ParTNer-STEPs: Parents in Transition – a Nurse-led Support and Transfer Education Program: study protocol for a randomised control trial

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Abstract

Background Transfer from paediatric to adult care for chronically ill adolescents is associated with no-shows and low treatment adherence, as well as anxiety and concerns among parents. Studies show that support for parents results in better transition for both adolescents and parents. The overall goal is to improve chronically ill adolescents' transition to adult care by preparing and supporting the parents. The study aim is to improve parents' (of chronically ill adolescents, 16-18 years) transition readiness by offering them a brief transition program.

Method The intervention will be evaluated in a randomised controlled trial (RCT) study over two years. The project will be carried out in four paediatric and adult outpatient clinics at Rigshospitalet, Copenhagen University Hospital, Denmark: nephrology, hepatology, neurology and rheumatology. The intervention consists of a brief transition program (ParTNer-STEPs) targeting parents of chronically ill adolescents aged 16,5 -18 years old. The program consists of three components: 1) a website with information about the adult department and legal changes as well as advice from other parents and young people, 2) online educational events (webinars) for parents and 3) transfer consultations across the paediatric and adult department. Based on a power calculation, we aim to include parents of minimum 62 adolescents. The trial is carried out in 2021-2023, with main measurements at pre-intervention baseline, at transfer, and three months follow-up (post-intervention). Primary outcome: Parents' transition readiness (TR). Secondary outcomes: Adolescents' TR, Allocation of responsibility, Uncertainty and quality of life.

Discussion The study will establish whether ParTNer-STEPs is effective in increasing parents´ and adolescents´ TR, reducing parental uncertainty, and facilitating a shift of treatment responsibility from the parents to the chronically ill adolescent.

Trial registration

Keywords Adolescent, chronically ill, parents, transitional care and patient transfer.

Background

Parents play an essential role during childhood. Especially in the case of chronic illness, parents have a great responsibility for their child's daily care and treatment. An important milestone in adolescence is gradual independence from parents, and in chronic illness, a gradual shift in treatment responsibilities from the parents to the adolescent is expected (Christie and Viner 2005, Williams, Mukhopadhyay et al. 2007, DiClemente 2009, Shaw, Heath et al. 2021).

Studies have found that parents of chronically ill adolescents form a particularly close bond with their child, and may fear handing over treatment responsibilities to the teenager (Akre and Suris 2014, Woodgate, Edwards et al. 2015, Thomsen, Khoury et al. 2019). This could delay individuation (Suris, Michaud et al. 2004). We have also found that parents were concerned and felt uncertain about their child's transition to adult care (Thomsen, Hanghoj et al. 2021).

The organisational differences in paediatric and adult care can make the transition difficult. Furthermore, the expectations of both the parents and the adolescent change profoundly with an increasing focus on the young patient´s autonomy (van Staa, Jedeloo et al. 2011). Studies have found that a significant proportion of chronically ill adolescents develop complications and experience exacerbations of their disease during the transitional phase (Gore, Bloem et al. 2011). In the case of organ transplantation, adolescents have a significantly higher risk of graft failure compared to children and adults (Andreoni, Forbes et al. 2013, Foster, Dahhou et al. 2016). Studies have shown that the transition phase also affects the parents significantly, including an increased risk of developing anxiety and stress (Akeson, Worth et al. 2007, Fredericks, Dore-Stites et al. 2011, Rutishauser, Akre et al. 2011, Heath, Farre et al. 2017, Sarigol Ordin, Karayurt et al. 2017).

Studies have showed that appropriate parental support can increase adolescents' adherence to treatment (King, Berg et al. 2012, Reed-Knight, Blount et al. 2014), while both parents' difficulties in delegating treatment responsibility and lack of parental support constitute significant barriers to adolescents' treatment adherence (Hanghoj and Boisen 2014).

Lack of transitional care before transfer to adult care is associated with an increased number of no-shows at outpatient clinics. International studies have found that 25-50% of chronically ill adolescents do not attend their first consultation in adult care and there is a significant over-frequency of no-shows in the 17 to 40-year-old group (Downing, Gleeson et al. 2013, Eriksen and Kjellberg 2013, Gleeson, Davis et al. 2013).

In the last decade, there has been an increased focus on transition programmes targeting adolescents (Gabriel, McManus et al. 2017, Schmidt, Ilango et al. 2020). A systematic review from 2017, a cohort study from 2018, and several recommendations conclude that health care professionals (HCP) also should focus on supporting parents in their transition and providing the parents with both help and tools to support their child´s transition (NICE 2016, Heath, Farre et al. 2017, Colver, McConachie et al. 2018, DanishHealthAuthority 2020). Our clinical experience has shown that adolescents´ self-management skills are mainly developed at home, guided by their parents, rather than in consultations with health professionals. Even though a need for parental support during transition has been established, there have, to our knowledge, not been developed and evaluated any transition programs targeting parents.

Based on The UK Medical Research Council's (MRC) guidance on developing, evaluating and implementing complex interventions (Craig, Dieppe et al. 2019) we have developed and pilot tested a brief transition program targeting parents, ParTNer-STEPs. The transition theory SMART guided the overall focus of the intervention. The program’s feasibility and relevance were secured by inviting parents, adolescents and HCP in a cocreation process during each step in the development phase (A thorough description of the development phase will be published elsewhere).

Material and method

Aim and hypotheses

The overall goal of this study is to improve chronically ill adolescents’ transition to adult care by preparing and supporting the parents.

We hypothesize that a nurse-led transfer intervention focusing on parents' knowledge, skills and attitudes will:

1) improve the parents´ readiness for their child’s transition to adult health care
2) support the parents’ gradual handing over of treatment responsibility to the adolescent and,

that an improvement in parental transition readiness will

3) strengthen the adolescent’s self-management skills and increase his/her readiness for transition.

Thus, the study aim is to improve parents’ (of chronically ill adolescents, 16-18 years) transition readiness by offering them a brief transition program.

Design

The study design is a randomized controlled trial (RCT) study with one intervention arm (ParTNer-STEPs: Parents in Transition – a Nurse-led Support and Transfer Education Program + standard care) compared with a control arm (standard care).

Setting

The intervention will be carried out at the nephrology, hepatology, neurology and rheumatology paediatric and adult outpatient clinics at Copenhagen University Hospital, Rigshospitalet, Denmark. We have chosen these four specialties, because low treatment adherence and non-attendance in the patient group could result in permanent disabilities or critical consequences. In Denmark, adolescents transfer to adult care when turning 18 years old regardless of the adolescent's maturity or transitional readiness. Each paediatric clinic has at least one youth ambassador (a nurse with special interest and training in adolescent medicine). The existing transitional care includes youth consultations using the split-visit model, where health care professionals (HCP) both spend time alone with the adolescent and with the adolescent and parents together (Borus and Woods 2016) with the THRxEADS anamnesis (Transition, Home, Medication and treatment, Education and Eating, Activities and affect, Drugs and Sexuality) (Chadi, Amaria et al. 2017) as the basis of the conversation as well as assessment of adolescent transition readiness. The clinics currently have no programmes targeting parents.

Participants

Eligibility criteria

Participants are parents, stepparents or guardians (will subsequently only be referred to as parents) of chronically ill adolescents affiliated with the four paediatric outpatient clinics. The adolescents will participate in the intervention and contribute with outcome measurements. Parents who meet the following criteria will be invited to participate in the study. *Inclusion criteria:* Parents to chronically ill adolescents who 1) are aged 16.5-17.5 years (can be recruited up to six months before transfer), 2) have been diagnosed for minimum six months, 3) have regular check-ups at the Department of Paediatrics and Adolescent Medicine's nephrology, hepatological, neurological and rheumatological outpatient clinics at Rigshospitalet, Denmark, 4) will be transferred to an adult hospital department and 5) are mentally and cognitively able to take responsibility for their own treatment. *Exclusion Criteria:* 1) Parents who do not read and speak Danish and 2) Parents of adolescents who will be transferred to their family doctor at the age of 18 year.

Recruitment

Potential participants will be contacted by the paediatric nurses at the four outpatient clinics and briefly informed of the study. If the parents are interested in the project, the project coordinator will provide the parents with oral and written information of the study, including the fact that they can withdraw from the study at any time without consequences for their child's treatment. There will also be provided written information to their adolescent child and the adolescent will also get the opportunity to speak directly to the project coordinator, if they have any questions. Finally, after time to consider their participation in the project, a written consent will be obtained. Under the recruitment process we will carefully consider the risk of coercion, autonomy, and confidentiality.

Randomisation

Randomisation will be conducted after screening and written consent of parents. Randomisation will by conducted by computer-generated (REDCap) random numbers as a dyad (adolescent and parents) with a ratio of 1:1 (using algorithm to stratify by the four outpatient's clinic). The dyads will be randomised into two groups 1) receive the intervention (standard care plus ParTNer-STEPs until their child´s transfer to adult care) or 2) standard care (control group). Once the database has defined a dyad's allocation, no changes can be made. Those randomised to the intervention arm will then receive access to the intervention materials.

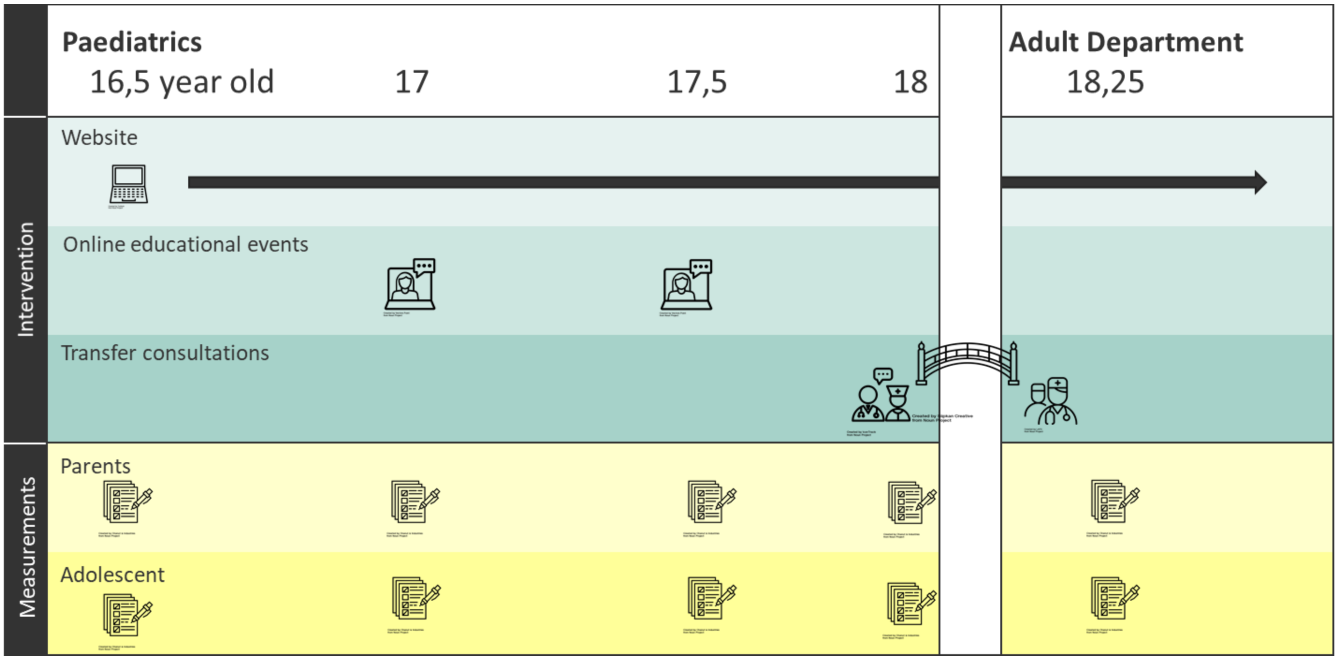
Intervention

The intervention consists of a transfer program (ParTNer-STEPs), offered to the parents from 6 – 18 months before their adolescent child is transferred to adult care (depends on when the participant is recruited before transfer).

ParTNer-STEPs (Parents in Transition – a Nurse-led Support and Transfer Education Program) (figure 1) consist of

1) an informative website
2) online educational events for parents
3) transfer consultations across the paediatric and adult department.

Figure 1: Model of the intervention



Informative website available for parents from recruitment until follow-up. The website will focus on:

- dissemination of relevant knowledge regarding legal changes, education questions etc
- guidance and tools in relation to how the parents can prepare their adolescent child
- introduction to adult care incl. expectations alignment
- experiences from other parents and adolescents
- Q&A incl. parents' possibility to submit own questions

Online educational events offered twice a year as an online webinar with short presentations on different topics. The webinar will not be available for parents after their child has transferred to adult care. The educational events will be focused on:

- Emotions and thoughts during transition
- Adolescence, chronic illness and autonomy
- Knowledge sharing

Transfer consultations across the paediatric and adult department. The transition consultations consist of:

- a preparatory consultation (3-6 months before transfer) with the paediatric nurse where focus is on the adolescent´s skills, expectations, goals and emotions).
- a farewell consultation with the paediatric nurse (0-3 months before transfer). Focus on relationships, expectations, goals
- a joint consultation (at transfer) where both the paediatrician and the adult physician will be present Focus on cooperation/partnership, relationships, knowledge
- a welcoming consultation with the nurse from the adult care (0-3 months after transfer) Focus on expectations, skills, relationships

HCP training

All HCP associated with the project will receive training in the intervention before onset. The HCP involved will receive a script for the four consultations, in which the purpose, content, procedure and the subsequent documentation are described. All nurses have or will receive training in developmentally appropriate communication and care.

Materials and procedures

Primary outcome

Transition readiness (TR)

TR measured by the questionnaire Medical self-management and transition readiness. The questionnaire is developed and validated by Williams et al, 2011 (Williams, Sherman et al. 2011). The questionnaire consists of 21 Likert-scaled items assessing the adolescent ‘s awareness of their health condition and ability to make decisions relevant to their health care needs. All items ask participants to respond on a five item Likert-scale (1=strongly disagree, 2=disagree, 3= neither disagree nor agree; 4=agree and 5= strongly agree). A high score indicates transition readiness. Answered by parents (primary) and adolescent (secondary outcome)

Main secondary outcome

Allocation of Responsibility (AoR)

AoR measured by the questionnaire Allocation of Responsibility developed and validated by Bilhartz et al, 2015 (Bilhartz, Lopez et al. 2015) consisting of 13 items. Respondents can choose from one of four answers: 1) parent/guardian takes primary responsibility, 2) responsibility is shared between the parent/guardian and the adolescent, 3) adolescent takes primary responsibility, or Not Applicable or No One Does This. A high score indicates a high level of adolescent responsibility. Answered by parents and adolescents.

Uncertainty

Parental uncertainty measured by the Uncertainty-Scale. The scale is developed and validated by Burström et al., 2019 (Burstrom, Acuna Mora et al. 2019) and measures parental uncertainty during transfer of their child from paediatric to adult care on a linear analogue scale from 0 (not uncertain at all) to 100 (extremely uncertain). A high score indicates a high level of uncertainty. Answered by parents.

Health-related quality of life

Health-related quality of life measured by EQ-5D-5L. The questionnaire comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. A low score indicates better health-related quality of life. Answered by adolescents

Experiences of transfer

Transfer experiences measured by a self-developed questionnaire with 11 items based on modifiable factors from the SMART transition theory (Schwartz, Brumley et al. 2013). All items ask participants to respond on a five item Likert-scale (1=strongly disagree, 2=disagree, 3= partially agree; 4=agree and 5= strongly agree). A high score indicates a positive experience of transfer. The questionnaire has been content and face validated by parents. Answered by parents.

Transfer satisfaction

Transfer satisfaction measured by a single question: '*On a scale of 0-100, how satisfied have you been with yours/your child's transition to the adult care*?' The scale is a linear analogue scale from 0 (very unsatisfied) to 100 (very satisfied). A high score indicates a high level of satisfaction. Answered by parents and adolescents.

Data collection and management

Data will be collected though questionnaires at baseline and every six months up to three months after the adolescent's transfer to adult care (Figure 2). Transfer time is registered as the date for the last consultation at paediatric. Questionnaires will be sent out via email or by post based on participants´ wishes. The questionnaires will take approximate 10 minutes to complete. All data will be handled confidential and stored in the password protected software REDCap.

Figure 2 Model of time frame

Questionnaires	Time frame				
	Baseline	6 months	12 months	Transfer	3 months follow-up
Socio-demographic					
Parents	X				
Transition readiness (TR)					
Parents	X	X	X	X	X
Adolescent	X	X	X	X	X
Allocation of Responsibility (AoR)					
Parents	X	X	X	X	X
Adolescent	X	X	X	X	X
The Uncertainty Scale					
Parents	X			X	
EQ-5D-5L					
Adolescent	X			X	X
Experiences of transfer					
Parents					X
Transfer satisfaction					
Parents					X
Adolescent					X

Statistical analysis

Sample size

No previous studies have focused on whether it is possible to increase parents´ transition readiness score (TR) by offering them a brief transition program. A previous cross-sectional study found that parents of chronically ill adolescents have an average TR score of 3.12 (SD 0.68) (Williams, Sherman et al. 2011). Based on our clinical experience, advice from the author of the primary outcome questionnaire, and a review of each item in the questionnaire (Medical self-management and transition readiness), we assume that we will be able to increase the parents' TR score in the intervention group with 0.5 points.

We are planning an RCT study with a continuous response variable from an independent control- and intervention group with 1 control(s) per intervention subject. Based on the above-mentioned cross-sectional study we assume the response within each group will be normally distributed with standard deviation 0.68. If the true mean difference in the intervention and control group is 0.50, we will need to include parents of 31 individual adolescents in each group to be able to reject the null hypothesis that the population means of the intervention and control groups are equal with probability (power) 0.80. The Type I error probability associated with this test of this null hypothesis is 0.05. Thus, we need to recruit a total of parents of at least 62 individual adolescents.

Data analysis

A detailed statistical analysis plan (SAP) will be developed when all participants have completed the final measurement (three months after the completed intervention) in collaboration with statisticians. We plan to include t tests, Pearson's Chi-square test, regression analysis, intention to treat and linear models. Logistic regression analyses will be carried out to describe transition readiness and allocation of responsibility within the intervention group and compare it to the control group's score. Both data from parents and their adolescent child will be analyzed, both as dyads and separately in groups of parents/adolescents. The SAP will be confirmed among all project group members before we will be looking into data.

Missing data, drop out and lost to follow up

Loss to follow-up and missing data for various reasons is impossible to avoid in randomized trials. We will apply the analysis framework in which missing data related to the intention-to-treat approach depend on making plausible assumptions about the missingness of the data and including all participants in subsequent sensitivity analyses.

1. Attempt to follow up all randomized parents, even if they withdraw from allocated treatment.
2. Perform a main analysis of all observed data that are valid under a plausible assumption about the missingness of the data (i.e., Model-based: data as observed; using linear mixed effects models, assuming that data are 'Missing at Random' [MAR]).
3. Perform sensitivity analyses to explore the effect of departures from the assumption made in the main (#2) analysis (i.e., a non-responder-imputation: using the value at baseline to replace missing data will correspond to a non-responder imputation; these models will potentially be informative even if data are 'Missing Not At Random' [MNAR]).
4. Account for all randomized parents, at least in the sensitivity analyses (covered by #2 and #3 above, plus the corresponding analyses based on the per protocol population).

The interpretation of the corresponding statistical measures of uncertainty of the treatment effect and treatment comparisons will involve consideration of the potential contribution of bias to the P-value, 95% confidence interval, and of the inference in general.

Our primary analysis population will be all parents with available data at baseline, statistically modelled using repeated-measures linear mixed effects models (see above). These models will be valid if data are 'MAR'. *Sensitivity:* We will analyze all variables, with missing data being handled by multiple imputation techniques. When the different sensitivity analyses agree, and the analyses on the sensitivity analyses and the main analysis lead to essentially the same conclusions, confidence in the trial results is increased.

Discussion

In the last decade, there has been an increased focus on transition programmes targeting chronically ill adolescents (Gabriel, McManus et al. 2017, Burke, Kirkham et al. 2018, Schmidt, Ilango et al. 2020). Although parents play a significant role regarding medication and treatment in the case of paediatric chronic illness, there is still a lack of structured programmes to support parents during their child's transition, including transfer from paediatric to adult care. To our knowledge, this is the first intervention that target parents of chronically ill adolescents during their child's transition to adult care tested in a randomised trial. Our intervention is developed based on the hypothesis, that a nurse-led transfer intervention targeting parents will both improve the parents´ readiness for their child's transition to adult health care and strengthen the adolescent's self-management skills. Our setup with both measurements from the parents and the adolescents will give us the opportunity to examine if ParTNer-STEPs is effective in increasing parents' and adolescents' transition readiness, reducing parental uncertainty and facilitating a shift of treatment responsibility from the parents to the chronically ill adolescent.

The intervention will be evaluated in multiple outpatient clinics across paediatric and adult care and performed by clinic staff with an interdisciplinary background in a real-life clinical setting. On that background, we have chosen a complex intervention design as the intervention will involve several interacting components (Craig, Dieppe et al. 2013, Craig, Dieppe et al. 2019). During the development phase we used participatory design to involve relevant stakeholders (parents, adolescents, and HCP) in the development of the program due to the absence of transfer interventions targeting parents. (Simonsen and Robertson 2013, Clemensen, Rothmann et al. 2017). Thus, we ensured the users' (parents) needs were being represented and met in the program by incorporating the principles of participatory design in the development of the intervention. Furthermore, the involvement of HCP secured the feasibility and relevance of the interventions in the clinical practice and increased the chances of successful implementation (Garne Holm, Brødsgaard et al. 2017).

Despite these efforts, the complexity of our intervention including multiple components, many stakeholders and different settings) may affect our results considerable. This is an area we will address during our discussion of the major findings. We will also, in line with the MRC recommendation, conduct a process evaluation, which will be reported subsequently.

A part of the intervention (the transfer consultations) will take place in the clinic and out of our control, why the performance/ execution of this part relay on the HCP participation and willingness to adhere to the consultation scripts. Thus, daily clinical issues as staff shortage, problems in the interprofessional cooperation and time pressure might hinder the HCP in conducting the intervention as described. We have tried to prevent this by including the HCP in the development of the intervention with continuous discussions of realistic workflows and resources. We will also be in close contact with the HCP during the intervention in order to detect and act on possible barriers/challenges e.g. vacancies.

Trial status

Recruitment starts in July 2021 and is ongoing.

Abbreviations

HCP: Health Care Professionals; RCT; Randomized Control Trail; TR: Transition Readiness; AoR: Allocation of Responsibility; SAP: Statistical Analysis Plan; MAR: Missing At Random; MNAR: Missing Not At Random'.

Declarations

Ethics approval and consent to participate

The project will adhere to the regulations established by the Ethical Guidelines for Nursing Research in the Nordic Countries, all relevant laws and regulations in Denmark, and to the Declaration of Helsinki II (World-Medical-Association, 2008) and is approved by the Danish Data Protection Agency, reference no. VD-2018-396. We have formally enquired the regional research ethics committee with a full clinical description of the project. They have reviewed the project and given us permission to perform the study (reference no. FSP 20031083). According to Danish legislation studies such as register research projects, interview surveys and questionnaire surveys can be performed without formal ethical approval cf. section 1 and 2 in the committee law as no human biological material is included (National Committee for Health Research Ethics https://en.nvk.dk/rules-and-guidelines/act-on-research-ethics-review-of-health-research-projects).

Before obtaining consent from the parents, ELT will provide all participants with oral and written information of the study, including the fact that they can withdraw from the study at any time without consequences for their child's treatment. We will carefully consider the risk of coercion, autonomy, and confidentiality. Written, informed consent to participate will be obtained from all participants.

Consent for publication

Not applicable.

Availability of data and materials

Data will be made available from corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors contributed to the design and/or delivery of the trial. ELT leads the overall research project and drafted the manuscript together with BAE and KB. SH and HH significantly supported the manual drafting. All authors were key to designing the intervention as well as the study design. All authors have inputted to the manuscript draft and have read and approved the final version.

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