



# Involving patients' perspective in the development of an internet- and mobile-based CBT intervention for adolescents with chronic medical conditions: Findings from a qualitative study

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## ABSTRACT

**Objective:** A user-centered approach is critical for increasing the adherence to and effectiveness of an internet- and mobile-based intervention program. Therefore, potential future intervention users were involved in the development of an internet- and mobile-based cognitive behavioral therapy program (iCBT) for adolescents and young adults (AYA) with chronic medical conditions and comorbid symptoms of anxiety or depression. We aimed to identify challenges and coping strategies of the intended target group, as well as their needs and preferred intervention characteristics for an iCBT program.

**Methods:** Twenty AYA (aged 14–20, 60% females) with either type 1 diabetes (55%), juvenile idiopathic arthritis (25%) or cystic fibrosis (20%) were interviewed in condition-specific focus groups (4–11 participants per group) either via videoconferencing or face-to-face. Transcript verbatim data was analyzed using content analysis.

**Results:** Frequently reported disease-specific burdens were among others fear of disease progression, non-acceptance of disease and stressful incidents related to and aversions against medical therapy. Most frequently reported coping strategies included, seeking social support and accepting the disease. Recommendations for the content of an iCBT for comorbid symptoms of anxiety and depression comprised: dealing with disease-related fears and getting advice on health-promoting lifestyles. iCBT characteristics considered preferable by participants were: providing individual feedback by a real-person; implementation of a feature to monitor treatment progress; youthful and varied content presentation; time per session not exceeding 1 h; non-involvement of parents. A mobile-based reminder feature was considered useful, and individual tailoring and self-determination of iCBT content was considered desirable.

**Conclusions:** The findings highlight important patient perspectives and age-specific recommendations which can help design more optimal iCBT interventions for AYA with chronic medical conditions.

## 1. Introduction

The prevalence of chronic medical conditions is increasing among adolescents and young adults (AYA) aged 12–21 (Van Der Lee et al.,

2007). In this age group, cystic fibrosis (CF; Farrell, 2008), juvenile idiopathic arthritis (JIA; Palman et al., 2018), and type 1 diabetes (T1D; DiabetesDE, 2010) are prevalent disorders associated with significant suffering and burden of disease (Sawyer et al., 2007). These chronic

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medical conditions have several common characteristics, such as frequent personal monitoring and the necessity of continuous medication (Sawyer et al., 2007); however, there are also specific differences between disorders, e.g. the course of disease or functional impairments.

AYA with chronic medical conditions often experience functional impairments at school or work, during leisure time, or in social activities (Hanns et al., 2018). Furthermore, physical impairments and psychological burdens hamper AYA in their daily lives (Sawyer et al., 2007). Hence, it is not surprising that chronic medical conditions are correlated with an increased risk of depression (Pinquart and Shen, 2011a) or anxiety (Pinquart and Shen, 2011b) in AYA. Comorbid depressive and anxiety symptoms can additionally impact AYA's quality of life, treatment adherence, and outcomes (Havermans et al., 2008) as well as negatively impact the long-term outcomes of the disease (Fidika et al., 2014). Therefore, evidence-based psychological interventions are necessary to address the specific problems and needs of this particular patient group.

The effectiveness of cognitive behavioral therapy (CBT) for treating mild to moderate symptoms of depression and anxiety in children and adolescents is well established (e.g. Zhou et al., 2015; Zhou et al., 2019). There is also evidence supporting that CBT can reduce symptoms of mental comorbidities in children and adolescents with chronic medical conditions (Thompson et al., 2011). However, access to those evidence-based interventions is often limited (Stiles-Shields et al., 2016), and only a small portion of affected AYA ultimately receive psychotherapeutic treatment (Delamater et al., 2017). Reasons for the low uptake rate of psychotherapies might be systematic gaps in healthcare systems as well as the lack of financial and personnel resources, but they might be also due to patient-related factors, such as suboptimal disease awareness or fear of stigmatization (Gulliver et al., 2010). Internet- and mobile-based cognitive behavioral therapy (iCBT) approaches, with potential high scalability, constitute an opportunity to overcome these barriers and may complement existing evidence-based mental health care supplies (e.g. face-to-face psychotherapy; Andersson and Titov, 2014).

Meta-analyses indicate that iCBT may reduce internalizing disorder symptoms in AYA with various mental disorders (Domhardt et al., 2020a; Hollis et al., 2017). However, evidence regarding the effectiveness of iCBT in targeting psychological comorbidity in AYA with chronic medical conditions is limited (Thabrew et al., 2018). Various advantages of internet- and mobile-based interventions (IMI), like anonymity and non-stigmatization (Cuijpers et al., 2008), potential scalability for larger numbers of patients, or easy access irrespective of space and time (Andersson and Titov, 2014), are accompanied by limitations that are yet to be resolved. For example, the low treatment adherence rate in IMI is a major concern for most digital interventions (Christensen et al., 2009; Eysenbach, 2005).

Treatment adherence can be operationalized as the extent to which a participant completes a therapeutic intervention (Eysenbach, 2005). As such, treatment adherence has a direct impact on the treatment dosage, thereby influencing psychological outcomes (Calear et al., 2013). Currently, predictors of treatment adherence to iCBT are not well understood. Program content and guidance by a personal coach are likely major influencing factors (Hollis et al., 2017). The existing evidence suggests that the contents of an iCBT treatment need to be perceived as helpful, personal, relevant to the patient's own experience, and of reasonable extent in order to increase treatment adherence (Beatty and Binnion, 2016). Thus, the intended users' needs and preferences should be a priori identified and acknowledged, when developing and designing a new iCBT program (Hill et al., 2018). Qualitative research methods constitute one way to reach a better understanding of patients' attitudes and perspectives, psychosocial context, and individual requirements (Wu et al., 2016; Yardley et al., 2016), as well as to determine the target group's preferences and needs regarding characteristics of a new intervention (Thompson, 2014).

The present study follows these recommendations and aims to involve the patients' perspective into the development of an iCBT for

AYA with chronic medical conditions and comorbid symptoms of depression and/or anxiety (called "youthCOACH<sub>Chronic Condition (CD)</sub>"). This iCBT intervention will later be evaluated on a larger scale in a multicenter randomized controlled trial (Lunkenheimer et al., 2020) within the project "Chronic Conditions in Adolescents: Implementation and Evaluation of Patient-centered Collaborative Healthcare (COACH)", focusing on mental health in AYA with the chronic medical conditions, CF, JIA, and T1D. By including these three conditions, a more comprehensive picture of the diverse burdens, needs, and perspectives of affected AYA can be drawn, informing the development of iCBT programs for AYA with different chronic medical conditions.

Three main research questions guided the present study:

- (1) *What are the most important challenges for AYA with a chronic medical condition?*
- (2) *Which strategies do AYA with a chronic medical condition use to cope with their disease-related challenges?*
- (3) *Which characteristics and contents of youthCOACH<sub>CD</sub> do AYA with chronic medical conditions consider desirable and helpful?*

## 2. Methods

### 2.1. Design

Focus groups constitute a qualitative research method for gaining in-depth insights into relevant aspects of intervention development. In order to develop informed, tailored interventions for AYA with common chronic medical conditions and comorbid mental health symptoms, we sought to gain insights into the perspectives, needs, and preferences of AYA with CF, JIA, and T1D. Therefore, three mixed-gender, semi-structured focus groups were implemented — each comprised of AYA suffering from the same chronic medical condition in order to establish homogeneous groups and allow for comparisons between conditions.

The study was approved by the Ethics Committee of Ulm University (number 292/18) and carried out in accordance with the Declaration of Helsinki. All participants provided written informed consent prior to enrollment.

### 2.2. Sampling

Inclusion criteria were being between 12 and 21 years of age and suffering from either T1D, JIA, or CF. To assess patient perspectives across a broader range of depression and anxiety symptoms associated with chronic medical conditions, AYA with and without self-reported symptoms of anxiety and depression were included. Central for inclusion were one of the three chronic medical conditions and willingness of participants to share their experiences living with their respective condition as well as their coping strategies to navigate current or previous (mental) health problems. Participants were recruited via social media posts in self-help groups, messages to mailing lists of self-help associations, and directly approaching eligible patients at three pediatric clinics specializing in rheumatic arthritis and diabetes care. Recruitment took place from May to December 2018.

### 2.3. Study procedure

After participants provided informed consent, an initial questionnaire was administered in order to confirm the respective chronic medical conditions and assess levels of depressive and anxiety symptoms.

The focus groups were guided by the first author, accompanied by one co-moderator (AS or LR). Following the recommendations of Krueger and Casey (2014), the duration of each focus group was limited to 70 min. An interview schedule consisting of 14 questions was applied. Participants were asked to note and classify their burdens and challenges in three categories (green = not challenging; yellow = sometimes

challenging; red = very challenging), answer open-ended questions about strategies and needs, provide feedback regarding drafts of iCBT components (e.g. illustrations, a video, tasks; [www.minddistrict.com](http://www.minddistrict.com)), and reflect and discuss the other participants' perspectives. The presented iCBT components are provided in supplementary material Fig A.1 and A.2.

The interview schedule was developed based on a systematic literature search and expert discussion within the research team, in accordance with the recommendations by Krueger and Casey (2014). The interview schedule is provided in Table A.1.

We decided to implement two focus groups in an online-setting using video conference. This approach made it possible to reach participants in more remote areas who would not have been otherwise attainable. Furthermore, on-site focus groups were not feasible for AYA with CF due to their infection status with different pathogens to prevent the transmission of germs. Therefore, the focus groups for AYA with CF and JIA were carried out via video conferences on a secure online platform ([www.gotomeeting.com](http://www.gotomeeting.com)). There is evidence that online interaction is similar to face-to-face interaction (Hoffman et al., 2012), and both settings seem to have similar effects on information elicitation (Reid and Reid, 2005). Participants of the online focus group were able to see and listen to each other via headsets or speakers and microphones as well as webcams. AYA of online focus groups were informed before the focus groups that they needed this technical equipment in order to participate. Questions were posed verbally and presented visually via presentation slides. The focus group for AYA with T1D was conducted on-site at a diabetes clinic. All participants received a 20€ voucher as compensation for their efforts.

## 2.4. Questionnaires

Participants were asked to complete a questionnaire on their symptoms of depression and anxiety before the focus groups, either digitally on a secure platform ([www.Unipark.de](http://www.Unipark.de)) or by paper and pencil.

### 2.4.1. PHQ-ADS

To gain insight into the participants' symptoms of depression and anxiety, a combined Patient Health Questionnaire Anxiety and Depression Scale (PHQ-ADS) was used (Kroenke et al., 2016). The 8-item depression module of the Patient Health Questionnaire (PHQ-8; Kroenke et al., 2009) and the General Anxiety Disorder Scale (GAD-7; Löwe et al., 2007) were combined, enabling differentiation between mild, moderate, and severe levels of anxiety and depression; higher scores indicate higher symptom burden. The GAD-7 scale showed high internal consistency (Cronbach's  $\alpha = 0.85$ ), indicating high reliability, in a large German general population sample (Hinz et al., 2017). The PHQ-9 showed excellent internal consistency with Cronbach's  $\alpha$  amounting to 0.89 in a primary care sample of  $N = 3890$  (Kroenke et al., 2001). The PHQ-8 is highly consistent with the PHQ-9 and identical cut-off points can be used (Kroenke et al., 2010). The PHQ-ADS also showed good omega hierarchical index in three trials including patients with chronic pain and cancer ( $\omega = 0.89-0.91$  for people with chronic pain,  $\omega = 0.74$  for people with cancer). Furthermore, the PHQ-ADS showed good internal reliability in these three trials with Cronbach's alpha ranging between 0.80 and 0.90 (Kroenke et al., 2016). Participants were asked to report symptoms of depression and anxiety with regard to 1) the past week (= "present sum score") and 2) their entire lifetime (= "past sum score").

## 2.5. Data analysis

Sample characteristics were analyzed using SPSS 24.0 (IBM Corp, 2016). All focus group meetings were electronically audio-recorded and transcribed verbatim using transcription tools by MAXQDA (VERBI Software, 2019). Subsequently, transcripts were systematically analyzed with the QCAmap software (Mayring, 2014), using techniques for

qualitative content analysis as outlined by Mayring (2015). Categories were assigned deductively following six main steps. First, a category system including main categories and subcategories was defined based on relevant findings. Second, after a transcript review, a coding guideline with definitions, anchor examples, and coding rules for each category was specified. Third, after another transcript review, the category system was revised. Fourth, the first author coded the transcripts using the revised category system. Fifth, a second independent coder experienced in qualitative research (KB), who was not a member of the study group, repeated the coding process. Finally, the coders discussed deviant decisions to reach consensus. The applied category system is provided in the supplementary material, Fig. A.3.

## 3. Results

### 3.1. Participants

The sample characteristics are displayed in Table 1. A Kruskal-Wallis test showed that there were no significant differences between the three focus groups regarding age ( $H(2) = 4.81, p = .09$ ), PHQ-ADS present sum score ( $H(2) = 4.46, p = .11$ ) or PHQ-ADS past sum score ( $H(2) = 5.10, p = .07$ ). Pearson's chi-squared test with Monte-Carlo significance test procedure tended to show significant differences in gender distribution between focus groups ( $X^2(2, N = 20) = 6.06, p = .057$ ).

### 3.2. Research question 1: challenges of AYA with a chronic medical condition

#### 3.2.1. AYA with T1D

The AYA with T1D ( $N = 11$ ) reported the following psychological challenges: significant fear of developing long-term complications of diabetes, such as retinopathy or neuropathy (7 participants, 64%); difficulties accepting the diagnosis and the lifelong challenges and treatment requirements (e.g. insulin injection; 6 participants, 55%); worries regarding (possible) restrictions in everyday life and activities (5 participants, 45%). Reported physical challenge (implying significant psychological burden) was: experiences of acute metabolic complications, such as severe hyperglycemia and hypoglycemia requiring assistance (9 participants, 82%). Furthermore, AYA with T1D reported significant social burdens, including: feeling embarrassed when injecting insulin in

**Table 1**  
Participant characteristics within and across groups.

Chronic condition groups				
Group characteristics	T1D ( $N = 11$ )	JIA ( $N = 5$ )	CF ( $N = 4$ )	All ( $N = 20$ )
Gender (female)	4 (36.4%)	4 (80%)	4 (100%)	12 (60%)
Age, years				
<i>M</i>	15.2	15.4	17.3	15.7
<i>SD</i>	0.98	1.34	1.89	1.46
Range	14–17	14–17	16–20	14–20
PHQ-ADS, present sum score				
<i>M</i>	9.55	6.6	18.5	10.6
<i>SD</i>	7.4	8.11	11.93	9.13
0–9	7 (63.6%)	4 (80%)	0 (0%)	11 (55%)
10–19	3 (27.3%)	0 (0%)	3 (75%)	6 (30%)
20–29	1 (9.1%)	1 (20%)	0 (0%)	2 (10%)
$\geq 30$	0 (0%)	0 (0%)	1 (25%)	1 (5%)
PHQ-ADS, past sum score				
<i>M</i>	6.45	11.2	19.25	10.2
<i>SD</i>	6.01	9.09	10.21	8.86
0–9	8 (72.7%)	3 (60%)	1 (25%)	12 (60%)
10–19	3 (27.3%)	1 (20%)	1 (25%)	5 (25%)
20–29	0 (0%)	1 (20%)	1 (25%)	2 (10%)
$\geq 30$	0 (0%)	0 (0%)	1 (25%)	1 (5%)

Note. PHQ-ADS (Kroenke et al., 2016): minimal symptoms: 0–9; mild symptoms: 10–19; moderate symptoms: 20–29; severe symptoms  $\geq 30$ ; JIA = Juvenile idiopathic arthritis, CF = Cystic Fibrosis; T1D = Type 1 Diabetes mellitus.

public (5 participants, 45%); receiving unwanted excessive care from family and friends. Additionally, compulsory self-management tasks, such as frequent glucose checking and insulin injections, were considered as very burdensome (8 participants, 73%).

3.2.2. AYA with JIA

In the group with JIA (N = 5) the following significant psychological challenges of living with the condition were reported: distress and impairment in everyday life due to chronic joint pain (2 participants, 40%); serious aversions against certain medications (e.g. certain smells), which reminded them of injecting such medications (2 participants, 40%). Furthermore, physical burdens, which are closely related to the psychological challenges, were reported: painful burning feelings when injecting medications (4 participants, 80%); required immunosuppressive drugs leading to frequent infections (2 participants, 40%). Additionally, two persons reported experiences of being treated differently by others. Finally, burdening self-management requirements, such as injections and medication intake (2 participants, 40%), were reported.

3.2.3. AYA with CF

In the group of AYA with CF (N = 4) the following psychological burdens due to the chronic medical condition were reported: stressful incidents during medical therapy causing symptoms of anxiety (4 participants, 100%); treatment-related fears and aversions as well as fear of disease progression (4 participants, 100%); feeling of inferiority when comparing themselves with healthy peers and considering their shorter life expectancy (2 participants, 50%). Furthermore, the group mentioned the following serious physical impairments: pain due to (complications with) intravenous (IV) therapy (4 participants, 100%); consequences of impaired lung function (4 participants, 100%) and higher risk of infection and/or pneumonia (4 participants, 100%); frequent hospitalization (4 participants, 100%). Additionally, the AYA with CF were familiar with social challenges including: experiences with peers and others lacking understanding of the disease (4 participants, 100%); unwanted excessive care from relatives (4 participants, 100%); inability to participate in peer group conversations on certain topics (e.g. contraceptive pill in girls; 2 participants, 50%). Finally, time management, particularly finding a balance between school, medical appointments, physiotherapy, social/family life, and leisure time, as well as frequent absences from school due to disease-related tasks and treatment requirements were reported to constitute pronounced difficulties (4 participants, 100%). Exemplary verbatim quotes of the participants regarding perceived challenges are provided in Table 2.

3.3. Research question 2: applied strategies to cope with the chronic medical condition

3.3.1. AYA with T1D

The participating AYA with T1D reported applying diverse coping strategies. They referred to their families as an important social resource for coping with the condition (5 participants, 45%). Furthermore, most of them considered it desirable, or even necessary, to accept all of their disease-related tasks as a normal part of life to be able to live a satisfying life and also treat their diabetes properly (8 participants, 73%).

3.3.2. AYA with JIA

Similar to those with T1D, the participants with JIA also identified their families and close friends as important social resources (3 participants, 60%). In addition, one person considered it helpful to talk to peers with the same disease. Furthermore, two participants reported trying to accept their condition and to not regard it as too large of an obstacle (2 participants, 40%).

3.3.3. AYA with CF

AYA with CF also referred to family members who listen, support, and motivate as the most important resource for coping with the

**Table 2**  
Exemplary verbatim quotes of the participants regarding perceived challenges and applied coping strategies due to the chronic condition.

	T1D	JIA	CF
Perceived challenges			
Psychological burdens	“Understanding that it will never go away was like a slap in the face.” “I was afraid of not being able to do all the things I used to do.” “(...) fear to have a high sugar level or to get a hypoglycaemia.” “I don’t want to go blind someday.”	“(...) due to this medication I have developed some kind of nausea, or irritation when smelling alcohol or disinfectant.” “(...) somehow all my medications are yellow and I have slowly developed an aversion toward yellow color on the days when I have to inject myself.”	“Eight years ago, I underwent IV-treatment which had gone wrong and I have felt anxious about every small thing ever since.” “At 35, I just can’t take it anymore (...) to me, dying at this early age would be the worst thing that could ever happen.” “(...) a basic fear of somehow getting worse.”
Physical impairment	“(...) tough times with many hypoglycaemic and hyperglycaemic episodes”	“I often have pain in my hand, especially when I write. And I cannot do as much sports as I would like to do.” “When I started taking the medications, I became a chronically ill person. That was very dreadful!” “Every two weeks I have to take the medications and this is a really burning sensation.”	“During IV-treatment you get antibiotics through your veins in the evening and in the morning. And these hurt.” “I’ve already stayed in hospitals for IV-treatment four times this year.” “Taking the stairs is too hard for me, I will be out of breath.”
Social burdens	“Showing the disease and its related tasks in the public or for example in school is sometimes burdensome.” “Comparing myself with others that I need to measure my blood sugar and inject myself in between, when we do an activity together, can be burdensome. “	“They talked about me like ‘well she has nothing at all’. That’s the worst to me.” “Maybe that sounds strange, but I really don’t like to be pitied or getting an extra treatment or something comparable.”	“Not being able to participate discussions about certain topics, such as contraceptive pill can be burdensome.” “My mother’s friend asked her how she can leave me alone at home since I was a sick child. That really hurt me because in my opinion that is not true. I always managed everything myself. (...) It really hurts to understand what other people think about me.”
Self-management	“For a longer time period I did not measure my blood sugar frequently. And I also did not inject myself. (...) in the end, I always had high blood sugar levels.”	“(...) in general, my time schedule is very busy.”	“I think balancing school, private life, and all hospital appointments is very hard to reconcile.”
Coping-strategies			

(continued on next page)

Table 2 (continued)

	T1D	JIA	CF
Social support	“What really helped me, were my parents who supported me.” “Acceptance of my friends was really important to me.”	“I talked about my disease with my parents and many friends.” “At some points, I thought I would be the only one facing this issue, but talking to others who have the same challenge really helped me.” “It does not really help me to talk about it with others”	“When I felt very bad last year, I had a good friend who was there for me every single day.” “I always enjoyed being visited in hospital by friends and family.” “My mum always motivates me [to do the disease-related tasks].”
Acceptance and positive mindset	“Medicine might become really marvellous someday.” “(…) accept to regularly inject myself, measure my blood sugar level, and change my insulin sensor (….) because (…), well, it comes with the disease.”	“I’m not used to it yet, but I can handle it better. In general, I try not to see it as too much of an obstacle.”	“I think that I cannot change having this disease, but I can lead a good life with it and do not need to feel downhearted because of it.” “I try to stay positive every single day.”

condition (4 participants, 100%); furthermore, they regarded close friends (those who visit them in hospital and demonstrate understanding and respect) to be of high importance for them (4 participants, 100%). Achieving functional disease acceptance and developing a more positive and optimistic mindset to live a “good” and satisfying life, were further strategies used for coping with the condition (3 participants, 75%). Exemplary verbatim quotes of the participants regarding applied coping strategies are also provided in Table 2.

3.4. Research question 3: requested contents and interventions for the “youthCOACH<sub>CD</sub>” program

The contents and interventions for an iCBT suggested by the AYA are provided in detail in Table 3. Collectively, participants requested educational or interventional components regarding (dealing with) disease-specific fears as well as negative emotional reactions, achieving higher acceptance and integration of the disease, increased motivation and volition, more optimal self-management and health behavior, general behavioral activation as well as the acquisition of social skills regarding the condition (e.g. talking about disease-related topics more openly).

Additionally, participants in each focus group suggested several disease-related topics for which they requested psychoeducation. Those with CF reported that learning about the positive aspects of sports and potential consequences of smoking or contraceptive pills were desired topics for them. AYA with JIA requested the topic of physical exercise, and participants with T1D wished to be able to track their daily meals in order to better manage their blood glucose levels.

According to the AYA’s reports, an appealing presentation format and design is just as important as the content of the iCBT program or app. Participants in all three groups stated that a youthful font (incl. The logo) and youth-specific language, including typical juvenile expressions and avoiding scientific language, would be important. Furthermore, all AYA agreed upon a temporal frame of the program lessons, timed at 60 min per week or less. Most of them preferred to accomplish the intervention module in the evening. Moreover, participants across groups expressed their willingness to take up an additional treatment

Table 3

Participants’ recommendations for contents and interventions of a new internet- and mobile-based cognitive-behavioral intervention.

Contents/interventions	T1D	JIA	CF	Exemplary quote
Dealing with disease-specific fears	36%	20%	100%	“The fears: So that one learns how to deal with them and that they can perhaps be slightly reduced.”
Dealing with the fear of disease progression	36%	–	100%	“That I am no longer afraid of secondary illness.”
Dealing with depressive thought patterns	9%	40%	75%	“And what I would also consider to be good is, how one could get positive thoughts again.”
Regulation of strong emotional reactions	–	20%	25%	“Perhaps, so that one doesn’t immediately freak out when something doesn’t work right away, but is calm at first and then maybe think of something positive.”
Acquisition of skills to talk with others about disease-related topics	36%	60%	50%	“(…) better explain to other people in your environment who have not yet had much contact with the disease, such as sports teachers”
Supporting acceptance of the disease as part of one’s life	27%	100%	25%	“You need to accept it.”
Supporting motivation and volition	64%	20%	75%	“I am not sure, maybe there’s some motivational help or something that makes you really go out, no matter what the weather, and run, so that you just feel better.”
Optimize self-management skills to deal with daily, disease-related challenges	36%	60%	75%	“That’s why I think this everyday routine is the most important thing for now.”
Providing information about behavioral activation	36%	20%	75%	“It is not so easy for sad ones in front of their PC to become active.”

Note. Percentual figures refer to the number of individuals who endorsed each topic (T1D: N = 11; JIA: N = 5, CF: N = 4).

task (e.g. mood diary) for 5 min a day via a mobile app. Only one participant with CF considered an additional daily task to be inconvenient. In addition, AYA across groups agreed that regular motivational reminders via an app would be desirable and that an app-based monitoring system for personal treatment progress could support treatment motivation and adherence. Three individuals across groups considered it likely helpful to be able to set their own goals at the beginning of the iCBT and monitor the progress of goal attainment throughout the treatment phase. While participants of all groups agreed that involving parents or legal guardians would be “demotivating or disruptive,” there were different perspectives regarding possible exchanges with other patients (i.e. program users); On one hand, three of those with CF stated that exchange with other patients with a potentially worse course of the disease might increase their personal distress and fear and should thus be optional. On the other hand, those with JIA and T1D and one of those with CF regarded potential exchange with other affected AYA as probably helpful (e.g. supporting the positive experience of “not being alone”). Again, consensus emerged regarding the content presentation, which should be vivid, varying, enriched by “evidence-based facts and others’ life-experience” (implemented by realistic peer vignettes), and free from lengthy texts. Another relevant issue for participants across all groups was individuality (i.e. tailoring of intervention content). All participants with CF explained that it would be important for them to be

able to decide whether a content is relevant for them or not; and participants across groups expressed that a therapist or guide (i.e. e-coach) should respond to the user with personalized feedback.

## 4. Discussion

### 4.1. Key findings

The present study aimed to gain an in-depth understanding of participants' personal needs and requests for a novel iCBT for AYA with chronic medical conditions. This user-centered developmental approach aimed to contribute knowledge on how to achieve enhanced adherence rates and effectiveness of iCBT interventions for AYA. We identified AYA's most relevant challenges due to three different chronic medical conditions. The majority of AYA with a chronic medical condition may struggle from 1) fear of disease progression, 2) fear of disease-specific complications, 3) serious incidents and aversions related to the medical therapy, 4) non-acceptance of the disease, 5) burdensome disease-management tasks, and 6) social challenges in the context of family and peers. Moreover, our findings highlight some disease-specific burdens and personal requests that might be relevant to intervention development. The present findings are in accordance to prior evidence derived from studies focusing on chronic medical conditions in AYA (Sawyer et al., 2007).

A major intention of this qualitative study was to identify common coping strategies of AYA with a chronic medical condition. In summary, AYA in each of the three groups utilized similar strategies for coping with their condition, including: 1) seeking social support from family and peers, 2) accepting the condition and its associated requirements, and 3) developing/sustaining a positive mindset. It is well established that AYA with a chronic medical condition benefit from functional personal resources (e.g. personality factors such as resilience, or social networks) and develop individual strategies (e.g. disease perception, positive mindset) when coping with their disease-related challenges and burdens (Petrie and Jones, 2019). Jaser et al. (2017) found that the use of appropriate coping strategies in dealing with diabetes-related stress predicts better quality of life and fewer symptoms of depression in AYA with T1D. These results support a positive impact of adaptive coping strategies on emotional well-being and psychological functioning. Furthermore, the participants in this study expressed their need to exchange with other affected peers. This coping strategy seems to be common among AYA as well as adults with a chronic medical condition (Petrie and Jones, 2019). Novel iCBT interventions for AYA with a chronic medical condition and comorbid depression or anxiety symptoms should acknowledge the possible value of social support strategies for coping with the condition and aim to support social interaction among the participants as well as significant others (Stiles-Shields et al., 2016). Besides implementing specific intervention content about social competence skills, integrating social support features (such as chat with other users) into the iCBT program might be useful. However, possible adverse effects of peer influence, such as social contagion, which is assumed to occur, for example, in non-suicidal self-injury behaviors (Plener et al., 2018), may need to be accounted for (e.g. via monitoring and moderating discussion forums by healthcare providers). Also, evidence regarding potential beneficial effects of the implementation of peer support in IMI targeting depression in chronic medical conditions is still very limited (Franco et al., 2018). Due to the different attitudes toward exchange with others expressed by study participants depending on their chronic condition, it might be more appropriate to offer such features optionally. Another important component of social support in AYA is parental support. However, most participants indicated that they would not want parental support as part of an iCBT intervention. Since several studies found no association between parental involvement in IMI for AYA and treatment effectiveness (Domhardt et al., 2020a; Ebert et al., 2015; Hollis et al., 2017), it seems this might be an intervention component of minor importance. Yet, future research is needed to

determine the potential impact of parental support in relation to the age and developmental aspects of participants in more detail.

Another relevant coping strategy for the target group is developing a positive mindset toward living with the condition and trying to achieve functional acceptance and integration of the condition and its requirements into one's life. In line with these findings, Casier et al. (2013) found a positive relationship between acceptance of disease and daily well-being and mood in adolescents suffering from CF or diabetes. Furthermore, evidence suggests strong associations between higher disease acceptance and increased well-being and quality of life as well as less depressive symptoms in adults with diabetes (Schmitt et al., 2014; Schmitt et al., 2018), suggesting high clinical relevance of this issue. Therefore, iCBT interventions should support coping efforts by means of cognitive restructuring (i.e. developing functional thoughts toward the chronic condition) as well as supporting integration of the condition into the patients' self-concept. It would also be conceivable to incorporate psychotherapeutic elements focusing on promoting acceptance of unchangeable issues in life, e.g. by means of the Acceptance and Commitment Therapy approach (Hayes et al., 2006).

In a third step, we identified relevant requests and recommendations for iCBT for AYA with chronic medical conditions, in line with recommendations by Hill et al. (2018). We focused on outcomes and target domains from the patients' perspective and their understanding of successful psychotherapy and helpful support in coping with their challenges (Cuijpers, 2019). Although we observed many similarities in the recommended content across patient groups, disease-specific characteristics and differences should also be considered when designing the iCBT program. Hence, the challenge of developing a generic psychosocial intervention for AYA with chronic medical conditions is to create modules relevant for as many members of the target population as possible while providing content and tasks specifically for the challenges and developmental stage of each individual. In order to warrant a tailored iCBT approach, users should be able to decide for themselves whether or not an intervention task is meaningful for them. Wozney et al. (2017) found that the opportunity to decide whether an exercise or intervention is relevant for oneself can yield greater engagement in as well as satisfaction with IMI for AYA with depression. Another feature supporting the tailoring of the intervention is personal feedback from a personal coach, which was considered essential by the interviewed participants. Furthermore, this kind of guidance was found to be a relevant moderating factor in the effectiveness of IMI (including increased adherence) and thus should be implemented in an iCBT for AYA (Hollis et al., 2017; Wozney et al., 2017). Recently, much research is being conducted on guidance provided by automated software such as chatbots and artificial intelligence-based coaches that provide personalized and tailored feedback (e.g., Fitzpatrick et al., 2017; Ly et al., 2017). In the upcoming years they might be an alternative to the recommended human-based guidance.

To enable consideration of the patient-defined outcomes, the iCBT should implement a goal-setting intervention (e.g. Target Complaints approach by Battle et al., 1966). Specific daily tasks such as self-monitoring features (e.g. mood or symptom diary) or automated reminders are key elements for monitoring symptom improvement and should therefore be included (Clarke et al., 2009; Wozney et al., 2017). Furthermore, specific characteristics such as youth-typical language, realistic vignettes, or helpful scientific facts were regarded relevant by many participants, suggesting beneficial effects in new iCBT programs (e.g. higher acceptance of the program). These suggestions are supported by a recent study which found that general appeal (content and intervention presentation are attractive to the user group) and surface credibility increased the users' engagement and satisfaction with an IMI (Wozney et al., 2017).

### 4.2. Limitations

Besides several strengths, this qualitative study has also limitations,

particularly with regard to the representativeness of the results. First, the sample including a total of 20 participants was rather small, and including additional AYA with chronic medical conditions could have yielded additional insights. However, this was not possible within the timetable for the development process of the iCBT intervention within the multicenter COACH project and due to difficulties of recruiting the specific target groups (Lunkenheimer et al., 2020). We had started to recruit in clinics through flyers, but in the further course of the project it turned out that recruitment through social media and mailing lists of self-help groups was much more successful. Despite the small sample size, the qualitative research approach yields a substantial and in-depth information base. Focus groups consisted of 4–11 participants. Empirical findings on the optimal group size is mixed with ranges between 4 and 12 in common practice (Masadeh, 2012), which was the benchmark for the chosen focus group sizes in this study. However, a recent systematic review showed that in order to reach saturation at least 12 participants per focus group are required (Vasileiou et al., 2018). Second, only one focus group per chronic medical condition was conducted. Current research supports that more than 80% of all relevant aspects can be discovered within two to three focus groups (Guest et al., 2017). Although it could be assumed that three focus groups per condition were necessary to achieve this approximate theoretical saturation, the data comply with our main purpose to gain in-depth findings and context-embedded results, which are fundamental for an iterative intervention development process (Yardley et al., 2015). In order to foster generalizability, it might be useful to implement further groups per condition with larger group sizes in future studies. Following Vasileiou et al. (2018) saturation for AYA with chronic medical conditions could have likely been reached with a total of at least 36 participants.

Notably, the specification of frequencies of reported topics should provide a notion of their putative relevance, while the generalization of the findings across AYA with other chronic medical conditions may not be warranted (Wu et al., 2016). Furthermore, psychological symptom levels as well as gender distributions tended to vary within focus groups, preventing further subgroup analyses. In particular, the focus group of patients with CF consisted only of female participants. This could be a reason why there was a 100% agreement on many aspects in this focus group. It might be important to include male participants and further age groups to gain more insights in future studies.

Finally, we conducted focus groups in both an online setting and face-to-face. As described above, research on information elicitation indicates no difference between these settings (Hoffman et al., 2012; Reid and Reid, 2005). Research comparing face-to-face cognitive behavioral therapy with videoconference-based CBT also showed no significant differences (Stubbings et al., 2013). On the other hand, differences in conversation online and offline are evident in practice, especially when it comes to difficult topics. However, we did not find differences in our focus groups, but further research on this topic could be valuable.

#### 4.3. Conclusions and future directions

Future studies should aim to better understand the perspective of

other stakeholders in order to increase the uptake, adherence, and the effectiveness of iCBT (Hill et al., 2018). Additionally, because group dynamics are present during focus groups, which may hinder participants explaining other opinions on topics, comparing our focus group-derived results to those of other methodological approaches, e.g. one-to-one interviews, could be of value. The next step in the development of youthCOACH<sub>CD</sub> will be to incorporate the participants' recommendations into the iCBT and to yield initial statements about its feasibility via pilot testing (Lunkenheimer et al., 2020). The findings of this qualitative study identified relevant intervention characteristics and potential change mechanisms from the patient perspective, which are to be verified with subsequent analyses within the evaluation of youthCOACH<sub>CD</sub> (Domhardt et al., 2019; Steubl et al., 2019). A better understanding of the putative factors and mechanisms of change in IMI might contribute to the development of empirically-informed interventions for advanced treatment programs yielding more optimal treatment outcomes (Domhardt et al., 2020b).

To conclude, our findings provide important insights into the challenges and needs of AYA with chronic medical conditions, highlighting key areas to be addressed by psychological IMIs in order to improve comorbid depressive and anxiety symptoms. The patient-centered recommendations derived from this study might also be relevant for future interventions for AYA, e.g. targeting other disorders or psychosocial aspects.

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Declaration of competing interest.

HB is a consultant for different insurance companies, health care associations, and psychotherapy chambers and gives talks and workshops and conducts third party-funded projects on e-health interventions. All other authors declare no competing interests.

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## Appendix A

**Table A.1**

Interview schedule of focus groups.

Discussion guideline	
1.	Think of a difficult disease period. What was particularly burdensome to you during this period?
2.	Currently the main challenges in my daily life are...
3.	Think of a stressful period in your life. What helps you to feel better in this time?
4.	Do you sometimes wish for more support?
5.	How do you like the project logo?

(continued on next page)

Table A.1 (continued)

Discussion guideline	
6.	How do you like the video? (presentation of video draft)
7.	Do you think it would be useful to offer Internet-based training? What are the advantages and disadvantages?
8.	Imagine your friend had the same chronic condition: Which therapy contents would you recommend to him or her?
9.	How much time could you spend on training in everyday life?
10.	What would motivate you to participate in the online training program?
11.	What goals do you want to achieve by participating in the online training program?
12.	In which case would you like to participate in the online training program yourself?
13.	What is the most important recommendation to you?
14.	Is there another important aspect you would like to address?

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