Original Article

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Transition us together: development of a parent-centered toolkit to support adolescents with rheumatic disease transition to adult care

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Abstract

Objectives: While the transition period can be a difficult time for adolescents with chronic health conditions, parents also face challenges in understanding their changing role and how to support their children. To date, minimal interventions have focused on supporting and empowering parents during this period.

Methods: We co-created a toolkit with and for parents to help prepare them for their child's transition to adult care. The toolkit was created using an iterative process of reviewing existing resources with integrating feedback from rheumatology patients and parents. Input was sought from the Family and Youth Advisory Councils at McMaster Children's Hospital in Hamilton, Canada.

Results: The two components of the toolkit include a Transition Road Map and a Parent Guide to Transition. Five

domains of transition readiness were established as pillars of the Road Map. Within each domain, a checklist to achieve self-management was established. The Parent Guide was developed to highlight important information including defining transition, outlining differences between pediatric and adult care, and providing tips on helping and supporting adolescents.

Conclusions: A Parent Toolkit directed at the Transition from Pediatric to Adult Rheumatology Care was developed and underwent extensive review with multiple stakeholders. Ongoing research on its impact on transition readiness is underway.

Keywords: (3–5): transition to adulthood; empowerment; rheumatology; self-management; toolkit.

Introduction

The management of pediatric chronic disease is complex due to the intricacies of treatment, the attention required for disease monitoring, and the interplay between physical health, psychosocial wellbeing, and developmental status. These challenges are heightened as adolescents transition from child-centered to adult-oriented healthcare systems. This transition period is marked by higher symptom burden, morbidity and mortality, and poor medical adherence [1–3]. Within pediatric rheumatology specifically, up to 50% of transfers to adult care are unsuccessful, with loss-to-follow-up and low treatment adherence as the most common issues [4]. The transition period also poses unique challenges to parents and caregivers (herein referred to as “parents”), as they struggle to define new roles and responsibilities in their child's care [5].

As families navigate the transfer from pediatric to adult care, feelings of uncertainty can emerge. Parents report anxiety over leaving pediatric specialists and a lack of information about transition [6, 7]. High levels of parental uncertainty can pose a barrier to an effective transition [8]. Conversely, parents report that playing an active role in

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transition planning fosters security and confidence in themselves and their teens [9].

The transition from pediatric to adult care necessitates a restructuring of roles, with transfer of responsibility shifting from parent to adolescent. Abrupt removal of a parent's roles and responsibilities in their child's health-care management can be disempowering and/or distressing [10]. Importantly, families who struggle most with renegotiating responsibilities report less successful transitions and poorer future health outcomes [11, 12]. This underscores the need for parental support and guidance in navigating this process.

Self-management and self-advocacy skills are predictors of successful transition to adult care. Although parents recognize the importance of promoting independence, they can struggle with knowing how to do this while balancing their child's medical safety [13]. Interestingly, parents who report more concern and uncertainty related to transition are more likely to assume greater responsibility and less likely to encourage self-advocacy [11]. These adolescents report deficits in understanding their disease and are less likely to communicate directly with healthcare professionals. Therefore, providing parents with tools to promote self-advocacy and self-management skills early is critical for ensuring a successful transition.

Despite parents having identified a need for guidance and support in navigating the transition period, there are few interventions aimed at assisting them through this complex and challenging journey. The resources that do exist (e.g., websites, pamphlets) are typically integrated in healthcare practice, with sparse literature on the impact of these interventions on the transition process. With this in mind, our team developed a parent-oriented toolkit for the transfer from pediatric to adult rheumatology care, with the intention of promoting a smooth and effective transition.

Methods

Our multidisciplinary team at McMaster Children's Hospital (MCH) in Hamilton, Ontario, Canada began the design of a transition toolkit, targeting adolescents aged 14–18 years and their parents, with a review of the literature and identification of existing transition resources from other academic pediatric centers [14]. Our team members include pediatric and adult rheumatologists at McMaster University, an Advanced Clinical Practitioner in Arthritis Care physiotherapist, pediatric rheumatology clinic nurse, physiotherapist, and child life specialist, a pediatric resident, the Director of Rheumatology Research, adolescent patients and parents from pediatric rheumatology clinic, and a dual (pediatric and adult) trained physiatrist with special clinical and research interests in transition to adulthood

and a CanChild Scientist, a research center dedicated to generating knowledge and transforming lives of children and youth with developmental conditions and their families [15]. Components deemed to be of highest importance to our patient population based on discussions we had with the team were selected to incorporate. It was decided that the toolkit should contain separate parent and patient components, aligning to complement each other. The "Parent Guide" (herein referred to as the "Guide") would include information on the transition process, differences between pediatric and adult care, differences between the role of the parent in each setting and how to support adolescents through the process. The "Transition Road Map" (herein referred to as the "Road Map"), aimed to helping parents guide their adolescents, would identify key areas ("domains") of transition readiness: Self-Advocacy, Medication Management, Overall Health and Safety, Lifestyle and Behaviors, and Future Planning. Within each domain, a checklist of items to achieve independence towards transition was created (Table 1). These key outlines were taken forward through the iterative process described in Figure 1 and below.

Results

Identification of topics relevant to transition care

At each stage, feedback was sought from team members. The domains and key skills/responsibilities were compiled and presented, individually, to three adolescent rheumatology patients (2 male, 1 female) identified by the clinical team as patients interested in co-creating these tools. Each patient independently engaged in an hour-long discussion with the Research Director. The discussion focused on each domain name, content within each domain, wording of skills and visual presentation. Following the flow of Figure 1, this iterative review process led to the development of drafts of content for each component of the toolkit. This information was relayed to a graphic designer to yield drafts for further review.

Review of materials with key collaborators

After the initial design was completed, the Guide and Road Map were presented to the MCH Family Advisory Council (FAC) along with key members of hospital administration. Feedback was provided on content, readability, organization, and comprehensiveness. It was identified that the Parent Guide should include differences between pediatric and adult care, and where the parents can turn to for help. During review, parents also reported "I wish this existed when my teen transitioned" and "I hope this Guide comes to nephrology clinic". Their feedback was incorporated, and the Road Map alone was

Table 1: Transition readiness domains and checklists developed for the transition road map.

Transition-readiness domain	Checklist components
Self-Advocacy	I ask my healthcare provider questions about my health at each visit I am comfortable meeting with my healthcare providers on my own I understand what patient privacy and confidentiality means (for example, who can get information about your health or who can know about it) I understand what it means to consent to healthcare treatments I ask for what I need from my healthcare provider I can describe my disease to someone when I am asked I know how/where to access mental health support if I need it I know how to advocate for myself if I require special supports in my school (college or university) or my workplace (special seating, keyboard, access to note taker, accommodation for exams, arranged dismissals, etc.)
Medication Management	I know the names and doses of the medications I take or have a list of them on me at all times I take my medications without being reminded I know why I take my medications I know the side effects of my medications I refill my own prescriptions before they run out I know how to contact my pharmacist if I need to I know how to store my medications I know how/when to take my medications
General Health	I carry my own health care I book my own medical appointments I know all my healthcare providers and who to contact when I need help or have a question I know if I have any medication allergies I know what to do in a medical emergency (who to call, where to go) I will contact my doctor if I need to I understand my tests and procedures (joint injection, surgery, etc.) and any risks associated with them
Lifestyle and Behaviors	I discussed how alcohol can affect my health and any interaction with my medications I discussed how tobacco, marijuana and other drugs affect my health and any interactions with my medications I understand the importance of a healthy diet and physical activity for my health I know how to prevent unplanned pregnancies and sexually transmitted infections (STIs) I understand how my health and medications could affect pregnancy
Future Planning	I discussed my current health/medication insurance coverage and how that may change over time as I get older I am able to get myself to and from my healthcare appointments I know how to access supports for getting to and from my appointment if I need help I know how to access supports for getting around (being social, visiting, school, shopping, errands) I have an idea about what I want to do in my future (college, university, work) and how I can access resources to help me get there I know how to access financial support for living and school/work expenses if I need it I know how to access support for assistance with driving/getting a driver's license

subsequently presented to the MCH Youth Advisory Council (YAC). It was highlighted that priorities included adding similar content from the Parent Guide to the Road Map including differences between pediatric and adult care and adding a reminder to the Parent Guide to encourage independence in the process. Again, we heard comments such as “I wish this existed in pediatric cardiology clinic”. Feedback was incorporated with the help of the graphic designer to refine the toolkit for final review by the research team and members of the Pediatric Rheumatology Transition Clinic.

Final products

The Guide and Road Map were printed and brought to the Pediatric Rheumatology Transition Clinic. The finished and printed copy of the product was reviewed with three patients and families and minor adjustments were made following this feedback. The final products have since been printed and begun distribution in our Pediatric Rheumatology Transition Clinic at MCH. The toolkit is available online on the CanChild website (<https://www.canchild.ca/en/research-in-practice/current-studies/trust-study>).

Figure 1: Steps in the development of transition road map and parent guide.

Discussion

For the development of the Parent Guide, initial searches revealed scant existing transition resources directed to empowerment and support of parents. As a result, our multidisciplinary team identified areas important for parents to understand based on clinical experience and conversations with parents regarding what they wanted and needed to know. The result was the development of a Guide that includes definitions of healthcare transition, the importance of helping to prepare adolescents for the transition process, and ways to support adolescents through the process.

For the development of the Road Map, existing guides/tools were reviewed to outline the process of transition to adult care within a variety of pediatric subspecialties. Upon identifying the five domains (Self-Advocacy, Medication Management, Overall Health and Safety, Lifestyle and Behaviors, and Future Planning), checklists within each were created. Each checklist was intended to be generalizable to adolescents with any rheumatic condition while also being adaptable to other

pediatric subspecialties. Further, each could be completed at an adolescent's own pace, in any order, and can be taken with them as they begin adult care for ongoing goal setting. The goal is that parents will work through the checklists with their adolescent and encourage goal setting and transfer of responsibility over time.

It took approximately one year to develop the final Transition Toolkit and is directed at Pediatric Rheumatology parents and their adolescents but can be used beyond transition to adult care for those that need it. Checklists are intended to be used in any order, and at each adolescent and parents' own pace. Finally, the content can be adapted to other pediatric subspecialties. These items have been printed and begun distribution in clinic at enrollment in our ongoing research study which will evaluate their impact on transition readiness for our patients over time.

Limitations of this study include that feedback was received from a single institution, and that the toolkit is only available in the English language, however future directions involve the translation of material to other common languages and formats.

Conclusions

Transition from pediatric to adult care is a difficult time for children with chronic diseases and their families and is associated with increased morbidity and mortality. Research to date has focused on resources for adolescent patients themselves, with limited resources for parents to support their children through this process. Herein, we developed a Parent Toolkit directed at the Transition from Pediatric to Adult Rheumatology Care. The development was a multi-phase iterative process with involvement of multiple stakeholders from a variety of backgrounds, most importantly patients and parents, to ensure the toolkit is both valuable and usable.

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