Original Article

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Effectiveness of a generic transition-oriented patient education program in a multicenter, prospective and controlled study

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Abstract

Objectives: For young people (YP) with a chronic condition growing up is a challenging process. This stage of life is associated with a higher risk for non-adherence, insufficient disease control, acute deteriorations and irregular consultations. Patient education programs can support YP cope with the independent disease management and the transition into adulthood. However, there is a lack of transition-oriented patient education programs for most chronic conditions. In this study, an existing generic transition-oriented education program was expanded by a module for parents and evaluated in a multicenter study all over Germany.

Methods: YP with chronic conditions and their parents were quasi-randomized into a control group (CG) and an intervention group (IG). The IG took part in the 1.5-day standardized education program ModuS-T while the CG received treatment as usual. The education program was designed as a compact workshop in a group setting for youth (15–24 years) and their parents. The education program contained youth specific topics such as the transfer to adult care, the influence of disease on the daily life of YP, and other important issues like detachment from

parents, occupational career, intimate relationships and family planning. The parent module dealt with the topics transition from child-centered to adult health services, and supporting children to become adults. The program focused on improving competencies relevant for transition and self-management skills of the families. Satisfaction with the program, transition-specific knowledge, transition competencies, patient activation and health-related quality of life (HRQoL) were measured at baseline and after 4 weeks.

Results: A total of 300 YP (overall mean age 17.6 years; 47% female; IG = 166, CG = 134) with 12 different conditions and their parents participated in 37 transition programs. The participants were highly satisfied with the program. The program significantly affected transition-specific knowledge, transition competence and patient activation ($p < 0.001$). There were no effects on HRQoL.

Conclusion: The generic transition-oriented education program empowers YP with chronic conditions and their parents in the transition process. Due to a modular approach, the program is successful in a variety of chronic conditions.

Keywords: adolescents; chronic condition; empowerment; modular education; patient education; transition.

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Introduction

Young people (YP) growing up with a chronic condition face the complex process of transition from adolescence to adulthood. In addition to the normal developmental challenges such as moving out from home and starting a career, YP with an additional chronic condition must assume responsibility for their disease management. An unsuccessful transition is associated with a higher risk for non-adherence, insufficient disease control, acute deteriorations, irregular consultations [1–4], and therefore increasing health care costs [5, 6].

Thus, health care structures ensuring a smooth transfer into adult care, as well as transition competencies of YP, should be strengthened [7–9]. This is in line with the views of youth. YP want more disease-specific knowledge to become a manager of their condition in daily life and they wish support and guidance in how to communicate their health related needs [10, 11].

An important approach for strengthening competencies of a patient is empowerment. Empowerment is a process through which patients gain greater control over decisions and actions affecting their health [12]. It includes self-efficacy, as well as knowledge, skills, attitudes and self-awareness to influence their own health behavior [13]. An effective method of strengthening these capacities of YP is patient education [14].

In Germany, only a few education programs specifically for YP exist, and all of them are condition-specific [15]. For many conditions, especially rare conditions, a transition-oriented program is missing. Since transition into adulthood shares many similarities across conditions, a generic approach could help to close the gap of support for YP. Disease-specific modules could add special medical topics, such as family planning or the influence of alcohol, cigarettes and illegal drugs on the condition. Such a modular approach is already implemented in Germany for basic patient education programs for children with a chronic condition and their families [16]. Inspired by this modular approach and based on focus interviews with YP, a generic transition-oriented patient education program was developed [10]. In a quasi-experimental study, the program showed positive effects on the transition competence and self-efficacy of YP with type I diabetes (T1D), cystic fibrosis (CF) and inflammatory bowel disease (IBD) [17].

The evaluation of the program had revealed that, in addition to the YP, parents also have specific needs in the transition process. They often still take care of the disease management and fear deteriorations of the health care after transition. In the sensible period of transition, the role of parents concerning the chronic condition appears to be significant but has to change over time [18, 19]. For this reason, the developed educational program was complemented by a parent module. In this module, the parents received information about the transition process and discussed their new role as a coach for their children. Additionally, we developed a website with information about the transition phase because the internet is a key source of information for YP [20]. This website was used during the workshops and for further information at home.

The purpose of this implementation study was threefold: (1) to demonstrate the efficacy of a modular transition

education program for YP and their parents (ModuS-T) in regular health care services, (2) to include a variety of less common conditions, and (3) to evaluate the effects of an additional module for the parents of the YP.

Methods

In this multicenter, prospective controlled study, the effect of ModuS-T in a group setting was compared with the usual care of YP with a chronic condition. Outcome parameters were assessed before and after the treatment and 4 weeks later (program satisfaction only in the intervention group). Families were surveyed by means of standardized questionnaires. The study was approved by the appropriate Ethics Committees, and conducted in accordance with the Declaration of Helsinki. All participants were informed of the purpose and procedures of the study. Informed consent was obtained from all participants before data collection.

Study design

Across Germany, 29 pediatric outpatient clinics, two hospitals and two self-help groups took part in the study. To represent a variety of conditions, education programs were provided for 12 different chronic conditions: asthma, attention-deficit/hyperactivity disorder (ADHD), T1D, phenylketonuria, IBD, CF, chronic kidney disease, epilepsy, liver or kidney transplantation, esophageal atresia, juvenile idiopathic arthritis and Ehlers-Danlos syndrome. Patients between 15 and 24 years old with one of these conditions were informed about the study by their physician and were asked for participation. The exclusion criteria were as follows: (1) transfer to adult care has already been completed, (2) learning disabilities or (3) insufficient German language skills. Participants of the intervention group (IG) attended a 1.5-day education program. Because no other transition education program was available, the control group (CG) received care as usual, including individual medical care and counselling as needed. Assignment to the groups was based on patient availability at predefined workshop dates.

Implementation

Thirty-seven ModuS-T programs were carried out between 2013 and 2014. ModuS-T lasted 1.5 days over two consecutive days for a group of 3–12 YP. It focused on

Figure 1: Components of the transition patient education program ModuS-T.

youth-specific topics such as separation from parents, career choices, transition from child-centered to adult health services and effects of the lifestyle of YP on the disease (Figure 1). Apart from the module “Doc special”, which dealt with condition-specific issues such as medical treatment, the influence of alcohol, cigarettes and illegal drugs and family planning, all components were generic. To increase empowerment of YP and their parents, the program imparted transition-specific knowledge and competencies. With activating methods such as group discussions, role playing and case studies for solving medical and social problems, the self-awareness of the YP should be strengthened. Meeting a young adult who has already been transferred to adult care should enable peer learning. The young adult reported on his or her transition experiences and answered further questions. In addition, a physician practicing adult medicine was invited to inform the YP about special issues related to adult care and the transition process.

The half-day parent program was conducted in parallel with the YP program. The parent module contained topics such as the transfer to adult care and social legislation changes arising from majority. Furthermore, psychosocial issues of growing-up with chronic conditions were discussed. The parents got the chance to exchange their sorrows related to their children’s detachment and to develop possible solutions for their problems.

During the program, the newly developed transition specific website <http://www.between-kompas.de> was presented to the participants. With separate units for YP and parents, the website informed about employment, changing doctors, health, living with a chronic condition and

sexuality. The participants were instructed how to search for information about the transition process on this and other websites. We also integrated the website’s interactive transition-specific quiz in the workshops.

The standardized programs were offered by a trainer team. A psychologist conducted the generic modules of ModuS-T. A pediatrician conducted the condition-specific module. To assure quality, both had to prove longstanding experience with youth with chronic conditions, and the psychologist received a 2-day train-the-trainer workshop appropriate for ModuS-T. For further standardization, a trainer manual and handouts for the YP were used [21].

Instruments

The instruments reflect the intended targets of the program (increased transition specific knowledge and competencies). We did not expect impacts on more general outcomes; however, we assessed health-related quality of life (HRQoL) to detect possible future effects in a follow-up questioning. Additionally, participants completed questionnaires on sociodemographic variables and program satisfaction.

For sociodemographic information, we included items from the German Health Interview and Examination Survey KiGGS [22]. Socioeconomic status (SES) was parent-reported by the Winkler-Index [23]. The Winkler-Index consists of five questions assessing parental education and occupational status. SES was categorized into low, medium or high. A positive migration background (MB) was defined if one of the parents was not born in Germany.

With self-constructed items, we asked the YP for their current engagement and the school education level which they aspired. To assess the subjective general health status of the YP, we used a 5-point Likert-scaled item with given answers ranging from “very good” to “very bad” [24]. In addition, YP and parents assessed disease control with a self-constructed 5-point Likert-scaled item with given answers ranging from “very good” to “not at all”. With two further questions, YP and parents reported the current and future proportion of the responsibility of parents for the condition of the YP.

The transition specific knowledge was assessed by a self-constructed standardized questionnaire with 20 multiple choice questions (parents 13 questions) with one correct and three incorrect answers. The questions were developed from the subjects of the program. We used the proportion of correct answers for statistical analysis.

The German Patient Activation Measure® 13 for Adolescents (PAM® 13 for Adolescents) was used to measure the engagement of the YP in their health care (Cronbach's $\alpha = 0.79$ [25]). It includes 13 items on a 4-point Likert-scale assessing the knowledge of the patients, skill and confidence for self-management of their own health. A sum score was calculated and transformed to a standard metric ranging from 0 to 100, with higher scores representing higher levels of activation.

To assess the subjective transition-specific competence, we included the transition competence scale (TCS; Cronbach's $\alpha = 0.80$ [26]). The TCS consists of 10 items capturing three dimensions of transition-specific competence (work-related preparedness [TC-a], condition-related knowledge [TC-b] and health care competence [TC-c]). A global score was calculated as a sum score of all 10 items. Higher scores represented higher competence. Because at the time of this study only a preliminary version of the TCS existed, we included only eight of the 10 items (all of TC-a and TC-c, one of three items of TC-b). The eight items were sufficient to calculate the global TCS score. With an item-scale-correlation of 0.58, the single item of the TC-b subscale is a sufficient representation of the TC-b subscale.

The HRQoL of the YP was assessed with the DIS-ABKIDS Chronic Generic Measure (DCGM-37; Cronbach's $\alpha = 0.70$ – 0.87 [27]). This questionnaire consists of 37 Likert-scaled items assessing a global score and six dimensions: independence, emotion, inclusion, exclusion, physical limitations and treatment. The scores were transformed to a range from 0 to 100, with higher scores representing higher HRQoL. HRQoL was also measured with the German standard version of the SF-8 [28], a short form of the SF-36 [29]. It consists of eight single-item scales

addressing eight domains (physical functioning, role limitations due to physical health, bodily pain, vitality, social functioning, mental health and role limitations due to emotional problems). Scores range from 0 to 100.

Satisfaction with the program was measured with a slightly adapted version of the ZUF-8 (Cronbach's $\alpha = 0.91$ [30]), the German version of the Client Satisfaction Questionnaire. This questionnaire consists of eight items with a 4-point Likert-scale. A sum score was calculated ranging from 8 to 32, with higher scores representing higher satisfaction.

Analysis

Descriptive analysis included frequencies, mean values (M) and standard deviations (SD) for each time of measurement and was stratified by group (IG/CG). For the sample description, group differences were measured with t-tests and χ^2 -tests. Group effects were analyzed with repeated measurement covariance analysis (RMVCA). Analyses were conducted using IBM SPSS Statistics for Windows, Version 22. Due to repeated tests, the level of significance for all statistical tests was set at $\alpha = 0.01$.

Results

Descriptive characteristics

Of 970 YP invited to the study, 504 initially declared their interest (response rate 52%; Figure 2). During the following study procedure, 87 (31%) YP in the IG and 65 (29%) YP in the CG withdrew their participation. The recruitment centers reported that most of the participants refused or withdrew participation due to lack of time or lack of interest. Of the 160 participants in the CG, 75 (47%) reported that they were interested in the program but had no time at the predetermined date of the education program, 43 participants (27%) had no interest in the program and 26% gave no reason for not attending.

In the final sample, we included all patients with complete datasets, and only those patients of the IG of whom both the YP and at least one parent participated in the entire program (IG 166, CG 134). Loss to follow-up was comparable in both study groups (IG 13%; CG 16%). Table 1 shows the different conditions in the IG and the CG. Both groups did not differ significantly in respect to the conditions ($p = 0.086$).

Table 2 shows the sample characteristics. The sample included 300 participants with an age range from 15 to 23

Figure 2: Flow of participants.

IG, intervention group; CG, control group; YP, young people; n, sample size; t0, prior to education program; t1, after education program; t2, 4 weeks after education program.

Table 1: Patients' chronic conditions in the IG and the CG.

	IG	CG	Total
	n (%)	n (%)	n (%)
Asthma	10 (6.0)	6 (4.5)	16 (5.3)
Attention deficit hyperactivity disorder	28 (16.9)	28 (20.9)	56 (18.7)
Type I diabetes	33 (19.9)	26 (19.4)	59 (19.7)
Phenylketonuria	4 (2.4)	3 (2.2)	7 (2.3)
Inflammatory bowel disease	33 (19.9)	15 (11.2)	48 (16.0)
Cystic fibrosis	3 (1.8)	5 (3.7)	8 (2.7)
Chronic kidney disease	6 (3.6)	6 (4.5)	12 (4.0)
Epilepsy	12 (7.2)	11 (8.2)	23 (7.7)
Organ transplantation	13 (7.8)	9 (6.7)	22 (7.3)
Juvenile idiopathic arthritis	13 (7.8)	10 (7.5)	23 (7.7)
Esophagus atresia	5 (3.0)	13 (9.7)	18 (12.0)
Ehlers-Danlos syndrome	6 (3.6)	2 (1.5)	8 (2.7)

IG, intervention group; CG, control group; n, sample size.

years (47% female). There were no significant differences in age ($p = 0.0215$), sex ($p = 0.247$), SES ($p = 0.744$) or MB ($p = 0.823$) between the study groups. However, the

study groups differed with respect to the current occupation ($p = 0.004$). More YP of the IG were still at school compared to the CG. Therefore, all analyses for group effects were controlled for the current occupation (still at school or not). A dropout-analysis showed no statistically significant differences in the described sample characteristics between participants of the sample with a complete dataset ($n = 300$) and those who dropped out between baseline questioning and follow-up questioning ($n = 52$).

Program evaluation

Parents and YP were highly satisfied with the program. In the ZUF-8, YP assessed the program with a mean score of 27.8 (SD 3.1; 8 = "unsatisfied" to 32 "very satisfied"). Parents reported a mean score of 26.5 (SD 3.7). Four weeks later, 46% of the YP and 55% of the parents reported that the program had positive effects on their daily life.

Table 2: Sample description.

	IG M (SD) n (%)	CG M (SD) n (%)	Total M (SD) n (%)	p-Value
n	166	134	300	
Age	17.5 (1.4)	17.7 (1.9)	17.6 (1.6)	0.215
Female	83 (50)	58 (43.3)	141 (47)	0.247
SES (parent reported)				0.744
Low	20 (12.1)	15 (11.5)	35 (11.8)	
Medium	72 (43.6)	63 (48.1)	135 (45.6)	
High	73 (44.2)	53 (40.5)	126 (42.6)	
Without MB (parent reported)	140 (87.0)	111 (87.4)	251 (87.2)	0.823
Occupation				0.002^a
Working	6 (3.6)	5 (3.7)	11 (3.7)	
Pupil	128 (77.1)	82 (61.2)	210 (70.0)	
Student	4 (2.4)	10 (7.5)	14 (4.7)	
Training	18 (10.8)	34 (25.4)	52 (17.3)	
Unemployed	1 (0.6)	0 (0)	1 (0.3)	
Other	9 (5.4)	3 (2.2)	12 (4.0)	
Education				0.004^a
Still at school	136 (81.9)	89 (67.4)	225 (75.5)	
Aspired educational level				0.661
<12 years	44 (33.3)	31 (36.9)	75 (34.7)	
≥12 years	88 (66.7)	53 (63.1)	141 (65.3)	
School finished	73 (24.5)	43 (32.6)	73 (24.5)	
Highest educational level				0.151
12 years	14 (46.7)	28 (65.1)	42 (14.0)	
≥12 years	16 (53.3)	15 (34.9)	31 (10.3)	
Subjective health status	3.1 (0.7)	3.2 (0.7)	3.1 (0.7)	0.175
Disease control				
Self-report	3.1 (0.7)	3.3 (0.6)	3.2 (0.7)	0.107
Parents-report	3.3 (0.7)	3.3 (0.7)	3.3 (0.7)	0.781

IG, intervention group; CG, control group; n, sample size; M, mean value; SD, standard deviation; MB, migration background; SES, socioeconomic status. ^aStatistically significant.

The assessed effects of the program are shown in Table 3. At baseline (t0) the t-tests showed a significantly higher transition-specific knowledge ($p = 0.002$) and higher transition competences ($p < 0.01$) in the CG compared to those of the IG. Four weeks after the program (t2), RMVCA showed statistically significant higher improvements in the IG in all program targets compared to those in the CG ($p < 0.001$). In the IG, the proportion of correct answers in the transition-specific knowledge test increased by 14.7% in YP (CG 0.3%) and by 8.2% in parents (CG 1.6%). The patient activation measured with PAM[®] 13 for Adolescents increased by 6.7 points in the IG (CG 0.4). The global score of the transition competence scale improved significantly in the IG (by 29.1 points) compared to those measures in the CG (3.6 points), as well as all three subscales: work-related preparedness, condition-related knowledge, health care competence. No significant effects were reported for the proportion of disease responsibility of the parents and HRQoL.

Because of the small number of patients with different chronic conditions, differential effects across conditions were not analyzed.

Discussion

The results of this study demonstrate the efficacy of a transition-oriented patient education program for YP with a variety of chronic conditions under real life settings. The program improved transition-related knowledge, competencies and activation of YP. These resources are important components for patient empowerment. The additional parent module increased the transition-specific knowledge of the parents. Satisfaction with the program was high in YP and parents. In qualitative interviews (data not shown here), participants reported a great interest especially in information about the transition process and social legislation (e.g. services provided by health insurance, rights and obligations of employees).

Table 3: Outcome changes from pre-intervention to 4 weeks follow-up by intervention group (IG) and control group (CG).

	n	IG		p-Value	n	CG		Time * group		
		t0 M (SD)	t2 M (SD)			F	p-Value			
Adolescents										
Knowledge	164	44.9 (16.0)	59.6 (19.2)	0.002	131	51.4 (20.5)	51.7 (20.8)	27.6	<0.001 ^a	
PAM® 13 for Adolescents	151	68.3 (14.1)	75.0 (13.5)	0.488	110	69.2 (16.1)	69.6 (16.8)	8.1	<0.001 ^a	
Transition competence scale										
TCS	144	52.6 (18.8)	81.7 (16.4)	<.001	112	60.6 (21.3)	64.2 (22.0)	63.3	<0.001 ^a	
TC-a	165	65.3 (26.2)	88.5 (15.7)	0.013	128	72.7 (29.0)	74.5 (24.9)	27.3	<0.001 ^a	
TC-b (single item)	157	57.7 (35.9)	84.5 (23.4)	0.003	123	69.1 (31.7)	69.1 (32.8)	22.9	<0.001 ^a	
TC-c	159	39.7 (19.9)	75.1 (21.5)	0.003	125	47.4 (25.5)	54.5 (25.9)	56.9	<0.001 ^a	
Proportion of the parents' disease responsibility										
At the moment	163	53.1 (30.9)	46.3 (25.6)	0.312	123	57.3 (31.3)	54.6 (31.9)	1.2	0.312	
In the future	154	28.0 (25.3)	22.1 (20.6)	0.826	123	27.3 (27.3)	28.5 (28.9)	4.0	0.020	
Disabkids										
Global	164	76.8 (12.8)	77.9 (12.7)	0.072	128	79.5 (14.0)	79.8 (14.8)	0.4	0.683	
Independence	165	80.9 (12.9)	83.3 (12.3)	0.494	130	81.8 (15.6)	83.0 (16.2)	0.7	0.508	
Emotion	164	73.9 (18.7)	75.7 (18.0)	0.109	130	77.6 (20.9)	77.0 (20.6)	1.2	0.300	
Inclusion	164	81.3 (13.7)	81.7 (13.1)	0.930	127	81.3 (14.8)	81.8 (15.2)	0.6	0.573	
Exclusion	162	80.1 (15.4)	80.3 (16.5)	0.018	127	84.3 (15.4)	84.2 (16.2)	0.1	0.870	
Physical limitations	164	74.4 (15.6)	74.2 (16.2)	0.102	129	77.6 (16.0)	79.1 (17.8)	0.8	0.438	
Treatment	140	69.7 (21.4)	71.1 (21.0)	0.310	103	73.0 (20.5)	72.2 (21.0)	0.8	0.454	
SF-8										
Physical component summary	162	51.1 (5.7)	51.1 (5.8)	0.228	129	51.8 (5.5)	51.5 (5.8)	0.5	0.600	
Mental component summary	163	49.4 (6.1)	49.7 (6.3)	0.022	127	50.9 (5.7)	50.4 (6.3)	1.7	0.193	
Parents										
Knowledge	163	67.1 (15.6)	75.3 (15.0)	0.573	130	67.8 (15.7)	69.4 (15.1)	8.0	<0.001 ^a	
Proportion of the parents' disease responsibility										
At the moment	161	61.2 (28.8)	54.3 (27.7)	0.119	129	67.1 (28.8)	63.9 (30.1)	0.6	0.530	
In the future	158	34.6 (26.3)	27.7 (23.4)	0.319	130	37.2 (29.3)	34.2 (28.8)	0.7	0.510	

t0, prior to education program; t2, 4 weeks after education program; n, sample size; M, mean value; SD, standard deviation. ^aStatistically significant.

There are only a few studies investigating the effect of a transition-oriented patient education in a group setting [14, 31]. In a previous quasi-experimental study by Schmidt and colleagues, a generic transition-oriented education program improved transition-specific health literacy of YP with T1D, CF and IBD [17]. Our study is in line with these findings, and we were able to include even a greater diversity of conditions. Using the TCS [26], Schmidt et al. measured an improvement of transition competence of the YP from 40.1 to 50.4 in the IG. In our study, we could show an improvement from 52.6 to 81.7. The difference between our study and the previous study in the degree of improvement of the measured transition competence is possibly due to the different follow-up period. Schmidt et al. had a follow-up period of 6 months while our follow-up was after 4 weeks. Moreover, the measured transition competence depends on the diagnosis with its specific settings [17, 32].

Furthermore, our study showed a significant improvement of the transition-specific knowledge of YP and parents. Transition-specific knowledge is an important outcome since it increases the capacity to make informed decisions and improves adherence [33, 34]. We suppose that a better transition-specific knowledge helps the YP and their parents cope with the challenges in the transition period.

ModuS-T also enhanced the level of engagement of the YP in their disease management assessed with the PAM® 13 for Adolescents. The mean baseline scores of approximately 68 points were comparable to levels measured in the validation study of the PAM® 13 for Adolescents [25]. After the program, the patient activation level in the IG improved significantly to a mean score of 75 points (69.6 points in the CG). In a recent study of an 8-months transition intervention, there were comparable effects on patient activation [35]. After a

6-month review period, the mean patient activation score improved from 72 to 81. All in all, our results support the hypothesis that ModuS-T enhances the empowerment of the YP and their pro-active role in managing their condition.

We did not detect any effects on HRQoL. Although HRQoL is an important outcome [27, 33], an effect of ModuS-T 4 weeks after the intervention was not expected. We would expect to detect effects on HRQoL at a later point of time. Therefore, a follow-up questioning after transition would be interesting.

To the best of our knowledge, this is the first time that a special module for parents was offered within a transition-oriented educational program for YP with chronic conditions. The parents were very satisfied with the module. However, in qualitative interviews (data not shown here), the parents wished a longer and more extensive education program starting at the beginning of adolescence. These statements express a need for ongoing multi-disciplinary support during the transition process. Therefore, in future interventions, the module for parents will be extended by an interview with a physician practicing adult medicine and more time for exchanging experiences within the group. Additionally, it would be desirably to offer a parent module at the beginning of adolescence.

There are several limitations of the study. Due to limited funding, the follow-up period of 4 weeks was short. This is regrettable since the long-term effects of transition are especially important. Because of the short follow-up period, we did not measure health-related outcomes or costs. Furthermore, we suppose that the failed effects of HRQoL were also due to the short follow-up period. In the meantime, we realized funding for a follow-up questioning after 24 months. Results will be presented after study completion.

In addition, there might be a bias in the allocation of the patients to the groups. We had expected that most of the families in the CG would not attend the program due to time problems. In fact, 27% of the CG reported that they had no interest in the program. A group allocation bias is supported by the significant group differences in transition competencies at baseline. Participants of the CG started with higher scores in all transition competencies, but they did not differ in other relevant sociodemographic characteristics. This is a well-known problem of education program studies. Only a randomization could prevent this bias. However, a randomization was, in our opinion, unrealizable and ethically inadequate.

Another bias could arise from the high drop-out rate. Although the loss to follow-up from t0 to t2 was relatively small at only 15%, 30% of the YP who initially agreed

to participate in the study withdrew participation before t0. Among scheduling problems, families perhaps initially did not reject the recommendation of their physician to attend the program but in the end refused attendance. A final assessment is not possible because we have no data on these families. However, recruitment problems and high drop-out rates are typical for studies with YP.

Another limitation affects the self-constructed transition-specific knowledge questionnaire. Psychometric studies had not been performed prior to the study. Hence, no statements to the psychometric properties of the questionnaire could be made.

Conclusion

ModuS-T effectively supports YP with chronic conditions in mastering the vulnerable period of transition from adolescence to young adulthood. Parents benefit from an additional module addressing their role in the transition process. Further studies are needed to assess the cost-effectiveness of the program and to detect long-term effects.

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Author Contributions

Dr. Menrath designed the data collection instruments, coordinated and supervised the data collection, performed the statistical analyses, interpreted the results, discussed the findings and drafted the initial manuscript. Dr. Ernst developed the ModuS-T-program, conceptualized and designed the study, assisted to design the data collection instruments, interpreted the results, and assisted in drafting the initial manuscript. A shared first authorship is indicated, because the project was a large multi-center study with 33 centers and more than 500 participants. Dr. Ernst developed the ModuS-program and supervised the trainers and centers in educational aspects. She was the responsible project manager. Dr. Menrath was responsible for the evaluation, data collection and statistical analyses. He supervised the centers with regard to methodical aspects. Both had a key role in the study and for drafting the manuscript. Dr. Szczepanski developed the ModuS-program, conceptualized and designed the study, and discussed the findings. Prof. Dr. Lange developed the ModuS-program, conceptualized and designed the study, interpreted the results, and revised the manuscript. Mrs. Bomba developed the ModuS-T-workshop for youths and revised the manuscript. Dr. Muehlan supported data analyses and interpretation, and revised the manuscript. PD Dr. Staab developed the ModuS-program and the study design. Prof. Dr. Thyen developed the study design, designed the data collection instruments, performed the statistical analyses, and revised the manuscript. All authors approved the final manuscript as submitted.

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