Original Article

Subjective Unmet Needs for School Health Services among Adolescents with Different Disabilities: A Population-Based Study in Finland

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Abstract

Background: Subjective perceptions of unmet needs for health services among adolescents with different disabilities remain largely unstudied, even though various international conventions on the rights of people with disabilities oblige signatory governments to improve the equality of access to services.

Aims: The aim the study was to examine the need for, and accessibility to, support and help from school health services among adolescents with different disabilities. A second aim was to determine whether these unmet needs are related to certain sociodemographic factors.

Methodology: A nationwide, population-based cross-sectional study design was used. The data were collected from the 2017 School Health Promotion study in Finland. The study population consisted of 72,994 8th and 9th grade adolescents (aged 14–16) who responded to a web survey, reflecting a response rate of 63%. The data were analyzed by cross-tabulation, chi-square tests and logistic regression.

Results: The most common self-reported disabilities among adolescents were difficulties in remembering and learning (6-7%). However, a troubling 18-29% of adolescents with major difficulties reported that they had needed support from a school health nurse but had not received it. Moreover, 26-36% of adolescents with difficulties who had needed support from a physician had not received it. Adolescents with disabilities have approximately two- or three-fold higher risks of unmet needs than adolescents without disabilities. Adolescents with difficulties concentrating showed an over three-fold higher risk for unmet needs than other adolescents. The identified differences were evident even after sociodemographic factors were controlled for.

Conclusions: Disabled adolescents may well have more health needs than other adolescents, and some of these needs may be unidentified. Thus, disabled adolescents may not receive the support and help they require. In this respect, there are challenging differences between adolescents with and without disabilities.

Key words: adolescent, disability, population-based study, school health services, unmet needs for support and help

Introduction

International conventions on the rights of children (Unicef, 1989) and persons with disabilities (United Nations, 2006) oblige signatory countries to improve the equality of access to services for adolescents with disabilities by removing obstacles, providing appropriate support and bettering their chances of equally participating in community life. The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity

participation limitations or restrictions. Environmental factors are considered to interact with all of these constructs (WHO, 2001).

Adolescents with disabilities are more often from families with poor economic situations and/or that belong to minority groups than adolescents without disabilities (WHO, 2011, Groce, Kett 2014). Adolescents with disabilities show more cases of risky behavior, unhealthier lifestyles (Stokes, Turnbull, Wyn 2013), higher rates of obesity, and lower physical activity (Suarez-Balcazar et al. 2018) than adolescents without disabilities. Furthermore, disabled adolescents experience several health inequalities (Suarez-Balcazar et al. 2018). For example, they are more likely to experience loneliness and social isolation (WHO, 2011, Stokes, Turnbull, Wyn 2013), as well as suffer from mental health problems such as depression (Berg et al. 2015), than adolescents without disabilities. They also have fewer opportunities to create social networks and confidential relationships (Stokes, Turnbull, Wyn 2013). Disabled adolescents suffer from negative attitudes towards disability, which can lead to bullying, discrimination and social isolation (WHO, 2011).

The concept of unmet need is a subjective measure of access to health care, and moreover, one that has been shown to be a fundamental determinant of health (Fjær et al. 2014). Carr and Wolfe (1976) define unmet need as the differences between services judged necessary to deal appropriately with health problems and services actually received. Unmet need has also been defined as the individually perceived subjective perception of not receiving appropriate health services (Fjær et al. 2014).

This is an important field of research, as recent decades have been characterized by growing concern for those who are most vulnerable to unmet health care needs, including people with disabilities (Hwang et al. 2011, Casey, 2015, Mahmoudi, Meade 2015). Worldwide rates of unmet health care needs are noticeably higher among people with disabilities than among people without disabilities (McColl, Jarzynowska, Shortt 2010, Casey 2015. Sakellariou, Rotarou 2017). Disabled adolescents have also been found to be more likely to report foregone health care than adolescents who are not disabled (Ford et al. 1999).

Research on unmet health care needs has mainly been carried out in the US and Canada (Fjær et al. 2014); as such, there is limited comparable European-based research. European countries mainly have universal health care systems; this is also the case in Finland. The Finnish health care system is based on preventive health care and comprehensive health services. School health services are part of the primary health care system. All comprehensive school pupils, including adolescents with disabilities, are entitled to these services, which are universal, statutory and free of charge. School health

services are provided by school health nurses and physicians (Health Care Act 1326/2010, Government Decree 338/2011).

However, since earlier studies have mainly targeted the adult population (Hwang et al. 2011, Mahmoudi, Meade 2015), little is known about adolescents' perceptions of unmet health care needs, and even less is known about the perceptions of unmet need among adolescents with disabilities (McColl, Jarzynowska, Shortt 2010, Casey 2015, Sakellariou, Rotarou 2017). Thus, this study aimed to examine the need for, and accessibility to, support and help from school health services among Finnish 8th and 9th graders with various disabilities. An additional whether aim was to determine any sociodemographic factors (gender, immigrant status and family's perceived financial situation) were related to adolescents' unmet needs for support and help.

Material and methods

Study design: A nationwide and populationbased cross-sectional study design was used.

Data collection: The data used were collected from the School Health Promotion (SHP) study, which is a nationwide study carried out by the National Institute for Health and Welfare (2018) in Finland. The SHP study is designed to examine adolescents' well-being and health as well as school and service experiences. The data were gathered in spring 2017 through a classroom web questionnaire which took 30-45 minutes to complete.

The target population was 116,475 8th and 9th graders aged 14-16. A total of 73,680 adolescents responded, reflecting a response rate of 63%. Unfortunately, disability has been identified as a theme that urges adolescents to give mischievous responses (Robinson-Cimpian, 2014). In this case, a total of 686 respondents (0.9%) were deleted from the final data due to practically improbable combinations of answers concerning disability; these respondents reported serious disability across all of the measured functions. Such adolescents would, in all likelihood, be unable to attend normal schools and respond to the questionnaire. Thus, the study population consisted of 72,994 adolescents.

Measures: The needs for, and accessibility to, support and help from school health services were measured with the following question:

During this school year, have you received support and help for your well-being from the following adults at your school? 1) school health nurse and 2) physician. Students were asked to respond to the question using a four-point response scale: 1) yes, a lot; 2) yes, some; 3) no, but I would have needed it; and 4) I have not needed any help. The adolescents who answered using options 1, 2 or 3 were considered in need of support and help. Point 3 measures subjective unmet need. Only the adolescents who reported a need for support and help were examined when subjective unmet needs were analyzed, and these adolescents were divided into those who had received a lot or some support and those who had not received help for their well-being. In previous studies, overall unmet need for health services has been assessed by a similar, single question, in which adult respondents are asked to evaluate their need for health services during the last 12 months (Fjær et al. 2014, Casey, 2015).

Disability was measured by asking adolescents if they have difficulties in: 1) seeing (if you wear eyeglasses or contact lenses, evaluate your vision while wearing them); 2) hearing (if you use a hearing aid, evaluate your hearing with your hearing aid on); 3) walking a distance of about 500 meters, e.g. once around a sports field (if you use an assistive device, evaluate your device); mobility while using that 4) remembering things; 5) learning new things; or 6) concentrating on something that you enjoy doing. The response alternatives were: 1) not difficult at all; 2) a little difficult; 3) very difficult; and 4) I cannot do it at all. The respondents were classified into two categories no difficulties (alternatives 1 and 2) and major difficulties (3 and 4) - according to their responses to the six functions. Measuring disability was based on an international functional recommendation for measuring disabilities among adolescents through а population survey (Berger et al. 2016, Washington Group on Disability Statistics 2018). The sociodemographic factors examined were gender, immigrant status and family's perceived financial situation.

Statistical analysis: Data were analyzed using SPSS Statistics (25.0, IBM) by cross-tabulations, chi-square tests and logistic regression analysis. Logistic regression was used to estimate odds ratios (OR) and 95% confidence intervals (CI) for unmet need for support and help from the school health nurse and physician (dependent variables). The independent variables used were different disabilities and sociodemographic factors. The relationship between major difficulties and unmet needs was first studied by unadjusted regression models, and then by adjusting models for sociodemographic factors. All of the performed analyses included a statistical significance threshold of p<0.001 to reduce the chance of false positive results (a Type I error risk).

Ethical considerations: The study is based on the National School Health Promotion study, which was approved by the ethical committee of the National Institute of Health and Welfare. Research ethical guidelines were followed at all stages of the presented study.

The ethical principles of the Helsinki Declaration were followed (World Medical Association, 2013). Approval for the SHP study was granted by the ethical committee of the National Institute for Health and Welfare (11/2016, §752). The adolescents completed a web survey anonymously during a school lesson. The participants were informed about the nature of the study and its confidentiality, as well as about the voluntary nature of participation. Parents were informed about the study prior to data collection through the school web-based information system. Conducting a study is considered part of normal school activities; therefore, the consent of parents was not required.

Results

Background factors: Slightly more than half of the participants were girls. More than one-tenth had an immigrant background, while approximately one-third perceived their family's financial situation to be moderate or poor (Table 1). According to the self-evaluations, the most common disabilities among 8th and 9th graders were major difficulties in remembering (7.2%)and learning new things (5.7%). Moreover, 3.5% of adolescents had seeing difficulties while 2.3% percent reported difficulties concentrating. Major difficulties in hearing (1.5%) and walking (1.0%)were quite rare (Tables 1 and 2). A larger proportion of girls than boys reported major difficulties in seeing (p<0.001) and cognitive functions, i.e. remembering, learning and concentrating (p<0.001). There was little difference between boys and girls concerning

difficulties in hearing and walking. A larger proportion of adolescents with immigrant backgrounds reported major difficulties in all physical and cognitive functions (p<0.001) when compared to native Finns. Furthermore, a greater proportion of adolescents who perceived their family's financial situation to be moderate or poor reported major difficulties with all functions than adolescents who perceived their family's financial situation to be good (p<0.001) (Table 1).

Needs for and accessibility of support and help: Approximately half (46–54%) of the adolescents with major difficulties reported having needed support and help from a school health nurse during the previous school year. They reported that they had received a lot or some support and help, or remained without help even though they may have needed it. Moreover, about 33-48% of the adolescents with major difficulties had needed support and help from a physician. These proportions were significantly greater than what was reported by adolescents with no major difficulties (p<0.001). Slightly more than onethird (35–36%) of adolescents without difficulties had needed support and help from the school health nurse, while 23% of these adolescents reported needing help from the physician (Table 2).

Of the 8th and 9th grade students with major difficulties, those with walking difficulties had particularly needed support and help from both the school health nurse (54%) and physician (48%). These proportions were lowest in adolescents with major difficulties in seeing (46% and 33% needed help from school health nurses and physicians, respectively).

Sociodemographic factors	Prevalence		Major difficulties in (%)					Unmet needs for				
	%	n	seeing	hearing	walking rememberi	remembering	g learning	concentrating	school health nurse		physician	
									OR	95% CI	OR	95% CI
Gender												
Boy ¹	49.3	35,770	3.0	1.5	1.2	5.3	3.9	1.6				
Girl	50.7	36,722	3.9*	1.4ns.	0.9*	9.1*	7.4*	2.9*	1.74²	1.60-1.90	2.00 ²	1.83-2.19
Immigrant status												
Native ¹	87.2	60,044	3.0	1.2	0.7	6.8	5.3	2.0				
Immigrant background	12.8	8,832	5.7*	2.4*	2.5*	9.7*	7.4*	3.7*	1.24²	1.11-1.39	1.32²	1.18-1.47
Family's perceived financial situation												
Very or fairly good ¹	68.2	46,888	2.9	1.1	0.7	5.1	4.1	1.5				
Moderate or poor	31.8	21,887	4.5*	2.0*	1.5*	11.4*	8.7*	3.8*	1.90²	1.75-2.07	2.22 ²	2.04-2.43

Table 1. Sociodemographic factors, different disabilities and unmet needs for school health services among adolescents (n=72,994).

¹Reference group in logistic regression models, ²p<0.001, *Pearson's chi-squared test (γ^2 =40.7-889.1, df=1, p<0.001)

Table 2. Needs for and accessibility of support and help from school health services among adolescents with different disabilities (n=72,994).

Major difficultiens in	Prevalence		Support and help from school health nurse and physician ¹									
			Yes, receive	d a lot	Yes, recieve	d some	No, but woul	d have	Have not needed any			
							needed suppo	ort/help	support/help			
			health nurse	phycisian	health nurse	phycisian	health nurse	phycisian	health nurse	phycisian		
	%	n	%	%	%	%	%	%	%	%		
Seeing (yes)	3.5	2,457	11.4	8.6	26.2	15.9	8.1	8.4	54.3	67.2		
no	96.5	68,251	9.0	6.1	22.9	13.5	3.8	3.6	64.3	76.8		
Hearing (yes)	1.5	1,033	14.0	9.7	25.3	16.0	11.8	13.6	48.9	60.7		
no	98.5	69,458	9.0	6.2	23.0	13.5	3.8	3.6	64.2	76.7		
Walking (yes)	1.0	721	16.7	13.6	24.0	18.6	13.6	15.3	45.8	52.5		
no	99.0	70,018	9.0	6.2	23.0	13.5	3.8	3.6	64.2	76.7		
Remembering (yes)	7.2	5,185	10.0	6.9	28.2	16.5	10.0	10.4	51.8	66.2		
no	92.8	66,437	9.0	6.2	22.6	13.4	3.4	3.2	65.0	77.3		
Learning (yes)	5.7	4,080	11.3	8.0	27.2	16.2	11.8	11.4	49.7	64.5		
no	94.3	67,372	8.9	6.1	22.8	13.4	3.4	3.3	64.9	77.2		
Concentrating (yes)	2.3	1,650	10.9	7.1	26.6	19.3	15.2	15.0	47.2	58.6		
no	97.7	69,717	9.0	6.2	22.9	13.4	3.6	3.5	64.4	76.9		

¹The differences between adolescents with and without different disabilities are statistically significant,

Pearson's chi-squared test (χ^2 =201.3-793.3, df=3, p<0.001)

Major difficulties in	Unmet needs for support and help from									
	school	health nurse			physician					
	Unadju	usted models	Adjust	ed models ²	Unadju	sted models	Adjusted models ²			
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI		
Seeing (no) ¹										
Yes	1.83*	1.55-2.17	1.63*	1.37-1.93	1.87*	1.57-2.22	1.58*	1.32-1.90		
Hearing (no)										
Yes	2.54*	2.03-3.17	2.31*	1.83-2.92	2.89*	2.31-3.63	2.52*	1.98-3.21		
Walking (no)										
Yes	2.80*	2.17-3.61	2.51*	1.91-3.30	2.56*	1.99-3.29	2.20*	1.67-2.91		
Remembering (no)										
Yes	2.44*	2.18-2.72	2.08*	1.85-2.33	2.67*	2.39-3.03	2.16*	1.91-2.45		
Learning (no)										
Yes	2.83*	2.52-3.18	2.40*	2.12-2.71	2.80*	2.47-3.17	2.24*	1.96-2.56		
Concentrating (no)										
Yes	3.56*	3.03-4.19	2.99*	2.53-3.54	3.22*	2.71-3.82	2.55*	2.12-3.06		

Table 3. Regression models of unmet needs for support and help from school health services among adolescents (n=72,994).

¹Reference group in parenthesis,

²Adjusted for gender, immigrant status and perceived family's financial situation, *p<0.001

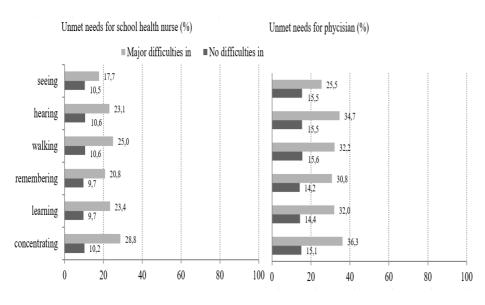
Adolescents with major difficulties had received more support and help from the school health nurses than adolescents without major difficulties (38–41% vs. 32%, p<0.001). Correspondingly, a larger proportion of adolescents with major difficulties had received more support and help from a physician when compared to adolescents without major difficulties (23-26% vs. 20%, p<0.001). However, a greater proportion of adolescents with major difficulties - when compared to adolescents without difficulties were also left without the support and help they needed from both school health nurses (8-15% vs. 3-4%, p<0.001) and physicians (8-15% vs. 3-4%, p<0.001). The results show that 18-29%of adolescents with major difficulties who reported a need for support and help from a school health nurse had not received it. Unmet needs for support and help from school health nurses were more common among adolescents with major difficulties than among adolescents

without difficulties (10-11%)p<0.001). Moreover, 26-36% of adolescents with major difficulties who reported a need for support and help from a physician had not received it. Unmet needs for support and help from physicians were more than twice as common among adolescents with major difficulties than among other adolescents (14-16%, p<0.001). Adolescents with difficulties concentrating reported unmet needs for support and help: more than a quarter (29%) reported unmet needs from the school health nurse, while more than a third (36%) reported unmet needs from the physician (Figure 1).

Factors related to unmet needs for support and *help:* Girls were at a higher risk than boys for unmet needs for support and help from both the school health nurse and physician. Correspondingly, adolescents with immigrant backgrounds were at greater risk of unmet needs than adolescents who were native Finns. In

addition, adolescents perceiving their family's financial situation to be moderate or poor had a roughly two-fold higher risk of unmet needs for support and help from both the school nurse and physician than adolescents who perceived their family's financial situation to be good (Table 1). Adolescents with major difficulties in hearing, walking, remembering and learning had a more than two-fold higher risk of unmet needs for support and help from both the school health nurse and physician than adolescents with major difficulties. Adolescents with major difficulties

in seeing had an almost two-fold higher risk of unmet needs than other students, while adolescents with difficulties concentrating showed an over three-fold higher risk of unmet needs than other adolescents. Controlling for sociodemographic factors in the regression models reduced the risk of unmet needs among adolescents with major difficulties, but differences in unmet needs between adolescents with and without difficulties were still evident (Table 3).



*The differences between adolescents with and without different disabilities are statistically significant, Pearson's chi-squared test (χ^2 =51.6-329.0, df=1, p<0.001)

Figure 1. Unmet needs for support and help from school health services among adolescents with and without disabilities who reported need for support and help (n=72,994).

Discussion

Discussion of the results: This study provided new empirical knowledge about unmet needs for support and help from school health services among adolescents with various disabilities. The results showed that a greater proportion of adolescents with different disabilities had required support and help from school health services than adolescents without disabilities; this was particularly evident for those with walking difficulties. A positive result was that a greater proportion of adolescents with disabilities had received some or a lot support and help than adolescents without disabilities. Previous studies (WHO 2011, Stokes, Turnbull, Wyn 2013, Groce, Kett 2014) have shown that disabled adolescents experience more well-being- and health-related challenges than other adolescents, which can result in different support needs. Adolescents with disabilities have lower selfreported health (WHO 2011, Stokes, Turnbull, Wyn 2013, Groce, Kett 2014), indulge in more risk-related behaviors and have less healthy lifestyles (Stokes, Turnbull, Wyn 2013, Suarez-Balcazar et al. 2018) than adolescents without disabilities.

A worrying result of this study was that a greater proportion of adolescents with different disabilities _ when compared to other adolescents - were left without the support and help they needed. Even after controlling for sociodemographic factors, adolescents with different disabilities showed approximately twoor three-fold higher risks of unmet needs than adolescents without disabilities. These findings agree with previous results concerning the adult population, as people with disabilities generally have higher unmet health care needs compared to people without disabilities (McColl, Jarzynowska, Shortt 2010, WHO, 2011, Casey, 2015). In addition, Ford et al. (1999) found that disabled adolescents were approximately twice as likely to report foregone health care than adolescents who were not disabled.

The results also revealed disparities between different disability groups in unmet needs. Adolescents who had major difficulties in concentrating on something they enjoy showed the highest risk for unmet health needs. An explanation for this finding is that the service needs of these adolescents are likely to be very different from those of, for example, adolescents with seeing or hearing difficulties. This finding is perhaps not surprising given that disabled people are a highly diverse group of people with different health care needs (WHO, 2011, Groce, Kett 2014, Rowland et al. 2014). Based on previous knowledge, the needs of children and adolescents with disabilities have not been responded to adequately and equally in the service system. For example, the poor coordination of services, along with inadequate skills of professionals, can affect the quality, availability and sufficiency of services for adolescents with disabilities (WHO, 2011, Stokes, Turnbull, Wyn 2013, Groce, Kett 2014). However, it should be stressed that a majority of school health nurses are invaluable frontline staff who facilitate equitable access to care and play an important role in maintaining the health safety net for underserved adolescents (Parasuraman, Shi 2015).

The results showed that girls were at a greater risk than boys of having their needs unmet. This echoes earlier studies which have reported that unmet health care needs are more common in women than in men (McColl, Jarzynowska, Shortt 2010, Hwang et al. 2011, Fjær et al. 2014). In the present study, adolescents with

immigrant backgrounds and adolescents perceiving their family's financial situation as moderate or poor were more likely to be left without the support and help they needed than other adolescents. Earlier studies have also linked unmet health care needs with belonging to a cultural minority group (Ford et al. 1999, Heslin et al. 2006, Hargreaves et al. 2015), having an immigrant background (Fjær et al. 2014) and suffering from poor financial conditions (McColl, Jarzynowska, Shortt 2010, Hwang et al. 2011, Fjær et al. 2014).

The availability of, and access to, school health services may have affected the respondents' subjective perceptions of unmet needs. In 2016-2017, school health nurse services were available in almost every comprehensive school in Finland, but physician services were missing from more than every tenth school (National Institute for Health and Welfare 2017). Although Finnish school health services have been mainly reported to be easily accessible, more than a tenth of adolescents still described school health services as being difficult to access, and there is variation between service providers and schools (Kivimäki et al. 2019). The results raise concerns about the wellbeing of adolescents who are the most vulnerable to unmet needs. Any prevalence of unmet health care needs among adolescents which have previously reported to be rather common (Ford et al. 1999, Hargreaves et al. 2015) – is worrying because these unmet needs are an independent predictor of poor health outcomes during adult life (Hargreaves et al. 2015). On the other hand, while adolescents may have theoretical access to health services, actually seeking help and their experiences of health care services are often affected by fear of concern about confidentiality, stigma. professionals' respectful and friendly attitudes, the possibility of being involved in decisionmaking and the accessibility of services in an age-appropriate environment that provides continuity of care (Ambresin et al. 2013).

More research is needed to understand which disability subgroups are most at risk, as well as the factors that contribute to the subjective experience of unmet needs. Moreover, it is important to study how availability, accessibility and acceptability of welfare services influence unmet needs. Implementing a qualitative approach and more objective measures could be important to studying unmet needs among

adolescents with various disabilities in terms of quality of care.

Strengths and limitations: A particular strength of this study is that it draws on nationwide, population-based SHP study data, which represent most Finnish comprehensive schools. Since most children and adolescents in Finland attend public schools, the study sample of 8th and graders can thus be considered as 9th adolescent representative of the entire population. This can be extended to mean that the data also represent all socioeconomic groups. The study was anonymous and voluntary and was carried out according to uniform principles. The participation rate (63%) was notably high when compared to other population-based surveys, and a majority of the dropout was only due to absence from school (Kivimäki et al. 2019).

Regarding limitations, the study only included self-report measures, and no objective measures were used. This may have produced some socially desirable responses and lead to the possibility of recall bias. Another limitation is that the study used the Washington Group short set of questions on disability. These questions do not include depression, anxiety or behavioral difficulties (e.g. autism and ADHD), which may have been prevalent disabilities in the studied age group. The question of unmet need is also likely to be affected by cultural context and the specifics of a particular health care system (Fjær et al. 2014). School health services are organized in different ways (Baltag, Pachyna, Hall 2015), so the results should only be generalized to universal health care systems.

Conclusions: According to the results, adolescents with disabilities are more likely to be left without the support and help they need from school health services than other adolescents. They showed higher risks for unmet needs from both the school health nurse and physician. It seems likely that adolescents with disabilities have complicated well-being- and health-related needs, and that some of these needs may remain unclear. Some disabled adolescents are also at risk of accumulating multiple threats to their continued well-being. Thus, adolescents may not necessarily receive the required support and help which they feel they need for the maintenance and promotion of their well-being. In this way, the results of this study show that there are

challenging differences between adolescents with and without disabilities, but universal school health services and school environments can play key roles in reducing these differences and promoting equality. The results highlight that more attention needs to be paid to supporting adolescents with cognitive difficulties, girls and adolescents with immigrant backgrounds and/or from families facing poverty.

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