Development of a Complex Intervention to Support Parents of Chronically Ill Adolescents in Transition From Pediatrics to Adult Care (ParTNer-STEPs)

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Abstract

Background Transfer from pediatric to adult care for chronically ill adolescents is associated with outpatient non-attendance and low treatment adherence in adolescents, and with anxiety and concerns among parents. Recent studies have shown that parent involvement results in better transitions. The aim of this paper was to describe the development, through participatory design, of a brief transition program targeted to parents of chronically ill adolescents.

Methods The study was based on the UK Medical Research Council's (MRC) framework on developing and testing complex interventions. To increase the program's feasibility and relevance, participatory design was chosen as the overall method. A collaboration group of parents, adolescents and health care professionals (HCP) were actively involved in the development of the program. The program was developed in three development stages, in accordance with the MRC framework: 1) identifying the evidence base, 2) identifying theory, and 3) modelling process and outcomes.

Results Together with the collaboration group, we developed a brief transition program targeting parents, by undertaking an iterative process, involving a literature review, individual interviews, workshops, online brainstorming and multiple pilot tests. The program, called ParTNer-STEPs (Parents in Transition – a Nurse-led Support and Transfer Educational Program) comprised three components: 1) an informative website, 2) online educational events for parents, and 3) transfer consultations with providers from both pediatrics and adult care.

Conclusions The MRC framework was successfully applied to develop a brief transition program targeting parents of chronically ill adolescents. By incorporating the principles of participatory design in the development phase, we ensured that both parents' and adolescents' needs were represented and addressed in the program. Furthermore, the involvement of HCPs ensured the feasibility and relevance of the intervention in clinical practice and will increase the chances of successful implementation.

Trial registration ClinicalTrials.gov ID NCT04969328

Background

The transfer from pediatrics to adult care for chronically ill adolescents is associated with medical complications, outpatient non-attendance and low treatment adherence (1–3). Lately, it has become evident that one of the most important factors in a successful transition and transfer to adult care is appropriate parental involvement and parental transition readiness (4–6). The parents' role is also highlighted in transition theories, e.g., the social-ecological model of adolescent and young adult readiness to transition (SMART) (7). In that model, the parents' ability to coach and support their child in gaining self-management skills is described as a facilitator of the transition process (8).

The parents' role in their child's treatment changes profoundly as adolescence progresses (6, 9, 10); during the care transition, parents need to navigate between two opposing roles: while they need to take

an active role, by coaching and supporting their child in becoming an independent and competent patient, they also have to adapt to a more passive role and hand over the treatment responsibility to their child. Studies have found that parents of chronically ill adolescents feel responsible for their child's daily care and treatment and may fear handing over treatment responsibilities to their child (11, 12). Parents ask for support to withdraw and adapt to their new role as 'consultants', instead of 'managers' (13–17). Additionally, studies have found that parents are both anxious about leaving pediatric care and have an increased risk of developing anxiety and stress during their child's transition (6, 10, 14, 18–20).

In the last decade, there has been an increased focus on transition programs targeting adolescents (21, 22). A systematic review from 2017, a cohort study from 2018, and several guidelines conclude that health care professionals (HCP) also should focus on supporting parents in their transition and give parents help to support their child's transition (5, 6, 23, 24). Despite this, there is a lack of tested transition programs targeted to parents.

In conclusion, there is a need to develop and test interventions tailored to the needs of parents of chronically ill adolescents, to support and prepare them for their child's transfer to adult care. Thus, the aim of this paper was to describe the development, through participatory design (PD), of a brief transition program targeted to parents of chronically ill adolescents.

Methods

Design

We chose a complex intervention design, because the final intervention will involve several interacting components and be developed and evaluated in multiple outpatient clinics across pediatric and adult care and implemented by multidisciplinary HCPs in a clinical setting. The study is based on the UK Medical Research Council's (MRC) framework on developing, evaluating, and implementing complex interventions. The MRC framework consists of four key phases: development, piloting, evaluation, and implementation (25, 26). This article will report the development phase.

In addition to the complex intervention design, we chose PD to ensure that the users' needs were represented and addressed in the program (27, 28). The two first PD steps, "needs assessment" and "ideas generation", were integrated into the development phase (see Figure 1). By involving a collaboration group that included parents, adolescents, and HCPs, we ensured the feasibility and relevance of the intervention in clinical practice and increased the chances of successful implementation (29).

Setting

The intervention was developed at the pediatric and adult nephrology, hepatology, neurology and rheumatology outpatient clinics at Copenhagen University Hospital Rigshospitalet, Denmark. We chose these four specialties because low treatment adherence and non-attendance in their patient groups could

result in permanent disabilities or critical consequences, e.g., organ failure, brain damage or permanent joint destruction.

In Denmark, adolescents transfer to adult care when they turn 18, irrespective of the adolescent’s maturity or transitional readiness. The existing transitional care in pediatrics includes assessment of adolescent transition readiness and split-visit consultations, where HCPs (nurses and physicians) both spend time alone with the adolescent, and with the adolescent and parents together. However, the outpatient clinics currently have no initiatives that target parents.

The collaboration group

Parents, young people and HCPs with affiliation to one of the four included outpatient clinics were invited to participate in the development of the intervention, by contributing their experiences, views, and needs. Parents who participated in initial needs assessment interviews (17) were invited to assist in the development of the program by being part of the collaboration group. We also invited young people from the local youth panel (a group of young people aged 14-25 with a wide range of chronic diseases (n=18), along with HCPs from the involved outpatient clinics in pediatric and adult care (n=21). A total of six parents, three young people and six HCPs chose to participate in the collaboration group (Table 1).

Table 1 Participants in the collaboration group (n=13)		
Parent (n=6)	Parent of (gender, age)	Outpatient clinic
Father	Female, 19	Nephrology
Father	Female, 18	Nephrology
Mother	Female, 19	Nephrology
Mother	Male, 20	Hepatology
Mother	Female, 18	Rheumatology
Mother	Female, 20	Rheumatology

Young people (n=3)	Age	Outpatient clinic
Female	19	Nephrology
Female	21	Hepatology
Female	23	Hepatology

Health care professional (n=6)	Affiliation	Outpatient clinic
Physician	Pediatric	Hepatology
Head nurse	Pediatric	Hepatology, Rheumatology Nephrology, Neurology
Head nurse	Adult	Hepatology
Assistant head nurse	Adult	Nephrology
Nurse	Pediatric	Rheumatology
Nurse	Pediatric	Hepatology

Results - Developing A Complex Intervention

Overview of the intervention development process

According to MRC's framework, a complex intervention is developed in three stages: 1) identifying the evidence base, 2) identifying/developing theory, and 3) modelling process and outcomes. Figure 1 shows how these stages were executed and the individual steps towards the final development of the brief transition program. The intervention was developed in an iterative process with ongoing pilot-testing over a 36-month period. To reduce the complexity of the description of the intervention, the overall stages in the MRC framework are presented below, together with the respective method and findings of each stage.

MRC stage 1: Identifying the evidence base

The development of a complex intervention requires a review of the existing evidence to inform all steps of the development process (30). In line with this, we conducted both a literature review and needs assessment interviews with parents.

1a Literature review

Literature on parents' needs and recommended interventions was identified through a systematic literature search in the databases Medline and CINAHL (9th October 2018). The search strategy and findings are reported in Figure 2. Extracts from the review formed the interview guide for the needs assessment interviews.

1b Needs assessment

In addition to the literature review, we conducted individual interviews with parents of chronically ill adolescents in accordance with the PD first step (needs assessment). The principal aim in needs assessment is to identify and analyze specific needs by actively engaging the users (27).

A total of 11 parents of chronically ill adolescents (aged 16-19) were interviewed during January and February 2019. A semi-structured interview guide was developed based on the results from the above-

described literature review. It consisted of: 1) broad questions: to examine the parents' feelings, experiences, or expectations in relation to their child's transfer to adult care, and 2) structured questions: to identify preferred initiatives. Data were analyzed using the interpretive description method (31).

Findings We found that the participants preferred initiatives that focused on transfer and not transition, including knowledge regarding adult care and getting to know the adult team. Our results pointed to three specific ideas for transfer initiatives, i.e., an informative website, educational events for parents, and a transfer consultation with HCPs from both pediatric and adult care. The overall findings can be found in Figure 1. A full description of the method and findings is reported in detail elsewhere (17).

MRC stage 2: Identifying theory

Drawing on existing theory helps to identify what is essential, relevant and feasible, to inform the intended goals of the intervention and inform the content and delivery of any intervention (32).

2 Theoretical framework

We identified three transition theories, by Meleis (33), Schwartz et al. (8), and Geary and Schumacher (34). They all state that the process of transitioning from pediatric to adult health care is part of a larger theoretical framework for transition affecting both young people and their parents (35). We chose the transition theory Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) developed by Schwartz et al. as the theoretical framework for the intervention (7). The authors give the following as the definition; *SMART applies a social-ecological framework to transition readiness, emphasizing multiple factors, stakeholders, systems and their reciprocal relationships influencing the readiness for and likelihood of success in transfer to adult-oriented care* (8). We found this theory relevant, given that our intervention is based on collaboration between multiple stakeholders (adolescents, parents and HCPs) and because it will take place in the context of a clinical setting and multidisciplinary teams. According to SMART, transition readiness is based on both pre-existing "objective" and less changeable factors (e.g., IQ, socio-demographics and medical status) and modifiable "subjective" factors in the patient, parents and HCPs that can be targeted by interventions. These factors are: knowledge, beliefs/expectations, goals/motivation, skills/self-efficacy, relationships/communication and psychosocial functioning/emotions (7). The modifiable factors guided the modelling process (stage 3b).

MRC stage 3: Modelling process and outcome

Modelling a complex intervention can clarify the assumptions about the effect behind the intervention and increase the understanding of the mechanisms and components (36).

We chose to divide the modelling process into three substages: 1) Conducting a workshop with the collaboration group (ideas generation), 2) Online brainstorm regarding possible outcomes, and 3) Modelling the intervention using logic modelling.

3a Ideas generation

We conducted the workshop in line with the world café method, as this method engages people in meaningful group dialogue on complex issues, where all participants are the experts of their own lived experiences (37). Chronically ill young people, parents and HCPs from the collaboration group were invited to participate in the workshop.

The workshop took place January 2020 in an informal setting, in accordance with the world café principles described by Estacio and Toni, 2016 (38). The world café concept was effectuated by having three tables focusing on one of the three preferred initiatives from the need assessments interviews (website, educational events and transfer consultations). The participants (n= 14) were divided into groups of four or five, so every group included at least one young person, one parent and HCP from different outpatient clinics. The groups rotated between each table every 20 minutes; thus, all participants debated all three intervention components. A facilitator at each table led the rounds with different type of questions; 1) reflection questions, 2) content questions, and 3) design questions [see Additional file 1]. Prior to the table discussions, initial findings from the needs assessment interviews and modifiable factors from SMART was presented and discussed with the participants, in accordance with the principles of ideas generation (the second PD phase) (27). The workshop was audio recorded and subsequently transcribed verbatim. Data (digital records and notes from participants and three table facilitators) were analyzed separately, table by table, using a thematic analysis approach inspired by Braun and Clarke's 6-step model (39).

Findings The analysis provided us with an initial draft of the three intervention components (website, educational events and transfer consultation). An overview of themes, categories and quotes can be found in Additional file 2. The main findings can be summarized as follows:

The participants wanted an informative website with a focus on knowledge sharing, with regard to not only expert knowledge but also personal experiences and advice on how to handle the transition process.

"... that at the same time there is this personal aspect, some personal stories with young people or parents of young people. Because I think the combination, where there is some knowledge and then something about how it is experienced to be this person." (young person)

The website should also contain an introduction to the adult department and give the parents the chance to interact with both medical experts and other parents.

Educational events should include several short presentations with various topics, such as patients' rights and support opportunities, together with knowledge about adolescence and chronic illness. It was also important to the participants that parents and adolescents had the opportunity to ask questions and network with peers.

"So it is not necessarily the educational evening in the teaching sense or meaning. It is much more that there is an opportunity to share some experiences and ask if there is anyone who has some good advice and how is it going with that" (HCP)

The participants emphasized that a transfer consultation should focus both on coming to an official closure of the years of treatment in the pediatric department, and on an introduction to adult care.

"I think it's important to be finished with the old. I think that is very important for the new process. So a good ending" (Parent)

The transfer consultation should also focus on alignment of expectations, an introduction of the adolescent and her/his perceived need for parental involvement. Finally, the consultations should promote cooperation between departments and ensure a consistent and joint treatment plan.

"Our mutual collaboration with children and adults becomes hugely important there, and so we have to air our dirty laundry internally and not [in front of the young person and the parents]" (HCP)

3b Outcome brainstorm

We held two online brainstorm sessions with three parents and two adolescents from the collaboration group (April 2020). Parents and adolescents were asked to consider how the transfer program could affect them and their child/parents, respectively, and which changes they thought could happen. During the sessions, parents' and adolescents' suggestions were drawn in a joint virtual mind map.

Findings The participants suggested a range of possible outcomes [see Additional file 3]. Suggested outcomes, such as transition readiness, self-management, handing over responsibility and uncertainty guided the final selection of outcomes.

3c Logic modelling

A logic model of the intervention can provide an overview of how an intervention works and how the theory and assumptions underlie the intervention. Thus, the logic model links short and long-term outcomes with the intervention's activities and theory, by covering six core elements: Objectives, Inputs, Activities, Outputs, Outcomes and Impact (40, 41). *Objectives* clarify the work focus, which usually describes changes in, e.g., knowledge and skills. *Inputs* cover the resources needed to implement the intervention (e.g., equipment, staff and cost). *Activities* describe specific intervention actions. *Outputs* cover the measurable product of program activities. *Outcomes* describe the intermediate outcomes, such as changes in, e.g., knowledge, skills or behavior. *Impact* covers the outcomes that partly depends on the interactions that lies outside of the control of the program (41).

Authors ELT, KB, BAE, HH and SH all contributed to the final modelling of the intervention. The final model incorporated results from the workshop, outcome brainstorm and feedback from the collaboration group (Figure 3). Facilitators of the transition process from the SMART theory guided the framework of the logic

modelling process. The quality of the model was assessed by using the Kellogg Foundation checklist (40). The model was presented and debated with the collaboration group before final approval.

4. Final intervention

The final intervention, ParTner-STEPs (Parents in Transition – a Nurse-led Support and Transfer Educational Program), was developed by the research team (authors) based on the logic model and results from the workshop and in close cooperation with the collaboration group (Figure 4). ParTner-STEPs consists of three components: 1) an informative website, where parents, adolescent and HCPs provided content to the website and gave feedback on the website design and composition. 2) Educational events, which, because of the COVID-19 pandemic were converted into online webinars. Time and weekday, among other things, was decided by the parents. 3) Transfer consultations, where number of consultations, scripts and documentations tool were developed in close cooperation with HCPs from all eight outpatient clinics (nurses and physicians from both pediatric and adult care).

Website

The website will be available for parents from recruitment until three months after transfer. The website is divided into six subpages, covering a range of needs and topics:

- *'What is good to know before my child turns 18?'* focuses on relevant knowledge regarding social benefits, educational support and health care-related legal changes, e.g., confidentiality
- *'How can I prepare myself and my child during the transition?'* contains tools and advice on what the parents can expect of their adolescent child and how they can guide and prepare them
- *'What can I and my child expect of the adult department?'* gives a written and visual introduction to the four adult departments
- *'What do other parents and adolescents say about the transition?'* presents personal stories with experiences and advice. The site also links to relevant podcast, books and short videos regarding adolescence and chronic illness.
- *'Questions and answers'* contains frequently asked questions and the opportunity for parents to submit their own questions, which will be answered and subsequently uploaded to the website
- *'Ideas for website improvements'*

Online educational events

Online educational events will be offered to parents twice a year as a webinar with short presentations (10-15 mins) on different topics. The webinar will not be available for parents after their child has transferred to adult care. The webinar will take place on a weekday from 7-9 pm. Parents will be encouraged to invite their adolescent child to the webinars. The topics will change from time to time but will always contain: 1) personal experiences/presentations from an adolescent or parent, 2) presentations from professionals outside health care, e.g., student counselor, psychologist or social worker, 3) general presentations on adolescent medicine, e.g., adolescence, chronic illness and autonomy.

At each webinar, the participants will be divided into disease-specific breakout rooms, where they can meet representatives from the adult department and network with the other parents.

Transfer consultations

Transfer consultations consists of, in total, four individual consultations. The timing and setting of the consultations, i.e. pediatric or adult care, varies from what is feasible in each outpatient clinic, but the number of consultations and content will be the same. The HCP will receive a script for the four consultations, in which the purpose, content, procedure and the subsequent documentation are described (a detailed description can be provided by contacting the first author). The four transfer consultations consists of:

- A preparatory consultation (3-6 months before transfer) with the pediatric nurse where a transfer document will be completed in collaboration with the adolescent and the parents. The transfer document will focus on the adolescent's life with a chronic condition, independence, need for parents' support and expectations/emotions regarding the transfer.
- A farewell consultation with the pediatric nurse (0-3 months before transfer), where the family gets the opportunity to say proper goodbye to the pediatric care team and be informed about what to expect in adult care.
- A joint consultation (at transfer) where both the pediatrician and the adult physician are present. Focus will be on a common treatment plan, partnership and meeting the adult treatment team.
- A welcoming consultation with the nurse from the adult care (0-3 months after transfer), where the transfer document will be discussed, and the family will be welcomed to the adult department.

Discussion

The aim of this paper was to describe the development, through participatory design, of a brief transition program targeted to parents of chronically ill adolescents. In accordance with the MRC framework, we have described the development of a complex intervention integrating PD. The MRC framework was a feasible and systematic step-by-step approach in designing an intervention with several interacting components that is carried out in a setting that spans across specialties as well as pediatric and adult departments. Despite the highly systematic and structured approach of the MRC framework, the complex setting caused some challenges in regard to diverse cultures and norms among the eight included outpatient clinics. These challenges called for pragmatic decisions, which we made by integrating the principles of PD in the development phase. Our choice to apply PD allowed us to invite both young people, parents and HCPs to participate in the development of the intervention and thereby tailor the program to their specific needs and working routine. We believe that this approach has strengthened and qualified the entire intervention, as the collaboration group contributed with perspectives beyond our own perspectives as researchers (42). PD also contributed to ensuring that the needs of the parents were met in the program, and for this reason we believe that the risk of high drop-out rate was reduced in our study.

Our brief transition program consists of three components: a website, online educational events and transfer consultations. Findings from our workshop showed that parents and young people preferred an informative website focusing on the dissemination of expert knowledge, personal experiences and advice on how to handle the transition process. Holtslander et al. have identified similar needs and preferences of parents and service providers of adolescents with type 1 diabetes, during the development of an online support intervention. They found a need for information, e.g., expert knowledge, emotional support, transition-related questions and the opportunity to connect with peers (43). This suggests that parents' needs are similar across diagnoses. During the development of the educational events, we found that the participants were focused on usual youth topics as well as personal experiences and advice from parents and young people who already had transferred to adult care. Previous educational interventions have, like ParTner-STEPs, addressed topics that are not only related to illness and treatment, but also topics that affect out-of-hospital life, such as college planning and social/youth life (44, 45). Joint consultations have been recommended as one of the cornerstones of successful transfer (4–6, 46). We also found that joint consultations were important for both young people, parents and HCPs. In line with evidence, the opportunity to meet the adult treatment team in a safe environment and the importance of collaboration across departments was highlighted as a facilitator of the transition process by participants (5).

The NICE guideline, Transition from children's to adults' services for young people using health or social care services, highlights the importance for involving parents, sharing working documents, meeting the adult care team and informing the family about what to expect from adult services (24). Our brief transition program meets these recommendations in at least one of the three components (website, educational events and transfer consultation). Based on findings from our interviews and workshop, we have also included the opportunity for parents to benefit from other families' approach by sharing their experiences and good advice on the website or at educational events.

Research has shown that involvement of parents results in better transitions, which is why it is recommended to support parents during transition (5, 6, 23, 24). We have not been able to identify similar interventions that might suggest what a transition program targeted to parents would look like. The next step is, then, to evaluate the effect of our brief transition program by conducting a randomised controlled trial study involving the four outpatient clinics, together with process evaluation.

Strengths and Limitations

We chose to develop a brief transition program in close cooperation with parents and young people, who contributed with a variety of perspectives. This approach ensures better representation of the users' needs and prevents potential inconsistency between their preferences and the scientific focus of research (42). One limitation is the under-representation of male participants in the collaboration group. All young people were women, only two of the six parents were men, and only one parent of a male adolescent participated in our collaboration group. The absence of male participants is a common limitation and reflects clinical practice, given that mothers most often are the primary caregivers to chronically ill children and adolescents (11, 47). Furthermore, the process of going through the many steps in the MRC

framework is time consuming: it took three years from the literature review (2018) to the final adjustments in mid-2021. However, the lengthy development phase is also a strength, as the program's legitimacy is ensured, based on the empirical, theoretical and comprehensive knowledge base.

Conclusions

Transitional care is a complex process, because it involves adolescents, their parents and HCPs and covers modifiable subjective components. Thus, the MRC Framework was successfully applied to develop a brief transition program targeting parents of chronically ill adolescents.

By incorporating the principles of participatory design in the development phase, we ensured that both parents' and adolescents' needs were represented and met in the program. Furthermore, the involvement of HCPs secured the feasibility and relevance of the intervention in clinical practice and will increase the chances of successful implementation.

Abbreviations

HCP: Health Care Professionals; MRC: Medical Research Council; SMART: the Social-ecological Model of Adolescent and young adult Readiness to Transition; PC: Participatory Design.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the Helsinki II Declaration (48) and approved by the Danish Data Protection Agency (no. P-2020-550). According to Danish regulations, register research projects, interview surveys and questionnaire surveys must only be notified if human biological material is included in the project (National Committee for Health Research Ethics <https://en.nvk.dk/rules-and-guidelines/act-on-research-ethics-review-of-health-research-projects>). Based on this, we contacted The Regional Committees on Health Research Ethics for Capital Region of Denmark (no. FSP 20031083), who reviewed the project description and gave us ethical approval to perform the study. Participants from the workshop received oral and written information before signing consent forms. No minors under the age of 18 participated in the study. The collaboration group's role, tasks and recognition followed the EULAR recommendations regarding patient representatives in scientific projects (42).

Consent for publication

Not applicable.

Availability of data and materials

The datasets supporting the conclusions of this article are included within the article and its additional files (Appendix 1-3).

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors contributed to the development of the intervention. ELT led the development phase and conducted the literature review, interviews, workshop and brainstorm meeting. KB was a facilitator in the workshop and followed the development phase closely. All authors (ELT, KB, BAE, SH and HH) were central to the data analysis and in the design and modeling of the intervention. ELT drafted the manuscript together with BAE and KB. SH and HH contributed significantly to the preparation of the manuscript. All authors read and approved the final version of the manuscript.

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Figures

1. Identifying the evidence base	1a Literature review		1b Needs assessments			
	<p>Method</p> <p>Literature review of parents’ needs and recommended initiatives</p> <p>Findings</p> <p>Recommended initiatives categorised in themes</p> <ul style="list-style-type: none">- Educational events- Peer-support groups- Meeting the adult care staff- Online support- Joint consultation <p>(Figure 2)</p>		<p>Method</p> <p>Individual interviews with parents of chronically ill adolescents (n=11)</p> <p>Findings</p> <p>The parents’ preferred initiatives:</p> <ol style="list-style-type: none">1) Online support/website2) Educational events3) Transfer consultation <p>Overall findings:</p> <ul style="list-style-type: none">- Feeling acknowledged vs. feeling excluded- Perceived differences between paediatric and adult care- Feeling safe vs. entering the unknown (Thomsen et al. 2021)			
2. Identifying theory	2 Theoretical framework					
	<p>Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART)</p> <p>Focus on the modifiable factors: knowledge, skills/self-efficacy, beliefs/expectations, goals/motivations, relationships/communications and psychosocial/emotions</p> <p>(Schwartz et al. 2011)</p>					
3. Modelling process and outcome	3a Ideas generation		3b Outcome brainstorm		3c Logic modelling	
	<p>Method</p> <p>World café workshop with parents, chronically ill adolescents and health care professionals (n=14)</p> <p>Findings</p> <p>Initial draft of the three initiatives</p> <p>See supplementary materials (Appendix 2)</p>		<p>Method</p> <p>Virtual brainstorm on possible outcome with collaboration group (three parents and two adolescents)</p> <p>Findings</p> <p>Transition readiness, self-management, handing over responsibility and uncertainty</p>		<p>Method</p> <p>A basic logic model was developed based on results from workshop and outcome brainstorm and guided by the SMART theory</p> <p>Findings</p> <p>Figure 3</p>	
	The fully developed intervention					
4. Final intervention	<p>Method</p> <p>The final intervention was developed based on results from the three above-mentioned development phases, and adjusted in cooperation with the collaboration group as well as clinical staff from the included outpatient clinics in order to increase the intervention’s relevance and feasibility.</p> <p>Results</p> <p>ParTner-STEPS: Parents in Transition – a Nurse-led Support and Transfer Educational Program (Figure 4)</p>					

Figure 1

The overall process of developing a brief transition program

Search strategy	Flow chart of the screening process	Review findings
<p>Search term Parent*[Title] OR Mother*[Title] OR Father*[Title] AND Transfer*[Title] OR Transition*[Title] AND adolescent*</p>	<pre>graph TD; A[Unique records in total (n=342)] --> B[Records after title screening (n=72)]; A --> C[Records excluded at title (n=270)]; B --> D[Records after abstract screening (n=20)]; B --> E[Records excluded at abstract (n=52)]; D --> F[Studies included (n=12)];</pre>	<p>Parents’ suggested interventions, categorised in themes</p>
<p>Title screening: Excluded if:</p> <ul style="list-style-type: none">• Not in English• Parents’ needs not addressed• Transfer to own home, motherhood, school or transfer from intensive care to regular ward• Published before 1998		<p>Educational events with various topics related to being a parent of a chronically ill adolescent and the transition phase (DaWalt et al., 2018; Taylor et al., 2017; Akre et al., 2015)</p>
<p>Abstract screening: Excluded if:</p> <ul style="list-style-type: none">• Adolescent with cognitive disabilities• Parent’s views on a youth program/intervention		<p>Peer-support groups with opportunities for sharing experiences in person or online (Akre et al., 2018; Akre et al., 2015; Kingsnorth et al., 2011; Holtz et al., 2018)</p>
<p>Full-text screening: Eligibility if:</p> <ul style="list-style-type: none">• Parent intervention and parents’ need for an intervention		<p>Meeting the adult care staff before transfer (van Staa et al., 2011; Colver et al., 2018; Suris et al., 2017)</p> <p>Online support - a website or app with advice and guidance (Holtz et al., 2018; Holtslander et al., 2012)</p> <p>Joint consultation with staff from paediatric and adult care, including the parents (Rutishauser et al., 2011; Heath et al., 2017)</p>

Figure 2

Search strategy, flowchart and results

Figure 3

Basic logic model of the intervention

Figure 4

Model of ParTNer-STEPs

Supplementary Files

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