


ORIGINAL ARTICLE

Negotiating safety and responsibility in caregiving to children receiving hospital-at-home: A Norwegian study of parents and homecare nurses' experiences

Line Aasen PhD Fellow¹  | Anne-Kari Johannessen PhD, RN^{1,2} |
Ingrid Ruud Knutsen PhD, RN¹ | Anne Werner PhD Medical Sociology²

¹Department of Nursing and Health Promotion, OsloMet – Oslo Metropolitan University, Oslo, Norway

²Health Services Research Unit, Akershus University Hospital (Ahus), Lørenskog, Norway

Correspondence

Line Aasen, Department of Nursing and Health Promotion, OsloMet, Kunnskapsveien 55, 2006 Kjeller, Norway.
Email: laasen@oslomet.no

Funding information

Oslo Metropolitan University

Abstract

Healthcare policies in Western countries increasingly emphasise the avoidance of hospitalisation to reduce hospital admissions. Hospital-at-home for children is a treatment offered to children at home that would otherwise require hospitalisation. Norway practices a model where homecare services play a significant role in assisting the hospital when children need home visits beyond the capacity of what the hospital can offer. Although homecare nurses' work has been affected by several changes in recent decades, few have reported on what these changes imply for homecare nurses' work and family caregivers. The aim of this study was to explore how parents and homecare nurses worked and collaborated in home visits to children receiving hospital-at-home, focusing on how they negotiated caregiving. We conducted 16 interviews: six interviews with parents and 10 interviews with homecare nurses. The interviews were analysed thematically. Both parents and homecare nurses described these home visits as challenging, indicating experiences of distrust. Parents had carefully observed homecare nurses, checking whether they knew how to treat the child and perform the clinical procedures. Homecare nurses had invested much energy into being perceived as calm and trustworthy by the parents. We applied the perspective of negotiation to understand the work and collaboration reported by parents and homecare nurses when unsafety or uncertainty was experienced during home visits, revealing the complexity of their roles in dealing with such events. The results showed the reciprocal dependency between the parents and the homecare nurses that enabled them to perform caregiving work in partnership, sharing responsibility. Our findings suggest that the collaboration with hospital-at-home has an impact on the feeling of safety and control for both parties. We question whether there is a danger of too much responsibility being left with the parents when homecare services are involved.

KEYWORDS

children's nursing, home care, hospital-at-home, informal caregivers, interaction in health care and community settings, qualitative study

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1 | INTRODUCTION

During the last three decades, we have seen a reorganisation of healthcare services in Western countries that seek to achieve more cost-effective solutions and reduce capacity pressures on hospital care (Lappegard & Hjorthdal, 2014; Ministry of Health and Care Services, 2009; Skinner et al., 2020). Various hybrid service models combining hospital and home treatment have been developed (Gonçalves-Bradley et al., 2017), and this shift from hospitalisation to homecare includes healthcare for children as well. The family caregiver role is also changing; according to health policy documents, informal caregivers are expected to play more active roles as members of the patient care team and to take on greater responsibility for managing safe care for the sick person (Ministry of Health and Care Services, 2014–2015; WHO, 2021).

Hospital-at-home (HAH) for children is a service that offers treatment to children at home who would otherwise require hospital admission (Parab et al., 2013). Homecare services to children are organised differently in different countries (Gonçalves-Bradley et al., 2017; Parker et al., 2013); most commonly, various hybrid forms of ambulatory services combining hospital and home treatment (Castor et al., 2018; Jones et al., 2020; Lee et al., 2021). Norway practices a model in which health professionals employed by the hospital paediatric department deliver care in the family's home to carefully selected hospitalised children with various diagnoses (Aasen et al., 2018). When children need home visits beyond the capacity of what the hospital can offer, nurses from homecare services play a significant role, in assisting HAH in conducting the visits.

Previous research has reported that HAH is medically safe and that parents often prefer this type of care for their children, when offered, rather than staying in hospital (Parab et al., 2013). In an earlier study, we found that parents based their trust in the services on whether the professionals were competent to care for their child's diseases at home (Aasen et al., 2018). Likewise, hospital nurses and physicians emphasised the importance of nurses having solid skills when treating hospitalised children at home (Aasen et al., 2021). Other researchers have noted that the treatment of children at home is challenging for homecare nurses due to a lack of experience, training or education in paediatric nursing (Castor et al., 2017; Lee et al., 2021). Whilst homecare nurses' practice is becoming increasingly advanced, it is also becoming more difficult due to a lack of knowledge transfer from hospitals to homecare and to the challenges of working alone in the context of a private home (Melby et al., 2018).

A growing body of literature sheds light on the relationship between formal and informal caregivers (Zhuolu et al., 2019). Mostly, this literature is based on different types of formal caregiving, including nurse visits, to older patients or end-of-life patients and informal care given by family members. Difficulties in encounters between nurses and caregivers have been reported, together with the emotional support provided by nurses to family members and the experiences of complementary relationships between

What is known about this topic?

- Hospital-at-home for children is medically safe and parents often prefer this type of care when offered to their children, compared to staying in a hospital.
- Treatment of children at home is challenging for homecare nurses due to the lack of experience, training or education in paediatric nursing.
- Homecare nurses' practice is becoming increasingly advanced and difficult due to the lack of knowledge transfer from hospitals to homecare and to the challenges of working alone in the context of a private home.

What this paper adds?

- The perspective of negotiation brought new insight on collaboration between formal and informal caregivers in home visits to children, illuminated aspects of distrust and how to overcome such barriers.
- To develop a partnership, it is important to parents and homecare nurses that the services practice continuity of care, so that family caregivers have few homecare nurses to relate to.
- The homecare nurses need preparation from hospital nurses before home visits to children in order to develop the competence needed to perform the clinical work and contribute to parents feeling of safety.

the parties (Büscher et al., 2011; Gill et al., 2021; Hengelaar et al., 2017). Although homecare nurses' work has been affected by several changes in recent decades, there have been few reports on what these changes imply for the nurses' work (Gill et al., 2021; Melby et al., 2018) or how informal caregivers influence the home-based work of formal caregivers (Zhuolu et al., 2019). To our knowledge, there is also limited research exploring the significance of the home as a setting for hospital treatment for the relationship and collaboration between homecare nurses and children's parents as caregivers. In our study, the informal caregivers are the parents of the children receiving HAH and the formal caregivers are the homecare nurses.

In several studies, the concept of negotiation has been applied to explore the work of and collaboration between family caregivers and health professionals (Aasbø et al., 2017; Allen, 2000; Büscher et al., 2011; Swallow et al., 2013). Strauss (1978) has argued that negotiation occurs as a means to achieve understanding and agreement when uncertainty, disagreements and ambiguity exist. Negotiation is defined as a mode of social interaction utilised by actors when they must deal with each other to get something accomplished, and these interactions range from explicit negotiations or discussions of work to informal tacit understandings and subtle agreements (Conrad & Bury, 1997). Drawing on Strauss and colleagues' theory of the division of labour, in which care is defined as 'work', Allen (2000) has

argued that family caregivers may challenge the routines and work of nurses by negotiating care standards, expertise and responsibility.

The perspective of negotiation may offer a useful approach to understanding the work and collaboration of parents and homecare nurses when uncertainty or difficulties occur and how these are managed, illuminating the complexity of their roles in home visits to children. The aim of this study was to explore how parents and homecare nurses worked and collaborated in home visits to children receiving HAH, focusing on how they negotiated caregiving.

2 | METHOD

2.1 | Design and study context

In this study, we used a qualitative method with an exploratory design. The setting of the study was HAH services, established in 2008 and 2016, at two large hospitals in eastern Norway. These services are offered to children from the neonatal stage to 18 years old with a variety of diagnoses. The children must be in a stable phase of their illness and the care considered medically justifiable. The most common treatments are intravenous antibiotics, intravenous nutrition and tube feeding, and examples of diagnoses are infections, cancer and newly diagnosed diabetes. The distance to the hospital cannot be more than a one-hour drive by car. In some cases, assistance from a homecare service is required due to the distance or the need for several visits per day. Nevertheless, the hospital retains the primary responsibility for the treatment of these children.

2.2 | Data collection and material

We conducted 16 interviews, i.e., six interviews with parents whose children were receiving HAH and 10 interviews with homecare nurses who had collaborated with a hospital in visiting children as part of HAH. The study participants were recruited with assistance from the head nurses in the homecare services and the two HAH services. The sample included parents and homecare nurses with different backgrounds and experiences, including both long-term and short-term treatment and palliative care to children aged 1–12 years with different diagnoses. The interviews were conducted between September 2020 and May 2021 and lasted about an hour each. The parents' ages ranged from 29 to 44 years, and in two of the interviews with parents, a partner was present. The first author (LA) conducted the interviews in the families' homes or online due to the COVID-19 pandemic (see Table 1). The homecare nurses, aged 28–59, were interviewed in the homecare office or online. The interview guides that were used consisted of open-ended questions. In the interviews, we asked the parents about their experiences of receiving HAH when the homecare services carried out the visits. Similarly, we asked the homecare nurses about their experiences with visits to sick children and their parents. The audio-taped interviews were transcribed verbatim by the first author.

TABLE 1 Participants—demographic background data

Years	n = 6 ^a
Parents	
25–30	1
31–35	2
36–40	3
41–45	2
Gender	
Women/men	6/2
Education	
High school	3
University degree	5
Children's age	1–7, mean age 4 years
Years	n = 10
Homecare nurses	
25–29	1
30–39	2
40–49	3
50–59	4
Gender	
Woman	10
Health profession—education	
Registered nurse	5
Assistant nurse	1
Additional education	4
Length of work experience	
5–10 years	4
11–20 years	1
21–29 years	2
30–40 years	3
Treated children's age	2–12, mean 6 years

^aIn two interviews both parents were present.

2.3 | Ethics

The study followed the ethical principles for medical research involving human subjects of the Declaration of Helsinki. The Regional Committee for Medical and Health Research Ethics, Southeast Norway, found the project to be outside the remit of the Act on Medical and Health Research (ref. 47184). The local privacy legislation authority at the two hospitals approved the study (ref. 2019_134,19/29832).

Written informed consent was obtained from the participants before data collection. The participants were informed that their participation was voluntary, that the collected data would be kept confidential, and that they could withdraw from the study at any time and without any consequences. All quotations used are anonymised by assigning a number to each of the interviewed participants and a label of either 'homecare nurse', 'mother' or 'father'.

TABLE 2 Sub-themes and main themes developed

Main themes	Sub-themes parents	Sub-themes homecare nurses
1. A complex assignment for all involved	The parents described the homecare nurses as uncomfortable and stressed during the home visits	The homecare nurses felt insecure during home visits to children
	The parents had requested hospital-at-home due to a strong desire to stay at home	Homecare nurses exerted themselves to enable hospital-at-home for children
2. Negotiating safety and trust in caregiving	The parents experienced the visits of homecare nurses as implying more responsibility and work than when the HAH nurses came	The homecare nurses felt the parents were watching and controlling them
	The parents kept a close eye on the homecare nurses—carefully observing whether they knew how to treat the child and perform the procedures, and guided them	The homecare nurses invested much energy into being perceived as trustworthy by the parents, making them and the child feeling safe
3. Negotiating responsibility in caregiving—development of a partnership at home	The parents took responsibility for different tasks in relation to the visits from the homecare nurses	The homecare nurses described the parents as supporting and facilitating the visits
	The parents emphasised continuity in care as it is important for a good collaboration with the homecare nurses	The homecare service put a lot of effort in ensuring continuity of care and emphasised that good preparation, planning and collaboration with HAH was a prerequisite for performing home visits to children with calmness

2.4 | Data analysis

The data comprised transcripts of the interviews. We applied a thematic analysis as described by Braun and Clarke (2006), comprising six phases: (1) Familiarising yourself with the data. (2) Generating initial codes. (3) Searching for themes. (4) Reviewing themes. (5) Defining and naming themes. (6) Producing the report (Braun & Clarke, 2006). The research team routinely met during the analysis process to discuss coding and themes. Transcripts were read several times and initial ideas were noted to allow familiarisation with the data. Rather than a strictly linear process, this is a reflexive and recursive coding process of organising ideas that captures a meaning-based pattern across the data, as well as different manifestations of that pattern (Braun et al., 2019). Starting with the empirical data, we used an inductive approach, in a data-driven process (Braun et al., 2019; Braun & Clarke, 2006).

During the process of generating codes, searching for patterns or themes within the data, we became particularly aware of similarities in the experiences of the parents and the homecare nurses, specifically regarding challenges or difficulties experienced during the visits. Initial coding was then undertaken across all the data and determined separately for data from the parents and the homecare nurses. The data were organised into themes and sub-themes, focusing on similarities in the parents' and homecare nurses' experiences of unsafety and uncertainty in the home visits and the different ways they related to these experiences as described by the two parties. The theoretical perspective of negotiation by Strauss (1978) made us attentive to how the parents and homecare nurses managed unsafety and uncertainty in home visits through how they

worked and collaborated. In the analysis, we applied the theoretical perspective of negotiation by Strauss (1978) in relation to the negotiation of caregiving between formal and informal caregivers. Finalised themes were then reviewed and refined according to the perspective of negotiation (Allen, 2000; Strauss, 1978) and in 'dialogue' with the data (Braun & Clarke, 2006) (see Table 2).

3 | RESULTS

3.1 | A complex assignment for all involved

In their stories, the parents and homecare nurses in many ways mirrored each other's experiences. Many parents described the homecare nurses as uncomfortable and stressed during the home visits and compared them with the HAH nurses in terms of skills and attitudes, suggesting that the HAH nurses showed calmness and self-confidence in how they conducted procedures. Most parents found it straining to receive home visits from several different homecare nurses who might not know the procedures. A father said:

There were different nurses coming from the home-care services each time. This could easily lead to mistakes since the new nurses didn't know the procedure. That worried us a lot. The nurses who regularly were 'checking in' knew the procedure. The new nurses often had trouble with the pump, which led to issues where the nurse just couldn't get it done.

(Father no. 1)

All the interviewed parents had actively requested HAH because of a strong desire to stay at home with their children. In some cases, this implied that the treatment had to be given by homecare nurses. A mother said:

It was positive having the homecare services around as well. I experienced that their level of competence became better with time, but my choice would have been hospital-at-home, regardless. As long as you have the hospital nurses 'checking in' here every now and then, it gives me this sense of safety.

(Mother no. 2)

Many of the interviewed homecare nurses confirmed the parents' perceptions: they felt insecure during the home visits to children because they primarily cared for older patients. None of the homecare nurses had been involved in more than one or two cases of collaboration with the hospital regarding children receiving treatment at home. Some of the homecare nurses had not been trained in the clinical procedures in question, whilst others said they were familiar with the procedures but that conducting them on children was different to conducting them on older patients. A homecare nurse said she sometimes felt so uncomfortable that even well-known procedures became difficult:

I tend to get very nervous when I'm doing procedures and the family is watching. Even though I have done it a hundred times before, I still get nervous. I'm scared of making mistakes and scared to make a fool out of myself in front of the family. We are supposed to do things we are more than capable of, but sometimes things don't work out the way we want. This makes us feel very stupid, and then the parents too think that we don't know what we're doing, which again is making us doubt ourselves.

(Homecare nurse no. 4)

Having to deal simultaneously with a sick child, the procedure and collaboration with parents made the visits complicated for the homecare nurses. Nevertheless, despite the challenges, they described, and the ambivalence they had towards visiting hospitalised children at home, most found HAH to be a good solution for both the children and their parents. They, therefore, exerted themselves to enable it when asked to support the hospital. A homecare nurse said:

The way I see this, nothing would be better for this child than to be able to stay at home, because they wanted this so much. So, what I'm thinking is that this was what they wanted—to be home and be a family, like they are used to.

(Homecare nurse no. 1)

3.2 | Negotiating safety and trust in caregiving

Because different homecare nurses would often come to visit the child, the parents could find that the visits implied more responsibility, work and burdens for them than when the HAH nurses came, as the HAH nurses were practising continuity of care. Most of the parents said that they carefully observed new homecare nurses, checking whether they knew how to treat the child and how to perform the clinical procedures. In some cases, the parents had to supervise the homecare nurse during the procedure or help them to find the right equipment. If the parents felt the procedures were not being done in an aseptic manner, they became worried. In such situations, the parents found it important to discuss with the homecare nurses how the procedure, in their opinion, was supposed to be done, hopefully ensuring that the procedure was conducted in a proper manner. A mother said:

I felt the homecare nurses were not very hygienic—that wore me out. Sometimes, I felt I had to tell the homecare nurses. I tried to say it in a way like—'If it were me who was going to do this [procedure], then I would do it this way or that way...'

(Mother no. 4)

Many of the homecare nurses underscored that home visits to children whose parents watched closely were a new and uncomfortable situation. Some of them reported that the parents questioned the way they performed procedures, pointing out that they did so differently from the HAH nurses. A homecare nurse said:

So, if you feel like working in your own peace and are being distracted, you can ask to be let alone—but you can't do that when the case is a child! If there are any stressful family caregivers hanging over you in an older patient's home, then I would [ask] them to leave.

(Homecare nurse no. 2)

A homecare nurse said she felt the parents were watching her 'like a hawk', making her feel 'very anxious'. Most of the homecare nurses said that they had invested a lot of energy into being perceived as calm and trustworthy by the parents during the home visits. They reported that they disciplined themselves in order to conduct procedures without fidgeting and made strong efforts to strengthen the families' feelings of safety during the home visits. If they felt insecure about a procedure, they would sometimes bring a colleague to the family's home, as one said:

I found that I had to be sure of this—and I wanted this to go exactly right, so I contacted another nurse from the homecare services, and we visited

together, so she read the procedure and I operated the pump.

(Homecare nurse no. 3)

3.3 | Negotiating responsibility in caregiving— Developing partnerships during home visits

Almost all the homecare nurses described how they wanted to support the parents and said that this relationship created the foundation for caring for the child. This support included spending time in the family's house and not doing things in a hurry, even if this meant that the next patient on their list would have to wait. The homecare nurses were dependent on the parents' efforts as caregivers to support them in the work of gaining the child's trust. In retrospect, they emphasised their appreciation for the parents as collaborators. Some of the nurses also described how the parents facilitated the process, taking responsibility for making the child feel safe and prepared, both before and during the home visit. A homecare nurse said:

His parents were so calm and clever with him. Therefore, having the parents around was not a problem. They talked with him before we came, so he was prepared when we arrived. We gave him the medicines while he was eating, so he was [kept] busy.

(Homecare nurse no. 1)

Most of the homecare nurses noted that, after they had visited the children several times, the initial fears had lessened, and they became a team collaborating to accomplish the work during the home visits. In the interviews, both the homecare nurses and the parents reported positive experiences from sharing responsibility for different tasks in relation to the visits, which led to safety and calmness for the child. When a good relationship was established, the homecare nurses experienced the parents trusted them.

Although continuity of care was rare in the homecare service, some said that the service put a lot of effort into ensuring that only a few homecare nurses visited the children and their parents. One said:

We tried to have the same staff visiting each time because we didn't want to jeopardise the safe environment we had for her. We sought to choose nurses in permanent positions who had the most shifts, rather than the people who were just working that one shift. We put a lot of effort into earning and keeping her trust, for sure.

(Homecare nurse no. 8)

In line with the homecare nurses, the parents also emphasised the importance of having the same homecare nurse for each visit. Being familiar with each other implied that the nurse understood the family and how they preferred the work to be done. The parents reported being more relaxed in such situations and with how the nurse was doing the work, as expressed by a father:

There were three or four homecare nurses who had had good training from HAH. When they came, we didn't have to sit around and pay attention. Homecare nurses who came often knew the procedure. [Then] everything went just fine.

(Father no. 1)

According to all the interviewed homecare nurses, the transition phase from the hospital was important for providing good and safe services to the children. This entailed meeting in person before the child left the hospital, and preparing a plan, resulting in written agreements and procedures. Several homecare nurses also emphasised the importance of practising procedures with the HAH nurses in advance. Knowing that they were doing the procedures the same way as the HAH nurses were reassuring to the homecare nurses. They also got the opportunity to watch how the HAH nurse collaborated with the child and the family, getting tips on how to perform home visits.

Good preparation before the child came home created calmness and certainty for the homecare nurses and enabled them to develop a more predictable and safer basis for a sound partnership with the child and their parents. Daily phone calls from the HAH nurses to share information also made the homecare nurses feel part of the child's treatment team:

The HAH nurses took care of it if something was unclear or if there was something I was concerned about—like prescriptions for medication. They called me and let me know—like 'Now this and this is taken care of.' So, I felt like we were a team.

(Homecare nurse no. 10)

4 | DISCUSSION

The results illustrate the complexity of the relationships and the roles of homecare nurses and parents when children receive treatment at home. Our findings show the reciprocal dependency between the parents and the homecare nurses that enabled them to perform caregiving work in partnership. When there was continuity of care, there was greater potential for developing a collaboration between the parents and homecare nurses and for sharing the caregiving role and tasks, with the common goal of getting the procedure done proficiently. Through this partnership, a routine for working together could be formed, creating predictability for the child. For both parties, a close collaboration with HAH nurses was also important.

Several previous studies in different healthcare settings have explored the difficulties when homecare nurses conduct caregiving for children at home. Castor et al. (2017) found that such care was challenging for homecare nurses, regardless of the specific tasks, merely because the patient was a child, whilst Samuelson et al. (2015) found that most homecare nurses perceived themselves as having limited knowledge of caring for children. Reid (2013) and Quinn and Bailey (2011) described how homecare nurses caring for children in palliative care at home reported pressure to rapidly learn new skills and a strong desire to perform optimally; a lack of specific knowledge and experience relating to equipment, procedures and pharmacology were also mentioned as representing further challenges.

In this study, we used the perspective of negotiation to understand the work and collaboration reported by parents and homecare nurses when unsafety or uncertainty was experienced, revealing the complexity of their roles in dealing with such events during home visits. This has brought new insights into collaborations between informal and formal caregivers and has illuminated aspects of distrust and how to overcome such barriers. In this social setting, work, roles and responsibilities were all turned somewhat upside down; homecare nurses, who would normally expect to be the expert, instead considered themselves in this situation as 'novices' or with limited expertise, and the parents sensed that insecurity. The homecare nurses, therefore, exerted themselves to gain the trust of the families, suggesting that professionalism and trustworthiness were at stake and were the topic of negotiations.

The parents needed the arrangement to work in order to be able to remain at home, but at the same time, the safety of the child was at risk. From the perspective of negotiation, Nadai and Maeder (2008) argued that there are certain features of a social world that cannot be negotiated, and the safety of the child was obviously never a matter for negotiation. Dickinson et al. (2006) found that parents of chronically ill children learn through experience that negotiations between the family and health professionals produce the best results if the parents take 'control' of the relationships. On the same theme, Allen (2000) argued that nurses seek to control the conditions of their work whilst patients and their families seek to control the conditions of their hospital experiences. From the homecare setting, we found that the parents sought, in different ways, to control the situation to ensure medical safety when the homecare nurses visited. This is in line with Nilsson et al. (2018), who reported that hospital professionals experienced parents as being the experts in their own everyday lives, leaving the hospital staff as novices with feelings of professional anxiety and a need to defend their professional identities. Notably, Allen (2000) stated that, although the nurses in her study recognised that family caregivers were a valuable resource, they nevertheless found it difficult to draw on this knowledge without undermining their own sense of professional competence.

Having close contact with the HAH nurses was emphasised by both parents and homecare nurses. For the parents, the caregiving of the HAH nurses was the 'gold standard' of practice and having

them visit at least occasionally added to the parents' feelings of security. The collaboration with HAH was also important to the homecare nurses, who underlined the importance of HAH being easy to reach for advice and to feel ensured that they were included in the HAH team when supporting them. Other studies have also noted the importance of close collaboration between the hospital and municipal homecare (Castor et al., 2017; Samuelson et al., 2015; Stevens et al., 2004).

Preparation and the opportunity to train on procedures with the HAH nurses prior to the child returning home seemed to add to the homecare nurses' feelings of safety and prepare them to provide hospital treatment to sick children at home. Such preparation may increase homecare nurses' paediatric competence and make them more qualified to perform their tasks and meet the families' needs. Predictability, preparedness and insight would have a positive impact on the partnership with the parents, and such preparation may well increase the parents' trust in the homecare nurses. Investing time and gathering information from HAH nurses to clarify roles and the division of tasks is likely a prerequisite for good collaboration with parents and may reduce the stress and uncertainty of having little or no experience in paediatric nursing. This may be important in helping reduce the parental experience of unsafety when homecare nurses visit and in creating a sense of seamless service delivery. In a study of paediatric palliative care in an adult palliative care service, O'Leary et al. (2006) found that the parents frequently double-checked advice given by the palliative care team with the hospital paediatric team, and the current study further highlights the importance of good collaboration between HAH and homecare services in the transition to home treatment.

Our findings suggest that parents and homecare nurses' negotiations about sharing the responsibility of work led to a partnership when continuity of care was present. According to Dickinson et al. (2006), it was when both practitioner and family come to know 'the face' of the other that unique, effective and satisfying relationships develop. Consistency in the delivery of care to sick children at home is underscored in several studies (Brenner et al., 2021; Gill et al., 2021; Kirk, 1999; Law et al., 2011), but in our study, continuity in homecare services was sometimes a challenge. Nevertheless, our findings suggest that being supported by different homecare nurses was accepted by parents because receiving treatment at home was so important. This is in line with Kirk (1999) and Aasen et al. (2018), who found that the preference for being at home was due to the importance of being in a familiar environment and living family life as normally as possible.

Although the main responsibility for the child's treatment lies with the hospital, our results suggest that the homecare nurses and parents also negotiated responsibilities for caregiving as part of finding a way to collaborate. Thus, some parents in this study took responsibility for ensuring procedures were done correctly. We, therefore, question whether there is a danger of too much responsibility being left with the parents when homecare services are involved.

4.1 | Limitations and strengths

Our data were collected from interviews with six parents and 10 homecare nurses. Due to the COVID-19 pandemic, it was challenging to recruit parents, and we acknowledge that this is a small sample. Interviewing more parents might have generated a broader picture, but a strength of the study is that we still managed to conduct interviews covering experiences from both long-term and short-term treatment. Furthermore, the homecare nurses confirmed the parents' experiences in various ways, and in the data from the 16 interviews, the two groups complemented each other's experiences and perceptions of home visits.

Some interviews with parents and homecare nurses were conducted online due to the pandemic, which might have affected their conduct because the interviewer and interviewee were not in the same room. This leaves us to reflect on how the setting was different and wonder if there was less potential to catch nuances to what the interviewer was expressing through body language.

The authors of this paper have previously published two articles regarding HAH, and earlier findings might have coloured the analysis and the research process (Aasen et al., 2018, 2021). Additionally, the first author (L.A.) is an intensive care nurse with extensive working experience with sick children and their parents, which might have influenced how she emphasised and followed certain themes in the interviews and conversations with the nurses and parents. However, throughout the research process, these possible issues were consciously counteracted by continually discussing the interviews and the analyses with the co-authors, who have different academic backgrounds.

5 | CONCLUSION AND IMPLICATIONS

This study explores the collaboration between homecare nurses and parents of children receiving HAH, applying the perspective of negotiation, which adds new insights into the work and collaborations of formal and informal caregivers during home visits and illuminates aspects of distrust and how to overcome such barriers. Our findings suggest that collaboration with HAH has an impact on the experiences of safety and control for both parents and homecare nurses. We question, however, whether too much responsibility can be placed on parents when homecare nurses conduct the visits. For the parents to develop a partnership with the homecare nurses, fewer nurses should be involved with a given patient and the nurses need preparation before the child returns home in order to develop the competence needed to perform the work.

AUTHOR CONTRIBUTIONS

The first author, Line Aasen, had the primary responsibility for the data collection. The study design, analyses and article writing have been done in collaboration with the second author, Anne-Kari Johannessen and the last author, Anne Werner. The first author

made the interview guide, conducted and transcribed the interviews under the supervision of the co-authors. The third author Ingrid Ruud Knutsen contributed to the study design, data analysis and suggested improvements to drafts of the manuscript. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST

The authors of the current study have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

The study followed the ethical principles for medical research involving human subjects of the Declaration of Helsinki. The Regional Committee for Medical and Health Research Ethics, Southeast Norway, found the project to be outside the remit of the Act on Medical and Health Research Act (ref. 47,184). The local privacy legislation authority at the two hospitals approved the study (ref. 2019_134,19/29832). Written informed consent was obtained from the participants before data collection, and the participants were informed that their participation was voluntary, that the collected data would be kept confidential and that they could withdraw from the study at any time.

ORCID

Line Aasen  <https://orcid.org/0000-0001-6307-6449>

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