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Symptoms and quality of life indicators among children with chronic medical conditions

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Abstract

Background—Children with chronic conditions often experience numerous symptoms, but few research studies examine patterns of symptoms and quality of life (QoL) indicators.

Objective—To examine if reliable latent classes of children with chronic medical conditions can be identified based on the clustering of symptoms and QoL indicators.

Methods—Structured interviews were conducted with children ages 9 to 21 living with chronic medical conditions (*N* = 90). Multiple symptoms (e.g., pain, sleep, fatigue, and depression) and

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QoL indicators (e.g., life satisfaction and social support) were measured. Physical health and emotional, social, and school functioning were measured using the Pediatric Quality of Life Inventory (PedsQL). Latent class analysis was used to classify each child into a latent class whose members report similar patterns of responses.

Results—A three-class solution had the best model fit. Class 1 (high-symptom group; *n* = 15, 16.7%) reported the most problems with symptoms and the lowest scores on the QoL indicators. Class 2 (moderate-symptom group; *n* = 39, 43.3%) reported moderate levels of both symptoms and QoL indicators. Class 3 (low-symptom group; *n* = 36, 40.0%) reported the lowest levels of symptoms and the highest scores on the QoL indicators.

Conclusions—The three latent classes identified in this study were distributed along the severity continuum. All symptoms and QoL indicators appeared to move in the same direction (e.g. worse symptoms with lower QoL). The PedsQL psychosocial health summary score (combining emotional, social, and school functioning scores) discriminated well between children with different levels of disease burden.

Keywords

Children with chronic medical conditions; Symptoms; Quality of life; Latent class analysis

Introduction

Approximately 43% of children under 17 years of age [n = 40,833 (out of 91,640)] are estimated to have one or more chronic health conditions associated with body function, activity, or participation (e.g., depression, anxiety problems, autism spectrum disorders, developmental delay, asthma, diabetes, epilepsy or seizure disorder, or brain injury) according to the 2007 National Survey of Children's Health.[1] The children with chronic health conditions often experience pain, fatigue, and emotional distress and other problems that may affect their well-being.[2-7] Quality of life (QoL) has been defined as an individual's perspective on satisfaction across many realms of one's life[8], and health-related QoL includes aspects of overall quality of life that are directly related to health—either physical or mental.[9-11]

In addition to symptoms associated with their medical conditions, children with chronic medical conditions may have poorer QoL (e.g., worse physical and psychological functioning and lower satisfaction with life) due to reduced activity levels and restrictions in participation compared to their typically developing peers.[11-14] Recently, more attention has been given to the measurement of health-related QoL in children and adolescents.[15-19] For example, a study with children with moderate-to-severe plaque psoriasis found that health-related QoL is an important indicator of the burden of illness, and that these children had significantly lower QoL compared to their healthy peers.[20] Previous studies also reported that adolescents with spina bifida (SB) had fewer positive experiences with family, peers, and schools (e.g., less participation in social groups, less social acceptance, and lower scholastic competence and academic grades), which may be one of the reasons for higher levels of depressive symptoms.[21] Pain in children with SB has also been reported to have a negative impact on their QoL.[6] Eddy and Cruz (2007) found that children (mostly with cancer) often reported fatigue and, as a result, lower QoL.[22] One study also examined the contribution of recurrent musculoskeletal pain and mental health problems in children with cerebral palsy (CP) and found that pain and higher levels of mental health problems were associated with the reduced ability to accomplish daily activities and fulfill social roles.[23]

Several pediatric QoL measures have been frequently used to measure QoL of children with chronic disease. The Child Health and Illness Profile (CHIP) has been used in population-based assessment of the association between health care and school systems with the health and well-being of children.[24-26] The Child Health Questionnaire (CHQ) examines a wide variety of physical and psychosocial domains.[27] The Pediatric Quality of Life Inventory (PedsQL) has been used to assess children's perceptions of QoL, including the physical, psychological, and social functioning of the child, and it has been the most widely used pediatric QoL measure.[28]

Most studies investigate one specific symptom or QoL indicator; few research studies consider the pattern of symptoms such as pain, fatigue, depression, and QoL indicators in children and adolescents with chronic medical conditions. The purpose of this study was to investigate the presence of distinct latent classes of young individuals with chronic medical conditions that differ on their profiles of symptoms and QoL indicators. Latent class analysis (LCA) is a statistical approach that is used to investigate the presence of distinct latent classes of individuals based on similarities and differences in response patterns – in this case, symptoms and QOL indicators - and estimate for each respondent the probability of membership in a class. We refer to *classes* of individuals here, rather than to *groups* because classes are based on unobserved variability in a latent categorical variable represented by observed symptom clusters (e.g., patterns of symptoms), while groups are based on known characteristics (e.g., gender or age). In pediatric research, for example, one study examined the patterns of the relationship between bed sharing and breastfeeding and identified 4 classes (i.e., nonsharers, early bed sharers, late bed sharers, and constant bed sharers). The predominance of breastfeeding was significantly higher among the classes of early and constant bed sharers.[29] LCA has also been used in pediatric research to identify multiple subtypes of maltreatment,[30] to investigate latent classes with different levels of risk for Type 2 diabetes,[31] to classify patterns of eating and physical activity,[32] and to identify profiles of adolescents that differentiate depressive symptoms and aggressive behavior.[33]

Methods

Participants

Parents of children who were seen in outpatient rehabilitation clinics at two Pacific Northwest children's hospitals within the last three years were sent a letter inviting them and their child to participate in a longitudinal study of symptoms in children with chronic medical conditions. Families interested in participation were screened by research staff using the following eligibility criteria: the child (1) was diagnosed with a chronic condition associated with pain and/or fatigue such as SB, CP, neuromuscular disease (NMD), spinal cord injury (SCI), or limb deficiency (LD) [congenital or amputation (AMP)] (2) was between the ages of 8 and 21 years; (3) was able to understand and read English; (4) was able to understand and meaningfully respond (as assessed by parent report for children under

18 and direct report by children over 18); and (5) had previously reported at least some pain and/or fatigue. In addition to rehabilitation clinics participants were also recruited from local camps for children with chronic medical conditions.

Interviewers were trained in strategies for interviewing people with speech disorders and other limitations. Response keys were used to make responding easier for children with speech problems. One hundred and thirteen children completed the baseline interview and were invited to complete additional interviews every three months for a total of five time points. Ninety completed the first three-month follow-up survey, which included relevant measures of quality of life (e.g., Children's Depression Inventory), and the current study is based on data from this survey time point (age range of 9-21). Approximately 30% of participants had mobility restrictions (used a mobility aid such as a wheelchair or walker) while moving around house and about 38% of participants had mobility restrictions while moving away from home. Parents could choose to be present during the child's interview, and this was the case for approximately 50% of the baseline interviews. However, we requested that parents not assist or contribute to their child's interview. The interview typically lasted about 30-45 minutes, and participants received $25 for completing each survey with an additional $25 bonus for completing all five surveys.

Children 18 years and older signed a consent form that described the study and the risks and benefits of participating. Participants younger than 18 years were asked to sign an assent form that described the study in age-appropriate language (one form was used for children aged 8–13 and a second for children aged 14–17), with parental consent required for participation. The study protocol was approved by the University of Washington Institutional Review Board, the Washington State University Institutional Review Board, and the institutional review boards of participating children's hospitals.

Data Collection

Interviews were conducted in person or over the telephone by trained research staff. A parent, guardian, or camp counselor was present if the child or adolescent participant so desired. Validated measures of pain, fatigue, social support, emotional health, and physical function were administered, including items developed as part of the National Institutes of Health Patient Reported Outcomes Measurement Information System Project (www.nihpromis.org).[34,35]

The presence of chronic pain was assessed with the following question: In the last three months have you had any pain that bothered you? The PedsQL Multidimensional Fatigue Scale (MFS);[36,37] was used to assess fatigue. The 18-item MFS is composed of three subscales: general fatigue (6 items), sleep/rest fatigue (6 items), and cognitive fatigue (6 items). Higher scores on MFS indicate fewer fatigue symptoms. Good internal consistency has been reported for the MFS (alpha = 0.9).[36]

Depression was measured by the Children's Depression Inventory Short Version (CDI),[10] which consists of 10 items. The CDI scores range from 0 to 20, with higher scores indicating more depressive symptoms. The raw score is converted to a T-score, which can be compared to scores of children of the same age range and gender. A T-score of 65 and above (1.5 SD above the mean) indicates clinically significant depressive symptoms.[38] Various raw cut-off scores have also been used for CDI full and short versions.[39] For this study, a raw total score ≥8 for both girls and boys age 7-12 years and a raw score ≥9 for boys age 13 and older were considered to be indicative of clinically significant depression, in accordance with the CDI technical manual.[38] The CDI provides scores that are comparable to the longer 27-item version of the CDI ($r = 0.9$) and demonstrates an acceptable alpha reliability coefficient (alpha = 0.8).[10]

Physical health and emotional, social, and school functioning were assessed with the 23-item PedsQL subscales[40] with response options expanded to include ‘unable to do’ to ensure appropriate response options for all respondents, but the scores were derived using the published scoring instructions. There is a distinct subscale for physical health (i.e. Physical Health Summary score). The Psychosocial Health Summary score is a mean of the emotional functioning, social functioning, and school functioning subscale scores. Scores on each subscale range from 0 to 100 with higher scores indicating better QoL. Good internal consistency has been demonstrated for the Physical Health Summary Score (alpha = 0.8) and the Psychosocial Health Summary Score (alpha = 0.8), and scores are moderately correlated with reports of morbidity and illness burden.[37] The PedsQL is a user-friendly instrument often used in clinical or research settings. [41]

Social support was assessed using the 12-item Multi-dimensional Scale of Perceived Social Support (MSPSS).[42,43] The MSPSS assesses social support across three relevant domains of family, friends, and significant others, and higher scores represent greater perceived social support. The MSPSS was shown to have good internal (0.85-0.91)[43] and test-retest reliability (0.72-0.85) as well as moderate construct validity.[42,44,45] Higher MSPSS scores are associated with lower levels of depression and anxiety as measured by the Hopkins Symptom Checklist (HSCL).[46] The response options range from 1=very strongly disagree to 7=very strongly agree. This response set was found problematic in our previous studies with adults, so we modified the response options to a 5-point scale (never to almost always) that are preferred and better understood by children and adults.[2, 47] The revised response worked well and made the MSPSS more age-appropriate, as children had no difficulties using the revised responses options. For instance, in responses to questions such as “I can talk about my problems with my friends” and “My family really tries to help me,” children readily picked a response from the response set of “never true” to “almost always true”. Although the MSPSS was not specifically developed for the youth population, it has been successfully used in adolescents (with the original response categories).[48,49]

Children completed the 6-item Brief Multidimensional Student's Life Satisfaction Scale (BMSLSS)[50] to assess perceived QoL. Scores can range from 0 to 24, and higher scores indicate better life satisfaction. The measure demonstrated adequate internal consistency (alpha = 0.8) and was strongly correlated with two other life satisfaction measures: the Multidimensional Students' Life Satisfaction Scale total score ($r = 0.7$) and the Students' Life Satisfaction Scale total score ($r = 0.6$).[50]

Sleep problems were assessed by the 26-item Children's Sleep Habits Questionnaire child self-report version.[51] The CSHQ is comprised of three subscales (Bedtime, Sleep behavior, and Daytime sleepiness) and an overall sleep functioning score. A higher score indicates more sleep problems. The CSHQ showed adequate internal consistency for both a community sample of children with no sleep disorders (alpha = 0.7) and a clinical sample of children being evaluated for a sleep disorder (alpha = 0.8). Test-retest reliability was acceptable (range 0.6 to 0.8), and CSHQ scores were consistently higher for the clinical sample as compared with the community sample, supporting the validity of the CSHQ as a measure of children's sleep habits.[51]

In addition to clinical and demographic items, participants responded to the Wide Range Achievement Test 3–Reading Subtest (WRAT–3)[52] as a proxy for literacy level. Assessment of literacy level is important in survey research and reading ability is a stronger and independent predictor of health outcomes than, for instance, years of education.[53] The WRAT is a commonly used brief test of literacy in adult and child populations.[54] It contains a reading subtest that is used to test reading ability independent of reading comprehension. The WRAT 3 reading subtest is provided in the “blue” and “tan” parallel forms. Each version contains 42 different words. According to the WRAT-3 Administration Manual, individuals are asked to pronounce the list of words in ascending order of difficulty and are instructed to stop once 10 consecutive pronunciation errors have been made. Both subtests also have 15 letters to be read aloud if the participant is not able to pronounce at least five words correctly prior to reaching the test discontinue point of 10 consecutive words mispronounced. Raw scores are based on a participant's overall response; final standardized scores are scaled on the norm to correspond to median performance for specific age groups.[52] Each age group has a scale mean of 100 and a standard deviation of 15; higher scores indicate better literacy.

After different classes were identified by the results of the LCA analyses, descriptive statistics of the average and worst pain intensity were calculated for each latent class separately for variables that were not included in the LCA model. These variables included pain questions as follows: (1) “In the past week, how bad was your worst pain?” (no pain [0] to very bad pain [3]); (2) “On a typical day, how much do you hurt?” (not at all [0] to a lot [3]). Descriptive statistics were also computed for the children's demographic characteristics, primary conditions across latent classes and PedsQL psychosocial health summary score, a composite of scores on emotional health, socializing, and school functioning were also computed by each class.

Statistical Analyses

LCA groups individuals into different latent classes based on unobserved variability in a latent categorical variable reflected in patterns or clusters of symptoms or characteristics. Individuals within a particular class share homogeneous characteristics and demonstrate heterogeneous characteristics across different classes.[29] The important difference between the LCA and the analyses that compare known groups is that LCA defines the classes empirically, from the data, rather than using a measured variable (such as gender or age). LCA has been used extensively in health research.[55-58]

How well individuals have been classified into each latent group is evaluated by a statistic called entropy. Entropy has a range of 0 to 1, with higher values of entropy indicating a better classification of individuals. Entropy of .8 or greater indicates good classification.[59] Identifying the model with the optimal number of latent classes is guided by comparative measures of model fit that include Bayesian information criteria (BIC),[60,61] but interpretability of the latent classes is equally important when selecting a final model. The goal of the current study was to use LCA to identify distinct classes of children and adolescents with chronic medical conditions based on the patterns of symptoms and QoL indicators. Accordingly, the number of latent classes was guided by both BIC indices of comparative fit and entropy measures. Descriptive statistics were also calculated for the children's demographic characteristics and primary conditions. Subsequent exploratory analyses included analysis of variance to assess statistical significance of the differences between the latent classes on demographics and other characteristics that were not included in the statistical model (i.e. not used to derive the latent classes). Data preparation and descriptive summaries were carried out using SAS[62] and SPSS[63] and LCA was carried out using Mplus.[64]

Results

Participants

Table 1 summarizes the demographic characteristics of the sample. The average age of the sample was 14.8 (SD = 3.2; range = 9.4 – 21). Most of the children with chronic medical conditions were white (76.7%), and females (53.3%) slightly outnumbered males. The average standardized WRAT score was 97.4 (SD = 21.6), which was slightly lower than the mean of 100 for the general population. Parental education data were available for 59 of the 90 children participants (66%), as parental participation was voluntary. The majority of the parents who responded to the questionnaire were college graduates (51%). Table 1 also summarizes the primary medical condition or diagnosis of the children for the current study. CP (24.8%) and SB (17.8%) were more highly represented than other conditions. Nearly one-third (27.7%) of the participants, however, reported more than one condition (total endorsements: $N = 101$) such as diabetes, bone tumor, scoliosis, asthma, or Guillain-Barre Syndrome.

While the child was being interviewed, parents were asked to complete a separate questionnaire about their child. The paired t tests compared the responses of children and parent Based on t tests, we did not see any difference in baseline mean scores of children and their parents for measures of friend and family support, school functioning, and depression (family support: $t = -0.32$, $df = 96$, $p > 0.05$; friend support: $t = 0.44$, $df = 93$, $p > 0.05$; school functioning: $t = 1.36$, $df = 93$, $p > 0.05$; and depression: $t = -0.77$, $df = 59$, $p > 0.05$).

Table 2 presents correlations between symptoms and QoL Indicators included in the latent class analysis. Correlations ranged in magnitude from 0.2 (physical health and social support) to 0.7 (fatigue and sleep problems, fatigue and school functioning, physical health and social functioning). The majority of correlations observed were moderate in magnitude, and all correlations were in the expected directions.

Latent Class Analysis

Multiple latent class models were constructed with 1 through 6 latent classes, and BIC comparative model fit criteria suggested that the 3 or 4 class solutions were optimal. (Table 3) The three class solution was selected as the best model because the 4, 5, and 6 class solutions included a class comprised of a single participant. Entropy statistics for each model were all > 0.90 suggesting more than adequate classification.

Table 4 summarizes the symptoms and QoL indices used to derive the latent classes as well as the demographic and clinical descriptors of each latent class. As expected due to the study eligibility criteria, all three classes reported substantial chronic pain in the last three months. Class 1 (*n* =15), the high-symptom group, had an average age of 14.4 (SD = 3.3) and was predominantly female (60%) and white (76.9%). The average standardized WRAT score was 96.1 (SD = 18.0). SB and NMD were the most frequently endorsed single conditions in this class (23.5%). This group reported the most problems with symptoms (i.e., sleep, fatigue, and depression) as measured by the children's sleep habits, MFS, and CDI. 26.7% of participants were identified with clinically significant depression based on CDI cutoff criterion. 80% of participants reported bothersome pain in the last three months. Average scores on the QoL indicators such as social support and satisfaction with life were the lowest of all three classes. This class also reported the highest mean scores on two pain items (i.e., “How bad was your worst pain?” and “On a typical day, how much do you hurt?”) and had the lowest average psychosocial health summary scores.

Class 2, the moderate-symptom group, had an average age of 15.1 (SD = 3.0), was predominantly white (86.1%), and was nearly evenly distributed with respect to gender (48.7% female). The average standardized WRAT score was 95.7 (SD = 24.0), and 36 (92.3%) participants endorsed the item indicating bothersome pain in the last three months. Only one (2.6%) participant was identified with clinically significant depression based on CDI cutoff criterion. SB and CP were most commonly endorsed primary conditions (20.0%). 92.3% of participants reported bothersome pain in the last three months. Members of this class reported moderate levels of most of symptoms and QoL indicators.

Class 3, the low-symptom group, had an average age of 14.8 (SD = 3.5), was predominantly white (84.8%), and the majority were female (55.6%). The average standardized WRAT score in this class was 100.0 (SD = 20.9). This class included the highest proportion of CP among diagnostic conditions (35.9%) and reported the lowest levels of fatigue, sleep, and depression. 75% of participants reported bothersome pain in the last three months. In addition, this class reported the highest average scores on life satisfaction, social support, and physical health, as well as emotional, social, and school functioning measured by the MSPSS, SWLS, BMSLSS, and PedsQL. No one was identified with clinically significant depression. 75% of participants reported bothersome pain in the last three months. This class also reported the lowest mean scores on two pain items. Class 3 also had the highest average score on PedsQL psychosocial health summary and the lowest averages on two pain items.

Figure 1 illustrates the distribution of scores on the PedsQL indicators, which are on the same scale (i.e., one summary score and four subscales). Lower scores represent more problems with emotional, social, and school functioning and physical health. As clearly shown, Class 3 had the highest scores on all of the PedsQL indicators, whereas Class 1 had the lowest scores.

Between class differences

While the classes were similar on age, there was some separation among the classes on gender (high symptom class had a higher proportion of females), ethnicity (the moderate symptom class had the highest proportion of white children), and literacy (the low symptom class had the highest mean reading score), although these differences were not statistically significant. The presence of chronic pain was the only symptom that was higher for the moderate-symptom class than for the high-symptom class, but the ratings of worst and average pain followed the pattern of the variables included in the model (i.e., the highest level of pain was reported by the high-symptom class and the lowest by the low-symptom class). This suggests that pain intensity is distributed similarly to the other symptoms and QoL indicators. Average pain intensity was statistically significantly different between the high and low symptom classes, but was not different between the high and moderate and moderate and low symptom classes. The three latent classes were statistically significantly different on the PedsQL psychosocial functioning summary score with mean scores of 84, 60, and 37 ($F = 156.3$, $df = 89$, $p < 0.001$).

Discussion

The LCA results identified three latent classes that differed according to the level of symptoms and QoL indicators. The classes separated along the continuum of disease burden with all the symptoms and QoL indicators moving in the same direction. The higher the level of symptoms (such as sleep problems and fatigue) children report, the lower the social support, social and school functioning, and student's life satisfaction.

One of the limitations of the current study is potential bias from recall and self-report. Other limitations also include small sample size in the overall sample and, by extension, in the latent classes. Because questionnaires were voluntary, the information about parent education is incomplete. In addition, the sample was composed of the children with many different chronic medical conditions, and that makes it difficult to generalize findings to specific diagnostic groups. Future studies are needed to replicate this analysis with larger samples of children with greater racial/ethnic and socioeconomic diversity both within and across chronic medical conditions before generalizing these findings to the broader population of children with chronic medical conditions.

The PedsQL is the most widely used QoL instrument[65,66] used in studies with children with migraine,[67] cancer-related pain and emotional distress,[40] juvenile idiopathic arthritis[68] as well as cardiology, orthopedic, and rheumatology outpatient settings.[69] Additional research is always warranted with empirically derived classes, but in our study this PedsQL seems the best predictor of class membership. These preliminary results suggest that a PedsQL psychosocial health summary score under 40 likely indicates a child with high symptoms and low QoL, a score between 40 and 70 indicates moderate symptoms and QoL, and the score over 70 suggests low symptoms and higher QoL. Our results are similar to Varni at al. (2003)[70] in that the score that best discriminates between moderate and low symptoms is between 40 and 70 (i.e., child self-report score of 66.03 and parent proxy-report score of 64.38). The result of our study added a cut-off point of 40 that indicates a child with high symptoms and low QoL. This finding is important since it is often not practical to administer a large battery of test to determine classes. Thus, this indicator can be used to predict class membership in clinical practice or future research.

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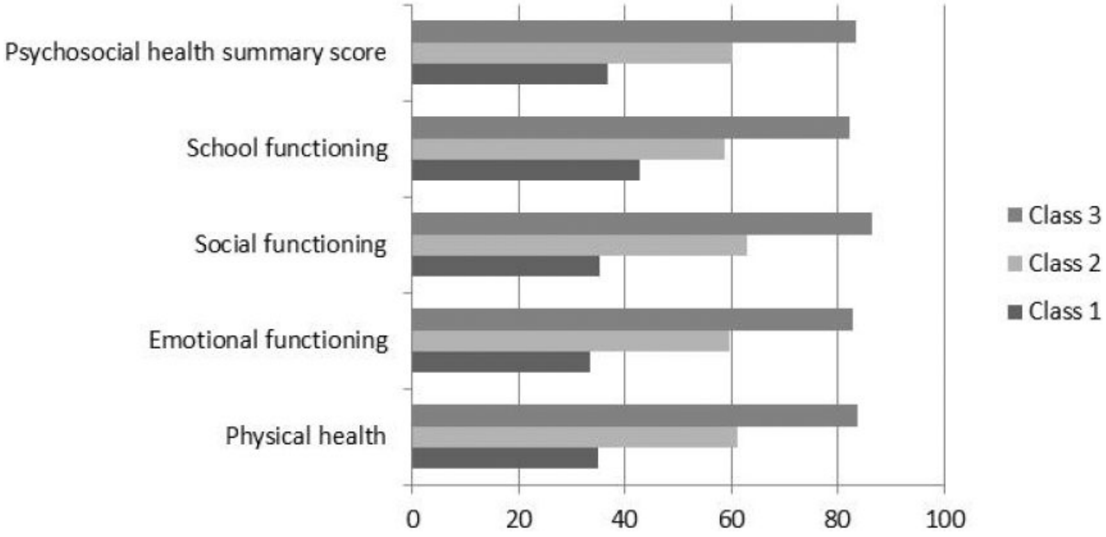

Figure 1. Averages of PedsQL Indicators across Latent Classes

Table 1
Demographic and Clinical Characteristics of Sample

	Mean (SD)
Age	14.8 (3.2)
Standardized WRAT score[a]	97.4 (21.6)
	n (%)
Female	48 (53.3%)
Non-Hispanic White[b]	69 (76.7%)
Education (parents)[c]	
High school degree/GED	4 (6.8%)
Some college/technical degree/AA	25 (42.4%)
College / advanced degree	30 (50.9%)
Primary conditions[d]	
Spina bifida	18 (17.8%)
Cerebral palsy	25 (24.8%)
Neuromuscular disease	14 (13.9%)
Congenital limb deficiency	6 (5.9%)
Amputation	6 (5.9%)
Spinal cord injury	4 (4.0%)
Other conditions	28 (27.7%)

Note.

[a] The calculation is based on 79 participants.

[b] The calculation is based on 82 participants.

[c] The calculation is based on 59 parents.

[d] Participants could endorse more than one condition and calculations are based on the total endorsement (total *N* =101).

WRAT = Wide Range Achievement Test

GED = General Educational Development

AA = Associate of Arts

Table 2

Correlation among Symptom and Quality of Life Indicators for Latent Class Model

Measure	**Sleep problems**	**Fatigue**	**Social support**	**Physical health**	**Emotional functioning**	**Social functioning**	**School functioning**	**Student's life satisfaction**
Sleep problems								
Fatigue	-0.7							
Social support	-0.3	0.4						
Physical health	-0.6	0.6	0.2					
Emotional functioning	-0.6	0.6	0.4	0.6				
Social functioning	-0.6	0.6	0.4	0.7	0.6			
School functioning	-0.5	0.7	0.3	0.6	0.6	0.5		
Student's life satisfaction	-0.6	0.5	0.3	0.4	0.4	0.5	0.3	
Depression	0.3	-0.5	-0.5	-0.3	-0.6	-0.5	-0.3	-0.5

Table 3

Latent Class Model Fit Criteria

Number of classes	BIC	Entropy
1	5765.3	-
2	5533.1	0.91
3	5479.8	0.92
4	5478.4	0.94
5	5488.8	0.95
6	5494.2	0.95

Table 4

Symptom and Quality of Life Indicators and Demographic Descriptors of Latent Classes

	Latent Class 1 (High-symptom)	**Latent Class 2 (Moderate-symptom)**	**Latent Class 3 (Low-symptom)**
	***n*= 15 (16.7%)**	***n* = 39 (43.3%)**	***n* = 36 (40.0%)**
Symptom and Quality of life indicators for latent class model			
	Mean (SE)	Mean (SE)	Mean (SE)
Sleep problems	42.7 (1.4)	37.2 (0.9)	30.4 (0.7)
Fatigue	44.1 (3.3)	60.5 (2.5)	83.1 (2.0)
Social support	3.0 (0.1)	3.3 (0.1)	3.7 (0.1)
Physical health	34.9 (6.5)	61.1 (2.9)	83.6 (3.3)
Emotional functioning	33.4 (4.2)	59.6 (3.3)	82.7 (2.7)
Social functioning	35.4 (4.2)	62.8 (2.6)	86.3 (3.6)
School functioning	42.7 (4.7)	58.8 (3.1)	82.1 (2.7)
Student's life satisfaction	17.2 (0.9)	19.4 (0.6)	22.8 (0.4)
Depression	6.1 (1.0)	2.1 (0.3)	0.80 (0.2)
	n (%)	*n* (%)	*n* (%)
Clinically significant depression (from depression scores)	4 (26.7%)	1 (2.6%)	0 (0%)
Bothersome pain (In the last three months, have you had any pain that bothered you?)	12 (80%)	36 (92.3%)	27 (75%)
Demographic and clinical descriptors of latent classes			
	Mean (SD)	Mean (SD)	Mean (SD)
Age (SD)	14.4 (3.3)	15.1 (3.0)	14.8 (3.5)
Standardized WRAT score (SD)[a]	96.1 (18.0)	95.7 (24.0)	100.0 (20.9)
How bad was your worst pain?[b]	1.8 (0.9)	1.2 (0.7)	1.2 (0.9)
On a typical day, how much do you hurt?[c]	1.3 (1.0)	1.0 (0.6)	0.7 (0.7)
PedsQL psychosocial health summary score	36.8 (11.8)	60.2 (8.2)	83.5 (8.5)
	n (%)	*n* (%)	*n* (%)
Female	9 (60.0%)	19 (48.7%)	20 (55.6%)
Non-Hispanic White[d]	10 (76.9%)	31 (86.1)%	28 (84.8%)
Education (parents)[e]	*n* = 10	*n* = 25	*n* = 24
High school degree/GED	0 (0.0%)	2 (8.0%)	2 (8.3%)
Some college/technical degree/AA	3 (30.0%)	21(44.0%)	11 (45.8%)
College / advanced degree	7 (70.0%)	2 (48.0%)	11 (45.8%)
Primary conditions[f]			
Spina bifida	4 (23.5%)	9 (20.0%)	5 (12.8%)
Cerebral palsy	2 (11.8%)	9 (20.0%)	14 (35.9%)

	Latent Class 1 (High-symptom)	**Latent Class 2 (Moderate-symptom)**	**Latent Class 3 (Low-symptom)**
	***n*= 15 (16.7%)**	***n* = 39 (43.3%)**	***n* = 36 (40.0%)**
Neuromuscular disease	4 (23.5%)	7 (15.6%)	3 (7.7%)
Congenital limb deficiency	0 (0.0%)	2 (4.4%)	4 (10.3%)
Amputation-upper extremity	0 (0.0%)	5 (11.1%)	1 (2.6%)
Spinal cord injury	1 (5.9%)	2 (4.4%)	1 (2.6%)
Other conditions	6 (35.3%)	11 (24.4%)	11 (28.2%)

Note.

[a] Calculations are based on 15 participants for class 1, 34 for class 2, and 30 for class 3.

[b] Calculations are based on 12 participants for class 1, 36 for class 2, and 26 for class 3.

[c] Calculations are based on 12 participants for class 1, 36 for class 2, and 27 for class 3.

[d] Calculations are based on 13 participants for class 1, 36 for class 2, and 33 for class 3.

[e] Calculations are based on 10 participants for class 1, 25 for class 2, and 24 for class 3.

[f] Participants could endorse more than one condition.

Calculations are based on the total endorsement (total N = 101; class 1: n = 17; class 2: n = 45; class 3: n = 39).

SE = Standard error; SD = Standard deviation; WRAT = Wide Range Achievement Test; GED = General Educational Development; AA = Associate of Arts.