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Support for Siblings of Children With Complex Care Needs: Public Health Nurses' Perceptions of Their Role in Primary Schools

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ABSTRACT

Aim: To explore the role of public health nurses (PHNs) in Norwegian primary school health services in supporting siblings who have a brother or a sister with complex care needs.

Design: A qualitative, exploratory design using focus groups combined with visual methods.

Methods: Nineteen Norwegian PHNs participated in three focus group discussions between May and September 2022. The nurses were asked to draw themselves as PHNs working in primary schools. Braun and Clarke's reflexive thematic approach was used to analyse the transcribed interviews. The drawings were analysed using critical visual analysis methodology.

Results: The findings revealed that PHNs in primary schools focused on establishing good relationships and found it important to be flexible and creative. However, a challenge to successful service provision in supporting siblings and their families was that the nurses lacked support for the implementation of health promotion interventions and often felt alone. The analysis elicited three main themes: 'the importance of relationships and flexibility in meeting siblings' needs', 'feeling alone with responsibility for supporting siblings' and 'the forgotten children: a need for coordinated services'.

Conclusion: PHNs in school health services are in a unique position to provide support to improve siblings' mental health and well-being. To fully benefit from PHNs' potential to support siblings, there is a need to clarify guidelines and develop evidence-based interventions.

Impact: This study provides valuable insights for health authorities, educators and practitioners on what inhibits sibling support in Norway. The study highlights the potential for PHNs to play a significant role in delivering timely health-promoting interventions for these siblings in school settings independent of context.

Reporting Method: This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Patient or Public Contribution: No patient or public contribution.

Summary

- Although there are global differences in school nursing, this study increases awareness of siblings' needs for health promotion initiatives on an international scale.
- Understanding the role of PHNs is an important contribution to improving the provision of care and support systems for siblings of children with complex care needs in a variety of settings.
- To fully benefit from PHNs' position and their potential to support siblings of children with complex care needs, there is need to clarify existing guidelines and develop evidence-based interventions suitable for school health services in diverse cultural settings.

1 | Introduction

This study is part of a larger ongoing action research project that explores how to optimise the ability of primary school health services to promote the mental health and well-being of siblings of children with complex care needs (CCNs). CCNs refer to multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis (Brenner et al. 2018). The number of children with CCNs is increasing, and it has been estimated that 15%–20% of children live with a chronic condition in Western countries (Brenner et al. 2018; McKenzie Smith et al. 2018). This figure suggests that there are a large number of children who are siblings of a child with CCNs (hereafter referred to in this article as siblings). The purpose of this study is to explore the role of public health nurses (PHNs) in primary schools in supporting siblings. There is a paucity of data on how school health services support siblings (Bergvoll et al. 2023), and there is potential for greater involvement of schools (Gan et al. 2017). PHNs are an integral part of school health services in many countries (Norwegian Directorate of Health 2021; World Health Organization 2021) and are key professionals who can reach, support and empower school-aged siblings and initiate collaboration with parents and other professionals.

Having a brother or sister with CCNs affects children's daily lives. Siblings are vulnerable and may be at risk of developing psychological problems (Alderfer et al. 2010). Findings indicate that siblings of children with CCNs can experience stress and challenges, including less social interaction and more problems at school than other pupils (Hill and Brenner 2019). Moreover, siblings report difficulties in family relationships, insufficient time with their parents, as well as worries and feelings of frustration towards their ill sibling. Siblings' contradictory feelings about their everyday situation are well known (Nygård, Clancy, and Kitzmüller 2023; Park, Ryu, and Yang 2021). Siblings can experience feelings of shame, guilt and pressure to behave and not cause trouble at home (Lummer-Aikey and Goldstein 2021). However, siblings also achieve increased empathy, maturity and responsibility (Knecht, Hellmers, and Metzing 2015; Nygård, Clancy, and Kitzmüller 2023). The experience of living with a brother or sister with chronic illness can have both positive and negative effects on siblings' mental health. However, the literature consistently states that siblings of CCNs must be regarded as at risk for poorer mental health (Nygård, Clancy, and Kitzmüller 2023). Healthy ageing starts with the young, and siblings need access to timely supportive care and efforts should be made to develop appropriate interventions from a young age. Providing school health services to support vulnerable children in primary schools is an investment for the future.

1.1 | Background

In Norway, healthcare is organised at national, regional and municipal levels. In 2018, Section 10a of the Norwegian Health Personnel Act (1999) was amended to ensure that siblings of children with long-term illness receive necessary support. The act states that Norwegian primary healthcare services are responsible for providing information and support to these siblings. Further, specialist healthcare services are responsible for initiating and establishing collaboration in this area with primary care professionals (Lauritzen and Reedtz 2016; Health Personnel Act 1999). Unlike in many countries where PHNs deliver healthcare to the entire population, Norwegian PHNs focus specifically on children and adolescents (0–20 years), and their families at individual, group and community levels. They provide universal health promotion and prevention to this target group by offering health dialogues, referrals to other services, health education, family support, coordination and multiagency work. They do not provide curative care (Norwegian Directorate of Health 2021). The health-promoting role of school PHNs in Norway can be considered as similar to the role of school nurses in many other countries.

Primary schools in Norway cater for children aged 6–13, and school healthcare is a universal and statutory health service provided for pupils and their families (Health and Care Services Act 2011). A crucial aspect of school health services is accessibility; PHNs are located in schools and provide a drop-in service. This enables children and parents to visit without needing an appointment or referral. After the home setting, primary schools are the most influential environments for children, and investment in school health services is one of the most cost-effective approaches to providing health education and improving the health of school-aged children (World Health Organization 2021). Therefore, school settings provide a unique opportunity for early intervention, where PHNs play a critical role in identifying and addressing siblings' vulnerabilities at an early stage and providing interventions that can prevent long-term adverse psychological effects.

Previous research highlights the need for interventions for siblings of children with CCNs (Hartling et al. 2014; Haukeland et al. 2020; McKenzie Smith et al. 2018; Mitchell et al. 2021; Wolff et al. 2023). However, in most countries, the availability and provision of support for siblings and their families is inadequate, and their needs are often unmet (Nygård and Clancy 2018; Nygård, Clancy, and Kitzmüller 2023). School health service provision varies in Norway, with regional differences (Bergvoll et al. 2023). Based on a national survey, Bergvoll et al. (2023) found a large gap between the ideal and reality in school health services' identification of and provision of support to siblings. An important finding was insufficient

and unsystematic support from school health services. A previous study on PHNs' experiences of working with children of parents suffering from physical illness, mental health disorders or substance abuse (Granrud et al. 2022), showed that they lacked guidelines and procedures to identify these children, resulting in a lack of timely support. School-based initiatives should rely on evidence-based programmes, but school health services have currently no established programmes or interventions to support these siblings (Hartling et al. 2014; Mitchell et al. 2021; Norwegian Directorate of Health 2021). The role of PHNs in providing support to siblings of children with CCNs has been little explored (Bergvoll et al. 2023). An understanding of the role of PHNs is crucial for developing and implementing evidence-based interventions that are tailored to the needs of siblings in the school context, and for supporting the emotional well-being of these children (Gan et al. 2017). It is pertinent to conduct this research due to the amended legislation in Norway that strengthens siblings' rights to care (Norwegian Parliament 2017).

2 | The Study

2.1 | Aims

We aimed to explore the role of PHNs in Norwegian primary school health services in supporting siblings of children with CCNs, and specifically their views on their current clinical practice and how this can be improved to identify and provide support to siblings. The research questions were as follows: How do PHNs perceive their role in supporting siblings who have a brother or a sister with CCNs? What do PHNs perceive as the main challenges to successful service provision?

2.2 | Design

The study had a qualitative exploratory design, using focus group discussions (FGDs) and critical visual methodology to explore PHNs' perceptions of their role in supporting siblings in primary schools (Barbour 2018; Drew and Guillemin 2014). We chose FGDs as they can create a natural conversational setting, allowing participants to talk about their experiences and practices (Barbour 2018). We used group dynamics in combination with the participating nurses' drawings and generated data that could be compared and contrasted across groups. In accordance with previous studies (Drew and Guillemin 2014; Guillemin 2004; Laholt et al. 2017), the use of visual methods, such as drawings is beneficial in exploring how practitioners understand their role in multiple ways and acknowledge the various ways in which practices are understood and enacted. We used an integrated approach inspired by Laholt et al. (2017) and Guillemin's adaptation of Rose's critical visual methodology framework (Guillemin 2004; Rose 2023), involving the use of both visual and word-based methods. FGDs in combination with drawings enabled the participants to share perceptions of their role in an innovative way. The combination of drawings and narratives can enable participants to express their experiences in various ways, which has a positive effect on the group dynamics (Virole and Ricadat 2022). An essential aspect of the method was to ask participants to explain their drawings and the reasons behind their choices. This study has been reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, and Craig 2007).

2.3 | Participants

The data were gathered from 19 PHNs working in school health services in eight municipalities in three counties in northern and western Norway. Some of the PHNs worked exclusively in schools, while others worked in child health clinics and had regular office hours in schools. The participants were divided into three groups and PHNs from the same municipality and county were grouped together. Hence, all participants had at least one colleague in their group (Table 1).

A purposive sampling strategy was used. We sought to explore the perceptions of PHNs in primary schools from different-sized municipalities in order to cover both urban and rural areas. The inclusion criterion was being a qualified PHN with experience of working as a school nurse in primary schools. The PHNs were recruited in collaboration with leaders of public health services in all municipalities. The leaders distributed written study information to PHNs that met the inclusion criterion and had an interest in contributing to the study. PHNs who wanted to participate then directly contacted the first author. It was emphasised that participation was voluntary.

2.4 | Data Collection

A piloted topic guide (Barbour 2018) (Table 2) developed from previous research was used to facilitate discussions and drawings. We were particularly interested in exploring challenges highlighted in a recent national survey regarding inadequate routine support, working alliances and collaboration (Bergvoll et al. 2023). The survey represented the first phase in the ongoing action research project, and this study was the second phase. We conducted three FGDs ($N = 19$) from May 2022 to September 2022. Focus groups 1 and 3 ($n = 5$ and $n = 7$) were conducted face-to-face in a location of the participants' choosing. One FGD took place in a suitable meeting room on the researchers' university campus, and another at the child health clinic where the participants worked. Focus group 2 ($n = 7$) was conducted online using Microsoft Teams (UiT 2023), because these participants were situated in several different municipalities. The first author moderated the FGDs using four main topics which were discussed by the participants and followed up with questions (Table 2). We started the FGDs in an informal and relaxed manner to encourage the nurses to feel free to share their experiences. We provided the group with information about the purpose and framework of the group discussions.

The role of the moderator (first author) and the comoderator (fourth author) was to guide and listen but not control the discussions. The moderator was responsible for asking the questions and initiating group discussions, while the comoderator focused on observing and taking notes on the group interaction and identifying new leads as they appeared. At the start of the discussion, the moderator handed the participants a blank, unlined A4 card and a box of coloured pencils. The PHNs were

TABLE 1 | Overview of focus group participants ($N = 19$) and the data collection.

Focus groups (in chronological order)	Focus group 1, $n = 5$	Focus group 2, $n = 7$	Focus group 3, $n = 7$
PHN experience, mean year (min–max)	20 (8–32)	11.5 (5–18)	7.5 (3–12)
Number of participants with additional education, minimum 60 ECTS, since PHN education	2	3	1
Number of participants working in both child health clinics and school health services	3	5	1
Number of participants only working in school health services	2	2	6
Data collection setting	Face-to-face	Online	Face-to-face
Region	Northern Norway	Northern Norway	Western Norway
Number of municipalities represented	2	5	1
Number of participants representing municipalities by population size			
Fewer than 2000 inhabitants		2	
2000–4999 inhabitants		5	
10000–19999 inhabitants	2		
20000–29999 inhabitants	3		7

Abbreviations: ECTS = European Credit Transfer and Accumulation System, PHN = public health nurse.

asked to draw how they saw themselves as school nurses and were then asked to describe their drawings. This was followed by discussions of the role of PHNs in supporting siblings in school health services. Discussions had a respectful tone and lively interest, and we encouraged different opinions and views. All participants drew and described their role as PHNs, but only 13 gave their drawings to the moderators after the FGDs. Nevertheless, they all described their drawings. The discussions and the nurses' descriptions of their drawings were audio-taped. The moderators discussed their impressions from the meetings after each FGD. Each group met once for approximately 2 h, and the audio-recorded sessions were transcribed verbatim by the first author.

2.5 | Data Analysis

Analysis of the transcripts from the FGDs was guided by Braun and Clarke's (2022) reflexive thematic analysis procedure in combination with the integrated approaches to interpreting drawings of Drew and Guillemin (2014) and Laholt et al. (2017). Reflexive thematic analysis consists of six phases: (1) familiarisation with the data, (2) generating codes, (3) constructing themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report. The method of visual meaning-making (Drew and Guillemin 2014; Laholt et al. 2017) was used to analyse the drawings. It comprises three stages: the first stage involves a close analysis of each individual drawing and the participants' explanations, which explicitly represent their voices. Stage 2 represents the researcher-driven engagement, while stage 3 involves meaning-making through re-contextualisation and discussions (Figure 1). The researchers moved back and forth through Braun and Clarke's (2022) six phases. Data were analysed inductively, where patterns in the data were examined by identifying, generating and exploring themes based on codes grounded in the data (Braun and Clarke 2022). The first author read the transcripts several times to gain a better sense of the data. The transcripts were then cross-checked with the audio recordings and drawings (phase 1). Initial codes were generated, and similar codes were grouped together to form novel themes (phases 2 and 3). Based on the generation of initial codes and themes, the first and fourth authors brought together textual material and drawings using visual meaning-making as proposed by Drew and Guillemin (2014) and Laholt et al. (2017). With participant engagement, the first and fourth authors examined each drawing, paying attention to each participant's voice and their accompanying explanations and reflections on their drawings. Through researcher-driven engagement, we considered their symbolic representations, use of colour, the kinds of emotions and atmosphere they expressed and their choice of location (phases 3 and 4). The research team then collaborated to reflect on and interpret the meaning of the participants' drawings and their accompanying explanations. In phase 5, defining and naming themes, and in phase 6, producing the report (Braun and Clarke 2022), we re-contextualised and focused on novel findings when combining text and images by discussing how PHNs perceived their role in supporting siblings of children with CCNs (Figure 1).

We compared drawings and discussions from all three FGDs, read the text and refined the themes, finally presented as: 'the importance of relationships and flexibility in meeting siblings' needs', 'feeling alone with responsibility for supporting siblings'

TABLE 2 | Topic guide.

Themes	Questions	Probe
Opening 5–10 min	1. Thank you for participation. Please introduce yourself with your name and how long you have worked as a public health nurse in school health services	Name and experience of working in school health services in primary school
Theme 1: Perceptions of themselves in the professional role of public health nurses working in school health services 15 min	2. How do you experience your role as being a PHN in the school health service at primary school?	'Draw yourself as a public health nurse working in primary school'. And write three keywords that describe your role in everyday practice
	3. What expression do you have? 4. Where are you located? What are you saying?	After 5 min, ask: What have you drawn? The role and mandate of public health nurses in school health services
Introduction 15 min	5. What is your experience of how far your service focuses on siblings of children with complex care needs? 6. How would you describe the role of public health nurses working in school health services when it comes to supporting siblings?	Empirical and historical development (past–present–future) Legal rights were amended in 2018—primary health care services are now responsible for providing information and support to siblings
Transitions 15 min Theme 2: Exploring their views on the results from the national survey	7. How do these results comprise with your experiences?	Present the main results from the national survey of public health nurse leaders and public health nurses working in school health services—exploring health promotion interventions by public health nurses for siblings and regional differences Existing health dialogues in the services?
Theme 3: How can school health services identify and provide support to siblings? Key questions 30 min	8. How do you identify siblings in your work? 9. What types of support should this group of children optimally be offered? 10. Are there situations where you should take the initiative to offer siblings and parents more information about the services? 11. How can you increase awareness of siblings' needs in your services?	Systematic/routine practice? (contradictions?) 'Open door', partners—teachers, parents, other health professionals? Passive versus active (outreach strategy?) opportunities versus limitations/challenges
Theme 4: How to improve school nurses' dialogues with siblings and parents 15 min	12. Please tell me about your experiences of providing support to siblings of children with complex care needs 13. Tell me about an occasion when you felt that a dialogue with a sibling was 'successful'? 14. How can you tell if a dialogue was a 'success or a failure'? 15. Please tell me about challenges you have experienced in health dialogues with siblings and parents 16. How can we improve your skills in providing health promotion interventions to siblings?	Individual, groups, class-based? Establish trust and talk about difficult subjects? Ethical, practical aspects? What needs improvement in health dialogues with siblings and parents?
Final question 5 min	17. Check with comoderator about further questions	Did I miss anything important?
Summary	18. Have we forgotten anything that you think is important to include? ◦ Thank you for your participation in this interview. We will inform you about the main themes that emerged in all interviews when we have a reflection meeting	To public health nurses who attend reflection meetings

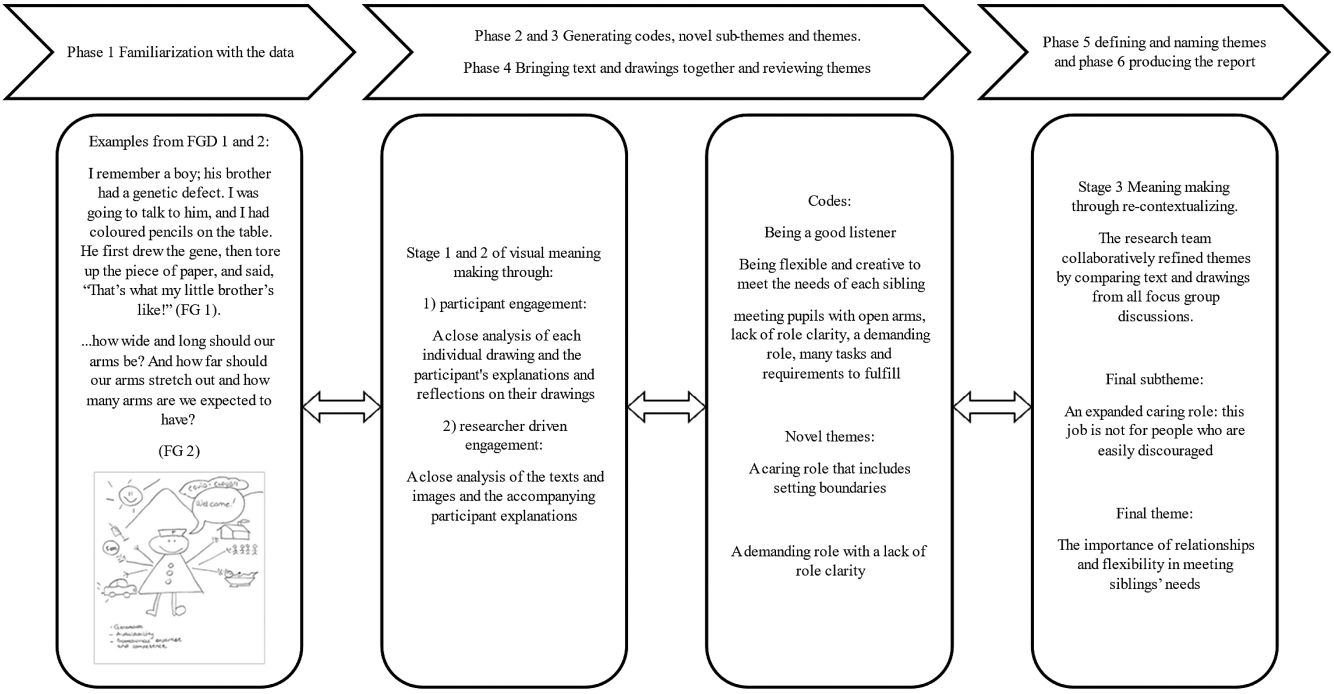

FIGURE 1 | Overview of the analytic process using reflexive thematic analysis (Braun and Clarke's 2022) in combination with visual meaning-making for analysis of drawings and accompanying explanations (Drew and Guillemin 2014; Laholt et al. 2017) for one theme starting in phase 1.

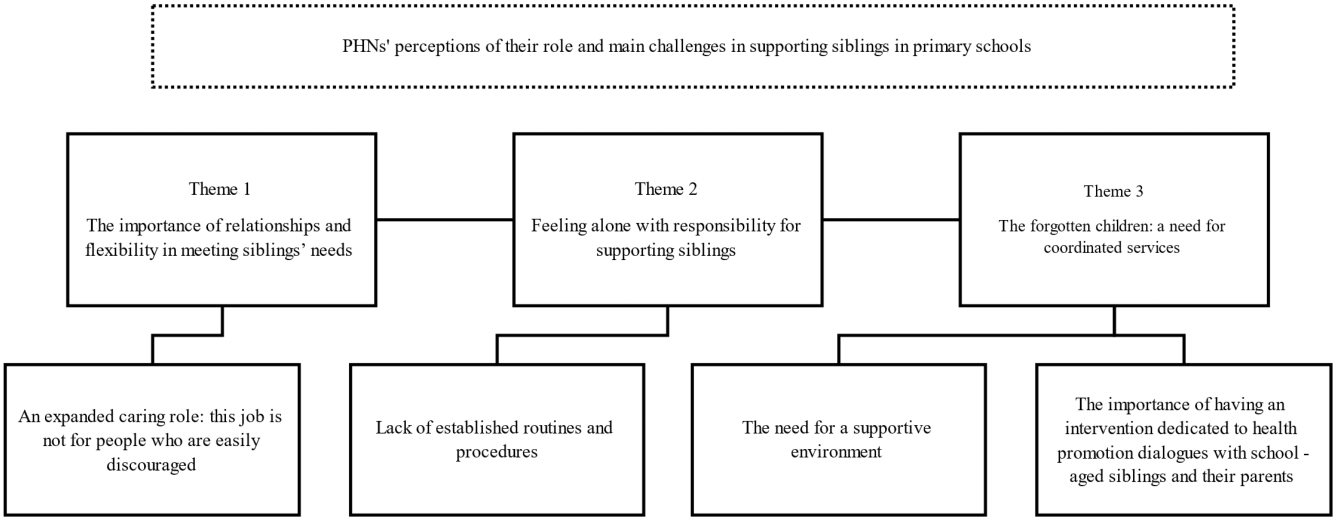

FIGURE 2 | Overview of themes and subthemes, and the relationship between themes and subthemes.

and 'the forgotten children: a need for coordinated services' (Figure 2). The abstracted themes are presented as narratives in combination with relevant drawings. All authors regularly reflected and collaborated on the analysis by discussing and reviewing the initial codes and themes before agreeing on the final themes.

2.6 | Ethical Considerations

The study was approved by the Norwegian Agency for Shared Services in Education and Research (No. 634360, date: 7 September 2022) and performed in accordance with the Helsinki Declaration (World Medical Association 2007). All participants were informed orally and in writing about the purpose of the study, and that they could withdraw at any time. Written informed consent was secured from each participant. Confidentiality and anonymity are potentially problematic in connection with FGDs, because of the researcher's limited control over what participants may subsequently communicate outside the group (Barbour 2018). The importance of mutual confidentiality within the group was expressly explained before each group discussion. No participants withdrew from the study, and all names in the article are pseudonyms.

2.7 | Rigour and Reflexivity

The first, second and fourth authors are all PHNs and have many years of experience in the field through research and practice. The third author is a professor of psychology. None of the researchers had an ongoing personal, clinical or research relationship with any participants. The four authors' perspectives were discussed during the analysis and the reporting. The first author led the analysis, while being aware that her experience could influence and potentially constrain her interpretation of the data. The approach to the analysis was collaborative and reflexive, aiming to achieve richer interpretations of meaning, rather than attempting to achieve consensus of meaning (Braun and Clarke 2022). The collaborative and reflexive approach involved being aware of one's own perspective, and using different perspectives to read the data and actively enhance reflexivity. Each member contributed to the team with unique perspectives that enriched the analysis. Throughout the process, all team members had several meetings to discuss and review subthemes and themes. Further, the data were collected from both rural and urban settings in the two regions of Norway, which provided comparative data that strengthened the transferability of the study findings. Using drawing as part of the focus group process enabled the researchers to see the participants' world more clearly and facilitate discussions and the sharing of perspectives (Guillemin 2004; Virole and Ricadat 2022).

3 | Findings

The study findings are based on three FGDs with 19 female PHNs. Six of the 19 nurses had additional education beyond their postgraduate or master's degree in public health nursing. Their experience as PHNs ranged from 3 to 32 years. An overview of the focus group participants is presented in Table 1. The drawings and FGDs revealed that the PHNs saw their role as primary school nurses as relational, flexible and creative. However, a challenge to successful service provision to support siblings and their families was that PHNs felt alone and uncertain about how to manage this responsibility. The findings also demonstrated a lack of organisational structures and procedures to identify siblings in need of support and showed that the nurses wished for better collaboration with other healthcare professionals and teachers and needed evidence-based interventions to help them support siblings.

3.1 | The Importance of Relationships and Flexibility in Meeting Siblings' Needs

Drawings and discussions from the FGDs showed that the PHNs perceived their role in relation to siblings as relational, flexible and creative. Patricia described her role: 'I have drawn myself and a child having a conversation, and I say, welcome with a big smile!... also, to the children who visit me when my door is open...and on the table, there are always coloured pencils' (FD 3, Figure 1). The PHNs acknowledged the important role they played in working with siblings and focusing on their mental health and well-being.

They highlighted the importance of being available for these children to gain their trust and of maintaining school health services as a universal service to ensure accessibility for siblings, parents and partners. A universal service was strongly felt to be an important factor in providing adequate support to siblings.

The PHNs spoke of how their involvement with siblings at schools evolved over time and discussed how personal commitment and relationships based on trust and respect gave them a firm foundation to enhance siblings' mental health and well-being. They also discussed the universal nature of their services, as expressed by Lauren (FG 3) 'the meaning of the fact that siblings know everybody goes there'. This resulted in less stigma and shame for siblings seeking support. Further, they felt that conversations with siblings were a natural part of their practice, and that the school nursing context was suitable for these health dialogues. They talked about how school nurses' health promotion work presupposes relationships and understandings based on children's and young people's needs, and that each encounter with siblings must be on the child's terms. They explained that implementing a health promotion approach involved engaging in open dialogues with siblings and their parents. They also saw the importance of client involvement and of providing support before problems arose in the family or with the siblings. Sarah said: '... I think we can help by advising the parents...' (FG 1) and '...you know, just the fact that she [sibling] had a place to talk was good for her and for her parents' (Mary, FG 3). The nurses felt that they could contribute to the siblings' well-being by listening to these children's perspectives to normalise their views, feelings and thoughts, and help them navigate the ups and downs of family life with an ill sibling.

They described how they needed to be creative and flexible to meet the needs of each sibling and family and how initial meetings with siblings had an informal atmosphere. Furthermore, the PHNs talked about and sketched different types of activities they did with siblings, such as playing games, drawing, telling stories and sometimes being with them in the playground, but mostly they conducted health dialogues with them. Patricia's drawings illustrate how the nurses tried to establish relationships with siblings (FG 3, Figure 3).

3.1.1 | An Expanded Caring Role: This Job Is Not for People Who Are Easily Discouraged

The PHNs emphasised that their role in primary schools when supporting siblings was to be respectful, helpful, accommodating and attentive to pupils, parents and other professionals. Building personal relationships with siblings and their families provided them with a sense of satisfaction. They were proud of having the opportunity to make a difference in people's lives. The caring role was expressed as being the optimal role for school nurses, but they often found it difficult to prioritise different tasks, to meet high expectations with limited resources or to fulfil many different roles. This was particularly prominent if they worked in both a child health clinic and a school. One nurse stated: 'I often take an accommodating approach saying, welcome, what can I help you with? I also make efforts every day to set limits, because there are a lot of different tasks in this job' (Ingrid, FG 1). Despite their heavy workload, the PHNs were deeply committed to their work and to fulfilling their

FIGURE 3 | Patricia's drawing illustrates the importance of good relationships and being creative and flexible when meeting the needs of siblings in primary school health services. Visual methods such as drawings and pictures, or playing games, were some of the activities shown to be helpful in establishing relationships and opening up dialogues with siblings.

responsibility towards siblings, even if it required a significant investment of time. Another nurse said: 'We have to stick it out, yes, if it takes fifteen years, well, that's part of the job. I actually think the other primary care services or the specialist system are not aware of that and they're trying to push responsibility onto us. You know, we must get better at setting limits for what we do' (Bethany, FG 2). Being a school nurse necessitated being tough and facing time pressure. Jessica said: 'We really have to be tough and strong in this job' (FG 2) and Olivia said: 'We have many roles, and if I'm absent from work for a while it's not just anyone who can take over, this job is not for people who are easily discouraged'! (FG 2).

The nurses described how the COVID-19 pandemic had influenced their everyday work as school nurses with increased work pressure and reprioritisation. Those working in smaller and rural municipalities found this to be more of a problem than urban nurses. They described their services as overloaded and working as PHNs in schools was compared to being an octopus. One nurse commented on her drawing: '... how wide and long should our arms be? And how far should our arms stretch out and how many arms are we expected to have'? (Mia, FG 2, Figure 4). The drawing illustrates how the PHN welcomes the pupils to her office in school, and the complexity of her role and nurses' difficulty in improving siblings' mental health due to the scope of their duties and diffuse boundaries in their role.

3.2 | Feeling Alone With Responsibility for Supporting Siblings

Across all FGDs and drawings, PHNs illustrated that the main challenge to successful service provision to support siblings was feeling alone with their responsibility towards siblings and their families. Feeling alone was associated with feeling responsible for the identification of siblings and provision of necessary support to them. It was not referred to as being alone physically or having an independent role as a primary school nurse. However, inadequate procedures for identifying siblings contributed to their feeling of being left alone with the responsibility of ensuring support to vulnerable siblings and their families. 'We have to be careful that we aren't left alone with responsibility for this work, having to inform teachers, having to identify these children, no, there must be a system that we can contribute to, not solely our responsibility, more system and cooperation is needed' (Nina, FG 1). The feeling of being left alone was reinforced by inadequate procedures in their own service provision as well as in other services. 'I don't think other clinicians mean to do this, neither in primary nor secondary care, but the result is the same, we're often left alone, and I've often felt that we get kind of worn out by it' (Mia, FG 2).

3.2.1 | Lack of Established Routines and Procedures

PHNs encountered challenges related to the lack of established routines and procedures in their work, coupled with resistance and attitudes from other PHNs and a lack of professional awareness of siblings' needs. One said: 'We have procedures for children of parents who have an illness, but not for siblings. And it's not because we don't think it's important, but it's because there are attitudes among other staff' (Sarah, FG 1). Across the groups, PHNs expressed self-criticism towards their own service and practice: '...there's something about us having to focus on this too, because we haven't exactly automatically focused on siblings, we have to focus on

FIGURE 4 | Mia's drawing illustrates the myriad of settings and tasks she has, yet she must be welcoming and attentive to each pupil who comes to her office. The 5-øre coin on the left refers to a Norwegian saying meaning that she has to 'change hats rapidly' in her work.

those children ourselves, we have to get better at talking about this and acting, you know, when we as a service are focused, we can identify more siblings' (Mary, FG 3). Olivia said: '... we have a way to go, because we do not have procedures for siblings...' (FG 2).

The PHNs mentioned several reasons why new routines were not implemented and systematised after the new legislation that had strengthened siblings' rights to care. They had found that their work with siblings involved haphazard support, which varied according to the people concerned. Information about siblings was often obtained through rumours or chance encounters. Olivia (FG 2) said: 'I think the word haphazard describes a lot of what we do, we simply don't know about everything, maybe we pick up something, a rumour or someone happens to come to us...'.

3.3 | The Forgotten Children: A Need for Coordinated Services

The PHNs spoke of the invisibility of siblings and described siblings of CCNs as 'the forgotten children'. They realised that siblings' legal rights were less recognised in all parts of the healthcare services than those of children with an ill parent. Lack of recognition of siblings' rights led to their invisibility and prevented them from receiving the support they needed. The nurses underlined the importance of collaborating with teachers, because teachers were the professionals who spent the most time in contact with pupils and could observe and identify siblings at an early stage. Teachers were sometimes aware of having siblings of chronically ill children in their class before the nurses. Yet, this did not necessarily mean that the teachers would contact the PHNs to enable support for the siblings. Nina said: 'If they [teachers] don't have the knowledge, it can be hard to be the sibling of someone who is struggling or is ill, because not everyone understands or knows, and then they don't think there's any connection...'. Sarah said: 'Many are afraid to ask. Some teachers are reluctant to get involved or to ask' (Excerpt from FG 1).

School PHNs noted that specialist healthcare providers often overlooked the care needs of siblings. Additionally, PHNs across all three focus groups reported experiencing poor communication from specialist healthcare providers. They also noted inadequate information sharing within primary care settings. After providing information, hospital clinicians felt no longer responsible for siblings. Astrid explained:

> 'There's a difference between just fulfilling a legal or a procedural requirement by talking to siblings and actually ensuring that the child understands

> the situation...I know of children who have been given information at the hospital and they haven't understood that this has been done, the children didn't understand...'
>
> (FG 1).

Moreover, these barriers made the nurses give priority to solving problems at the individual level. This resulted in secondary prevention interventions that were not provided until siblings clearly struggled and action was requested by parents or teachers. The PHNs spoke about the need for a health promotion approach and a focus on family-centred care. A family focus was lacking in general. They reported that services for siblings and their families were fragmented and focused mainly on children with illnesses. Mary said: 'Then they [the specialist services] bring together experts to discuss the child with a medical condition, but they don't talk about family situations, I find that sad...' (FG 3). PHNs often found themselves as the sole advocates for siblings in need of support.

In all three FGDs, the participants clearly felt that other professionals and parents had high expectations for PHNs' role, tasks and contribution to finding solutions to complex health issues.

> 'Then I realize that I'm the one who has to fit in with everything they [school] do, well, it's not like that... I have several schools to deal with and have regular days when I'm at the different schools... is it really the idea that I just have to fit into their system? ... and they [school management] often say: look, you're dealing with health issues and so you have to take responsibility for it ...'
>
> (Bethany, FG 2).

Parents and schools often expected quick fix solutions if the sibling showed signs of struggling. The participants discussed their difficulty in meeting all the demands, fitting in all they were expected to do and fulfilling the various expectations of others. Lack of time prevented them from providing adequate support to siblings; they pointed out that optimal support was often time-consuming. Their role differed from school to school, and was generally described as extremely varied, with unclear boundaries. Several PHNs also felt invisible to other professionals. Struggling to be visible and promoting awareness of siblings' needs was an important issue for them:

> 'We were able to introduce the topic at a meeting of general practitioners, and we formed a collaboration group of PHNs and doctors who developed procedures...but nothing happened afterwards...we had hoped for more from the doctors, but they were hardly aware that new legislation on siblings' rights had been introduced, and the project we initiated, that siblings have certain rights ....'
>
> (Astrid, FG 1).

However, the PHNs described a more visible role with teachers than with healthcare professionals and described the importance of being visible at school and not working alone on their cases. They emphasised the importance of having an outreach service in their schools, while being visible depended on their own efforts: '...when they [teachers] know something about the sibling of a child with a medical condition, they more easily inform us and collaborate, yes, they contact us more easily or help the parents to make contact...' (Victoria, FG 3).

Attending parents' meetings at schools and giving information to teachers about the needs of siblings was discussed as one way of promoting awareness of siblings' needs to teachers and parents. 'We now give presentations at our schools for teachers about children living with a family member affected by illness...' (Patricia, FG 3). None of the nurses discussed how they could be more visible to other professionals, but they mentioned the need for the leaders of services for children, young people and families to take responsibility for coordinating collaboration. Mary's drawing (Figure 5) illustrates the complexity of the PHNs' role in meeting individual pupils' needs, supporting families, collaborating with schools and multiagency work. Mary's explanations of her drawing were: '...I'm standing in the middle of this drawing, and I call parents, I cooperate with teachers about meetings with doctors and psychologists...and I try to be visible and think of the child's best interests' (FG 3).

Mary's drawing, supported by her explanations and reflections, in addition to the FGDs, illustrated that PHNs have a more visible role with teachers, pupils and parents than with other professionals.

3.3.1 | The Need for a Supportive Environment

The PHNs discussed how inadequate collaboration made them worry about making the wrong decisions. Lauren said: 'What I miss the most is the digital information, because when a child has been in hospital, that information does not necessarily reach us in the school health service. You know, that might be unfortunate and then we can easily make mistakes' (FG 3).

The need for a supportive environment was apparent and they lacked initiatives from the responsible doctor or nurses at the hospital or from general practitioners. The PHNs found that the degree of collaboration with teachers varied with the individual teacher. Most of the schools had an interprofessional team, but siblings' needs were rarely discussed at the team meetings. One of the drawings (FG 3, Figure 6) illustrates the nurses' need for interaction with other professionals and the importance of having procedures for shared responsibility and understanding with colleagues and other actors to provide timely support to siblings. 'I try to be a facilitator behind many things, and consensus in the group is important to me, and if we want to change things, we have to do it together ... to provide optimal support to siblings, we must shoulder the responsibility together' (Lauren, FG 3).

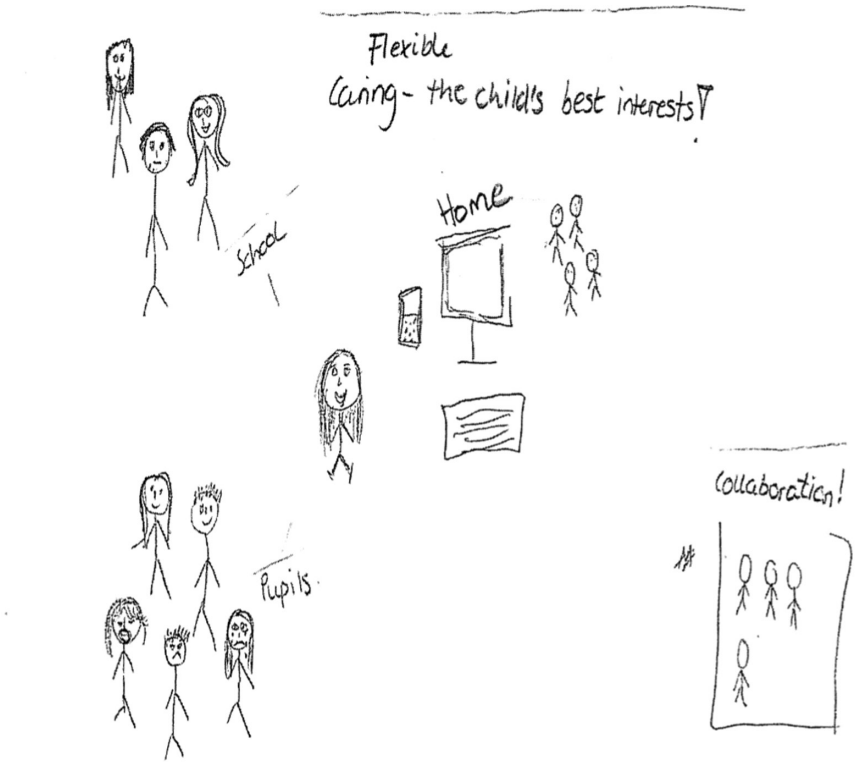

FIGURE 5 | Mary's drawing shows the complexity of the PHN's role in primary schools. Mary is standing in the middle of the drawing closest to pupils, school staff and parents. In the box, she has sketched other collaborators at a greater distance.

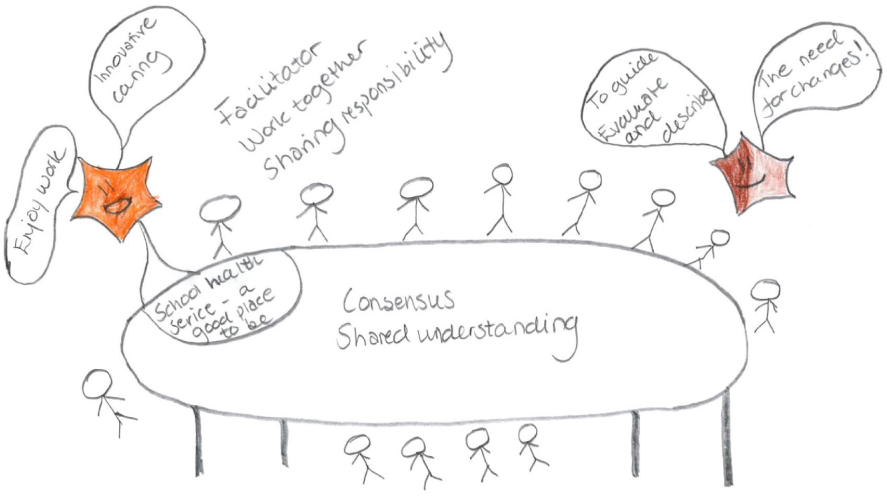

FIGURE 6 | Lauren's drawing illustrates the importance of having routines for shared responsibility and understanding with colleagues and collaborators. The two stars and keywords illustrate her vision of how practitioners could work together to make positive changes in their support for siblings.

3.3.2 | The Importance of Having an Intervention Dedicated to Health Promotion Dialogues With School-Aged Siblings and Their Parents

PHNs missed having manuals and guidelines that could enable them to deliver an evidence-based intervention to siblings. Their support to siblings was frequently based on their own prior experience. Mary said: 'I've missed having a manual that says something about how to have health dialogues with siblings, how should I conduct the conversation, what should I assess and what focus should I have... it's useful for us [PHNs] to have... because it's not ideal to just use your own experience...' (FG 3). The nurses typically worked one-on-one with siblings, but also found dialogues with siblings and parents and a group format to be fruitful. The use of support groups was not easy to arrange in a school nursing context, especially in smaller municipalities.

The nurses needed guidelines for the content of health dialogues with siblings and parents. An evidence-based intervention could function as a supportive tool for these dialogues and provide them with necessary updated evidence. The PHNs discussed how a standard guideline could prevent each individual nurse from approaching health dialogues with siblings and parents differently, leading to inconsistency in the quality of support provided. Karen said: 'It gets to be a bit random, you know, it's up to each nurse how they think it's best to do it, we need something more systematic, so everyone gets the same support' (FG 3). The nurses emphasised that having flexible guidelines could offer a clear direction when dealing with uncertainty, because encounters with siblings and parents were demanding. They talked about dealing with dilemmas, such as avoiding putting more strain on the parents and the power aspect in dialogues with siblings and parents. They, therefore, felt that it was difficult to treat siblings with a one-size-fits-all approach and that the role of school nurses extended beyond simple health assessments and dialogues. They were aware of the complexities of the lives of these families and the uniqueness of each sibling's situation.

4 | Discussion

The aim of the present study was to explore the role of PHNs in Norwegian primary school health services in supporting siblings of children with CCNs. The findings of our in-depth descriptive study reveal a need for health promotion interventions that can be adapted for use by PHNs to provide support to siblings. The findings underscore the unique position of PHNs in enhancing siblings' mental health and well-being, but to succeed in this, they need procedures and guidelines in clinical practice. The results confirm findings from existing research on PHNs' role and the provision of support to siblings in the Norwegian context (Bergvoll et al. 2023) and emphasise the challenges and potential solutions from the perspectives of PHNs.

4.1 | Challenges Faced by PHNs and the Need for Clear Guidelines

The PHNs in the present study described a vague role with unclear boundaries, where they felt alone with the responsibility of supporting siblings and uncertain in decision-making. The PHNs' universal service with open-door hours for all pupils at school made prioritising difficult. They faced high expectations from parents, teachers and collaborating clinicians, but felt that their services were often invisible to other healthcare professionals. The PHNs in this study discussed how low professional awareness of siblings' needs hinders support for these siblings in the school health service and throughout the healthcare system. In contrast to children and young people with chronically ill parents, siblings of children with CCNs are less likely to be perceived as a population with specific vulnerabilities and their need for support is often overlooked. Siblings of children with chronic illnesses have been referred to as 'glass children' (Hanvey et al. referred to in Nygård, Clancy, and Kitzmüller 2023), as healthcare providers tend to see right through them and mainly focus on the ill child. It is problematic that siblings' support needs can be overlooked by clinicians (Bergvoll et al. 2023; Nygård and Clancy 2018; Nygård, Clancy, and Kitzmüller 2023). High workload and low professional awareness of siblings' needs among PHNs, other healthcare staff and professionals working with children and families were obstacles to establishing procedures to provide suitable interventions.

The difficulty of working in a service that is invisible and helping 'invisible' children (Nygård, Clancy, and Kitzmüller 2023) underscores the need for more specific guidelines to clearly define PHNs' roles. More specific guidelines would help align their responsibilities with their training and personal understanding of their societal roles and improve collaboration with other professionals (Fixsen et al. 2005). The PHNs in our study emphasised the importance of being visible at school and not working alone on their cases. A previous study (Gan et al. 2017) has demonstrated the need for teachers to be aware of the possible psychological problems siblings may face, and shown that PHNs are particularly well-positioned to increase awareness of siblings' needs among school professionals. Some PHNs mentioned giving presentations to teachers at schools about how living with a family member who has a chronic illness can affect children's everyday activities and well-being. PHNs can advocate for the needs of all children in the family, thus raising awareness among teachers about the challenges faced by siblings of children with CCNs. Greater awareness of this can lead to a more supportive and understanding school environment. Nevertheless, when guidelines are broad and general, the expectations of other professionals can affect the way these nurses define and execute their roles.

Despite their various challenges, PHNs in this study were committed to their role and eager to fulfil their responsibilities. However, they felt that they could not shoulder the entire responsibility for siblings alone. It is widely agreed that interventions to change professionals' practice need to be clearly specified (Fixsen et al. 2005) and a clear, specific guideline could delineate the roles and responsibilities of PHNs and other healthcare professionals in supporting siblings and change current practices towards a focus on family care. PHNs play an indispensable role in healthcare, often serving as a bridge between communities, schools and healthcare facilities (Dahl et al. 2022). Their caring role is even more crucial in providing support to siblings, due to the universal service they provide. Most countries have school health services (World Health Organization 2021), and in Norway almost all children visit the school health services through a national school health programme (Norwegian Directorate of Health 2021). Routine consultations in schools could be an opportunity for PHNs to identify siblings in need of support by asking parents or pupils if they have a family member living with a chronic health condition.

4.2 | The Need to Implement Procedures and Interventions to Facilitate PHNs' Support for Siblings of Children With CCNs

The results emphasised the importance of having systematic procedures for shared responsibility with colleagues and other professionals for providing timely and necessary support to siblings. New interventions should enable practitioners

to collaborate more effectively, but this requires proper implementation. According to Fixsen et al. (2005), implementation involves targeted efforts to enact plans, decisions or interventions within a service or organisation, with three degrees of implementation: paper, process and performance. In paper implementation, decisions on innovations are rooted in formal resolutions. In process implementation, procedures and systems are changed to make it possible to materialise the innovations, and relevant participants are provided with necessary training. The most advanced degree of implementation is performance implementation, involving the development of procedures with functional tools that enable new skills to be adopted in clinical practice (Fixsen et al. 2005). In Norway, siblings' legal rights to support have been formalised (Health Personnel Act 1999; Norwegian Parliament 2017). According to amended legislation adopted in Norway in 2018, healthcare personnel are obligated to identify patients' siblings and to assess the family situation. They also have a duty to provide adequate support to families affected by childhood illness. The intention behind the amendment was to safeguard the support and care of siblings (Norwegian Parliament 2017). Fixsen et al. (2005) argue that paper implementation rarely leads to innovations in practice that will benefit clients. The findings of the present study indicate a lack of organisational structures and evidence-based interventions for use in clinical practice.

Norwegian PHNs are obliged by the guidelines for school health services to obtain health information on all school children in the local area and to provide support to children and families with special needs (Norwegian Directorate of Health 2021). Yet, the guidelines provide no established method or programme to support siblings of children with CCNs. Our findings illustrate that the lack of procedures and routines at the system level results in inconsistent support. This means that siblings will not necessarily receive the healthcare they are legally entitled to, and support from school health services will remain haphazard. Effective implementation strategies must involve multiple levels to achieve systematic improvements in the lives of siblings and their families. Changing clinical practice is challenging and the present study concurs with previous research that confirms that changes in legislation alone do not necessarily lead to a definitive change in practices to support children living with a family member who has a medical condition (Bergvoll et al. 2023; Granrud et al. 2022; Lauritzen and Reedtz 2016).

Healthcare professionals working with children and families often focused on the child with CCNs and were dominated by an individual patient perspective that did not include the whole family. Interestingly, health promotion interventions rarely took place and required collaboration between professionals from different services and organisations. Changes in how healthcare services are organised may have decreased the focus on family care, with increased specialisation resulting in greater focus on individuals at the expense of families. A person-centred care approach has become one of the major goals of health policy worldwide (Coyne, Holmström, and Söderbäck 2018). A comprehensive guideline could enable a change in perspective from an individual to a more family-centred approach, where the needs of all family members are recognised (Coyne, Holmström, and Söderbäck 2018). Moreover, clinicians traditionally focus on problems rather than on the capacities and resources of patients and families. Families are systems, and any change such as illness affects the system as a whole (Mitchell et al. 2021). Health promotion involves a holistic understanding of the complex lives these families lead; it requires a comprehensive approach, and the basis of the theory of health promotion is to consider health as a resource (World Health Organization 2021). A holistic, family-based approach is the strength of PHNs' competencies (Dahl et al. 2022), and it is, therefore, natural for them to focus on family healthcare. Family support can enhance the mental health and well-being of siblings. The absence of a family-centred approach in primary and secondary care may lead clinicians to overlook their legal responsibilities towards siblings, a concern that Norwegian health authorities should address.

Nevertheless, the PHNs in this study emphasised that optimising the school health service for siblings is possible despite their heavy workload. A step in the right direction is to develop a flexible manual or tool that takes account of both siblings' and parents' voices. Such a guideline could serve more as a framework within which PHNs can operate, rather than a rigid set of rules (Dahl et al. 2022). Guidelines and manuals are often also resources for ongoing professional development (Fixsen et al. 2005). Without these, PHNs might miss opportunities to enhance their skills and knowledge in the area of sibling support.

4.3 | Limitations

While this study provides valuable insights into PHNs' perceptions of their role and their core challenges and improvements in the identification of and support for siblings of children with CCNs, there are certain limitations to note. First, interviews were conducted during the later stages of the COVID-19 pandemic, which had affected PHNs' role and function. Due to COVID-19 with its increased work demands, heavy workload and redeployment of many PHNs from traditional health promotion services, the perceptions of the PHNs in this study may differ from those today, as more time has passed since COVID-19. Second, this study was limited to the perspective of PHNs working in school health services in Norway and did not include the experiences of service managers or other professionals involved. The perspectives of those groups would have increased knowledge of vital aspects of supporting siblings, since they are important facilitators and actors in primary and secondary care.

5 | Conclusion

There seems to be a long way to go before siblings of children with CCNs are systematically offered support as prescribed in Norwegian health legislation. Further, this study has shown that changes in legislation alone do not necessarily lead to definitive changes in practice. The study offers valuable insights into understanding the role of Norwegian primary school PHNs in supporting siblings of children with CCNs. This support is crucial for addressing the siblings' vulnerability to psychological issues, as they may face unique challenges that affect their mental health. By understanding roles and needs in this context, policymakers, educators and healthcare professionals can better

allocate and optimise resources. This will ensure that interventions are not merely reactive but proactive, thereby preventing more severe health challenges. PHNs in school health services have the potential to reach all siblings and their parents, but it is difficult to change clinical practice. We believe that the study illustrates the need for guidelines to clarify the role and responsibilities of PHNs and establish procedures for collaboration with other professionals. This may enhance professionals' awareness and knowledge of siblings' needs and contribute to changing their practice. Insights from the Norwegian context can inform international health policy development and PHN practitioners, particularly in creating supportive environments for families. This includes advocating for policies that recognise the needs of all family members, not just the individual with healthcare needs. Regardless of the setting, these study findings contribute to the global discourse on family-centred healthcare, particularly in terms of enhancing school nursing, public health nursing and other disciplines that provide health promotion in community settings. Further research is needed to explore the role of PHNs working in different contexts and to develop and implement adaptable evidence-based interventions that could enhance PHNs' ability to improve the mental health of siblings of children with CCNs from diverse cultural settings.

Author Contributions

All authors made substantial contributions to conception and design, or acquisition of data or analysis and interpretation of data; involved in drafting the manuscript or revising it critically for important intellectual content; given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors' contributions met the criteria for authorship recommended by the International Committee of Medical Journal Editors (https://www.icmje.org/icmje-recommendations.pdf). Lise-Marie Bergvoll drafted the manuscript, which all authors critically revised several times for important intellectual content. This qualitative empirical study forms part of a PhD, supervised by Anne Clancy, Monica Martinussen and Hilde Laholt. All authors contributed to the interpretation and revision of the content and agreed on the final version.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Peer Review

The peer review history for this article is available at https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.16515.

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