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ORIGINAL PAPER

Children with mental versus physical health problems: differences in perceived disease severity, health care service utilization and parental health literacy

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Abstract
Purpose To compare children with mental and physical health problems regarding (1) perceived disease severity; (2) the impact of their condition on their families; (3) their utilization of health care services (including satisfaction with care); and (4) parents' health literacy about their child's condition and its treatment. Furthermore, we examined whether parents' health literacy differs between types of mental health condition.
Methods Parental reports about their 9- to 14-year-old children with mental ($n = 785$) or physical health problems ($n = 475$) were analyzed from the population-based National Survey of Children with Special Health Care Needs in Switzerland.
Results Mental health problems were perceived as being more severe ($p < 0.001$) and exerting a larger impact upon the family (e.g., financial impact) than physical health problems. Furthermore, fewer parents of children with a mental health problem mentioned having a particular person or place to contact if they needed information or advice regarding the child's condition ($p = 0.004$) and were satisfied with the health care services their child received ($p < 0.001$). The odds of low health literacy was higher among parents with children suffering from mental health problems vs. parents of children with physical health problems (OR in the adjusted model = 1.92; 95 % CI 1.47–2.50; $p < 0.001$); this finding held generally for mental health problem (although only a trend was observable for internalizing problems).
Conclusions The large impact of children's mental health conditions on themselves and their families might be reduced by adapting the provision of health care and by increasing parents' health literacy.

Keywords Health literacy · Mental disorders · Health service utilization · Parents · Child health

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Introduction

Even though it is often assumed that youth is characterized by excellent health, it has been estimated that (at least) 10–12 % suffer from a chronic health condition [1, 2]. Mental health problems are, among other conditions, prevalent in this age group due to the early onset of many disorders [3–7]. Such problems also account for a large proportion of the disease burden in young people [7, 8], compromise various quality of life domains [9] and exert an additional impact upon parents (e.g., experiencing stigma or self-blame) [10–13].

The pronounced impact of a young person's mental health problems on him/herself and his/her family could be reduced through effective interventions [3, 4, 7]. However, it has been shown that only a small proportion of young people with an impairing mental health condition receive specialized mental health treatment [3, 6, 10, 14, 15]. Therefore, it appears that the gap between the need for and actual use of appropriate health care is larger for mental than for physical health problems.

Seeking and providing appropriate help for young people might, at least when the person is still very young [3], be

influenced by the health literacy of parents, which has been defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [16]. Health literacy for mental health problems—aka mental health literacy [17]—has been shown to be limited in general population adults [18–22] and youth [23–33], whereby many people fail to recognize and correctly label common psychiatric disorders and are limited in their knowledge about how to take appropriate action for themselves and others. These findings have particular relevance for caregivers of children with mental health problems.

The following research gaps regarding mental health problems of young people persist. First, most studies (except those assessing the burden of disease) have targeted either mental or physical health problems, even though a comparison between the two groups could help to prioritize the health goals of a population. Second, studies that have assessed knowledge about a mental health condition and its treatment largely were based upon vignettes portraying people with a mental disorder (i.e., hypothetical scenarios), rarely focusing on those actually affected by the condition, such as parents (e.g., [26, 27, 34–37]). Third, a description of health services' utilization among young children (under the age of 15 years) living in Switzerland is largely lacking. Lastly, the impact of a young person's mental health problems on the family was often not considered [10].

To address these research gaps, the current article compares children (aged 9–14) with mental and physical health problems in terms of (1) perceived disease severity; (2) impact of their condition on parents/families; (3) utilization of health care services (including not receiving needed care and satisfaction with care); and (4) parents' health literacy about the child's condition and its treatment. Since we were particularly interested in mental health conditions, we further examined whether the health literacy of parents differed as a function of different mental health conditions.

Methods

Procedures

Data from the National Survey of Children with Special Health Care Needs in Switzerland (conducted in 2010/2011) were used. Its protocol was approved by the ethics committee of the Canton of Zurich. Demographic information for 16,496 children ages 9–14 years and their parents was obtained from municipalities and cantons (the sampling procedure has been described elsewhere [38]). Children under 15 years were chosen, as most other large-scale health surveys in Switzerland have targeted respondents age 15 years or older. The lower cutoff age of 9 years was applied so that children themselves were able to fill out a questionnaire in a subsequent part of the study (data not used for the present article, but presented elsewhere [39, 40]).

The main aim of the survey was to screen for children with special health care needs. When possible (i.e., if telephone numbers were found and parents could be reached by telephone), computer-assisted telephone interviews were conducted with the parents. Written questionnaires were sent to all parents who could not be reached by telephone [41]. It was emphasized that participation was voluntary. Altogether, 10,830 parents responded to the survey (response rate = 65.7 %), and their children were classified as 'children with special health care needs' (CSHCN; $n = 1{,}492$; 13.8 %), 'children without special health care needs' (controls; $n = 9{,}294$; 85.8 %) or 'not classifiable due to missing data' ($n = 44$; 0.4 %).

For the current analyses, only CSHCN whose parents had been reached by telephone were included, because only these proxies answered the questions used in these analyses. Of these 1,360 proxies, 100 were excluded because of missing data. Hence, the final analytic sample consisted of 1,260 CSHCN, which were further subdivided into 'CSHCN with mental health problems' ($n = 785$; 62.3 %) vs. 'CSHCN with physical health problems' ($n = 475$; 37.7 %). The 785 CSHCN with mental health problems were further divided into children with 'attention deficit/hyperactivity' ($n = 299$; 38.1 %), 'learning difficulties' ($n = 203$; 25.9 %), 'conduct problems' ($n = 81$; 10.3 %), 'speech/language problems' ($n = 34$; 4.3 %), 'internalizing problems' ($n = 46$; 5.9 %) and 'other' ($n = 122$; 15.5 %).

Variables

Socio-demographic characteristics of the responding parent

Gender (0 'mother' vs. 1 'father') and parent's education were used, because previous research has repeatedly shown that females [23, 24, 37, 42–46] and people with a higher level of education [43, 44, 46–49] have better health literacy. Parent's education was coded into 0 'low' (no secondary education, ISCED 1–2), 1 'intermediate' (secondary education, ISCED 3–4) and 2 'high' (tertiary education, ISCED 5–6) [50].

Socio-demographic characteristics of the child

Gender (0 'male' vs. 1 'female'), age, and nationality (0 'Swiss' vs. 1 'not Swiss') were used.

Type of health problem of the child

– *CSHCN with physical vs. mental health problems* In a first step, children were classified into CSHCN vs.

controls, based on the parent-reported five-item CSHCN screener [51]. According to this measure, a child was classified as having special health care needs if: (1) he/she presently experienced at least one of five health consequences and (2) this(these) health consequence(s) was(were) due to a health condition, which had lasted or was expected to last at least 12 months. The following five consequences are assessed by the CSHCN screener: (1) the need for or use of prescribed medicine (other than vitamins); (2) the need for or use of elevated levels of medical care, mental health or educational services; (3) functional limitations; (4) the need for or use of specialized therapies (e.g., physical, occupational or speech therapy); and (5) the need for or use of treatment or counseling for an emotional, developmental or behavioral problem. In a second step, CSHCN (i.e., those with a positive screening result) were further divided into those with physical vs. those with mental health problems. To do so, parents of CSHCN were asked to specify the main health problem their child has. The ICD-10 [52] was then used as framework to classify these open answers. If the mentioned problem was assignable to Chapter V (mental and behavioral disorders) of the ICD-10 (e.g., if the parent said that the main problem of the child is a conduct disorder), the child was allocated to the group 'CSHCN with mental health problems' (coded as 1). When the problem was, however, assignable to Chapters I–IV or VI–XIX of the ICD-10 (e.g., asthma), the child was grouped as 'CSHCN with physical health problems' (coded as 0).

– *Type of mental health problem* According to parental reports of the main health problem, CSHCN with mental health problems were further subdivided into children with 'attention deficit/hyperactivity', 'learning difficulties', 'conduct problems', 'speech/language problems', 'internalizing problems' and 'other' (including mental health problems with a low prevalence, like children with autism as well as mental health problems that were only described superficially). The category 'internalizing problems' included children with anxiety ($n = 31$) or depressive problems ($n = 15$). These two conditions were grouped together due to their small numbers.

Health characteristics of the child

– *Severity of the main health problem* The parents rated the severity of their child's condition on a five-point scale, ranging from 1 'not at all severe' to 5 'very severe'. Three levels of severity were used for the current article, namely 0 'not (at all) severe' (former category 1 and 2), 1 'moderately severe' (former category 3), and 2 '(very) severe' (former category 4 and 5).
– *Co-morbid problems* Parents indicated whether their child had any other mental or physical conditions besides the described main problem(s). Answers were coded into 0 'no' (i.e., no co-morbid problems) or 1 'yes' (i.e., at least one co-morbid problem).

Impact of the child's health condition

– *Financial problems* The respondent specified whether the health condition of his/her child had caused financial problems for his/her family (0 'no' vs. 1 'yes').
– *Additional income needed* The parents were asked whether they needed additional income to cover their child's health care costs (0 'no' vs. 1 'yes').
– *Job situation had to be changed* The respondent was asked whether he himself/she herself or any other family member had to reduce their working hours because of the child's health condition, whereby the following codes were used: 0 'no', 1 'reduce working hours' and 2 'give notice'.
– *Worries* Parents indicated how much worry or concern the child's condition had caused them over the past 4 weeks. Answers were categorized into 0 'no worries', 1 'some worries', and 2 'many worries'.
– *Limited time available for themselves* Answers to the question on whether parents felt limited in the time available for their own needs over the past 4 weeks because of the child's health condition were coded into 0 'no' vs. 1 'yes'.
– *Interrupted family activities* The frequency with which family activities (e.g., family meals) were interrupted due to the child's health condition over the past 4 weeks were coded into 0 '(almost) never', 1 'every now and again' and 2 'rather/very often'.

Utilization of and satisfaction with health services

– *Contact person/institution* The parents were asked whether there is a place or a specific person that they usually consult if they have any questions or need advice regarding the child's health (0 'yes' vs. 1 'no'). If the parents answered "yes", they were asked to specify the place or specific person (open-ended question). The answers were summarized into the following categories: (1) 'physician (excluding psychiatrists)/hospital', (2) 'psychologist, psychiatrist, psychiatric service', (3) 'relatives/friends', (4) 'alternative medicine practitioner', and (5) 'other/unspecified'.

- *Need for and receipt of needed care* The respondents were asked about their child's need for specific health services during the last 12 months (0 'no' 1 'yes'). If such a need was indicated, a follow-up question asked whether their child had received the needed care (0 'yes' 1 'no'). The following health services were prompted: (1) 'any specialist (e.g., dermatologist, pulmonologist, psychiatrist)'; (2) 'physiotherapy, ergo therapy, occupational therapy'; (3) 'speech therapy'; (4) 'psychological/psychiatric treatment' and (5) 'prescribed medication'.
- *Satisfaction with the health services that the child receives* Answers to this question were dichotomized into 0 'yes' (rather to completely satisfied) and 1 'no' (rather not to not at all satisfied).

Health literacy of parents

Health literacy was assessed briefly with two items from the Swiss Health Literacy Survey [53, 54] adapted to assess parents' knowledge concerning (1) their child's health problem, and (2) treatment of their child's condition. The answer format ranged from 1 'very poor' to 10 'very good' knowledge. Due to the high correlations between both items ($r = 0.70$; $p < 0.001$) and since they assess the same competence (knowledge about condition and treatment), the two items were averaged into a single health literacy score, which was then dichotomized into 0 'more knowledgeable' (scores 8–10) and 1 'less knowledgeable' (scores 1–7). This cutoff was chosen because values between 8 and 10 were, relative to values between 1 and 7, often represented (both in the two health literacy items and in the averaged score) and presumably indicated a high confidence of parents in their knowledge.

Statistical analysis

Socio-demographic and health characteristics (severity and co-morbidity) of CSHCN with mental vs. physical health problems were compared using Chi square analysis (categorical variables) and *t* tests (continuous variables). Chi square analysis was also used to examine associations between the child's health status (physical vs. mental health problems) on one hand and the impact of the child's condition, as well as utilization of and satisfaction with health services on the other. Logistic regression analyses were conducted to identify predictors associated with being less knowledgeable about the child's condition and its treatment (i.e., having poorer health literacy). The following predictors were included: (1) the respondent's gender and (2) education; (3) the child's type of health problem (model 1: physical vs. mental problems; model 2: physical vs. various types of mental health problems); (4) the severity of the child's health problem; (5) the existence of a contact person or institution that parents can usually consult if they have any questions or need advice regarding the child's health; (6) not receiving needed care; and (7) satisfaction with the health services that their child receives. The predictor 'not receiving needed care' was a summary score: children who did not receive any of the prompted health services (see above) were coded as 1, whereas all others were coded as 0. Crude odds ratios (OR) were calculated for the main predictor (type of health problem of the child). Furthermore, adjusted odds ratios (AOR) were calculated when all predictors were included in the model.

Results

Reported results are significant unless otherwise stated in the text.

Socio-demographic and health characteristics

Table 1 summarizes the socio-demographic characteristics of the total sample of parents and children, as well as characteristics of the CSHCN sub-samples with mental vs. physical health problems. Furthermore, the children's health characteristics are shown. Respondents were more likely to be mothers than fathers (84.3 vs. 15.7 %) and the percentage of mothers was higher among CSHCN with mental than CSHCN with physical health problems (86.2 vs. 81.1 %). Despite an overrepresentation of mothers, the terms 'respondents' and 'parents' are subsequently used to refer to both mothers and fathers. Most respondents had completed secondary (61.9 %) or tertiary (31.9 %) levels of education.

CSHCN with mental vs. physical health problems differed with respect to gender (more males among CSHCN with mental health problems), severity of the health condition (mental health problems were described as being more severe) and co-morbid problems (more often reported for CSHCN with mental health problems).

Impact of the child's health condition

More parents of CSHCN with mental health problems reported financial problems due to their child's condition and needed additional income to cover the health costs of their child (Table 2). Furthermore, more parents of CSHCN with mental health problems experienced some or many worries related to their child's condition, had limited time available for their own needs, and reported that family activities were at least every now and again interrupted due

Table 1 Socio-demographic characteristics of parents and socio-demographic characteristics and health condition of the children by their type of health problem

Total *n* (%)	Total sample	CSHCN with mental health problems	CSHCN with physical health problems	*p*
	1,260	785 (62.3)	475 (37.7)	
Parent's characteristics				
Gender				
Mother *n* (%)	1,062 (84.3)	677 (86.2)	385 (81.1)	0.014
Father *n* (%)	198 (15.7)	108 (13.8)	90 (18.9)	
Education				
Low *n* (%)	78 (6.2)	43 (5.5)	35 (7.4)	0.077
Intermediate *n* (%)	780 (61.9)	504 (64.2)	276 (58.1)	
High *n* (%)	402 (31.9)	238 (30.3)	164 (34.5)	
Child's characteristics				
Gender				
Male *n* (%)	800 (63.5)	531 (67.6)	269 (56.6)	<0.001
Female *n* (%)	460 (36.5)	254 (32.4)	206 (43.4)	
Age, years: mean (SD)	11.40 (1.48)	11.35 (1.45)	11.48 (1.54)	0.148
Nationality				
Swiss *n* (%)	1,153 (91.5)	721 (91.8)	432 (90.9)	0.579
Not Swiss *n* (%)	107 (8.5)	64 (8.2)	43 (9.1)	
Severity of health condition				
Not (at all) severe *n* (%)	394 (31.3)	181 (23.1)	213 (44.8)	<0.001
Moderately severe *n* (%)	562 (44.6)	379 (48.3)	183 (38.5)	
(Very) severe *n* (%)	304 (24.1)	225 (28.7)	79 (16.6)	
Co-morbid problems				
No *n* (%)	981 (77.9)	589 (75.0)	392 (82.5)	0.002
Yes *n* (%)	279 (22.1)	196 (25.0)	83 (17.5)	

CSHCN children with special health care needs

to their child's health condition. As for job situation, more parents of CSHCN with physical health problems or another family member had to give notice due to their child's health condition, whereas more parents of CSHCN with mental health problems had to reduce their work hours.

Utilization of and satisfaction with health care services

Findings on utilization of and satisfaction with health care are presented in Table 3. Parents of CSHCN with physical health problems were more likely to have a place or a specific person they usually consult if they have any questions or need advice regarding their child's health. Among parents who indicated that such a personal contact point exists, 'physicians/hospitals' were mentioned by more parents of CSHCN with physical health problems, whereas 'psychologist/psychiatrist/psychological services' and 'teacher/specialist pedagogues' were mentioned by more parents of CSHCN with mental health problems. However, even among parents of CSHCN with mental health problems, 'physicians/hospitals' were the most common personal contact/institution.

Some differences also were evident for parent-reported need for specific health services. While more CSHCN with mental health problems needed 'speech therapy' and 'psychological/psychiatric treatment', more CSHCN with physical health problems required 'specialized therapy' and 'prescribed medication'. As for the question of whether a child received needed care, only one significant group difference was identified: CSHCN with mental health problems were more likely not to receive needed 'physiotherapy, ergo therapy, occupational therapy'. Not receiving needed care varied between 0.7 and 13.8 % for CSHCN with mental health problems and 0.3 and 16.4 % for CSHCN with physical health problems, depending on the particular health service (see Table 3).

Health literacy of parents

The results of the logistic regression models are shown in Table 4. Unadjusted analyses revealed that parents of

Table 2 Impact of the child's health condition on parents by type of health problem

Total *n* (%)	Total sample	CSHCN with mental health problems	CSHCN with physical health problems	*p*
	1,260 (100)	785 (62.3)	475 (37.7)	
Financial problems exist				
No *n* (%)	1,068 (84.8)	646 (82.3)	422 (88.8)	0.002
Yes *n* (%)	192 (15.2)	139 (17.7)	53 (11.2)	
Additional income is needed				
No *n* (%)	1,053 (83.6)	633 (80.6)	420 (88.4)	<0.001
Yes *n* (%)	207 (16.4)	152 (19.4)	55 (11.6)	
Changes had to be made at work				
No *n* (%)	1,094 (86.8)	678 (86.4)	416 (87.6)	0.023
Reduce working hours *n* (%)	112 (8.9)	80 (10.2)	32 (6.7)	
Give notice *n* (%)	54 (4.3)	27 (3.4)	27 (5.7)	
Worries				
No worries *n* (%)	283 (22.5)	143 (18.2)	140 (29.5)	<0.001
Some worries *n* (%)	768 (61.0)	489 (62.3)	279 (58.7)	
Many worries *n* (%)	209 (16.6)	153 (19.5)	56 (11.8)	
Time available for themselves is limited				
No *n* (%)	1,004 (79.7)	595 (75.8)	409 (86.1)	<0.001
Yes *n* (%)	256 (20.3)	190 (24.2)	66 (13.9)	
Interrupted family activities				
(Almost) never *n* (%)	1,094 (86.8)	659 (83.9)	435 (91.6)	0.001
Every now and again *n* (%)	121 (9.6)	91 (11.6)	30 (6.3)	
Rather/very often *n* (%)	45 (3.6)	35 (4.5)	10 (2.1)	

CSHCN children with special health care needs

CSHCN with mental health problems were more likely to have poorer health literacy than parents of CSHCN with physical health problems. This pattern persisted for all mental health conditions. However, for internalizing problems only a trend was observable ($p = 0.076$). The finding for these predictors remained similar in the adjusted analyses. Again, only a trend was observable for internalizing problems ($p = 0.097$). Regarding various types of mental health problems, it stands out that the OR was largest for speech/language problems. Beside these predictors, not receiving needed care was associated with poorer health literacy. Furthermore, fathers and people with a low (vs. high) level of education were more likely to report poorer health literacy.

Discussion

In this population-based Swiss survey, mental health problems among children were perceived as being more severe and as exerting a greater impact upon families than physical health problems. Furthermore, fewer parents of CSHCN with mental health problems mentioned having a particular person or place to contact if they needed information or advice regarding their child's condition and were satisfied with the health services that their child received. However, there were almost no differences between the two conditions in terms of receiving needed care. Health literacy was poorer among parents of CSHCN with mental vs. a physical health problem. This finding held for all mental health conditions (although only a trend was observable for internalizing problems).

Child's health characteristics

Based upon the present results, it is conceivable that mental health conditions were, relative to physical health problems, perceived as being more severe because (1) they were more often accompanied by co-morbid problems (according to the parent's rating); (2) they had a larger impact on family life; and/or (3) parents were less literate regarding such conditions (the resulting uncertainty might have increased the parent's severity rating). The fact that mental health was worse among parents of children with mental relative to physical health problems (results not shown) might have also been a contributing factor, since

Table 3 Utilization of and satisfaction with health services by type of health problem

Total *n* (%)	Total sample	CSHCN with mental health problems	CSHCN with physical health problems	*p*
	1,260 (100)	785 (62.3)	475 (37.7)	
Have contact person/institution for information/advice *n* (%)	1,142 (90.6)	697 (88.8)	445 (93.7)	0.004
Physician (excluding psychiatrist)/hospital *n* (%)	925 (81.0)	519 (74.5)	406 (91.2)	<0.001
Psychologist/psychiatrist/psychiatric service *n* (%)	83 (7.3)	78 (11.2)	5 (1.1)	
Teacher/specialized pedagogue *n* (%)	27 (2.4)	23 (3.3)	4 (0.9)	
Alternative medicine *n* (%)	44 (3.9)	28 (4.0)	16 (3.6)	
Relatives/friends *n* (%)	28 (2.5)	19 (2.7)	9 (2.0)	
Other/unspecified *n* (%)	35 (3.1)	30 (4.3)	5 (1.1)	
Needed a specialist (e.g., dermatologist, pulmonologist, psychiatrist *n* (%)	579 (46.0)	330 (42.0)	249 (52.4)	<0.001
Not receiving needed care *n* (%)	15 (2.6)	11 (3.3)	4 (1.6)	0.195
Needed physiotherapy, ergo therapy, occupational therapy *n* (%)	287 (22.8)	168 (21.4)	119 (25.1)	0.134
Not receiving needed care *n* (%)	23 (8.0)	21 (12.5)	2 (1.7)	0.001
Needed speech therapy *n* (%)	272 (21.6)	217 (27.6)	55 (11.6)	<0.001
Not receiving needed care *n* (%)	39 (14.3)	30 (13.8)	9 (16.4)	0.631
Needed psychological/psychiatric treatment *n* (%)	288 (22.9)	255 (32.5)	33 (6.9)	<0.001
Not receiving needed care *n* (%)	26 (9.0)	22 (8.6)	4 (12.1)	0.510
Needed prescribed medication *n* (%)	605 (48.0)	290 (36.9)	315 (66.3)	<0.001
Not receiving needed care *n* (%)	3 (0.5)	2 (0.7)	1 (0.3)	0.515
Not satisfied with the health services that the child gets *n* (%)	149 (11.8)	113 (14.4)	36 (7.6)	<0.001

CSHCN children with special health care needs

caregivers with worse mental health were more likely to perceive their child's problem as more severe. The finding that mental health problems were relatively more severe is also inline with the large burden of disease [7, 8] as well as the compromised quality of life associated with such conditions [9]. Furthermore, stigma and self-blame associated with mental disorders [10–13] may lead parents to seek help only when the situation becomes severe. Lastly, a higher sensitivity of the CSHCN Screener for physical rather than mental health problems must be considered—i.e., it is possible that not only relatively severe mental health conditions, but also relatively milder physical health problems screened positive. This possible explanation needs to be elaborated in upcoming studies.

Impact of the child's health condition

Relative to physical health conditions, mental health problems exerted a larger financial impact (i.e., more parents reported financial problems due to their child's health condition and a need for additional income to cover associated health care costs). This result was most likely due to the greater severity of mental relative to physical health problems in the present study, which might have led to a greater health care service utilization in the former subgroup [55], and consequently to a larger financial impact of such conditions. In other words, the financial impact of physical health problems might have been underestimated, because of an underrepresentation of children with severe physical health problems (e.g., cancer) that require (cost)-intensive care. Furthermore, it seems that some parents of CSHCN with mental health problems were more likely to have sought health care for their child that was not covered by health insurance (results not shown).

The greater severity of mental health problems might also have contributed to the finding that these conditions worried parents more. Lastly, more parents of CSHCN with mental health problems felt limited in the time available for themselves (possibly due to the higher demand of supporting their child; e.g., regarding homework) and reported interrupted family activities (this was found for both externalizing and internalizing problems; results not shown).

Health service utilization and satisfaction with care

As mentioned above, parents of CSHCN with a mental health problem were less likely to have a person or place they felt they could contact when they needed

Table 4 Logistic regression models of lower health literacy predicted by parents' socio-demographic characteristics, children's health characteristics, utilization and satisfaction

Total	Total sample *n* (%)	Less knowledge about their children's health condition and treatment reported by parents			
		n (%) of less knowledgeable	Crude OR [CI]	Adjusted OR [CI][b] Model 1: type of health problem (physical vs. mental)	Adjusted OR [CI][b] Model 2: type of health problem (physical vs. various mental)
	1,260 (100)	435 (34.5)			
Child's health					
Type of health problem					
Physical health problem	475 (37.7)	118 (24.8)	1.0	1.0	Only included in model 1
Mental health problem	785 (62.3)	317 (40.4)	2.05 [1.59–2.64]***	1.92 [1.47–2.50]***	
Type of health problem					
Physical health problem	475 (37.7)	118 (24.8)	1.0	Only included in model 2	1.0
Mental: attention deficit/ hyperactivity	299 (23.7)	103 (34.4)	1.59 [1.16–2.18]**		1.50 [1.08–2.09]*
Mental: learning difficulties	203 (16.1)	93 (45.8)	2.56 [1.81–3.61]***		2.41 [1.69–3.43]***
Mental: conduct problems	81 (6.4)	36 (44.4)	2.42 [1.49–3.93]***		2.10 [1.28–3.46]**
Mental: speech/language problems	34 (2.7)	18 (52.9)	3.40 [1.68–6.89]***		2.72 [1.31–5.65]**
Mental: internalizing problems	46 (3.7)	17 (37.0)	1.77 [0.94–3.34]		1.73 [0.91–3.29]
Mental: other	122 (9.7)	50 (41.0)	2.10 [1.39–3.19]***		1.97 [1.28–3.02]**
Severity of health problem					
Not (at all) severe	394 (31.3)	118 (29.9)		1.0	1.0
Moderately severe	562 (44.6)	205 (36.5)		1.19 [0.89–1.58]	1.22 [0.91–1.63]
(Very) severe	304 (24.1)	112 (36.8)		1.04 [0.74–1.46]	1.08 [0.77–1.53]
Parent's characteristics					
Gender					
Mother	1,062 (84.3)	359 (33.8)		1.0	1.0
Father	198 (15.7)	76 (38.4)		1.57 [1.12–2.21]**	1.52 [1.08–2.13]*
Education					
Low	78 (6.2)	31 (39.7)		1.0	1.0
Intermediate	780 (61.9)	288 (36.9)		0.88 [0.54–1.43]	0.89 [0.54–1.46]
High	402 (31.9)	116 (28.9)		0.56 [0.33–0.94]*	0.56 [0.33–0.95]*
Utilization/satisfaction with care					
Contact person/institution for information/advice					
Yes	1,142 (90.6)	384 (33.6)		1.0	1.0
No	118 (9.4)	51 (43.2)		1.29 [0.86–1.92]	1.25 [0.83–1.87]
Not receiving needed care[a]					
No	1,172 (93.0)	386 (32.9)		1.0	1.0
Yes	88 (7.0)	49 (55.7)		2.20 [1.38–3.52]***	2.10 [1.31–3.37]**
Satisfaction with the health services that the child gets					
Yes	1,111 (88.2)	370 (33.3)		1.0	1.0
No	149 (11.8)	65 (43.6)		1.28 [0.88–1.85]	1.30 [0.90–1.89]

CI 95 % confidence interval, *CSHCN* children with special health care need

* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$

[a] Includes not receiving needed (1) care from a specialist (e.g., dermatologist, pulmonologist, psychiatrist); or (2) physiotherapy, ergo therapy, occupational therapy; or (3) physiotherapy, ergo therapy, occupational therapy; or (4) psychological/psychiatric treatment; or (5) prescribed medication

[b] All listed variables included in the model

information or advice about their child's condition. Parents who indicated such a personal contact most often mentioned general practitioners, rather than professionals with specialist training in mental health care. This finding is consistent with studies that have revealed that most parents perceive general practitioners as a helpful resource for children with mental health problems [35], even though not all of these health professionals might be sufficiently trained to detect and treat mental health problems [14]. Lastly, this finding might have been due to the greater accessibility of general practitioners than mental health professionals [56].

That CSHCN with mental and physical health problems did mostly not significantly differ regarding not receiving needed care contradicts the assumption that the treatment gap is especially pronounced for mental health conditions. Furthermore, the percentage of children with mental health problems who did not receive needed care (between 0.7 and 13.8 %) was much smaller than in other studies [6], which may, among other things, be attributable to methodological differences. In the current survey, parents were asked if their child needed a particular health service, and if so, whether the child received it. In this case, some parents may not have recognized an actual need. This contrasts with several other studies in which it was assumed that a need for health services was present whenever a child suffered from a mental health problem. The lack of recognition of any actual need may have been greater for mental than for physical health problems, due to the lower level of health literacy among parents and their belief that mental health conditions will improve without treatment [42]. Relatively low rates of unmet needs in the present sample may also have been due to it being mandatory to have health insurance in Switzerland; as such, most health services are covered. In contrast, the percentage not receiving needed care might be larger in countries with less comprehensive health insurance coverage. In the United States, for instance, nearly 80 % of youth ages 6–17 who were in need of mental health services (i.e., children who did not receive any mental health services in the past 12 months, despite exceeding a cutoff point on a mental health screening measurement) did not receive mental health care, and this rate was even greater among uninsured children [57].

That more parents of CSHCN with mental health problems were dissatisfied with the care of their child might, among other things, have been due to the limited expertise of the treating health professional (see above) and the subsequent suboptimal treatment course and outcome, as well as due to the parents' feeling that the treating professionals either did not exhibit enough interest [34] or displayed stigmatizing attitudes towards the child and his/her family [11].

Health literacy

Parents of CSHCN with mental health conditions reported lower health literacy than parents of CSHCN with physical health problems, possibly because mental health problems are often less visible (particularly internalizing problems) and because the underlying mechanisms of such conditions might be more difficult to understand. Furthermore, women (more precisely: mothers) and people with a higher level of education reported better health literacy, which confirms earlier findings (e.g., [23, 24, 37, 42–46] or [43, 44, 46–49], respectively). Lastly, not receiving needed care was associated with lower health literacy. A bidirectional association is assumed in this regard: better health literacy supports the help-seeking process of an individual with a particular health condition, or in our case help-seeking for one's child (e.g., health literacy might positively affect communication with health professionals and thereby facilitate receiving appropriate care; [19]). Seeking help might, in turn, further increase knowledge about a particular health condition and its treatment [37, 58, 59], through exchanges with professionals.

In the present study, parents of CSHCN with mental health problems reported lower health literacy than parents of CSHCN with physical health conditions, regardless of the type of mental health problem. That this difference was not statistically significant for children with internalizing problems might have been due to the small size of this group. Other authors have also reported that health literacy varies as a function of the mental health condition. The results described by Pescosolido et al. [42], for instance, indicate that health literacy is greater for depression than for attention-deficit/hyperactivity disorders. However, vignettes were used in the afore-mentioned study, which limits its comparability to our findings.

That parents of children with problems of speech/language reported the lowest health literacy in the present study is attributable to neither the high severity of these conditions nor the presence of co-morbid problems (results not shown). It is, however, possible that exchanges between treating professionals and parents about the speech/language problems of their child were suboptimal, leaving the parents with low health literacy. Conversely, this finding might have occurred because the CSHCN Screener was relatively more sensitive to detecting speech/language problems (because most of these children receive treatment) than other conditions (e.g., internalizing problems). If this was the case, parents of children with speech/language problems would have been included even if they had poor knowledge about their child's condition and its treatment, whereas only parents with relatively high literacy would have been included if their child, for instance, suffered from internalizing problems.

Study limitations

The following study limitations must be considered. First, the need for particular health services or functional limitations, as prompted in the CSHCN screener, might not have been recognized by some parents. This would have led to a negative screening result and subsequently to exclusion of a child (because only CSHCN were included). This bias would, at least partly, explain why some mental health conditions (e.g., internalizing problems) were underrepresented in our study, while other mental health problems were relatively often mentioned (e.g., learning difficulties). The need for particular health services (see Table 3) was also surveyed for all CSHCN (i.e., for those with a positive screening result) and might not have been recognized by all parents. Second, the classification in CSHCN with mental vs. those with physical health problems was based on the parents' reports about the main health problem of the child. The mentioned problem should not be mistaken as a clinical diagnosis, since it is possible that parents misinterpreted the symptoms of their child or were not able to recall the precise label of an already diagnosed health problem. We also cannot rule out the possibility that CSHCN with mental health problems concurrently suffered from physical health problems or vice versa. Furthermore, it sometimes might have been difficult for parents to specify a single main health problem of their child, since various health problems of equal importance might have co-existed. Also regarding other of the here-used indicators (e.g., co-morbid conditions), it must be considered that they reflect appraisals by the parents, which might differ from clinical assessments. Third, it is possible that some parents over- or underestimated their knowledge about the child's health problem and its treatment. However, the present results are consistent with earlier studies that assessed health literacy using other methods (e.g., better health literacy among women and respondents with a higher education) and, hence, seem to be valid. Nevertheless, subsequent studies need to assess health literacy more comprehensively (e.g., by including additional items). Fourth, certain variables that might have helped to explain the findings of the present study, such as experiencing stigmatizing attitudes, were not assessed. Fifth, only answers from one respondent were included. As demonstrated previously [40], the perspective of parents might be more negative than those of their children (especially for CSHCN with mental health problems). Subsequent studies should therefore also include variables that might influence the parents' reports (e.g., their own mental health), as well as information from other informants. Sixth, additional analyses showed that non-Swiss parents and people with a low educational level were underrepresented in our sample. Lastly, our study was cross-sectional, which restricts causal inferences.

Implications

In our sample, mental health conditions were described by parents as being more severe and as having a larger impact upon families than physical health problems. Even though the percentage of children with mental or physical health problems who did not receive needed care was relatively small, this group warrants further attention. Likewise, it is necessary to clarify why parents of children with mental health conditions were less satisfied with the care their child received. Lastly, our results indicate that health literacy needs to be improved among parents of children with chronic health problems, especially among (1) parents of children with mental health conditions; (2) caregivers with a low educational background; and (3) fathers. A parent's knowledge about their child's mental health condition and its treatment could, for instance, be ameliorated via general practitioners, who are often consulted if the parent has a question or needs advice. However, since general practitioners' expertise in mental health problems might be suboptimal [14], this endeavor would only be successful if these health professionals are accordingly trained [60].

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Conflict of interest The authors declare that they have no conflicts of interest.

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