by experienced paediatric oncology nurses and regular contact with the doctor. They furthermore conclude that, in future studies, interviews with children and siblings could be an important source of information for planning and delivering care suited to families' perceived needs.

In the intervention study by Hansson et al. (2013), a subsample of children ($n=28$) (age range 0–17, median 8) with cancer and their parents ($n=43$) in the home-care group and of children ($n=47$) and parents ($n=66$) receiving standard hospital care was studied. The families in the home-care group received a mean of 10 home-care visits (range 1–75). All parents in the HBHC programme were satisfied and preferred home care. There were no serious adverse events associated with the programme, and costs did not increase. Using the parent-reported and self-reported PedsQL Generic Core Scale and PedsQL Cancer Module and the psychosocial impact on the family as assessed by using the PedsQL Family Impact Module, adjusting for age, gender, diagnosis and time since diagnosis, Hansson et al. (2013) found significantly higher HRQOL scores on parent-reported physical health ($p=0.04$; 95% confidence interval [CI]: 0.2–19.5) and worry ($p=0.04$; 95% CI: 0.4–20.6) in the home-care group, indicating better physical health and less worry for children in the home-care group. No significant difference was found in the psychosocial impact on the family as measured by the PedsQL Family Impact Module (Varni et al., 2004). Hansson et al. (2013) conclude that specific aspects of children's HRQOL may be improved in a home-care programme and the psychosocial burden on the family does not increase.

In Hemle Jerntorp et al.'s (2021) phenomenological analysis of fathers' experiences of neonatal home care, they found that the general structure of the phenomenon could be described by the following four themes: the partner was constantly present in the respective fathers' minds; the fathers' were occupied by worries and concerns; the fathers felt that they were an active partner to the professionals and getting the opportunity to take responsibility when receiving neonatal home care; and the fathers were satisfied with the support and treatment during their respective infant's hospitalisation. However, there were times when they felt excluded and not fully responsible for their infant. The fathers prioritised the mother, thus ignoring their own needs. Furthermore, they worried about their infant's health and the alteration of their parental role. Neonatal home care was experienced as an opportunity to regain control over family life. Hemle Jerntorp et al. (2021) conclude that the general structure of the fathers' experiences highlights the importance of professionals becoming more responsive to fathers' needs and tailoring support to fathers by focusing on their individual experiences and needs.

In De Zen et al.'s (2021) pilot study, 35 children received 419 doses of intravenous chemotherapy at home (cytarabine, vincristine and vinblastine) in a home-delivered chemotherapy programme for children with cancer. The mean time spent on each home visit was 45 min. No adverse events were reported. Twenty-three of the twenty-five eligible families completed the survey, most of them being 'very satisfied' with the opportunity to maintain a work/domestic routine and reduce the time and financial burden of hospital access. Most of them were 'very satisfied' with the opportunity for their child to be less troubled by the treatment. Additionally, most reported being 'very satisfied' with the opportunity for healthy siblings to maintain their routine and cope with their brother's/sister's disease. Most perceived the programme as safe. All families recommended extending the programme to all children in the region. De Zen et al. (2021) conclude that this first Italian study supports home chemotherapy as safe, effective and positively influencing the quality of life for children and their families.

In de Flon et al.'s (2021) qualitative study of the experiences of children ($n=6$) with cancer aged 6–16 years and their parents ($n=8$), who were participating in a HBHC programme, four main categories emerged from the semi-structured interviews: the programme helped save the family time and energy; the programme helped them maintain their everyday lives; they trusted the healthcare professionals; they had mixed feelings about getting treatment at home. This HBHC project created good conditions for both the children with cancer and their parents to feel secure. In addition, home care can be very child-centric, with the caregivers involving the children by taking their thoughts and utterances into account. de Flon et al. (2021) conclude that the children appreciated being close to their own things and staying in a safe home environment with their family. The families wanted to meet healthcare professionals they already knew because this was perceived as creating a sense of security. In addition, the parents

wanted to be able to trust the healthcare professionals. It was desirable for the children that the healthcare professionals took the child's perspective into account, for example by involving them in their care.

Aasen et al. (2019) interviewed the parents of children aged 0–17 years, with varying diagnoses and care needs, about their perceptions of 'hospital-at-home'. The results show that the parents experienced hospital-at-home as providing for a calmer, more predictable family life as compared to hospitalisation. They argued that good information and training in medical procedures prior to hospital discharge made hospital-at-home easier to master. The participants pointed out the importance of the professionals' competence and their ability to interact with the child and the parent. The certitude that they could return to the hospital at any time made them feel safe and in control. The parents associated hospital-at-home with a kind of normalisation of their family life. They had a notable need for normalisation, and this was probably a motivation for agreeing to the hospital-at-home arrangement. The advantages of the children being able to meet friends to a greater extent and to attend school and kindergarten were also highlighted. It was easier for them to resume a normal family life. This was of great importance, for both the sick child and their siblings. It was also important for parents to have an active role in planning the return trip. Aasen et al. (2019) conclude that their findings indicate that hospital-at-home for children is a good solution if the parents are well prepared and feel in control. In addition, certain structural conditions must be in place before this type of health care can be established; there must be a certain number of patients and there must be a clear limit to the distance to the hospital. Policymakers should initiate more pilot testing of hospital-at-home for children, and users and clinicians should be involved in establishing and evaluating these services.

López et al. (2022) sought to describe the procedures and diseases treated during the first two years of a new paediatric hospital-at-home programme. The families of 290 out of a total 833 children with a median age of 5 years (IQR 2.3–9.5) were given an anonymous satisfaction survey, which was completed by 75% of the families ($n=217$). The most frequent illnesses were acute infections (37%) and acute respiratory diseases (17.3%) and 36% of the admissions underwent nocturnal polysomnography. Ninety percent of the families reported a high level of satisfaction. Perceived safety, overall satisfaction and degree of preference over conventional hospitalisation were evaluated on a five-point Likert scale. A score of 4 or 5 was obtained in 98.5% of the responses measuring satisfaction, 97.1% of the responses measuring safety, and 94.9% of the responses measuring preference. Only one family gave a score of 2 for preference. The advantages highlighted by families were greater comfort, privacy, ease of familial organisation and perception of earlier recovery. The few families who reported disadvantages found that the patient's participation in the programme led to an increased workload and raised doubts as to whether the healthcare personnel were conducting the procedures properly. López et al. (2022) conclude that a paediatric

hospital-at-home programme is a feasible, cost-effective alternative to hospital care. Further studies should compare evaluations of patients treated in a traditional hospital setting and evaluations of those treated in a hospital-at-home programme.

4.4 | Synthesis of results

The eight included studies were published in five different European countries between 2008 and 2022. Different methods and designs were used, and the characteristics of the data charted varied. Two populations of parents were most present in the experiences: parents of children with cancer (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013) and parents of preterm children (Hammarstrand et al., 2008; Hemle Jerntorp et al., 2021), one of these emphasising the fathers' perspective only (Hemle Jerntorp et al., 2021). Four of the studies explored the experiences both of parents and of children with cancer (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013). Only two studies were retrieved that looked at the experiences of parents of children in other somatic diagnosis groups such as acute infection, chronic disease, or a syndrome who were receiving HBHC, one of the two studying parents and the other, the families' experiences (Aasen et al., 2019; López et al., 2022).

The self-reported experiences of two populations of children were dominant: children with cancer and children with acute infections and respiratory diseases. In Hansson et al.'s (2012) qualitative study, children ($n=5$) with a cancer diagnosis aged 4–15 years participated in all or part of the interviews. In Hansson et al.'s (2013) intervention study, a subsample of children ($n=28$) (age range 0–17, median 8) with cancer participated in the home-care group. In De Zen et al.'s (2021) study, children with cancer ($n=35$) with a median age at diagnosis of 6 years (range 1–15 years, IQR 5 years) participated. In de Flon et al. (2021), children ($n=6$) with cancer aged 6–16 participated. In López et al.'s (2022) study, participants consisted of 833 children with acute infections (37%) and acute respiratory diseases (17.3%) and children admitted for nocturnal polysomnography, with a median age of 5 years (IQR 2.3–9.5).

The results of the identified studies on parents' experiences of receiving HBHC (Aasen et al., 2019; de Flon et al., 2021; De Zen et al., 2021; Hammarstrand et al., 2008; Hansson et al., 2012, 2013; Hemle Jerntorp et al., 2021; López et al., 2022) are predominantly positive. At the hospital, parents of children from the neonatal unit felt vulnerable and incompetent when caring for their child. At home, they felt comfortable and became gradually more confident. In their experience, HBHC activated the family's own resources and normalised family life (Hammarstrand et al., 2008). Fathers experienced neonatal home care as an opportunity to regain control over family life (Hemle Jerntorp et al., 2021). In parents of children with a cancer diagnosis, HBHC was experienced as enabling families to remain intact throughout the course of treatment, as it lessened the strain on the family and the ill child, maintained normality and

ordinary everyday life, and fulfilled the need for safety and security (de Flon et al., 2021; Hansson et al., 2012). The psychosocial burden on the family did not become greater with HBHC, which was experienced as a feasible alternative to hospital care and greatly preferred by the parents (Hansson et al., 2013). In a survey of the safety and family satisfaction of a home-delivered chemotherapy programme for children with cancer, most parents perceived the programme as safe and recommended extending the programme to all children in the region (De Zen et al., 2021).

Parents of children in other somatic diagnosis groups experienced the provision of HBHC as allowing a calmer, more predictable family life as compared to hospitalisation. They argued that good information and training in medical procedures prior to hospital discharge made hospital-at-home easier to master. The professionals' competence and their ability to interact with the child and the parent were experienced as important. The certitude that they could return to the hospital at any time made them feel safe and in control. The parents associated HBHC with a kind of normalisation of their family life (Aasen et al., 2019). In López et al.'s (2022) study, 90 percent of families reported a high level of satisfaction. A few families reported that the provision of HBHC led to an increased workload for the parents and raised concerns as to whether they were conducting the procedures properly.

In the four studies reporting on children's self-reported experiences (de Flon et al., 2021; De Zen et al., 2021; Hansson et al., 2012, 2013), it was found that HBHC enhanced quality of life during the child's illness trajectory (De Zen et al., 2021; Hansson et al., 2012, 2013). Hansson et al. (2013) used the parent-reported and self-reported PedsQL Generic Core Scale and PedsQL Cancer Module and the psychosocial impact on the family as assessed by the PedsQL Family Impact Module. HBHC decreased the strain on the ill child, maintained normality and ordinary everyday life, and fulfilled the need for safety and security (Hansson et al., 2012). By receiving care at home, the children could maintain a more normal life. They appreciated being close to their own things, staying in a safe home environment with their family, and receiving help from healthcare professionals they already knew (de Flon et al., 2021). It was desirable for the children that the healthcare professionals took the child's perspective into account, for example by involving them in their care (de Flon et al., 2021).

In general, few studies on HBHC were retrieved. Some research gaps were indicated in the included studies. Hansson et al. (2012) argue that, in future studies, interviews with siblings could be an important source of information for planning and delivering care suited to the families' perceived needs (Hansson et al., 2012). In De Zen et al.'s (2021) study it was stated that HBHC gave healthy siblings a chance to maintain their routine and cope with their brother/sister's disease. Hemle Jerntorp et al. (2021) argue that professionals should be more responsive to fathers' needs in the neonatal setting and to tailoring support for fathers in HBHC by focusing on their individual experiences and needs (Hemle Jerntorp et al., 2021). Only two studies were retrieved that studied the experiences of children with somatic diagnoses other than cancer or their parents (Aasen

et al., 2019; López et al., 2022). This finding represents a knowledge gap and calls for future studies to include children with different diagnoses and care needs and their parents when the experiences of HBHC are being explored. López et al. (2022) state that further studies should compare the evolution of patients treated in a traditional hospital setting and those being treated in HBHC.

5 | DISCUSSION

5.1 | Summary of evidence

Our findings indicate that HBHC is feasible and has no crucial negative effects for preterm or neonatal children, children with cancer, children in other somatic diagnosis groups (0–17 years), or their parents. HBHC seems to enhance children's quality of life during the illness trajectory (De Zen et al., 2021; Hansson et al., 2012, 2013). The strain on the ill child seems to be diminished, as they may maintain an ordinary everyday life (Hansson et al., 2012). They appreciate being close to their own things and staying in a safe home environment with their family, receiving help from healthcare professionals they already know (de Flon et al., 2021). Taking into consideration that children in general, and especially sick children, need safe, stable, nurturing relationships and environments to grow and thrive, this finding is not very surprising. Within the context of the intensive medical unit, Bricher (1999) identified the development of trusting relationships as essential to the provision of care for children. This finding has transfer value for the HBHC context, as the development of trust is inherent in the relationship between nurse and child, as well as between nurse and parents.

Parents of children from the neonatal unit reported that HBHC activated the family's own resources and normalised their family life (Hammarstrand et al., 2008; Hemle Jerntorp et al., 2021). They felt more comfortable and became more confident at home (Hammarstrand et al., 2008). According to the family members of children with cancer, HBHC enhanced their quality of life during the child's cancer trajectory, even though this mode of care also led to an increased workload for the parents. Parents of children in other somatic diagnosis groups experienced the provision of HBHC as allowing a calmer, more predictable family life as compared to hospitalisation (Aasen et al., 2019). Together with having good information and training in medical procedures prior to going home, the certitude that they could return to the hospital at any time made the parents feel safe and in control (Aasen et al., 2019). The parents preferred that the hospital was not too far away, and associated HBHC with a kind of normalisation of their family life (Aasen et al., 2019).

Aasen et al.'s (2019) finding of parents preferences in regard that certain structural conditions must be in place before this type of health care can be established, raises ethical and equality questions. The structural factors pointed out comply well to families living in big cities in industrialised countries, but does not comply very well to families living in decentralised areas or low income countries. Parents and children living in such settings, where

there may be shortage of resources such as availability of health-care providers, hospital services and medications, are doomed excluded from this mode of care. These aspects should be taken into consideration when implementing new modes of care. Parab et al.'s (2013) finding that current research did not provide supporting evidence of reduced access to hospital services or reduced hospital readmission rates for children with acute and chronic illnesses using specialist home-based nursing services, is also worth taking into consideration. The only summary finding across the studies was a significantly decreased length of hospitalisation (Parab et al., 2013).

Patient- and family-centred care interventions are increasingly being implemented in various settings (Park et al., 2018) and seek to involve children and families in treatment planning. To provide care that is truly child- and family-centred, providers must radically alter the way in which institutional structures, clinical practices, and policies are devised and carried out so that the recipients of the services feel safe and well taken care of.

In López et al.'s (2022) study, 90 percent of the families reported a high level of satisfaction when receiving HBHC. The overall positive experiences of HBHC as reported in our results show that this mode of care seems to enable children and parents to activate their own resources in their own homes to increase control and improve their own and their family's health and wellbeing. These findings reflect a view of health as articulated in Aaron Antonovsky's salutogenesis theory (Antonovsky, 1996), which is concerned with positive health, creating coherent living environments, strengthening socio-ecological health resources, and strengthening the sense of coherence of individuals and groups (Mittelmark & Bauer, 2022). As healthcare resources seem to become increasingly limited, new ways of taking care of children and their families are needed. These findings also align well with the statement by the European Association for Children in Hospital that the best interest of the child and the child's parents/caretakers should be taken into consideration whenever treatment and care are offered (European Association for Children in Hospital-for sick children, n.d.).

5.2 | Strengths and limitations

The performance of this scoping review was enhanced by the application of Arksey and O'Malley's (2005) framework and the rigorous PRISMA-Sc review guideline (Tricco et al., 2018). Authors with complementary competencies contributed to it, working in pairs on all of the steps in the screening process. All of the authors contributed to the analysis and to writing the paper. Our strict inclusion criteria—that services had to be managed, based on, or delivered by a hospital, and offered by ambulatory teams staffed by specialised paediatric nurses and other multi-professional hospital staff (Parab et al., 2013; Parker et al., 2012), and not by the municipality or by community-based healthcare teams (Castor et al., 2017)—must also be considered a strength, as there are several existing models for

organising, delivering and financing home care for children internationally and within countries (Parab et al., 2013; Spiers et al., 2012). Studies of services managed by the municipality or by community-based healthcare teams have not been included in this review, which may account for the small number of included studies.

A small number of studies were retrieved and included, and all the included studies were from European countries. No studies were included from other regions of the world, including low-income settings in which the implementation of HBHC can potentially face many challenges due to socioeconomic setbacks. The heterogeneity of the results in terms of methods, design, instruments used, and outcomes measured generates limited evidence. Thus, a knowledge gap has been identified, especially with regard to the lack of studies reporting on the experience of children with different diagnoses and care needs. Very few studies have yet compared the evolution of patients treated in the traditional hospital setting and the evolution of those in HBHC programmes (López et al., 2022).

6 | CONCLUSION

Children's and parents' experiences of receiving HBHC have been subject to little exploration. Populations of children with cancer and children suffering from infection, chronic disease and various syndromes, as well as their parents and parents of preterm/neonatal children, have been studied in this regard. Our findings indicate that HBHC is valued as an alternative to hospital care for children with cancer and is greatly preferred by their parents. Specific aspects of children's HRQOL were improved with HBHC programmes and the psychosocial burden on the family did not increase. Neonatal home care with the support of staff from the neonatal unit activates the family's own resources and normalises family life.

These findings support further investigating the users', especially children's, perspective in order to guide and inform best practice for providers of HBHC. In future studies, interviews with children with different diagnoses and their siblings could serve as an important source of information for planning and delivering care suited to families' perceived needs. A demand was identified for a broader, more diverse approach to the research into experiences of HBHC. Further studies should be designed to better delineate the full potential of this mode of care, as healthcare resources are becoming increasingly limited and new ways of taking care of children and their families are needed.

AUTHOR CONTRIBUTIONS

Elisabeth Grov Beisland: Conceptualization (lead); methodology (lead); formal analysis (lead); writing—original draft (lead); writing—review and editing (lead). **Jorunn Drageset:** Review and editing (equal). **Mari Gaupås Blindheim:** Review and editing (equal). **Gøril Tvedten Jorem:** Software (lead); data curation (lead). **Asgerd Litleré Moi:** Conceptualization (lead); methodology (supporting); review and editing (equal); formal analysis (equal).

FUNDING INFORMATION

This study received no external funding.

CONFLICT OF INTEREST STATEMENT

None of the authors has any conflict of interest to report.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Beisland, E. G., Drageset, J., Blindheim, M. G., Jorem, G. T., & Moi, A. L. (2024). Children's and parents' experiences of home care provided by hospital staff: A scoping review. *Journal of Clinical Nursing*, *00*, 1–15. <https://doi.org/10.1111/jocn.17109>