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Research Article

Youth and Caregiver Perspectives of Barriers and Facilitators to the Transition From Pediatric to Adult Care: A Qualitative Descriptive Study

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Abstract

Background: Transitions from pediatric to adult care can be a complex process for youth and their caregivers. Exploring barriers and facilitators to transitions from pediatric to adult care is critical to inform the design and implementation of evidence-based interventions to improve transition processes. Previous literature has focused on describing experiences with transition; however, determinants influencing transitions need further exploration. **Objective:** This study explored barriers and facilitators to the transition from pediatric to adult care from youth and caregiver perspectives to inform future intervention design, implementation, and evaluation to support transitions in care. **Methods:** This study used a qualitative descriptive design guided by the COM-B Model of Behaviour. Youth and caregivers of youth in Nova Scotia, Canada, were recruited for semi-structured interviews. Data analysis consisted of directed content analysis, followed by inductive thematic analysis to identify barriers and facilitators of transitioning from pediatric to adult care. **Results:** A total of nine youth and nine caregivers participated in the semi-structured interviews. We identified barriers and facilitators related to the COM-B Model of Behaviour's components of capability, opportunity, and motivation. Main themes from both the youth and caregiver participants relate to developing health literacy for transition processes, shifting roles to increase youth independence, and the importance of health system coordination. **Conclusion:** This project identified intersecting behavioural and contextual determinants related to youth and caregivers' capability, opportunity, and motivation that influence the transition of care process. These findings will be instrumental for designing and adapting interventions and policies to improve youth transitions from pediatric to adult care.

Keywords: behaviour change, transitions in care, pediatric, qualitative research

Introduction

Transitions from pediatric care into the adult care system for youth with complex health care needs is a common yet challenging process (Fegran et al., 2014). This transition for youth who are also experiencing complex health and social care needs often occurs at a pivotal time in their lives. Readiness to transition from a pediatric system to an adult system is individualized and influenced by many factors, including differences between adult and pediatric care models (Hislop et al., 2016). Youth often find shifting from family-centred to patient-centred care challenging due to the increased autonomy that is required in this setting (Li et al., 2024; Toulany et al., 2022). Caregivers (i.e., parents or guardians of youth) are also impacted by the transition from pediatric to adult care. Caregivers have expressed emotions such as grief, sadness, and desperation during the transition period (Edelstein et al., 2017; Ludvigsen et al., 2021; MacNeill et al., 2022; Rafferty & Sullivan, 2017). They often feel their children are transitioning into adult care based on age rather than level of maturity or preparedness, which leaves them feeling reluctant to engage in the transition process (Bratt et al., 2018).

Many barriers are known to hinder transitions in care (Gray et al., 2018; Varty et al., 2020). Interventions are needed to address these known barriers and support transitions from pediatric to adult care. Guidance from the Medical Research Council and National Institute for Health and Care Excellence suggests that interventions are more likely to be effective if conceptual theoretical models are used in the intervention development (National Institute for Health and Care Excellence, 2007; Skivington et al., 2021). For instance, the Behaviour Change Wheel is a systematic, theory-based guide to intervention design based on the principles of the COM-B Model of Behaviour (Michie et al., 2014). This model suggests that for any behaviour to occur there must be a change in one or more of the following: capacity, opportunity, and/or motivation. Michie et al. (2014) describes capacity as physical or psychological ability, opportunity as physical and social factors, and motivation as automatic and reflective processes that influence behaviour. The Behaviour Change Wheel has been used extensively to guide the design of interventions in health services (Craig et al., 2008; Michie et al., 2014).

To date, there has been limited theory-informed analysis of determinants influencing transitions from pediatric to adult care from youth and caregiver perspectives. To ensure successful development and implementation of transition interventions, a pre-implementation assessment of barriers and facilitators is an important first step (Grol & Grimshaw, 2003). The purpose of this study was to identify barriers and facilitators to youth's transition from pediatric to adult care services, from the perspective of youth and caregivers, to inform future intervention design, implementation, and evaluation.

Methods

Design

This study used a qualitative descriptive design involving semi-structured interviews and focus groups to identify youth and caregivers' perspectives on barriers and facilitators to the transition from pediatric to adult care (Lambert & Lambert, 2012). This current study accompanies a previous phase of the research that identified barriers and facilitators to the transition from pediatric to adult care from the perspective of adult and pediatric health care providers (Cassidy et al., 2022).

Setting

This study was conducted in Nova Scotia, Canada, which is home to one tertiary pediatric health centre (hereinafter referred to as the "pediatric health institution") that serves youth from three Maritime provinces. All adult services are under a separate health authority that serves the rest of the province (hereinafter referred to as the "adult health institution").

Integrated Knowledge Translation Approach

This project employed an integrated knowledge translation approach by engaging knowledge users as team members on the research project. Our knowledge users included administrators and health care provider representatives from the pediatric and adult health institutions and the provincial health department, as well as two patient partners who have lived experience transitioning from the pediatric to adult health institution. These team members were involved in different phases of the research process based on interest and capacity, including development of research questions, interview guide development, recruitment, data collection, data analysis, interpretation of findings, knowledge translation planning, and general project management. Further, the co-lead of the research team, JP, is the coordinator for the Transition of Care Committee (TOCC) based at the pediatric health institution. This committee includes youth, caregivers, health care providers, and community partners who have experience or interest in transition and transfer of care processes. Knowledge exchange meetings were held bi-monthly with the TOCC to facilitate two-way dialogue and feedback on different parts of the research project, including interview guide development, recruitment ideas, analysis of study findings, and knowledge translation planning. These meetings were co-facilitated by the two patient partners of the research team.

Theoretical Framework

This study used the Behaviour Change Wheel's COM-B Model of Behaviour to guide our barriers and facilitators assessment (Michie et al., 2014). As described above, the COM-B Model of Behaviour suggests that for a behaviour to occur, there must be a change in a person's capability, opportunity, and/or motivation. This theory-informed approach supports an exploration of all potential determinants of youths' and caregivers' capability, opportunity, and motivation related to transitions from pediatric to adult care (Michie et al., 2014). This model informed the study's interview questions and provided a framework for data analysis.

Participants

Participants were recruited using a stratified purposive sampling strategy with convenience sampling techniques (Palinkas et al., 2015; Teddlie & Yu, 2007). Pediatric patients were eligible to participate if they had experience with a transition in the past three years with one of three conditions of focus: inflammatory bowel disease, diabetes, or juvenile idiopathic arthritis. Caregivers were eligible to participate if they had a child who had gone through transition with one of the three conditions of focus. Youth and caregivers were also eligible if they were currently in the process of going through transition. We aimed to recruit six to 10 participants per focus group, with a goal of completing two youth focus groups and two caregiver focus groups, as outlined by Wilkinson's recommendations for conducting focus groups to uncover rich data for health-related phenomena of interest (Wilkinson, 1998). We applied Guest et al.'s (2006) qualitative sampling criteria (i.e., clarity of data, alignment with research question, variations and contraindications of data) to determine if additional interviews were needed following data analysis.

Materials

We developed a semi-structured interview guide (see Supplemental Materials) based on previous guides sourced from the literature that focused on examining transitions from pediatric to adult care (Grande et al., 2019; Newlove-Delgado et al., 2019; Ödling et al., 2020). The guides were organized based on the COM-B Model of Behaviour, and included questions regarding the participants' capability, opportunity, and motivation around transitioning from pediatric to adult care, as well as additional prompts if clarification of questions was needed (Michie et al., 2014). A draft interview guide was reviewed by seven youths and two caregivers, all of whom are members of the TOCC based at the pediatric health institution, to ensure questions were relevant and terminology was clear. The guides were refined and edited based on their feedback.

Procedure

Care team members from the ambulatory clinics who see patients with inflammatory bowel disease, diabetes, and juvenile idiopathic arthritis identified potential patients and caregivers who met the parameters of inclusion. A care team member provided a letter of information to potential participants containing contact information for the Research Assistant. Additionally, local organizations such as the Crohn's & Colitis Foundation, Arthritis Society Canada, Diabetes Care Program of Nova Scotia, and Brigadoon Village disseminated recruitment posters.

The Research Assistant met with all participants prior to data collection to review consent forms and obtain informed consent. If a participant was unavailable to attend the focus group time, we offered an option to participate in an individual interview. All participants who expressed interest agreed to participate. Consent forms were reviewed again at the beginning of the focus groups and interviews. Each focus group was facilitated by four members of the research team: the principal investigator (Author CEC), who has been trained in using the COM-B Model to conduct behavioural analyses and design interventions; the knowledge translation coordinator (Author JCK), also trained in the COM-B Model; and two knowledge user research partners (Author JP, health system partner; Author AH, youth patient partner). All focus groups and interviews were conducted via Zoom and audio-recorded using Zoom recording features. Focus groups and interviews lasted approximately 45–60 minutes.

Data Analysis

Each focus group and interview was audio-recorded and transcribed verbatim, with all information de-identified. As a pilot, four reviewers (CEC, JCK, RD, AM) reviewed two transcripts (two reviewers each) using Microsoft Word version 15. For each transcript, the primary reviewer used directed content analysis (Hsieh & Shannon, 2005) and a colour coding system to code similar statements into the three COM-B categories (Michie et al., 2014), while the second reviewer used the comment box to point out any discrepancies. Once the four reviewers had independently reviewed the two transcripts, a meeting was held with all reviewers to go through the two transcripts and come to a consensus on any discrepancies identified. Next, preliminary subthemes within the initial coding scheme of the COM-B Model (Michie et al., 2014) were identified using codebook thematic analysis

(Braun & Clarke, 2022). A codebook was developed based on the COM-B categories and affiliated subthemes, consisting of the following: code name, brief definition, full definition, when to use, when not to use, and an example (MacQueen et al., 1998). After development, all research team members reviewed the codebook, provided feedback, and adapted the codebook accordingly.

All transcripts were imported and coded in NVivo Qualitative Software version 12 (https://lumivero.com/products/nvivo/) by two reviewers (CEC, JCK) using the finalized codebook. From there, both reviewers worked together to further inductively examine the coded data to identify barriers and facilitators to the transition from pediatric to adult care. Next, a final list of themes and summaries was developed and reviewed by the research team. The initial findings were presented to the TOCC at the pediatric health institution, and theme refinement was conducted based on their feedback. Finally, to help with the interpretation of the study findings, we conducted a facilitated discussion with the TOCC and asked members what findings were most surprising and what findings were most helpful. Findings are presented in tabular and narrative format with quotes from youth and caregivers using pseudonyms.

Results

A total of 18 participants (youth *n*=9 and caregivers *n*=9) took part in this study. Youth and caregiver participants were independent of one another. Youth participants' ages ranged from 17 to 21 years. Most youth identified as female (*n*=8) and are currently in the transition process (*n*=5). Most caregiver participants identified as female (*n*=7) and as having youth currently undergoing the transition process (*n*=8).

The findings highlight barriers and facilitators to the transition in care from the pediatric to adult system from the perspective of both youth and caregivers. As described in the section to follow, we identified a range of barriers and facilitators across each of the COM-B components: capability (C), opportunity (O), and motivation (M) for youth, followed by caregivers (see Figure 1).

Youth Findings

Youth participants identified a range of barriers and facilitators regarding transitioning from pediatric to adult care including developing health literacy to support the transition process, readiness for independence, and health system coordination (Figure 1 and Table 1). These themes are further broken down into subthemes and categorized based on the COM-B components. Each subtheme will be described below.

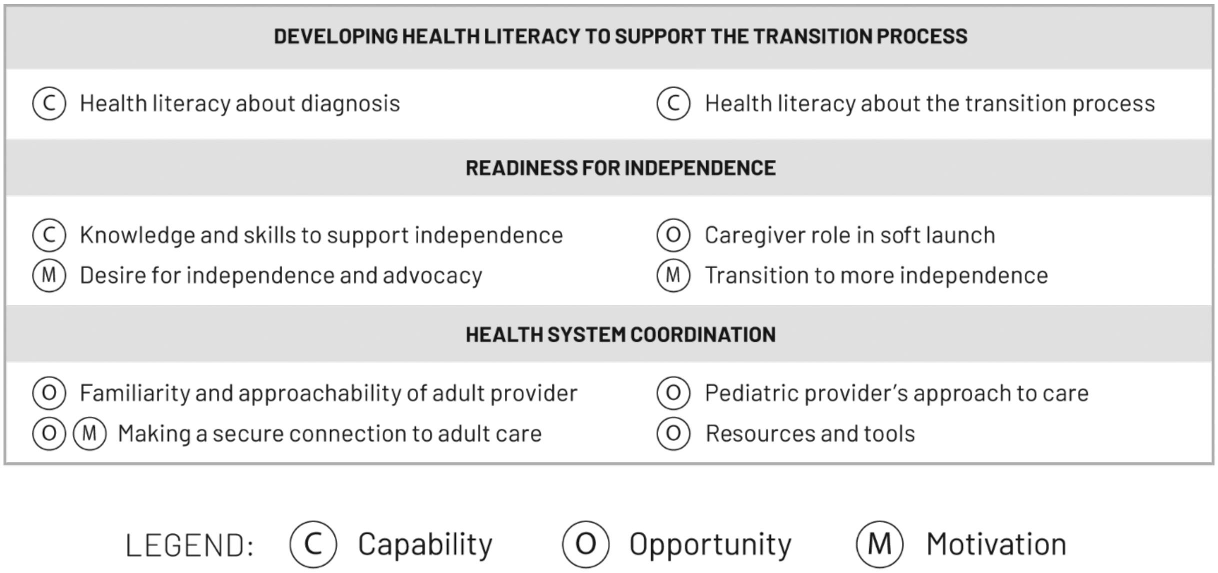
Developing Health Literacy to Support the Transition Process

Youth described needing knowledge related to their health and transition process to facilitate a successful transition. The first subtheme, **health literacy about diagnosis** (a capability), included developing their knowledge on finding, understanding, and using information related to their diagnosis and treatment. The second subtheme, **health literacy about the transition process** (a capability), included developing a specific set of knowledge and skills on finding, understanding, and using information related to their transition process.

Readiness for Independence

Support from caregivers and health care providers helped youth to build their readiness to be independent in their own health care management over time. The first subtheme, **knowledge and skills to support independence** (a capability), was described by participants as the need to learn specific knowledge and skills that would help them be independent in their care and health management.

Figure 1



DEVELOPING HEALTH LITERACY TO SUPPORT THE TRANSITION PROCESS

Ⓒ Health literacy about diagnosis
Ⓒ Health literacy about the transition process

READINESS FOR INDEPENDENCE

Ⓒ Knowledge and skills to support independence
Ⓜ Desire for independence and advocacy
Ⓞ Caregiver role in soft launch
Ⓜ Transition to more independence

HEALTH SYSTEM COORDINATION

Ⓞ Familiarity and approachability of adult provider
Ⓞ Ⓜ Making a secure connection to adult care
Ⓞ Pediatric provider's approach to care
Ⓞ Resources and tools

LEGEND: Ⓒ Capability Ⓞ Opportunity Ⓜ Motivation

The second subtheme, **caregiver role in soft launch** (an opportunity), relates to youth participants highlighting the pivotal role that their caregivers play in their transition. Caregivers facilitated the transition process when they incrementally prepared their child for transition over a period of time. They described this as a "soft launch" that included transferring the responsibility of certain tasks to youth. Some participants described the opposite effect of parents who did not provide this preparation, describing more of a last-minute push right before the transfer point that did not prepare the youth for transition.

The third subtheme, **desire for independence and advocacy** (a motivation), was described by youth as an interest in managing their care; they were motivated by wanting to become more independent.

The final subtheme, **transition to more independence** (a motivation), is what youth described as a parallel transition process that occurs alongside the transition from pediatric to adult care. Youth are simultaneously transitioning away from full dependence upon their parents/caregivers, described as "being babied," to starting to gain independence and advocating for themselves and their own care. It does not appear to be a linear transition, as youth move back and forth between these stages in their growth.

Health System Coordination

For youth, ideal health system coordination of the transition experience is a fluid process involving positive relationships with both pediatric and adult health care providers. The first subtheme, **familiarity and approachability of adult provider** (an opportunity), describes how several youth participants had the opportunity to meet their adult care provider before they were transferred from pediatric care provider at transition clinics (clinics where pediatric and adult providers meet together with youth to discuss transfer). Pre-transfer meetings were a critical facilitator to a positive transition, as it helped youth become comfortable with adult care providers.

The second subtheme, **pediatric provider's approach to care** (an opportunity), relates to the youth's experience with the pediatric provider's approach to transition, which can be a facilitator or barrier to transition. Participants noted that pediatric providers hinder the transition process when they talk about adult care in a negative light. This can create anxiety and fear of what is to come. Contrarily, pediatric providers can be key facilitators and supporters of transition when they consider it to be a continuum of care and ensure successful attachment after the transfer point.

The third subtheme is **making a secure connection to adult care** (an opportunity and motivation). Youth described a successful transition to be a seamless, fluid process where key players from both pediatric and adult care systems are involved. One participant used the analogy of tracking a package to ensure the youth is sent, tracked to ensure they reached adult care, and then followed-up with to ensure they were received.

The final subtheme relates to **resources and tools** (an opportunity) to support the transition process. Youth participants described a variety of different tools they have used to support the transition process, including written documents and digital applications. Others described potential tools that would facilitate the process, the majority of which focused on virtual methods to document transition-related information.

Table 1

Youth Perspectives on Barriers and Facilitators to the Transition from Pediatric to Adult Care

Themes	**Sub Themes**	**Quotes**
Developing Health Literacy to Support the Transition Process	Health literacy about diagnosis (C)	"I could tell immediately that the level of education, the level of insight that I was supposed to have regarding my own care, and specifically the continuation of care, right, not just the acute setting, but the chronic nature of it, you know, all of those became very apparent to me like personally at the age of 15 when I was first introduced to the adult health care system."—Isabella, Youth Participant
	Health literacy about the transition process (C)	
Readiness for Independence	Knowledge and skills to support independence (C)	"I wanted to be way more independent, way more adult. In the rheumatology clinic, they actually like taught me how to do my own like medication injections. So that was like actually a good thing that I got out of it." —Anthony, Youth Participant
	Caregiver role in soft launch (O)	"It was kind of one day he was just like hands off. And looking back, I wish it would have been more of like a soft launch, kind of, instead of just, lighting it all on fire… But ideally it would be like a soft launch, they're there to support you if you are having like troubles with it. And not like hard shoving you, like 'figure it out on your own, idiot,' kind of thing." —Kaheela, Youth Participant

Themes	**Sub Themes**	**Quotes**
	Desire for independence and advocacy (M)	"I was going to add that like I find personally that was one good thing about adult care, is I felt like I was listened to a lot more often. Like the things I was saying was taken a bit more seriously. Because I feel like obviously with pediatric care, kids just say things to say things. But like whenever I was saying something, I was like saying it to be taken seriously. And it wasn't. So that's why I feel like I actually like adult care a bit more."—Isabella, Youth Participant
	Transition to more independence (M)	"It was really quite sudden. Like I didn't expect that to happen. And I was quite… We kind of had a good thing going there at the [pediatric health institution], and then it was like all of a sudden, here you go, you're out in the world on your own, and you have to just figure this out." —Jade, Youth Participant
Health System Coordination	Familiarity and approachability of adult provider (O)	"But in like a real world, if this could happen, meet the doctors, meet my nurse, and know their faces and be comfortable around them. And then they will warn me of like what I should be responsible with. And then we could make a plan of what's going to happen when I see them. But I mean I know I'm an adult, and it would kind of be like last minute, but I just like structure."—Kaheela, Youth Participant
	Pediatric provider's approach to care (O)	"You know what I mean? Like that was like everyone was like, 'Oh, stay in pediatrics as long as you can because adult care sucks,' kind of thing. And that needs to like go out the window because there was definitely stress that came just because everyone made it such a big deal. And it wasn't as big of a deal as everyone made it out to be… My doctors when I was at pediatric [were saying it]. It was like you know when you're in high school, and they're like, 'Your profs in university won't care,' it was like that.

Themes	Sub Themes	Quotes
		Like the same idea. I remember that." —Ben, Youth Participant
	Making a secure connection to adult care (O, M)	"But the second part of what would make a good transition, I look at it as if somebody was sending off a package, they checked to see if the package landed and the people receiving it had received their package, and it was all good. It was landed, it was in the right hands, and it was everything was okay."—Aya, Youth Participant
	Resources and tools (O)	"I really wish there was a checklist. Because, yeah, that would be very helpful… I think like leading up to that transition, there should be a checklist to make sure like you have all the information you need, you know how to do this or that or… Yeah, just to make sure that you're ready."—Hana, Youth Participant

Note. C = Capability, O = Opportunity, M = Motivation

Caregiver Findings

Caregiver participants identified a range of barriers and facilitators regarding their youth transitioning from pediatric to adult care including their supporting role in their youth's health literacy, changing responsibilities and supporting greater independence, and health system coordination (Figure 2 and Table 2). These themes are further broken down into subthemes and categorized based on the COM-B components. Each subtheme will be described below.

Supporting Role in Youth's Health Literacy

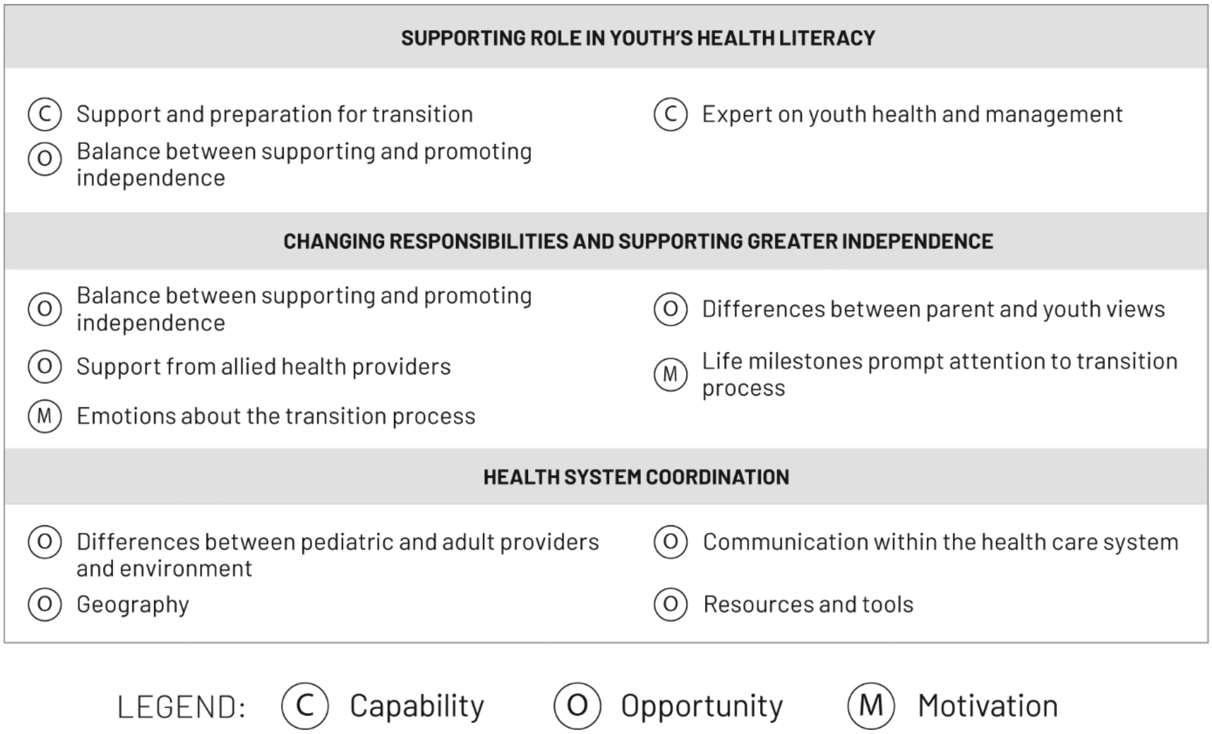
Caregivers helped facilitate the development of youth health literacy by preparing their children for transition through support and education. The first subtheme, support and preparation for transition (a capability), relates to the learnings and teachings facilitated by caregivers to prepare youth for transition at an early age. Early preparation and slow progression to begin transition was identified as a facilitator to supporting a successful transition.

The second subtheme, expert on youth health and management (a capability), is described as the knowledge caregivers possess of what has occurred throughout the history of their child's condition, from symptom onset and diagnosis and throughout their health history. Caregivers often helped with medical management of care such as helping to pick up prescriptions, scheduling meetings, or getting other material items.

The final subtheme, balance between supporting and promoting independence (a capability), relates to caregivers navigating the question of how to provide enough space for promoting independence and self-management while remaining a consistent support throughout transition. Caregivers expressed that they are constantly navigating the shifting balance of power between their youth and themselves.

Figure 2

Caregiver Perspectives on Barriers and Facilitators to the Transition From Pediatric to Adult Care



SUPPORTING ROLE IN YOUTH'S HEALTH LITERACY

- Ⓒ Support and preparation for transition
- Ⓞ Balance between supporting and promoting independence
- Ⓒ Expert on youth health and management

CHANGING RESPONSIBILITIES AND SUPPORTING GREATER INDEPENDENCE

- Ⓞ Balance between supporting and promoting independence
- Ⓞ Support from allied health providers
- Ⓜ Emotions about the transition process
- Ⓞ Differences between parent and youth views
- Ⓜ Life milestones prompt attention to transition process

HEALTH SYSTEM COORDINATION

- Ⓞ Differences between pediatric and adult providers and environment
- Ⓞ Geography
- Ⓞ Communication within the health care system
- Ⓞ Resources and tools

LEGEND: Ⓒ Capability Ⓞ Opportunity Ⓜ Motivation

Changing Responsibilities and Supporting Greater Independence

Caregivers described a shift of responsibilities to respond to changes in youths' needs for both independence and support. The first subtheme, balance between supporting and promoting independence (an opportunity), relates to the relational aspects of finding balance.

The second subtheme is related to the differences between parent and youth views (an opportunity). Some caregivers reported differing views on managing the health condition and transition and the need for compromise on the approach to care planning to support youth's needs.

The third subtheme, support from allied health providers (an opportunity), relates to how caregivers described allied health care providers, such as occupational therapists, physiotherapists, social workers, and psychologists as facilitators for youth in transition. Participants noted barriers to transition when allied health care providers were not part of adult care teams moving forward.

The fourth subtheme, life milestones prompt attention to transition process (a motivation), was described as a facilitator because overlapping milestone moments can prompt parents to become aware of the upcoming transition in care. Caregivers described these moments as birthdays, graduation, or the transition to post-secondary education/employment/programming.

The fifth subtheme, emotions about the transition process (a motivation), relates to the wide range of emotions that caregivers experience during the process of transition. Caregivers worry about their child being their own advocate and being able to communicate for themselves, and they also fear the unknown in the adult system regarding coordination and treatment. Contrarily, caregivers shared that they experienced a positive outlook for their children when there was a good relationship with the health care provider and experience with the adult health care system.

Health system Coordination

Caregivers described a range of barriers and facilitators related to health system coordination, which are reported here with four subthemes.

First, caregivers reported **differences between pediatric and adult providers and environment** (an opportunity) related to wait times, communication, and scheduling. Caregivers shared their experiences with the lack of follow-up in the adult system, and the lack of a key contact person. Participants attributed this to potential differences in priorities between adult and pediatric health care systems.

The second subtheme, **communication within the health care system** (an opportunity), relates to the communication styles and approaches used by the health system throughout the transition period. Caregivers shared that there was often a lack of communication between the different areas of the health system. The pediatric and the adult care systems communicated in different ways, which proved to be a barrier in navigating the transition process. According to caregivers, in the pediatric system there was intentional coordination embedded in conversations among different care providers, but the same was not seen among adult care services.

The third subtheme, **geography** (an opportunity), relates to the accessibility of the health care system. Caregivers described barriers to accessing services in rural settings, especially when systems do not communicate with one another (e.g., emergency care and primary care). Caregivers expressed significant challenges when seeking care for their child in adult settings, as they did not have access to their health care documents because the electronic health records are not integrated across the province or different health care settings.

The final subtheme focused on the **resources and tools** (an opportunity) caregivers had to support the transition process. Caregivers shared their preference for resources that were readily available and promoted in pediatric settings. Further, caregivers shared how technology and mobile apps are advancing and helping with self-management and medical care for their children.

Table 2

Caregiver Perspectives on Barriers and Facilitators to the Transition From Pediatric to Adult Care

Themes	Sub Themes	Quotes
Supporting Role in Youth's Health Literacy	Support and preparation for transition (C)	"But they are trying to make the child more independent, I think, too, and take control of the disease. And so it's good. But I think it's important to recognize that, too, that as a parent, you have to do that. But the child, too. You know, you have to teach the child to transition to be an adult, basically, I guess."—Lina, Caregiver Participant
	Expert on youth health and management (C)	"… in some ways I think from my experience, I'm more in tune. I know the diabetic terms and technology more than he does. So I'm thinking, well, when [son] transitions, is he going to transition and get an

Themes	**Sub Themes**	**Quotes**
		endocrinologist, or is he going to end up with a GP who may not have the knowledge and expertise that, you know, he needs? And that kind of is in the back of my mind."—Monica, Caregiver Participant "I still order the supplies and all that stuff. And it's like in my head, my plan is he's got to start transitioning, you know, to learn that, too." —Wendy, Caregiver Participant
	Balance between supporting and promoting independence (O)	"I mean that's hard because it's hard as parents to let go of that involvement as well. Not that you're not still involved when they're young adults, but you have to coach them and support them in a different way. So I think it was important for both of us that she had those opportunities, that we both felt confident, right. It really helped with her confidence. And she can… She is quite good at navigating and speaking for herself, I will say." —Andrew, Caregiver Participant
Changing Responsibilities and Supporting Greater Independence	Balance between supporting and promoting independence (O)	"I wanted to show him that we're there to support him, but also give him the right level of independence. So it's right from the get-go and this challenge of what does that look like when an 11-year-old really wants to kind of be independent in a lot of ways, and suddenly he couldn't be. So, yeah, right away." – Wendy, Caregiver Participant
	Differences between parent and youth views (O)	"…Supporting patient goals, I would say that was one of the other key things with our experience at the [pediatric health institution]. Was that many times… It clearly sometimes wasn't my goal. What

Themes	Sub Themes	Quotes
		was important was that they supported [daughter]'s goals, right, in a way that, you know, she always felt supported, that her goals were first and foremost of what everybody was working towards, right…" —Vera, Caregiver Participant
	Support from allied health providers (O)	"So tying it all together for him, the psychology team was crucial. And he still reaches out and wants to talk to them sometimes even about just other social things as well, maybe not even pertaining to his disease." – Nissa, Caregiver Participant
	Life milestones prompt attention to transition process (M)	"So then all of a sudden he started applying for universities and started getting a few acceptance letters, and trying to figure all that out. And then it was like, oh, wait a minute, he's not only going off to university, but now he's also going off to not the [pediatric health institution]. So what is that going to look like? How is that going to work out?" —Mona, Caregiver Participant
	Emotions about the transition process (M)	"So they have started at the last appointment kind of talking to her about that. And she is very independent, but she has some learning disabilities as well. So I do worry about her managing her appointments, and talking to doctors on her own, and those kinds of things. That part worries me." —Nissa, Caregiver Participant
Health System Coordination	Differences between pediatric and adult providers and environment (O)	"One of the biggest, I think, differences is that in the pediatric care, there is such regular follow-up. That adult health care is typically much more issue-related. You get seen for issues. As opposed to pediatrics, there's just this

Themes	Sub Themes	Quotes
		continuous system of contact with your pediatric care providers…” —Joan, Caregiver Participant
	Communication within the health care system (O)	“And it’s like to me that kind of made him a little more independent at his appointment because he was in front of the screen and I was in the other room kind of just listening. And he went through it with his endocrinologist. And it’s like, wow, cool, like he did well. And I think, you know, in a way it’s like the Zoom and this… If there’s a positive thing to COVID, it was that.” —Lina, Caregiver Participant
	Geography (O)	“And, you know, with us being an hour out of the [city centre], too, the systems don’t talk. So we go into emerg or we go into outpatients or we go somewhere else, even the family doctor, they can’t look up the same things as easy.” —Malika, Caregiver Participant
	Resources and tools (O)	“It’s the team at the [pediatric institution] tends to pick up on when other resources are required or could be useful. You know, like psychology or pain clinics or just those other specialty services in general. And we don’t have to source them so much on our own. They’re almost just there and being provided as needed.” —Monica, Caregiver Participant

Discussion

This study identified barriers and facilitators to the transition from pediatric to adult care from the perspectives of youth and caregivers using the COM-B Model of Behaviour (Michie et al., 2014). This study contributes to a growing body of evidence on transitions of care by providing important insights into the behavioural and contextual aspects of transition from the youth and caregiver perspective. Our analysis highlights important determinants related to youth and caregiver capability, opportunity, and motivation that future interventions and programs should target.

Capability

Youth and caregiver participants identified the need for specific knowledge and skills related to managing their health and navigating the transition process. Similar findings are highlighted in the literature. Gray and colleagues' (2018) systematic review identified knowledge as a common cited barrier in the transition process. Previous studies have designed, implemented, and evaluated youth transition programs aimed at improving health literacy to support transition (Huang et al., 2007; Melita et al., 2019; Varty et al., 2020). For example, Melita and colleagues (2019) introduced a program based on cognitive behavioural techniques and reported improved transition outcomes, including increased self-management skills. However, many of these interventions lack caregiver involvement (Melita et al., 2019). Participants in our study highlighted that caregivers have the expertise in their youth's health care throughout pediatric care and need to transfer that expertise to their youth during the transition to adult care. Future design of transition educational interventions should consider caregiver involvement alongside youth to (a) facilitate sharing of caregivers' expertise and (b) develop programs tailored specifically to caregivers' knowledge needs.

Opportunity

Previous research supports the involvement of caregivers in the transition process (Gray et al., 2018; Jivanjee et al., 2009; Varty et al., 2020). Caregivers provide a wealth of knowledge and support for youth, acting as an essential resource to support youth in a successful transition (Bratt et al., 2018; Varty et al., 2020). Before the transition begins, caregivers are often managing the youth's care (Bratt et al., 2018). During the transition, the caregiver's role evolves into that of a facilitator. By ensuring continued involvement throughout this process, caregivers support successful transition (Bratt et al., 2018). This should include their role in a "soft launch" that recognizes milestones to initiate the transition process early.

Relationships among youth, caregivers, and health care providers were identified as a critical barrier and/or facilitator to the transition process. Youth have often built trusting and well-established relationships with their pediatric care providers, leading to hesitancy in transitioning to comparatively unknown adult care (Mbalinda et al., 2020). Youth participants in our study illustrated how easy it can be for providers to influence the transition experience with their approach, both positively and negatively. Supporting transitions of care is a trust-building exercise; our findings reiterate previous research on the need for providers to earn trust among youth and caregivers to support the transition process (Bollegala & Nguyen, 2015).

Our previous qualitative study on health care providers' experiences with the transition from pediatric to adult care also identified relationship building as a key facilitator to the transition process (Cassidy et al., 2022). This relationship shift can be challenging, especially if youth and caregiver views are not aligned. Moving forward, providers may benefit from understanding the different emotions involved for both youth and caregiver, helping families to understand these natural points of conflict and helping caregivers focus on their broader goals for their youth's transition into adulthood. Further, providers should continue to collaborate with caregivers with stronger understanding of the shifting role of the caregiver to a facilitator during the transition process. Supporting this shift in responsibility may help caregivers empower youth to engage in conversations about their health care.

Motivation

Our study findings highlight the interconnections between social opportunity- and motivation-related barriers and facilitators. Many youth participants described a desire to manage their own care; they were motivated and wanted to become more independent. Previous studies have shown that youth are motivated by the desire for independence and moving away from having an "outsider" feeling as adolescents in a pediatric care setting (Varty et al., 2020). Much of the literature describes the transition from pediatric to adult care in a negative, challenging context (Fegran et al., 2014; Tuchman et al., 2008; Varty et al., 2020). Similarly, our youth participants described difficult conversations they had with providers and caregivers. However, they also highlighted the excitement and positive aspects of transition; these tap into youth's motivation, including optimism and beliefs about the future. Some research has found that youth report the transition from pediatric to adult care services to be a natural next step in their care: Youth may be apprehensive but also excited for transition and the prospect of becoming more independent decision-makers in their own care (Varty et al., 2020). This is a significant and unexpected shift from caregivers' and health care providers' traditional perspective of the transition process being clouded in negative feelings of anxiety, fear, and youth's uncertainty and lack of preparation (Varty et al., 2020). Incorporating the youth's perspective is important to showcase excitement that comes along with transitions. A culture shift is needed to transform our thinking of transition and design new interventions to support youth to leverage the positive and exciting elements of the process that come with taking those next steps in their health care journey.

Implications

This study has important implications for designing, implementing, and evaluating interventions to support the transition from pediatric to adult care. We used the COM-B Model of Behaviour to explore factors influencing transitions from pediatric to adult care from the perspective of youth and caregivers. By describing barriers and facilitators in behavioural and contextual terms, this theory-informed approach will inform the design of tailored interventions (Michie et al., 2014). Future research may continue to use the Behaviour Change Wheel to help with the design of new interventions to support transition of care that tap into the capability-, opportunity-, and motivation-related barriers and facilitators described in this study.

This study's focus on identifying barriers and facilitators to transition in care that could inform effective intervention design will be valuable for youth, caregivers, health care providers, and organizations aimed at improving the transition from pediatric to adult care. In our local context, the Transition of Care Committee (TOCC) identified this research as a significant priority for their work. They were a close research partner in our integrated knowledge translation approach, and the goals and objectives of the research project align well with the committee's mandate, as they are responsible for informing practice and guiding program development to support the transition from pediatric to adult care. The TOCC can use these findings to ensure transition interventions address the identified barriers and leverage the facilitators to transition of care. Similar transition groups or health care providers may find similar utility in the study findings to guide their practice and to design programs or interventions that address barriers and leverage facilitators in their local context.

This work also illustrates important implications for researchers and transition-of-care evaluation research. To date, the focus has been on youth health, knowledge and self-efficacy outcomes (e.g., A1C laboratory testing, self-efficacy, self-management), and health system resource use outcomes (e.g., emergency department visits, paramedic use, and hospitalization records; Mackie et al., 2014; Sequeira et al., 2015). Recent knowledge synthesis efforts have identified patient-centred quality indicators for the transition from pediatric to adult care, including education, continuity of care, satisfaction, and self-management (Bailey et al., 2022). Given our unexpected findings on youth's motivation for transitioning to adult care, there is an opportunity to expand on these patient-centred outcomes and identify motivation-based indicators. Future evaluation research should start to measure these patient-reported experience outcomes alongside more traditional health system outcomes.

Limitations

study findings should be considered with the following limitations. This sample included participants from similar demographic characteristics, including gender and race. Thus, our findings may not be representative and transferable to many youth and caregivers experiencing transitions from pediatric to adult care. This study would have benefitted from a more explicit health equity lens in the research team composition and study design, including recruitment, data collection, and data analysis methods, to provide a more diverse perspective on youth and caregiver experiences with transitioning from pediatric to adult care. Our study describes barriers and facilitators to the transition of care from pediatric to adult care; however, it could be strengthened with a subsequent study aimed at understanding the impact of health equity on the transition of care process and outcomes. This could include tailored recruitment efforts to a diverse sample of participants that is more representative of our local community, interview guide questions and probes that use an intersectionality-enhanced behaviour change framework, and a health equity framework for analysis (Etherington et al., 2020).

Conclusion

This qualitative descriptive study identified barriers and facilitators to support the transition from pediatric to adult care from the perspective of youth and caregivers. We used the COM-B Model of Behaviour to guide our data collection and analysis methods and identified intersecting behavioural and contextual determinants related to youth and caregivers' capability, opportunity, and motivation that influence the transition of care process. Moving forward, transition-in-care interventions should be multi-component and tailored to (a) support youth and caregivers' preparation for the transition process, (b) leverage the relational influences among youth and caregivers to facilitate the transition process, and (c) address the barriers to system-level coordination to ensure a secure attachment of youth in the adult care system. Overall, these findings contribute to a growing body of literature that can be used to guide transition-in-care intervention design, implementation, evaluation, and sustainability while improving outcomes for youth, caregivers, health care providers, and the health system as a whole.

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Conflict of Interest

Authors state no conflict of interest.

Declaration of Ethics

The authors received ethics approval from the IWK Health and Nova Scotia Health Research Ethics Boards (Approval #1026111).

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