Evaluation of a generic patient education program in children with different chronic conditions

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Abstract
For frequent pediatric chronic conditions, especially less common chronic conditions patient education programs are missing. A recently developed modular patient education approach (ModuS) combines disease-specific modules with generic psychosocial topics. ModuS was associated with increased disease-specific knowledge and improvements in families’ well-being in children with asthma. In this study we tested if new developed ModuS programs for seven, mostly less common, chronic conditions show comparable program-associated effects. ModuS education programs were offered to the affected child and its parents. Disease-specific knowledge, children’s self-reported health-related quality of life, life satisfaction and condition-specific burden were measured before, directly following and 6 weeks after participation in the program. The results were compared with families who received a ModuS asthma program. One hundred and sixty-eight children participated. Families were highly satisfied with the programs. Program participation was associated with increased families’ knowledge, children’s self-reported health-related quality of life and reduced condition-specific burden. The results were comparable with the results of 230 families who participated in a ModuS asthma program. The ModuS approach allowed the development of patient education programs for children with a variety of chronic conditions. Therefore, ModuS closed an important healthcare gap.

Introduction
In recent decades, the prevalence of children with chronic conditions has increased continuously [1, 2]. Approximately 16% of children and adolescents have specific health care needs [1]. Their families have to be trained in medical treatments and require help in coping with the extra burden caused by the chronic condition. Especially the psychosocial support is important, because children with chronic diseases have a decreased health-related quality of life (HRQoL) compared with healthy peers [3, 4]. To meet these requirements, patient education programs have been developed. The efficacy of condition-specific programs has been documented in several studies for different chronic conditions such as asthma or obesity [5–10]. These studies have demonstrated improvements in disease-specific knowledge, HRQoL, physical health outcomes and reduced use of healthcare resources.

However, even for the more common condition diabetes comprehensive, structured, age-appropriate and evaluated programs as recommended by medical guidelines are still missing in the majority of...
European countries [11]. There is a larger paucity of programs for less common conditions, such as cystic fibrosis, phenylketonuria and primary immunodeficiency [12]. The development of essential patient education is hindered by the low prevalence, the limited capacity of the treatment teams as well as high program-development costs [12]. This is even more regrettable since those families often suffer the most because they have limited contact with experts and other affected families, and evidence-based guidelines for treatment might be missing [13–15].

To overcome barriers to education programs for these families, the new modular approach for group education programs ModuS was developed. The aim of ModuS was to simplify the development of programs for chronic conditions in childhood. ModuS is conceptually based on a generic approach of understanding how a chronic condition impacts children’s and families’ lives. This concept assumes that psychosocial issues are at least equally as important as medical issues [16–20]. The concept implicates that all programs for chronic conditions in childhood share themes that are relevant to the adaptation to any chronic health condition. Therefore, ModuS consists of four generic modules (Module 0, 1, 5, 6) and three disease-specific modules (Module 2, 3, 4; Table I). Table I displays a detailed description of the modules. ModuS focuses on chronically ill children (7–12 years), adolescents (13–17 years) and their parents. The parents and the children are educated separately. The generic modules are predominantly conducted by psychologists and counselors. The disease-specific modules are conducted by the medical team. The programs’ quality is ensured by structured curricula, trainer education and quality management standards. The ModuS approach and the training manual as well as the train-the-trainer curriculum have been published by Ernst and Szczepanski [21]. For a detailed description of the ModuS approach and its development, see Ernst and colleagues [22].

Ernst and colleagues showed that a ModuS asthma education program was associated with increased disease-specific knowledge and improved families’ well-being [22]. This paper focuses on the development and evaluation of ModuS programs for seven mostly less common chronic conditions (PLCC). For a better interpretation of the results, we compared the results with the ModuS asthma education program. It was expected that, comparable with the ModuS asthma program, the PLCC improve the families’ disease-specific knowledge, the HRQoL, and life satisfaction of the affected child and diminish the families’ disease-specific burden. We did not explicitly assess the families’ psychosocial support but assumed that the supposed programs’ effects on HRQoL, life-satisfaction and families’ burden were mediated by the received psychosocial support.

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**Methods**

**Educational programs**

A ModuS program for children with asthma already existed [22]. The new education programs were developed by members of a German pediatric patient education association called KomPaS (https://www.kompetenznetz-patientenschulung.de). This association was launched 2008 to overcome the lack of pediatric education programs for chronic conditions and to harmonize existing patient education initiatives in Germany. All KomPaS members were invited to take part in the ModuS project to develop new education programs. Due to the specialization of the participants of the ModuS project for the following seven mostly less common conditions, disease-specific modules were developed and combined with generic modules: chronic inflammatory bowel diseases (IBD), cystic fibrosis (CF), phenylketonuria (PKU), nephrotic syndrome (NS), urinary incontinence (UI), chronic functional abdominal pain (CFAP) and primary immunodeficiency (PID). The disease-specific modules were developed by interdisciplinary expert groups in consideration of current medical, psychological and educational scientific knowledge and guidelines. The program’s duration depends on the specific condition (Table II). All PLCC of this study consisted of separate sessions for children and parents. Additional developed programs only for parents with children younger than 7 years with CF, NS,
<table>
<thead>
<tr>
<th>Module</th>
<th>Topics and targets</th>
<th>Methods and techniques</th>
<th>Trainer</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. Organization and preparation</td>
<td>Planning and organizing education courses, e.g. patient invitation, funding, necessary resources, legal aspects and educational material</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>1. Introduction and getting acquainted</td>
<td>Introduction of agenda, team members and participants; collecting wishes and needs • engendering trustful cooperation</td>
<td>Round of introduction to patient history Card survey Familiarization exercise</td>
<td>Psychologist Pediatrician</td>
<td>45 min</td>
</tr>
<tr>
<td>2. Explanation of the disease, its treatment and prognosis</td>
<td>Pathophysiology and symptoms, disease course and risks (not for children) and determinants of disease onset and course • understanding therapy needs and complications • reducing feelings of guilt and anxiety</td>
<td>Presentation Illustrative comparisons and exercises Self-reporting Self-monitoring of symptoms (possible homework assignment)</td>
<td>Pediatrician</td>
<td>45–90 min (depending on the disease)</td>
</tr>
<tr>
<td>3. Competencies and motivation for basic therapy</td>
<td>Principles of medical and non-medical basic therapy (e.g. diet and physical therapy), correct use of medical aids and challenges and barriers to therapy • qualification and motivation for long-term treatment</td>
<td>Presentation Demonstration Supervised skill training Self-reporting and group discussions Problem solving</td>
<td>Pediatrician, as appropriate Physiotherapist Dietitian or nurse</td>
<td>90–360 min (depending on the disease)</td>
</tr>
<tr>
<td>4. Competencies for preventing or managing acute crises</td>
<td>Triggers, warning symptoms and ‘red flags,’ coping with deterioration, and emergency management • ability to self-monitor and react to changes • confidence in acute crises and reducing fear</td>
<td>Presentation Self-reporting Demonstration Supervised skill training Role play or case reports Self-monitoring of triggers and symptoms (possible homework assignment)</td>
<td>Pediatrician, as appropriate Psychologist</td>
<td>45–135 min (depending on the disease)</td>
</tr>
<tr>
<td>5. Coping with the disease in family life, school and social activities</td>
<td>Dealing with the disease in the family, e.g. the burden and conflicts, distribution of tasks and responsibilities, strategies for nurturing and motivation (only for parents) and considering one’s own needs and personal relief Managing the disease in school and everyday life: informing others about the disease, and asking for help and support Social law and support (only for parents) • coping with the disease • improving self-confidence</td>
<td>Presentation Self-reflection Self-reporting and group discussion Problem solving Role play or case reports Goal setting</td>
<td>Psychologist</td>
<td>180–270 min</td>
</tr>
<tr>
<td>6. Completion and maintenance</td>
<td>Consolidation of course content, goals and future planning strengthening implementation of new skills</td>
<td>Reflection Quiz or other games for recapitulation Goal setting</td>
<td>Psychologist Pediatrician</td>
<td>45–90 min</td>
</tr>
</tbody>
</table>
### Table II. Condition-specific ModuS education programs for chronic conditions in childhood

<table>
<thead>
<tr>
<th>Chronic condition</th>
<th>Main topics and characteristics</th>
<th>Target groups</th>
<th>Time (in EU)</th>
<th>Trainer</th>
</tr>
</thead>
</table>
| Chronic inflammatory bowel disease (IBD) | Pathogenesis, symptoms and course of IBD  
Identifying triggers and individual stressors that promote deterioration  
Medical therapy and diet during basic therapy and acute flares  
Coping with the condition in daily family life | Adolescents aged 10–17 years and their parents  
24 EU adolescents | 10 EU parents and  
24 EU adolescents | Pediatrician/  
Gastroenterologist  
Psychologist  
Dietitian  
Nurse |
| Cystic fibrosis (CF)       | Pathogenesis, symptoms and course of CF  
Multidisciplinary therapy consisting of medication, inhalation, hygiene, diet and physiotherapy  
Strategies for preventing deterioration and distress  
Challenges and barriers to therapy in daily life and coping with the condition | Parents of children aged < 7 years  
Youth aged 13–17 years and their parents | 26 EU parents only  
36 EU youth and  
6 EU parents | Pediatrician  
Physiotherapist  
Dietitian  
Nurse  
Social worker |
| Phenylketonuria (PKU)      | Pathogenesis and consequences of PKU  
Therapeutic principal ‘diet for life’  
Estimating and calculating Phe values in food  
Intake of phenylalanine-free amino acid mixture  
Family planning (only for parents and youth)  
Challenges and barriers to ‘diet for life’ in daily life and coping with the condition | Parents of children aged < 7 years  
Children aged 8–12 years and their parents  
Youth aged 13–17 years and their parents | 11 EU parents and  
11 EU children/  
youth | Pediatrician  
Psychologist  
Dietitian |
| Nephrotic syndrome (NS)    | Pathogenesis, symptoms and course of NS  
Medical therapy during basic therapy and recurrence  
Self-monitoring for detecting deterioration  
Coping with the condition in daily family life | Parents of children aged < 7 years  
Children aged 8–12 years and their parents  
Youth aged 13–17 years and their parents | 16 EU parents and  
16 EU children/  
youth | Pediatrician  
Psychologist  
Nurse |
| Urinary incontinence (UI)  | Pathogenesis, causes and triggers of UI  
Identifying individual patterns of drinking, defecation and urination and stressors  
Specific perception training, relaxation techniques and stress management  
Strategies for dealing with UI in daily life and coping with the condition | Children aged 8–12 years and their parents  
Youth aged 13–17 years and their parents | 10 EU parents and  
18 EU children | Pediatrician  
Psychologist  
Nurse |
| Chronic functional abdominal pain (CFAP) | Pathogenesis and biopsychosocial model of chronic pain.  
Identifying individual stressors and conditions that promote further deterioration and strategies for preventing triggers  
Strategies for dealing with chronic pain  
Coping with the condition in daily family life | Adolescents aged 10–17 years and their parents  
16 EU parents and  
16 EU adolescents | 16 EU parents and  
16 EU adolescents | Pediatrician  
Psychologist  
If needed:  
Physiotherapist  
Art therapist |
| Primary immunodeficiency disease (PID) | Pathogenesis, symptoms and risks of PID  
‘Actors’ and functioning of the immune system  
Immune globulin therapy  
Possibilities of infection prophylaxis  
Coping with the condition in daily family life | Parents of children aged < 7 years  
Youth aged 13–17 years and their parents | 18 EU parents and  
18 EU youth | Pediatrician  
Psychologist  
Nurse |

Educational unit (EU) = 45 min.
PKU and PID (Table II) were not included in this study to guarantee a better comparability.

**Design**

The PLCC and the asthma programs were conducted mostly on two consecutive days in 24 institutions in Germany. The generic modules were always conducted by the same, highly experienced team of a nurse and a psychologist. The condition-specific modules were conducted by a local team including a physician specialized in the specific disease and, if needed, further specialists (e.g. physiotherapists and dieticians).

The required age of the children was 7–17 years. Children and their parents were informed about the study, and participation was voluntary. They gave written consent for participation. All ethic committees of the federal states where the programs occurred approved the study.

The evaluation was based on repeated standardized questionnaires using paper and pencil tests. Interviews about the disease-specific knowledge, the HRQoL, life satisfaction and disease-specific burden were conducted before the programs (t1) and again 6 weeks after the program (t3). Immediately after the program (t2) the parents and children evaluated the program. Only if parents and their child participated in the program the data were analyzed.

**Instruments**

**Socio-demographic data**

The parents’ socioeconomic status (SES) was measured by the Winkler-Index [23]. The Winkler Index was developed in the German Health Interview and Examination Survey for Children and Adolescents (KiGGS; [24]) and comprises 5 questions, which assess the parent’s level of education, occupational qualification, job position and net income of the family. We calculated a sum score and categorized the families’ SES on a 3 point ordinal scale of low, medium and high. Children were allocated to a positive migration background (MB) if one of the parents was not born in Germany.

**Behavioral problems.** We screened the children for behavioral problems by asking the parents to answer the German version of the Strengths and Difficulties Questionnaire (SDQ; [25]). The SDQ consists of 31 items. Twenty-five items measure symptoms of behavior problems, emotional problems, hyperactivity and peer problems. The items are rated to be ‘not true,’ ‘somewhat true’ or ‘certainly true.’ The impact of the reported symptoms is assessed by additional 6 items. The probability of mental health problems was predicted by a computerized algorithm, and the children were categorized into ‘no problems,’ ‘borderline’ and ‘behavioral/emotional problems’ [26].

**Program evaluation**

To measure the parents’ satisfaction with the program, a slightly adapted version of the ZUF-8 (Chronbach’s alpha 0.91), the German version of the Client Satisfaction Questionnaire (CSQ) by Atkinson, was used [27, 28]. All 8 items were added into a sum score with a minimum score of 8 and a maximum score of 32. The children’s satisfaction with the program was assessed by one self-constructed single-item. This item measured the general program satisfaction with school grades ranging from 1 (very good) to 6 (very bad).

**Knowledge**

To assess knowledge regarding the condition and its management, we used different condition-specific questionnaires. The knowledge questionnaires for both children and parents for the PLCC were self-constructed and developed as a self-reported measure. The construction of the questionnaires was based on literature reviews, therapy guidelines and expert consultations. The final versions consisted of 14–44 items depending on the condition. To assess disease-specific knowledge of the asthma group, a slightly modified version of a questionnaire developed by Schulte im Walde [29] was used. The children’s questionnaire contained of 19 items. The parent’s questionnaire consisted of 16 items. Statistical analyses were based on the gain of the proportion of correct answers.
Subjective health

For subjective health and well-being, we assessed the children’s HRQoL and life satisfaction. The children’s HRQoL was self- and parent-reported using the Disabkids Chronic Generic Measure (DCGM-37). This instrument includes 37 Likert scaled items on 6 dimensions. This instrument has good psychometric properties (Cronbach’s alpha of the child version was 0.70–0.87 and was 0.77–0.90 for the proxy version [30]). We transformed all Disabkids scores to a range from 0 to 100; higher scores indicate higher HRQoL. A general HRQoL score of the six dimensions is calculated. The children’s life satisfaction was parent-reported and based on the validated Cantril ladder [31]. The parents were asked to rate the current subjective life satisfaction of their children on a ladder with eleven positions ranging from 0 (the worst possible life) to 10 (the best possible life). Raw scores were used for statistical analyses.

Disease-specific burden was assessed by 4 parent-reported questions developed by Weyhreter [32]. With this instrument, the parents assess the overall burden of the child’s disease for themselves, their partners, the child himself/herself and possible siblings on one-dimensional 5-point Likert scales. For statistical analyses, we used raw scores. A mean score was calculated to combine the burden for both parents.

Analysis

Statistical analyses included descriptive analyses for frequencies, mean values ($M$) and standard deviations (SD). Chi$^2$-tests and unpaired and paired $t$-tests were used for analyzing group differences at baseline and training effects within the training groups, respectively. Differences between the PLCC and the asthma program were analyzed by repeated measurement covariance analysis (RMVA) controlled for children’s age and sex because both variables differed significantly in the treatment groups. Group differences of disease-specific knowledge were not analyzed due to the differences of the disease-specific tests. For all statistical tests, the significance level was set at $\alpha = 0.05$. Missing values were excluded pairwise.

Results

The whole study population consisted of 398 families (168 in the PLCC group, 230 in the asthma group); 18.1% were lost to follow up. In the PLCC group were children with IBD (41), CF (4), PKU (12), NS (13), UI (79), CFAP (9) and PID (10). For a sample description, see Table III.

Table IV shows the results of the baseline survey (t1). In the PLCC group, the children themselves and their parents reported a significant lower children’s HRQoL, lower children’s life satisfaction and higher family burden compared with the asthma group.

After the program, the parents and children in the PLCC group were very satisfied with the program. In the ZUF-8, the parents assessed the program with a mean score of 29.5 (SD 2.7). The children in the PLCC group assessed the program with a mean school grade of 1.6 (SD 0.8).

In the PLCC group, the programs were associated with a significant increase in the disease-specific
knowledge (Table V); from baseline to 6 weeks after the education program the parents’ proportion of correctly answered questions increased by 12%, the children’s by 25%.

The children in the PLCC group reported an improvement of their HRQoL after participation in the program ($P = 0.02$). The parent-reported children’s HRQoL did not change statistically significantly.

### Table IV. Group comparison at baseline

<table>
<thead>
<tr>
<th></th>
<th>Less common chronic conditions</th>
<th>Asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>$M$ (SD)</td>
</tr>
<tr>
<td>Disease-specific knowledge (% correct answers)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>130</td>
<td>68.3 (20.8)</td>
</tr>
<tr>
<td>Children</td>
<td>145</td>
<td>50.9 (21.5)</td>
</tr>
<tr>
<td>HRQoL (0 minimum–100 maximum)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proxy-report</td>
<td>164</td>
<td>73.6 (13.7)</td>
</tr>
<tr>
<td>Self-report</td>
<td>155</td>
<td>76.0 (11.9)</td>
</tr>
<tr>
<td>Life satisfaction (0 minimum–10 maximum)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proxy-report</td>
<td>163</td>
<td>7.4 (1.4)</td>
</tr>
<tr>
<td>Self-report</td>
<td>152</td>
<td>7.4 (1.9)</td>
</tr>
<tr>
<td>Family burden (0 minimum–4 maximum)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>158</td>
<td>1.8 (1.0)</td>
</tr>
<tr>
<td>Child</td>
<td>166</td>
<td>1.8 (1.1)</td>
</tr>
<tr>
<td>Siblings</td>
<td>142</td>
<td>0.9 (1.1)</td>
</tr>
</tbody>
</table>

$N$, sample size; $M$, mean value; SD, standard deviation; HRQoL, health-related quality of life.

*Univariate covariance analysis (ANCOVA) controlling for age and sex. Statistically significant $P$ values are in bold.

### Table V. Outcome parameters at baseline ($t_1$) and 6 weeks after education ($t_3$) in less common chronic conditions or asthma

|                      | Less common chronic conditions | | | | | |
|----------------------|--------------------------------| | | | | |
|                      | $n$   | $M$ (SD) | $M$ (SD) | $P$* | | | |
| Disease-specific knowledge (% correct answers) | | | | | | |
| Parents              | 113  | 68.2 (19.7) | 80.1 (15.3) | <0.001 | | | |
| Children             | 125  | 50.8 (22.2) | 75.3 (18.6) | <0.001 | | | |
| HRQoL (0 minimum–100 maximum) | | | | | | |
| Proxy-report         | 142  | 73.5 (13.4) | 73.8 (13.2) | 0.695 | | | |
| Self-report          | 130  | 75.5 (11.8) | 77.2 (13.0) | 0.020 | | | |
| Life satisfaction (0 minimum–10 maximum) | | | | | | |
| Proxy-report         | 142  | 7.3 (1.4) | 7.4 (1.6) | 0.316 | | | |
| Self-report          | 127  | 7.4 (1.9) | 7.5 (1.7) | 0.432 | | | |
| Family burden (0 minimum–4 maximum) | | | | | | |
| Parents              | 138  | 1.8 (1.0) | 1.5 (0.9) | <0.001 | | | |
| Child                | 146  | 1.8 (1.1) | 1.5 (1.0) | <0.001 | | | |
| Siblings             | 124  | 1.0 (1.1) | 0.8 (1.0) | 0.035 | | | |

$t_1$, before the programs; $t_3$, 6 weeks after the programs; $N$, sample size; $M$, mean value; SD, standard deviation; HRQoL, health-related quality of life.

*Repeated measurement covariance analysis (RMVCA) controlling for age and sex. Statistically significant $P$ values are in bold.
There were no significant changes of the parent-reported or self-reported children’s life satisfaction in the PLCC group. However, in the PLCC group, the overall burden due to the disease for the parents, the affected child and the siblings declined significantly ($P < 0.05$).

The results in the PLCC group were comparable with the results in the asthma group. There was only a significant time*group effect for the burden of the affected child. In contrast to the PLCC group, there were no program associated changes of the children’s burden in the asthma group. In addition, in the asthma group, the increase in parent-reported children’s life satisfaction reached statistical significance ($P = 0.002$). In general the SES and the MB did not have an effect on the results [33].

### Discussion

The main goal of this study was to evaluate if the generic ModuS approach, which is effective for children with asthma, is adaptable to different chronic conditions. For seven mostly less common chronic conditions, programs were developed. Program participation was associated with significant improvements of the disease-specific knowledge and the families’ well-being. The improvements were comparable with improvements associated with the ModuS asthma education program. Therefore, the modular approach appears to be transferable to different chronic conditions. Due to the structured modular curriculum with clearly defined educational topics, learning targets and educational techniques, ModuS provides a comprehensive approach to develop educational programs. This helps to close an important gap of support for families with different chronic conditions. The differentiation in generic and disease-specific modules simplifies the development of new educational programs. For the generic modules, a basic adaptation to local and disease-specific characteristics is mostly sufficient. Therefore, only the disease-specific modules have to be developed. In addition, the modular approach simplifies and reduces the need for trainer qualification. For new developed patient education programs, trainers with already basic qualifications for patient education programs only need an additional disease-specific training. Trainers with basic qualifications could lead the generic modules, and trainers with specialized qualifications could lead the disease-specific modules. All these aspects simplify and support the development of new educational programs and establish important common healthcare-structures for different chronic conditions.

In our study, the participants of the PLCC showed at baseline a lower HRQoL and a lower life satisfaction compared with children in the asthma group. The parents also reported greater family burden due to the specific condition. This finding might be because less common conditions like CF are often combined with a higher clinical severity and less developed care structures compared with asthma. Our findings were supported by the Disabkids’ norm sample for the HRQoL of children with different chronic conditions. In our study, at baseline, the self- and the parent-reported HRQoL of the children with asthma assessed with the Disabkids questionnaire was comparable with children with asthma in the Disabkids’ norm sample (self-reported: 80.6 versus 80.2; parent-reported: 80.7 versus 79.1) [30]. In the Disabkids field study, the HRQoL of children with conditions of mild clinical severity was 80.4, with moderate severity 75.1 and with high severity 67.2. Therefore, asthma is described as a condition of mild clinical severity. In our study, the mean self-reported HRQoL of children with less common conditions was 76.0 and 73.6 in the parents’ assessment. This finding displays the HRQoL of conditions of moderate severity. These results underline the need of comprehensive support for families with less common chronic conditions, e.g. by education programs. That the developed educational programs could help the families cope with the chronic condition is supported by the described improvements of the children’s self-reported HRQoL and the reduction of the families’ burden due to the chronic condition.

Contrary to the improvement of the children’s self-reported HRQoL, we did not find significant improvements in the children’s HRQoL assessed by the parents. Discrepancies between parents’
proxy reports and children’s self-reports have been reported in other studies [30, 34]. Due to different perspectives, the two assessments are not comparable and have to be measured separately [35].

The program participation was also associated with significant improvements of the children’s and parents’ disease-specific knowledge. Disease-specific knowledge is important because it largely determines patients’ self-management and adherence [36].

Apart from a slight improvement of the children’s life satisfaction assessed by the parents in the asthma group, there were no significant improvements in life satisfaction assessments. This finding supports the aspect that the broad construct life satisfaction is more general in nature and less influenced by a chronic condition [37]. In contrast, the HRQoL assessed by the chronic generic module of the Disabkids questionnaire is more sensitive to chronic conditions.

Our findings are supported by studies of more common chronic conditions. The shown improvements of HRQoL, families’ burden and disease-specific knowledge were in line with the effects of education programs for children with asthma [10, 38], atopic dermatitis [6, 39–41] and diabetes [42, 43]. Controlled studies of high quality of education programs for children with less common chronic conditions are rare. A study of a psychoeducational group intervention for adolescents with IBD showed a positive effect on the physical dimension of HRQoL (DUX-25, body image), but the intervention group included only 18 adolescents [44]. Another study of adolescents with IBD found a significant improvement of self-reported adherence to medication but did not measure HRQoL, disease-specific knowledge or life satisfaction [45]. A study of a psychoeducational group intervention for children with CF described significant effects on the children’s knowledge about CF and its management, but no effects on HRQoL [46]. Due to the high prevalence of UI there is a large number of studies on urotherapeutic interventions, but most of them focused on individual trainings or short instructions or assessed only urotherapeutic symptoms. Only Stauber et al. compared two different educational interventions in small groups of children with UI (knowledge-oriented education program with versus without stress management; [47]). In both groups daytime wetting decreased while adaptive coping with daily stressors increased. An improvement of the HRQoL-dimension self-esteem and maladaptive coping with illness-related stressors were only found in the intervention group. However, the sample size was not representative (intervention group n = 15, control group n = 10; only boys) and the intervention was different from our intervention since it was carried out in a 7-day-inhouse setting. We found no relevant studies of educational interventions for CFAP, PID, PKU and NS. Therefore, further studies are needed to explore the effect of educational programs on children and adolescents with less common chronic conditions.

Our study has strengths and weaknesses. Strengths are the large sample size and a low dropout rate. The modular approach of ModuS made it possible to include seven different conditions.

A second limitation is about the short follow-up period of 6 weeks due to a limited grant. A third limitation is that a control group was not included. Therefore, we could not make any assumptions concerning causes and effects. We could only describe associations and assume that the described changes are connected to program participation. In less common conditions a randomization in a control and an intervention group is difficult, because it further reduces the already small sample size. In pediatric studies randomization causes a high proportion of families refusing trial participation [48], inter alia, because of the additional time commitment [49].

A second limitation is about the short follow-up period of 6 weeks due to a limited grant. A third limitation is that the questionnaires of the disease-specific knowledge were not validated with the exception of asthma. Further studies are needed to assess the psychometric properties of the disease-specific knowledge tests. Another limitation is that we did not assess variables objectively measuring the health status and functioning before and after participation in the program. The heterogeneity of the sample with less common conditions did not allow the construction of a non-condition-specific
measurement of the burden of illness or general health status. We were also unable to report condition-specific effects due to small sample sizes. Further studies are needed to determine if the benefits might vary by condition. However, the conceptual framework of a generic approach allows us to assume an overall benefit for all groups.

Conclusion

With the ModuS approach new education programs for children with different chronic conditions were developed. The programs were associated with increased disease-specific knowledge and HRQoL and reduced disease-specific burden. Therefore, ModuS closed an important healthcare gap. All necessary documents could be downloaded free of charge, and clinicians are invited to use these materials.

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Conflict of interest statement

None declared.

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