


ORIGINAL ARTICLE

How do public health nurses in Norwegian school health services support siblings of children with complex care needs?

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Abstract

Aims: There is a paucity of data regarding the care and support provided by Norwegian school health services to siblings of children with complex care needs. Public health nurses are an integral part of these universal services, which focus on health promotion and disease prevention in primary and secondary schools. This study aimed to explore health promotion interventions by public health nurses for siblings in Norwegian schools and to identify regional differences.

Methods: An online national questionnaire was distributed to Norwegian public health nurses and leaders of public health nursing services ($N=487$). The questions were related to how the nurses support siblings of children with complex care needs. The quantitative data were analysed using descriptive statistics. An inductive thematic analysis of free-text comments was conducted.

Ethical Approval: The study was approved by the Norwegian Centre for Research Data.

Results: The majority of public health nursing leaders (67%) reported that the services in their municipality had no system to identify siblings or to provide them with routine care. However, 26% of public health nurses reported that routine support was provided to siblings. Regional differences were identified.

Study Limitations: This study included responses from 487 PHNs from all four health regions in Norway. The study design is limited and gives a brief outline of the current situation. Further data are needed to provide in-depth knowledge.

Conclusions: This survey provides important knowledge for health authorities and professionals working with siblings, about inadequate support and regional differences in care provided to siblings by school health services.

KEYWORDS

health dialogues, health promotion, public health nurse, relatives, school health service, siblings of children with complex care needs

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INTRODUCTION

In Norway, about 50% of the child population are family members of a person receiving care or treatment [1]. Approximately 65% of children in Norway (1095371) have at least one sibling [2]. Some will have a brother or a sister with complex care needs (CCNs). Children with CCNs are defined as having or being at increased risk of chronic physical, developmental, behavioural or emotional disorders and requiring healthcare of a type or amount beyond that required by children generally [3, 4]. Without a fully accepted definition of the concept CCN, and a wide variety of conditions that fall within this definition, it is difficult to estimate the prevalence of this growing population [5]. The exact percentage of children in Norway with CCNs is unknown. However, it is estimated that 18% of the child population have ongoing CCNs such as physical disabilities and mental health challenges [6].

Although the majority are healthy, findings indicate that siblings of children with CCNs can experience stress and challenges in their lives and may be at risk of developing mental health problems, involving less social interaction and more problems at school than other pupils [7–14]. Siblings growing up with a brother or a sister affected with chronic illness may experience a childhood with a range of negative emotions that may impact their psychological functioning, peer activities and cognitive development [15, 16]. These siblings may be vulnerable, and their needs are often neither acknowledged nor met [10, 14, 17]. Having a child with a chronic health condition affects not only siblings but also the entire family [18]. Siblings also report, a lack of time with their parents as well as worries and feelings of frustration towards their ill sibling [14]. Changes in family relationships often result in reduced communication and a suppression of healthy siblings' needs [17].

However, there is little research on the impact of this on family life and on nurses caring role [13]. Nygård and Clancy's study [13] revealed that these families need support and that nursing services do not always meet their needs. There is evidence that parents caring for a child with CCNs value open and reciprocal communication with nurses [13]. Public health nursing (PHN) services are in a unique position to provide care and supportive services to these families. Parents often shoulder most of the care burden, and their overwhelming parenting responsibilities can affect how siblings' needs are met [3, 13, 18].

In 2018, the Norwegian Health Personnel Act, §10a [19] was amended to ensure that siblings of children with illnesses receive necessary support; it states that Norwegian primary care services are responsible for providing information and support to these siblings [20]. However, research reveals little knowledge of how Norwegian primary care services address the problems of siblings of children with CCNs [21].

Norway has varying demographics, partly due to its wide variation in climate and geography. The geographical differences indicate diversity in socio-economic and health status that can lead to social inequalities in health [22]. The country is divided into four geographical areas, Western, Central, Northern and South-Eastern Norway with four corresponding regional health authorities [23].

Norwegian PHNs provide health promotion and disease prevention services to all children, young people and their families at the individual, group and population levels based on national guidelines for child health clinics (0–5 years), youth health clinics (12–20 years) and school health services (5–20 years) [24]. The regulations [25] require the provision of school health services in all primary (6–12 years), lower secondary (13–16 years) and upper secondary schools (16+ years), and the national guidelines lay down the legal requirements for recommended standards of practice for these services [24]. The aim is for low-threshold services to be available to all pupils and for PHNs to provide prescribed health examinations and health dialogues (including outreach services) for individual pupils and groups of pupils upon request [24]. Health dialogues are an integral part of PHNs' work in schools. The intention is to provide a safe space where pupils can talk about the challenges of everyday life and reflect on various topics concerning their health and well-being. Some dialogues are planned by the PHN and address a specific topic such as nutrition or sexual health, others are initiated by pupils, based on their personal needs, or by parents, teachers and other professionals. PHNs meet the pupils individually or in groups and can also provide home visits [24]. The national guidelines [24] strongly recommend that school health services provide tailored care and support to families with special needs by collaborating with healthcare workers from other disciplines.

Despite the amended Norwegian legislation that strengthens siblings' rights to care [19] and the national guidelines for school health services [24], siblings receive support from such services to a varying extent [21]. Several studies have pinpointed the need for interventions for siblings of children with CCNs [18, 26–29].

Healthy ageing starts with the young, and childhood experiences can affect well-being later on in life [30]. Supporting vulnerable siblings is an investment in public health. However, there is little knowledge of PHNs' current practices in providing health promotion interventions to school-aged siblings of children with CCNs.

Aims

The main purpose of this research is to survey existing routines in Norwegian school health services to determine

the extent to which they offer health promotion interventions to siblings of children with CCNs. Further aims are to examine regional differences in service provision and to explore the types of interventions offered by PHNs.

METHODS

Participants and procedure

An online national survey of PHNs' perceptions of routine support provided to siblings of children with CCNs in school health services was conducted. A sample of 3696 practising PHNs and their leaders were contacted and invited to participate through the Norwegian Nurses Organization's professional interest group of PHNs. The organisation includes around 94% of active PHNs [31]. In Norway, no figures are available for the actual number of PHNs working in school health services. The interest group provided assistance to post information about the survey on the organisation's Facebook account in March 2022, and 2 weeks later, all members with registered email addresses received the online questionnaire directly. The study was conducted during March and April 2022 using Nettskjema [32], a secure tool for online data collection. After three reminders, 951 PHNs responded. Thirty-four expressly declined to participate, whereas 186 did not complete the first two parts of the questionnaire. Part one contained study information and a consent form, while in part two, respondents were asked whether they were working as PHNs in health care clinics or in school health services. In accordance with the inclusion and exclusion criteria, 244 respondents were then excluded as they reported that they did not currently work in school health services, or that more than 3 years had passed since they had practised as school nurses. This left 487 respondents who answered the main questions about supporting siblings in part three and thus completed the survey. The respondents were PHNs who worked as school nurses ($n=405$), registered general nurses employed as school nurses ($n=9$) and leaders of public health services ($n=73$).

Because of the small number of male PHNs practising in Norway and the possibility of identifying male nurses' responses, gender was not included in the data. The study was approved by the Norwegian Centre for Research Data (Project Nos. 634360 and 411733). The study is reported in line with the relevant STROBE criteria [33]. The survey forms part of two ongoing research projects. One explores how PHNs can optimise health dialogues in primary schools, whereas the other involves the establishment of reading groups in secondary schools using fiction to promote the mental health and well-being of siblings in families who have a child with CCNs.

Questionnaire

The questionnaire was developed based on the legal requirements for care and support for siblings [19]. A preliminary pilot study was carried out in November 2021 with ten PHNs from three health regions. They assessed the appropriateness of the questionnaire, which resulted in minor changes to the wording.

The questionnaire consisted of three parts and ten questions. Part one of the survey contained information about the study, a brief description and definition of siblings of children with CCNs and a consent form. Part two asked where the respondents were working as PHNs and whether they were employed as PHNs or PHN leaders. The intention was to exclude non-active PHNs and PHNs working in child health clinics. Part three contained eight questions covering demographics (employment status, regional- and municipal affiliation and years of experience). The respondents were asked to answer the following main questions: (1) Are there established routines to identify siblings of children with CCNs in your municipality? (2) Are health dialogues for siblings routinely provided in your municipality? Both questions had yes/no/do not know options. (3) What type(s) of health dialogue are provided to siblings in local primary, lower secondary and upper secondary schools? Here responses were mandatory, and more than one option could be chosen. (4) To what extent do you have personal experience using health dialogues/other forms of support? Frequency was measured on a 3-point Likert scale (1 = very small extent, 2 = some extent, 3 = very large extent). Question one was only for leaders to answer, and questions three and four were only answered by those who responded 'yes' to question two. In addition, two open-ended questions enabled the respondents to write free responses. One invited them to describe other specific health dialogues or support, whereas the other ('other comments') enabled them to add further notes and comments and thus elaborate beyond the limits of the questionnaire.

Analysis

Descriptive statistical analyses were performed using the IBM Software Package for Social Sciences (IBM SPSS, 28). The results are presented as percentages and frequencies. Chi-square tests were used to test the significance of regional differences in routine health dialogues provided to support siblings of children with CCNs. The significance level was set to 0.05.

Additional statements from free-text responses to the two open-ended questions in part three of the questionnaire were analysed using reflexive thematic analysis

inspired by Braun and Clarke [34]. Recurring themes, words and units of meaning were coded, and content with similar meaning was grouped into subthemes [34]. The preliminary results of the coding were discussed by all authors before a consensus was reached on the final themes.

RESULTS

Based on the number of questionnaires distributed ($N=3696$), and of the PHNs responding ($n=951$), the response rate was 25%. Excluding nurses not working in schools and non-responders, our sample constitutes 13% of the total population of PHNs. The responses from the different health regions were, as expected, rather similar. Ranging from 11% to 18% of the total number of PHNs working in each region [31]. The majority of PHNs working in school health services (70%) and PHN leaders (94%) had six or more years of experience as PHNs. Most of the registered general nurses (88%) had under 5 years of experience as school nurses. The distribution of participants by groups, years of experience and regions are presented in Table 1.

Routines to identify siblings of children with CCNs

The majority of PHN leaders (67%) reported that there were no established routines in their municipality to identify siblings in families with children with CCNs, whereas the remaining 33% reported having a system in place to help identify siblings.

Providing routine health dialogues to siblings and regional differences in providing support

Most PHNs (60%) working in school health services and leaders stated that routine health dialogues were not provided to siblings of children with CCNs (Table 2). Twenty-six per cent of PHNs responded that routine health dialogues with siblings were offered by their school health service, whereas 14% of PHNs reported being unaware of whether such support was provided (Table 2).

There was a significant difference between the four regions in Norway in terms of reported support to siblings by school health services ($\chi^2_{(6)}=14.52$, $p<0.05$) (Table 2). Several PHNs in South-Eastern Norway (30%) reported that routines had been established to support siblings. In Western Norway, the figure was 25% and in Central Norway, 26%. However, only 15% of respondents from Northern Norway reported that there were standard procedures for supporting siblings.

What type(s) of health dialogue are provided?

Of the 487 PHNs, 129 (26%) stated that routine health dialogues were provided to siblings. They were also asked to specify what type(s) of health dialogue was provided to siblings in their school nursing practice, and these responses are presented in Table 3. The findings indicated that a greater variety of health dialogues was offered in primary (52%) and lower secondary

	PHNs	Other nurses employed as PHNs	Leaders of public health services	Total all groups
Respondents	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Years of experience				
0–2 years	35 (9)	4 (44)	1 (1)	40 (8)
3–5 years	85 (21)	4 (44)	3 (4)	92 (19)
6 years or more	285 (70)	1 (12)	69 (94)	355 (73)
Region				
Northern Norway	42 (10)	2 (22)	14 (19)	58 (12)
Central Norway	78 (19)	1 (12)	3 (4)	82 (17)
Western Norway	86 (21)	2 (22)	15 (21)	103 (21)
South-Eastern Norway	199 (50)	4 (44)	41 (56)	244 (50)

TABLE 1 Distribution of respondents by years of experience and region ($N=487$).

Abbreviation: PHN, public health nurse.

^aAll leaders reported being registered nurses with a post-graduate degree in public health nursing.

TABLE 2 Responses to the question: Are health dialogues for siblings routinely provided in your municipality? ($N=487$).

	Northern Norway	Central Norway	Western Norway	South-Eastern Norway	Total
	$n=58$	$n=82$	$n=103$	$n=244$	$N=487$
Regions	n (%)	n (%)	n (%)	n (%)	n (%)
Yes	9 (15)	21 (26)	26 (25)	73 (30)	129 (26)
No	45 (78)	54 (66)	57 (55)	136 (56)	292 (60)
Do not know	4 (8)	7 (8)	20 (20)	35 (14)	66 (14)

Note: $\chi^2_{(6)}=14.52, p<0.05$.

TABLE 3 Responses to the question^a: What type(s) of health dialogues are provided to siblings in local primary^b, lower secondary^c and upper secondary^d schools? (total number of options $N=1121$).

	Primary school	Lower secondary school	Upper secondary school	All schools
	n of options = 584	n of options = 378	n of options = 159	Total number of options = 1121
	n (%)	n (%)	n (%)	n (%)
Individual health dialogues with siblings	117 (20)	92 (24)	52 (32)	261 (23)
Health dialogues with parents	104 (18)	73 (19)	32 (20)	209 (19)
Health dialogues with siblings and parents	91 (16)	59 (16)	27 (17)	177 (16)
Group-based sessions with siblings	30 (5)	14 (4)	3 (2)	47 (4)
Home visits to siblings and their family	43 (7)	24 (6)	7 (4)	74 (7)
Classroom-based health dialogues	45 (8)	33 (9)	16 (10)	94 (8)
Use of fiction in individual health dialogues with siblings	35 (6)	15 (4)	2 (1)	52 (5)
Use of fiction in individual health dialogues with parents	19 (3)	13 (3)	2 (1)	34 (3)
Use of fiction in health dialogues with siblings and parents	17 (3)	9 (2)	1 (<1)	27 (2)
Use of fiction in group-based sessions with siblings	12 (2)	6 (2)	1 (<1)	19 (2)
Use of fiction in classroom-based health dialogues	16 (3)	8 (2)	2 (1)	22 (2)
Use of fiction in collaboration with teachers	16 (3)	7 (2)	1 (<1)	24 (2)
Use of fiction in collaboration with a librarian	3 (1)	4 (1)	2 (1)	9 (1)
Other dialogues	36 (6)	21 (6)	11 (7)	68 (6)

^aMore than one response option was possible.

^b6–12 years.

^c13–16 years.

^d16+ years.

(34%) than in upper secondary (14%). Individual health dialogues with siblings (23%), health dialogues with parents (19%) and health dialogues with siblings and parents (16%) were the most common forms of health dialogue. Classroom-based health dialogues (8%), home visits (7%), health dialogues in groups (4%) and the use of fiction in individual health dialogues with siblings (5%) were reported to be less common. The least common method reported involved incorporating fiction in health dialogues in collaboration with a librarian (1%). Nineteen per cent of the 129 PHNs stated that they provided routine health dialogues especially for siblings to

a very large extent, 54% to some extent and 28% to a very small extent.

Inadequate routine support for siblings from school health services

The analysis of the free-text responses ($n=178$) provided a deeper insight into PHNs' perceptions of their practice and their established routines for supporting siblings. The analysis resulted in three themes: problem-focused approach ($n=74$), lack of systematic support ($n=58$) and

variations in interprofessional collaboration ($n=46$). These themes are all reflected in one overarching theme: inadequate routine support (Table 4).

It emerged that support to siblings was provided when a problem was identified. This entailed health dialogues being initiated at the request of the sibling, the sibling's parents, or teachers when difficulties arose. Furthermore, PHNs described how routine support for siblings depended on collaboration with specialist health care or other services responsible for the child with CCNs. They described variations in interprofessional collaboration within primary care and with specialist care. Some of the statements mentioned limited collaboration with specialist healthcare services or with the school management and teachers, while others stated that the municipality had a separate unit responsible for coordinating support services for siblings. Some PHNs reported having provided support tools for

siblings or having referred siblings to other service providers. Nevertheless, routine support from school health services was generally described as inadequate. Siblings were described as a neglected area and it was considered necessary to increase awareness of their needs. Adequate routines and procedures were emphasised as important factors to enable PHNs to provide systematic support.

DISCUSSION

In a recent study by Haukeland et al. [21], school health services were found to be the most common providers of support to siblings of children as relatives of patients, but this was mostly upon request from families. However, in our study, 60% of PHNs' responses across all four health regions indicated a lack of established routines to provide

TABLE 4 Overview of overarching theme, themes, subthemes and quotes from analysis of Free-text responses from two open-ended questions.

Overarching theme	Inadequate routine support		
Themes	Subthemes	Quotes	
Problem-focused approach ($n=74$)	Support when a problem is identified	'I occasionally get in touch with siblings if they have some difficulties'	'If parents bring it up, they will be offered support'
		'Unfortunately, it's been a bit too haphazard the way healthcare services have notified us about siblings that may need support'	'I have provided support to siblings of a child with complex care needs, but only when the parents or the sibling requests it'
	Haphazard support	'Only occasional support'	'Supports is provided at the request of, and in consultation with parents'
Lack of systematic support ($n=58$)	Lack of routines and procedures	'Those without support are not systematically recorded, there is only occasional support'	'We should have a system so that everyone is identified and receives the same support'
		'School nurses follow up many siblings, but it is not systematised'	'...siblings are a neglected chapter...'
Variations in interprofessional collaboration ($n=46$)	Support is requested and missed	'...parents report a great need for support...'	
	Invisible and forgotten children	'...often these children are forgotten...'	
	Support from other professions	'...support is offered by a psychologist or family counsellor...'	'It is very rare for a general practitioner or other health care provider to contact the school health service about support for siblings'
Difficulties in collaboration		'Little cooperation with the school, on how to meet the needs of children who have siblings with special needs'	
	Successful interprofessional collaboration	'We have worked well in our municipality with the administrative unit, and cooperated with the specialist health service'	'... the municipality has a separate service that coordinates support for these children...'

Note: Total statements $n=178$.

care and support to siblings in the form of health dialogues, although there were significant regional differences. The aim of the national health policy guidelines [24] is, to establish a national standard for support and care for children, young people, and their families, to ensure quality and equity in school health service provision in all parts of Norway. Results from this study show clear differences where the Northern region provided less support and care to siblings of children with CCNs. This stands in contrast to the Norwegian public health goal to reduce social inequality in health at a time when health inequalities in Norway are increasing [22]. School nurses have a unique opportunity to identify siblings and offer timely support, as recommended by the national guidelines [24]. The guidelines indicate how laws and regulations are to be interpreted and applied by PHNs who provide support in school health services [24]. However, the findings of this study may suggest that the needs of siblings and their families who have children with CCNs should be mentioned more specifically in the national guidelines [24].

Several studies have named siblings to children who have CCNs as the silent or forgotten children [10, 11, 17]. It can be argued that inadequate routines for support by school health services is part of the reason why siblings remain invisible. They can be at risk of developing health and social problems [7–14]. However, PHNs are in a unique position to reach and empower school-aged siblings due to the universally low-threshold nature of their services. This study has shown that a lack of routines at the system level can hinder PHNs from providing low-threshold health promotion and preventative services to siblings. Established routines at the system level can enable PHNs to reach children who would not otherwise receive health services. This was highlighted by the respondents and these findings are supported by the study by Haukeland et al. [21]. Sibling support is strongly dependent on requests by parents or the siblings themselves. This may indicate that mainly families of higher socio-economic status will request and receive support from school health services. This corresponds to findings in Kivimäki et al. [35] study where school pupils with lower socio-economic backgrounds reported difficult access to school health services. This study has also shown that there are regional differences and that Norwegian school health services provide inadequate support to siblings. This study has shown that PHNs often had an approach that focused on individual problems more than more general health promotion and primary prevention focus on siblings of CCNs. This is in contrast to health policy regulations stating that Norwegian PHNs should focus on health promotion and primary prevention [25].

Strengths and limitations

This study included responses from 487 PHNs from all four health regions in Norway. In a recent Norwegian study [21], only 192 PHNs were involved, without any indication of geographical distribution. The present study had a higher response rate of school nurses (25%). This enhances the generalizability of the study findings. Nevertheless, no figures are available for the actual number of PHNs working in school health services in Norway, which means that the response rate could have been higher. The study design is limited and gives a brief outline of the current situation. Further data are needed to provide in-depth knowledge. A follow-up study comprising focus group interviews of school nurses is currently being conducted by the authors.

CONCLUSION

This study provides important knowledge for health authorities and professional practitioners about inadequate support, lack of established routines and regional differences in the support provided to siblings of children with CCNs by school health services in Norway. The results may also be of importance to a wider audience and increase awareness of siblings' needs, particularly in countries with similarly organised school health services. There is a clear need for further research into how school nurses can deliver improved health promotion interventions and support to siblings. In order to ensure that optimal support and care are delivered to these families it is important that the needs of all family members are recognised.

AUTHOR CONTRIBUTIONS

All authors' contributions met the ICMJE recommended criteria for authorship (<https://www.icmje.org/icmje-recommendations.pdf>). All authors agreed on the final version and contributed to drafting the article or revising it critically for important intellectual content. All authors had substantial contributions to concepts and design, acquisition of data or analysis and interpretation of data.

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CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

This study was approved by the Norwegian Centre for research Data (Project Nos. 634360 and 411733). All participants provided written informed consent prior to enrolment in the study.

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SUPPORTING INFORMATION

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

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