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## ADAPTATION OF CSHCN INSTRUMENT FOR THE USE IN ASSESSING THE PREVALENCE OF CHRONIC DISEASES IN CHILDREN AND ADOLESCENTS IN POLAND\*

### ADAPTACJA KWESTIONARIUSZA CSHCN DO OCENY CZĘSTOŚCI WYSTĘPOWANIA CHOROÓB PRZEWLEKŁYCH U DZIECI I MŁODZIEŻY W POLSCE

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#### STRESZCZENIE

W badaniach nad częstością występowania chorób przewlekłych u dzieci i młodzieży ostatnio podkreśla się wyższość metod oceniających ogólne konsekwencje choroby nad podejściem opartym na konkretnej diagnozie medycznej.

Celem pracy jest prezentacja budowy i trafności amerykańskiego kwestionariusza do identyfikacji dzieci wymagających specjalnej opieki medycznej (CSHCN – *Children with Special Health Care Needs*), z wykorzystaniem wyników ogólnopolskiego badania przeprowadzonego w 2003 roku na próbie 1718 osób w wieku 8-18 lat. Według opinii rodziców, w populacji dzieci normalnie uczęszczających do szkoły, kryteria CSHCN spełniało 14,5% badanych, w tym 16,5% chłopców i 13,5% dziewcząt. Nie stwierdzono związku klasyfikacji CSHCN z wiekiem dziecka i zamożnością rodziny, chociaż zarysowała się tendencja do częstszego występowania chorób przewlekłych w rodzinach ubogich. Kryteria CSHCN częściej spełniali mieszkańcy miast i dzieci rodziców z wyższym wykształceniem, a większe różnice zaobserwowano w zakresie korzystania z usług medycznych niż w występowaniu ograniczeń funkcjonalnych. Dzieci określone jako CSHCN gorzej oceniały swoje zdrowie, a liczba wizyt lekarskich i hospitalizacji w poprzednim roku znacznie przewyższała obserwowaną w grupie zdrowych, co świadczy o trafności tego narzędzia.

Polska wersja kwestionariusza CSHCN jest godna polecenia i powinna znaleźć zastosowanie w wielu krajowych badaniach stanu zdrowia dzieci i młodzieży.

**Słowa kluczowe:** choroby przewlekłe, dzieci, kwestionariusze

#### ABSTRACT

There are several methods for assessment the prevalence of chronic diseases among children and adolescents in population surveys. Recently developed consequence-based approach seems to be more powerful to identify individual impact of chronic condition on child and family by comparison to the traditional, disease-specific method.

The aim of this study was to describe the structure and validity of parent-reported CSHCN (*Children with Special Health Care Needs*) questionnaire and to test the performance of this screener in Polish population of children who normally attend schools. The survey was conducted in KIDSCREEN project in 2003 on the sample of 1718 children aged 8-18 years. The overall prevalence of CSHCN was 14,5% (16,5% among boys and 13,5% among girls). CSHCN status was not related to age of child and there was a tendency to higher prevalence of chronic diseases in poor families. Urban residents and children of parents with higher education more often met overall CSHCN criteria. Children identified as CSHCN were more likely to report poor self-rated health and frequent visits to doctor, which underlines validity of this instrument.

The Polish version of the CSHCN questionnaire seems to be a convenient instrument that should be applied in further population studies.

**Key words:** chronic diseases, children, questionnaires

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## INTRODUCTION

Children and adolescents suffering from chronic diseases require special attention due to the risk of significantly more frequent use of medical services and higher costs of treatment, as well as other social costs arising from the necessity to ensure appropriate care and provide suitable conditions for rehabilitation (1). Reliable information about the magnitude of the phenomenon would allow adequate assessment of medical care needs and evaluation of implemented social programmes. It ought to be expected that the problem will enlarge due to the following reasons: a) the rate of survival among children with congenital defects and metabolic disorders has increased; b) there are better opportunities for treatment of other serious diseases, e.g. cancer, chronic renal disease; c) more and more infants with low birth weight and the consequent prematurity complications survive; d) increase in numbers of children with asthma, symptoms of allergy, diabetes, obesity, behavioural disorders and many other chronic physical and mental disorders (2, 3, 4).

The aim of this study was describe the structure and validity of parent-reported CSHCN (*Children with Special Health Care Needs*) questionnaire and to test the performance of this screener in Polish population.

## DEFINITIONS OF CHRONIC DISEASES IN POPULATION STUDIES

There are several definitions of chronic diseases, which usually consider the duration of a disease, whether it is congenital or acquired, its influence on the functioning, expected survival and actual possibilities of complete recovery. In the US, since the mid 90's specialists used the concept of children with special health care needs. It was assumed that social programmes should reach those who need them most.

There are also several methods how to determine the prevalence of chronic diseases among children and adolescents and how to obtain reliable statistical data that could be used to monitor the phenomenon (5). The first disease-specific method is based on registers of diseases, mainly utilising data provided by health service sector. The second one is based on results of population health surveys, with self-reported data, or in the case of young children – information provided by their parents or guardians. The third method treats the use of medical services as a proxy measure of morbidity. In the case of surveys, there are two approaches described in the literature as *categorical* and *noncategorical*. The first approach uses a pre-prepared list of diseases, while the other is intended to describe the general burden of dis-

ease, regardless of the clinical diagnosis. The second one places main emphasis on the human being, not a "case", and multiple chronic diseases could be considered.

In Poland, the categorical method is still more widely used. In the health survey conducted by Central Statistical Office in 2004 in 20 thousand households, parents of the surveyed children were asked to report if their children suffered from one of the 16 listed diseases, while adolescents aged 15 to 19 were asked to report on 32 diseases. On the basis of this study it was estimated that among people aged up to 19, there are 2,05 million suffering from chronic diseases, which represents 21,9% of Polish population in this age group. In the same survey, parents were asked about functional limitations (troubles with: self-care, moving around, vision, hearing, speech). It has been demonstrated that these problems affected 609,5 thousand children aged 0 to 14 years. However, only 62,6% indicated concurrent chronic disease (6).

The categorical approach is often criticised due to the following reasons: researchers rely on parents opinion, it is uncertain if the diagnosis was confirmed by medical consultation, any diseases not found on the list are excluded and usually there is lack of information on how serious the sickness is. As a result of these limitations, children with e.g. correctable vision conditions and with minor faulty postures could be qualified as suffering from chronic diseases. The list of diseases includes cases that are easy to qualify and occur quite often. Therefore, children suffering from rare and difficult to diagnose diseases are often excluded, even when symptoms have already appeared, but the disease had not been diagnosed yet. Thus, we can expect that some problems will be overestimated, and conversely that some people with long lasting constraints affecting their everyday functioning, will be excluded.

Experiences from other countries indicate that the prevalence of chronic diseases among children and adolescents varies depending on the criteria assumed. *Stein and Silver* (7) demonstrated that in the US it ranges between 4% and 30%. In many countries, it was decided to implement new tools into population studies for identification of children suffering from chronic diseases. These tools are becoming more and more popular in Europe. Efforts towards conceptualisation and operationalisation of the perception of chronic disease in childhood were undertaken in the Netherlands (2, 8).

Two US questionnaires are now the most popular: 39-item QuICCC (*Questionnaire for Identifying Children with Chronic Conditions*) developed by *Stein et al.* (9) and the much shorter CSHCN (*Children with Special Health Care Needs*) developed *Bethell et al.*(10). A significant degree of concordance (90%) was found between classifications based on the longer and the shorter method.

## DESCRIPTION OF CSHCN SCREENER

According to definition developed by US Maternal and Child Health Bureau (MCHB) a child with a special health care needs: 1) has or is at risk of physical, developmental, behavioural or emotional conditions; 2) requires health services of a type or amount beyond average level (11). CSHCN screener consists of five question sequences including one filter item describing health consequences and two follow-up questions. Follow-up questions help to determine if the consequence is attributable to a medical, behavioural or other health condition lasting or expected to last at least 12 months. There is free access to CSHCN instrument and scoring system is well described on the website (12). Finally, CSHCN Screener has three domains: Q1) Use or need of prescription medications; Q2) Service use above the usual or routine level; Q3) Functional limitations as compared with others of the same age. The second one includes three detailed aspects: Q2<sub>1</sub>) Above average use or need of medical, mental health or educational services; Q2<sub>2</sub>) Use or need of specialized therapies; Q2<sub>3</sub>) Treatment or counseling for emotional or developmental problems. All these dimensions are not mutually exclusive categories. A child identified by the CSHCN screener can qualify on one or more domains, and he or she will meet overall criteria if any of those three main categories (Q1, Q2, Q3) mentioned above are reported.

The CSHCN questionnaire was translated into Polish language, and tested in 2003 in a nationwide study KIDSCREEN concerning health related quality of life. Although analysis of CSHCN was not the main goal of KIDSCREEN project, the experiences and the initial research results are worthwhile of popularisation. To my knowledge, this was the first and only attempt of using CSHCN in Poland.

## SAMPLE AND METHODS

The study was conducted in May 2003 on a representative group of 1718 children aged 8 to 18 years (mean age 13,2 years, SD=2,8). A separate questionnaire was completed by a child and one of the parents or guardians (13). The questionnaire for adults included CSHCN and a list of 18 chronic diseases, thus allowing comparison of the categorical and noncategorical approach. All questions included in the CSHCN were answered by 95,7% parents (N=1644). Results were analysed by gender and age of child, as well as social and demographic profile of their families, which included the following: place of residence (large cities, small towns, or rural area), wealth of family (FAS

– family affluence scale), level of education of father or mother (the higher one of the two). Validity of the CSHCN questionnaire was assessed by comparing ill and healthy children in respect to: self-rated health (SRH), school absence and the use of medical services in the past 12 months.

The postal survey was conducted on the sample of pupils from 130 randomly selected school classes in 7 voivodeships. Meetings were organised at schools, during which parents consented to participate, and made known their addresses, to which the questionnaires were mailed together with return prepaid envelopes. In order to increase the participation, two reminders were mailed. The response rate was 72%, taking as a denominator people present at the school meeting, who preliminary consented to participate in the study.

Descriptive statistics ( $\chi^2$  analyses) were used to compare characteristics of CSHCN versus children without special needs.

## RESULTS

The analysis has shown that 41,5% of children suffered from at least one of the 18 diseases listed. However the overall criteria specified in CSHCN were met by fewer children – i.e. 14,5%, which is considered as much more reliable result and comparable with foreign studies. Only in 20 cases, for child included in the CSHCN group, none of the listed diseases was reported. However, 68,3% of the children, who in the opinion of their parents suffered from at least one of the listed diseases, did not meet the CSHCN criteria. This could indicate that the ailments were not severe, not diagnosed by a doctor or not being of chronic nature. According to the components of CSHCN - 7,2% of the respondents had to take medication on a regular basis; 11,6% used medical services to a greater extent than their peers, while 4,5% were diagnosed to suffer from functional limitations. One of the abovementioned problems appeared in 8,4% of the respondents, two in 3,9%, while 2,2% of the respondents were affected by all three problems.

Table I presents results of the classification according to the CSHCN instrument, including demographic and social characteristics of the respondents. No significant differences depending on the age of the child and wealth of family were detected, although there was a tendency to higher prevalence of chronic diseases in poor families. In some cases the relationship is nonlinear (U-shaped). The criteria of CSHCN were met slightly more often by boys than girls. More children with special medical care needs were found in cities than in the rural areas, while even greater difference was found in the case of use of medical services. Also, a statisti-

Table I. Children with special health care needs (%) by sociodemographic characteristics

Tabela I. Dzieci wymagające specjalnej opieki medycznej (%) według cech społecznych i demograficznych.

Variables	N	Met CSHCN criteria (%)			
		Total	Q1: Need/use of prescription medicine	Q2: Above average need/use of services	Q3: Functional limitations
<b>Total</b>	<b>1644</b>	<b>14,5</b>	<b>7,2</b>	<b>11,6</b>	<b>4,5</b>
Gender					
Boy	741	16,5	8,3	13,6	5,3
Girl	903	13,5	6,3	9,9	3,7
<i>p</i>		0,045	0,111	0,018	0,119
Domicile					
Big city/suburbs	672	16,7	8,0	13,3	4,3
Small city	564	15,1	7,7	11,7	5,2
Countryside	400	10,0	5,2	8,5	3,5
<i>p</i>		0,010	0,190	0,060	0,409
Age					
8-11 years	537	14,0	6,6	11,7	3,9
12-15 years	681	14,4	7,4	11,3	4,9
16-18 years	426	14,5	7,7	11,7	4,5
<i>p</i>		0,792	0,786	0,975	0,674
Family affluence scale					
Poor (0-3 points)	616	16,1	8,4	12,9	5,8
Average (4-5 points)	786	13,5	6,1	10,6	3,2
Rich family (6-7 points)	223	13,9	7,6	11,2	5,8
<i>p</i>		0,379	0,259	0,380	0,036
Parents education*					
Primary or basic vocational	429	11,0	6,2	7,5	4,1
Secondary	826	14,6	7,1	11,6	4,6
High education	383	18,5	8,8	16,2	4,7
<i>p</i>		0,009	0,347	0,001	0,915

\* Highest in the household

cally significant relationship was found between the occurrence of chronic diseases and the parents' level of education. Children of parents with higher education more often met the CSHCN criteria. However, detailed analysis demonstrated that the significant difference also concerned higher use of medical services

Table 2 shows the relationship between the CSHCN and the other health indicators. The differences between healthy and ill children were statistically significant in all cases at the  $p < 0,001$  level. The percentage of children and teenagers, who had special medical care needs increased from 8,8% in the case of good health, up to 18,8% in the case of average assessment, and 38,3%, if health was assessed as fair or poor. Taking into

Table II. Self-rated health and health service use in chronically ill and healthy children, according to CSHCN criteria

Tabela II. Samoocena zdrowia i korzystanie z usług medycznych przez dzieci przewlekle chore i zdrowe, według kryterium CSHCN

Health indicator	CSHCN (+) N=239	CSHCN (-) N=1405	<i>p</i>
Self-rated health			
Excellent, very good	34,0	59,2	<0,001
Good	46,4	35,5	
Fair, poor	19,6	5,3	
Medical consultation, past 12 months			
None	9,7	35,7	<0,001
1-2	24,1	32,7	
3-4	23,2	18,2	
5 or more visits	43,0	13,4	
Hospitalization at least one night, past 12 months			
No	82,0	95,1	<0,001
1	13,3	4,1	
2 or more hospitalizations	4,7	0,8	

consideration the past 12 months, children who met the CSHCN criteria did in fact use medical consultations more often (90,3% vs. 64,2%), and a greater percentage of them were hospitalised at least once (18,0% vs. 4,9%). The number of school days missed due to health problem was much higher in the group identified by CSHCN screener, especially when functional limitation was detected (fig. 1).

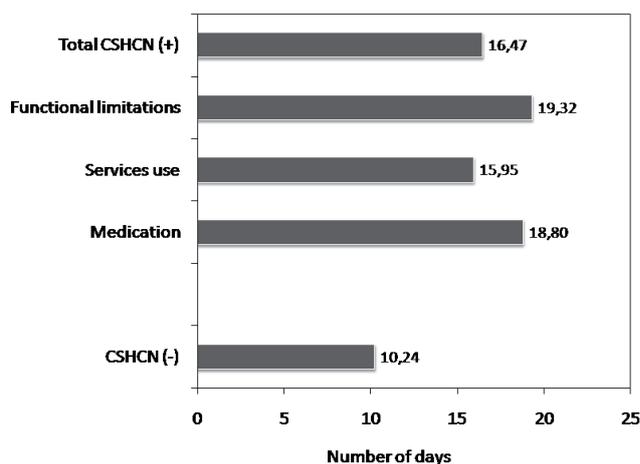


Fig. 1. Number of school days missed in the past 12 months by children aged 8-18 years according to CSHCN classification

Ryc. 1. Liczba dni nauki opuszczonych w ostatnich 12 miesiącach przez dzieci w wieku 8-18 lat według klasyfikacji za pomocą CSHCN

## DISCUSSION

According to experts of the World Health Organisation, we can expect a worldwide continuous increase in the share of chronic diseases in the total morbidity and mortality. In an editorial article published in 2007 in *Health Promotion International*, chronic diseases were described as an upcoming tsunami (14). Chronic diseases affecting adults still attract more interest than those affecting children. One ought to expect intensification of the scale of this phenomenon in the developmental age population. Although these are not fatal illnesses, they constitute a serious social problem, bearing in mind their influence on further functioning of young people. Regardless of the effects of the main disease, secondary problem could include social isolation, lowered self esteem, lower opportunities of gaining education, employment and having a family (15). Health problems restrict the social mobility, which causes intensification of health inequalities.

The percentage of children and adolescents who have special health care needs obtained in 2003 in Polish survey (14,5%) could be slightly underestimated, as the sample excluded children attending special schools and those who, due to poor health, periodically were absent or did not go to school at all. Results of the survey could be generalised only for the population of adolescents who normally attend schools. This means that in the population of pupils deemed to be in good condition, nearly 1/7<sup>th</sup> had considerable health problems. According to a report issued in 2007 by the Office of the Commissioner for Civil Rights Protection, the situation of chronically ill and disabled pupils is difficult. Therefore, one could state that the rights of chronically ill students to have equal opportunity for education as well as medical care corresponding to their needs are under threat (16).

It seems to be a good idea to popularise in Poland modern methods for assessment of the prevalence of chronic diseases among children and adolescents, including particular emphasis on tools for identification of people with special health care needs. According to empirical research, regardless of the type of illness, children and their families have a lot of common negative experiences, similar needs and expectations (17, 18).

Regardless of the data collection method and the tools used, the proper concept and definition of children requiring special medical care ought to be popularised. The extension of this definition by inclusion of children who are at risk of health problems due to living condition worse than average (poverty, nonintact family, living in more deprived areas) could be considered. As so far conducted analyses have demonstrated, that parents with university degree reported higher percent-

age of children meeting the CSHCN criteria. It could be assumed that these parents demonstrate greater interest in their children health and seek specialist consultation. Similarly, less frequent prevalence of chronic diseases in the rural areas, could be partly caused by different opportunities for diagnosis and more difficult access to specialist clinics than in cities. Despite these unexpected differences between social groups, CSHCN screener appears to capture very important information on chronic diseases prevalence and consequences that extends beyond the limited scope of disease-specific approach.

## CONCLUSIONS

The Polish version of the CSHCN questionnaire seems to be a good research instrument, which is understandable for parents. This short tool can be used across different modes of administration and be included in multi-aspect studies. Further work should include testing thereof on a clinical sample of families – parents and children with precisely diagnosed ailments. It would also be interesting to use this tool in correlation research, in order to conduct in-depth analysis of the influence of chronic diseases on psychosocial health. In the future, CSHCN could serve for various purposes such as: monitoring of the health of children and adolescents, analysis of health inequalities, assessment of the quality of medical care as well as planning and evaluation of intervention programmes.

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