



2020

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Recommended Citation

Dumais-Lévesque G, Pomey M. Exploring peer mentoring in pediatric transition: Perspectives of different stakeholders about accompanying patients in gastroenterology. *Patient Experience Journal*. 2020; 7(3):71-82. doi: 10.35680/2372-0247.1423.

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Cover Page Footnote

The co-authors thank Nadine Magali-Ufitinema for her work throughout the project and Jim Kroening for his significant re-reading, which helped bring greater clarity and focus to the article. They also thank all participants for their generous contribution. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

Exploring peer mentoring in pediatric transition: Perspectives of different stakeholders about accompanying patients in gastroenterology

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Abstract

The literature identifies several issues in the pediatric transition, such as the lack of coordination between pediatric and adult settings and young patients who are not exercising independence in the self-management of their disease. The objective of this study is to explore the potential for a pediatric transition program in gastroenterology, introducing an accompanying patient program to support the transition. A qualitative case study was conducted, including semi-structured focus groups and individual interviews with each group involved in the pediatric transition between two centres in Quebec. A thematic analysis of the collected data was performed using QDA Miner v5.1. In addition to the barriers documented in the literature, such as patients' poor knowledge of their disease, developmental immaturity and low level of independence, our analysis found that adolescents appear to be quite indifferent to their disease and to the transition. Once they are in an adult health centre, they develop an awareness of the disease's impact on their lives and would appreciate having support from a peer. In contrast, parents experience considerable anxiety before this transition, and would like to be in contact with other parents. Professionals, for their part, are open to the idea of establishing a peer support program to fill certain gaps in how transfers are organized. One way to improve the transition, as suggested by our respondents, is to set up a peer support program that should evolve over time, being initially implemented for the parents and then for the young adults.

Keywords

Patient engagement, accompanying patient, peer support, pediatric transition, qualitative methods, quality of care, action research, quality improvement

Introduction

The epidemiological transition currently underway is radically changing the organization of health care.^{1,2} Health care systems, which in the mid-twentieth century were organized around healing, are increasingly faced with issues related to monitoring chronic diseases.

In pediatrics, many patients who previously died before reaching adulthood now survive. A study by Van Cleave *et al.*³ based on the National Longitudinal Survey of Youth-Child Cohort (1988-2006) reports a prevalence of chronic disease in a 1994 cohort of sick children of 12.8%, compared to close to 25% in a 2000 cohort. This increase in prevalence is closely tied to improved treatments for these conditions.⁴ Nearly 90% of children with metabolic disorders, gastrointestinal diseases and cardiac malformations are now transferred to adult specialty medicine.⁵

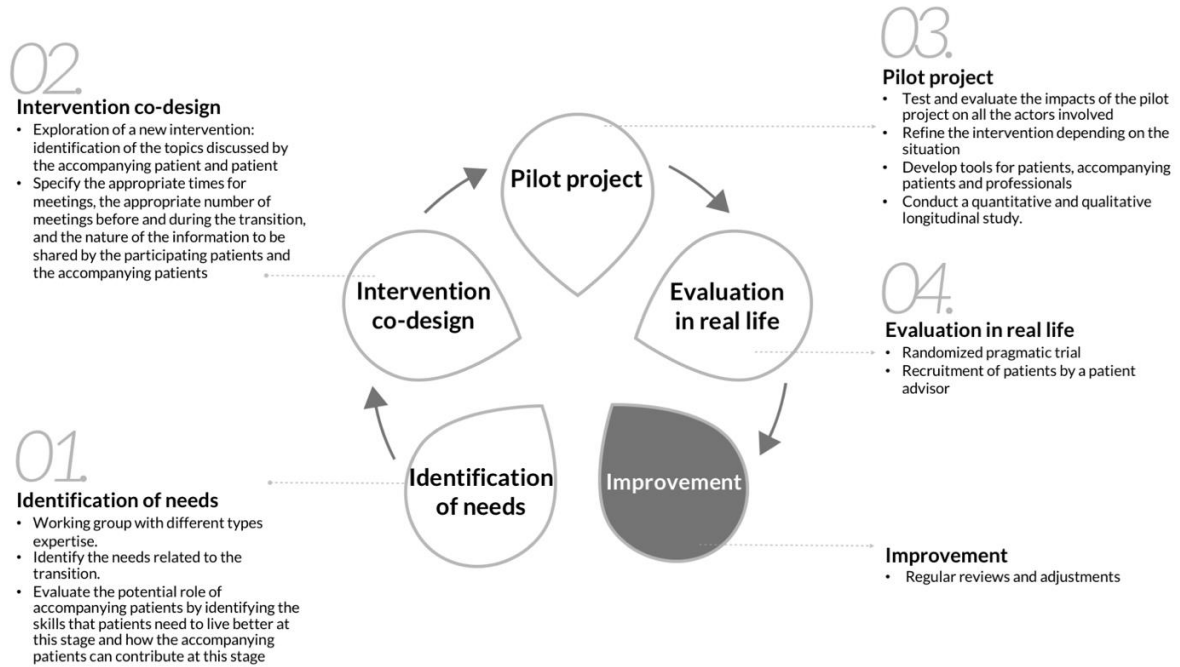
Over the past 30 years, various medical associations have identified the pediatric transition as a key period in the development of youth with special health care needs

(YSCHN).⁶⁻⁸ Under the leadership of these learned societies, a rich literature has developed, documenting the barriers to this transition. Such barriers include the young patients' lack of knowledge about their illnesses and poor self-management of their illnesses,⁹⁻¹¹ resistance to losing the pediatric therapeutic alliance,^{12,13} a lack of coordination among the different care settings and health professionals,^{11,14-16} the low priority given to this issue,¹⁶ and the need to recognize adult teams in order to meet the specific needs of this population.¹⁷

In Quebec, the prevalence of inflammatory bowel disease (IBD) in the general population is 671 cases per 100,000 people,¹⁸ compared to 15.4 cases of IBD per 100,000 people in the group under 20 years of age.¹⁹ Young people with a diagnosis of IBD are often forced to make several lifestyle changes, and the disease partially disrupts normal physical and psychological development.^{18,20}

In oncology, peer support has been shown to improve patients' coping skills and strategies (i.e. sharing methods for dealing with distressing emotions and making changes to the person-environment relationship that has been

Figure 1. Pomey model of co-construction in partnership²⁷



disturbed, causing the distress). This has helped patients be better prepared for consultation and treatment.²¹⁻²⁴

The objective of this article is to assess stakeholders' perceptions of: (1) how IBD patients are experiencing the transition between two health care organizations (one adult and one pediatric), and (2) the potential for a peer support program targeting the transition from pediatric to adult services.

Methodology

The methodology draws on an action research,^{25, 25-28} soliciting the active participation of each of the actors concerned by a specific problem in order to develop the most appropriate solutions to the problem (see Figure 1). The first step in this methodology involves a qualitative case study²⁹ in order to develop a good understanding of the phenomenon.

The context for this study was patients with inflammatory bowel disease (IBD) who were to be transferred, or who had been transferred, from a pediatric health center (PHC) to an adult health center (AHC) in Quebec, Canada. We conducted focus groups and semi-structured individual interviews to document their experiences during the transition.

Participant selection

Families of children with IBD were recruited by pediatricians in the PHC. The adolescents had to be between 15 and 18 years of age and able to speak English or French. The participants from the AHC had to be between the ages of 18 and 25 and prior patients of the PHC. They were also identified by the facility's gastroenterologists. All the selected individuals had detailed knowledge of the disease experience and/or transition process. This recruitment method was chosen to encourage a diversity of perspectives to cover as many facets of the same phenomenon as possible.²⁹⁻³¹ Everyone who met the selection criteria was approached to participate in the study without any subsequent sampling, implementing the strategy of using the entire target population.³⁰ Each participant was asked to complete a questionnaire to establish a demographic profile.

Concerning the healthcare professionals (HCPs), all the pediatricians and gastroenterologists at the two healthcare centers were invited, by email, to participate in a focus group.

Data collection methods

The qualitative data was collected from December 2017 to November 2018. We approached a total of 249 patients and their parents, nine adult healthcare providers (AHPs) and eleven pediatric healthcare providers (PHPs). Due to important limitations in the availability of the participants (school, work, etc.), it was decided to use either focus group or individual interview. Altogether, six focus groups

Table 1. Description and timing of individual interviews and focus groups

Population sub-group	Date	Number of participants (n=27)
Individual interviews		
Male patient of a PHC	June 2018	1
Female patient of a PHC	July 2018	1
Mother of a female patient of a PHC	July 2018	1
PHP	March 2016	1
PHP	November 2017	1
PHP	November 2017	1
Focus groups		
Patients at the PHC	November 2018	5
1st group – Parents at the PHC	June 2018	2
2nd group – Parents at the PHC	November 2018	6
Patients at the AHC	December 2017	3
Parents at the AHC	January 2018	2
Healthcare professionals at the AHC	March 2018	3

PHC: Pediatric health centre; AHC: Adult health center; PHP: Pediatric healthcare provider

and three individual semi-structured interviews were conducted with 27 individuals representing the following groups: minors/adolescent patients (MP), adult patients (AP), parents of MPs, parents of APs, and AHPs. The same interview guides were used for both interviews and focus groups. Those guides explored the same topics for each group while also inquiring for some specific aspects. Some of the PHPs were interviewed informally as part of preparing the project. Table 1 presents data on participants in these individual interviews / focus groups and their timing.

Data analysis

The qualitative data were analyzed using a hybrid deductive and inductive approach. Successive phases that combined deductive and inductive analysis were followed³² using QDA Miner Lite software: (1) the data was codified and categorized based on an a priori template of codes³³; (2) new codes and categories were identified through data-driven analysis³⁴; and (3) findings were formulated and verified. No differences were found between the data obtained through semi-structured interviews or focus group.

This study was approved by the University of Montreal Health Center Research Ethics Committee (Certificate no. 13.253), the Sainte-Justine Academic Health Center Research Ethics Committee (Certificate no. 2017-1438) and the University of Montreal Health Research Ethics

Committee (Certificate no. 17-014-CERES-D). Free and informed consent was obtained from each participant or, for minors, from a parent.

Results

Our findings are presented below in three sections. The first section provides a description of the approach and population characteristics. The second section presents how the various actors experienced the transition including the preparation for the transition and the post-transfer period. Finally, the third section describes the various actors' views on a proposed peer support program for better transitions.

Presentation of the respondents

The participating patients came mostly from middle-class families, practically all of them lived with their parents, and 70% of them were receiving a biological agent. The average age of MPs was 17.1 years, and the average age of APs was 20.7 years. The cohort's average age at diagnosis

Table 2. Demographic data on participating patients

Participant (fictitious name)	Sex	Age	Level of education	Occupation	Living environment	Family income	Age at diagnosis	Treatment	Parent(s)
Patients PHC									
Camillia	F	17	Secondary school	Student	Parents (divorced)	> \$100,000	6	5-ASA	Lucy
Bruce	M	16	Secondary school	Student	Parents (together)	> \$100,000	15	Monoclonal antibody (vedolizumab)	Sebastian and Helen
Franck	M	18	College	Student	Parents (together)	> \$100,000	15	5-ASA	Michael
Emmanuel	M	18	College	Student	Parents (divorced)	\$75,000 to \$99,999	10	Anti-TNF alpha (adalimumab)	Aaron
Adrian	M	16	Secondary school	Student	Parents (together)	\$75,000 to \$99,999	14	Anti-TNF alpha (infliximab)	Claire
Charles	M	19	College	Student	Parents (together)	\$50,000 to \$74,999	15	Anti-TNF alpha (infliximab)	Landon and Samantha
Fleur	F	16	Secondary school	Student	Parents (together)	\$25,000 to \$49,999	14	Anti-TNF alpha (infliximab) + MTX	Vivian
Patient AHC									
Mark	M	21	Secondary school	Artist	Parents (together)	> \$100,000	15	Anti-TNF alpha (adalimumab)	N/A
Emily	F	20	College	Student	Apartment	\$0 to \$24,999	16	Anti-TNF alpha (infliximab) + 6-MP	Adeline
Leah	F	21	University	Student	Parents (divorced)	\$75,000 to \$99,999	11	6-MP	Beckie

PHC: Pediatric health centre; AHC: Adult health centre; 5-ASA: 5-Aminosalicylic acid; TNF: Tumor necrosis factor; 6-MP: 6-Mercaptopurine (purinethol); MTX: Methotrexate

was 13.1 years (a figure highly influenced by some extreme values).

Table 2 presents a demographic profile of the participants (both minors and adults), as well as the name(s) of their parent(s) (if we met with them).

Table 3 presents the health professionals interviewed and their professions, by practice location.

How the various actors experienced the transition

This section presents how participants experienced the disease, then how the transition was prepared (including facing the differences between the pediatric and adult

world) and the difficulties encountered by patients post-transfer.

Living with the disease

There is no doubt that inflammatory bowel disease has an impact on patients' lives. Most patients had been through a difficult initial experience with the disease, and they spoke freely about this at our meetings. For some, the disease had caused social problems, since the symptoms and treatments distinguished them from their peer group.

“In Grade 10, I was five-foot-one. Five-foot-six was small. At 78 pounds, I felt smaller than everyone [...] You get bullied for that.” (Charles, YP)

Table 2. Health professionals met

Participant (fictitious name)	Profession	Sex
PHC		
Dr. Wilson	Pediatric gastroenterologist	F
Dr. Hedley	Pediatric gastroenterologist	F
Dr. O'Connell	Pediatric gastroenterologist	M
Dr. Richardson	Pediatric gastroenterologist	M
AHC		
Dr. McCarthy	Gastroenterologist	F
Dr. Sussex	Gastroenterologist	M
Emma	Nurse	F

PHC: Pediatric health centre; AHC: Adult health centre

“Everyone saw me losing weight. It made me feel... different.” (Emily, AP)

Nevertheless, once the diagnosis had been received, efficacious medications made it easier to live with the disease and limited its negative impacts.

“Since I'm on an anti-TNF, I can really live my life without thinking about what I've got, which is serious.” (Liam, AP)

“I just have to be careful about what I eat, but I'm fine.” (Fleur, MP)

The APs stated clearly that IBDs cause more discomfort because of the taboo around their diarrhea symptoms, as Emily told us: “At first I just didn't discuss it. I was 16, 17 years old, I wasn't comfortable going into it.”

Finally, the issue of rebellion during adolescence is also part of life with the disease, as expressed by the patient who was followed for the longest time in pediatrics: “I think there was a period, when I was around 12 to 14, when I didn't see the point of coming here. I really didn't care.” (Camillia, MP).

The transition to adulthood allowed many participants to express themselves more confidently and live more openly with the disease when they were with their loved ones. Some even began to use humour to lighten the emotional burden.

“If you're confident enough to be able to tell everyone and then you're open to it, for sure there'll be more understanding when you have to spend six-and-a-half hours going to the bathroom.” (Liam, AP)

APs also noticed that some residual symptoms have an impact on their lifestyles, especially with friends.

“A bit tired, but for me it's more, it's what I can and can't eat. It's really... Even with the medication it's a bit better, but there are still some things I just can't eat.” (Emily, AP)

For the parents, life with the disease begins with many concerns about their child's deteriorating health.

“Basically, we thought, ‘Well, she may die, because she's gotten so skinny.’” (Beckie, parent)

“They took his pressure, put him on the gurney right away, took him in the back, cut his shirt off and plugged him in. ... I was really scared.” (Aaron, parent)

These concerns also continue as the health problem develops.

“The first day he came home in Grade 6, the children fixed on the thing in his nose [the feeding tube]. One of them said, ‘Look at that, Mommy. Ahhh, he's sick, (emotional) he's sick.’” (Aaron, parent)

The parents also remarked that facing adversity has helped their children develop. The treatment can be difficult on a child, but the benefits far outweigh the disadvantages and they quickly return to their everyday lives.

“It changes a person's personality too, don't you think? I find that my daughter has changed ... it's made her more mature.” (Adeline, parent).

“A very, very restricted diet. No lactose, no gluten...For a guy, a young man 17, 18 years old, this isn't easy.” (Michael, parent)

“The cortisone period was fantastic.” (Helen, parent)

There are also social impacts, limiting the options in their child's life plan.

“There were odours too, when she went to the toilet. So that creates situations, she can't go see her friends anymore!” (Adeline, parent)

“She said, ‘I don't know if I'm going to be able to have children.’” (Beckie, parent)

For the AHPs, the patients' feeling of being different and their position of dependence affects the care that can be provided.

“They don't understand why they have to be on meds at the age of 21. They're a bit in denial. They've got their studies, their girlfriends, they want to travel, they want to do other things...” (Dr. McCarthy, AHP)

However, developmental issues are seen as having the greatest influence on life with the disease, since many patients are in denial.

“These are people who are a bit unstable and in complete denial of their illnesses. They're what I call ‘teenadults’; they're not adults, but they're not teenagers, either.” (Dr. Sussex, AHP)

Preparing for the transition

The second theme discussed with participants concerned how the transition is organized in the two care settings.

Overall, MPs appreciate the pediatric environment. However, they expect some differences between their current care and the adult world, even though they were not particularly anxious about the change in setting.

“The atmosphere at the children's hospital isn't much like that of a hospital. It's a really nice experience there. [...] In the adult world, you're supposed to manage things on your own.” (Emmanuel, MP)
“Well, it doesn't change much in terms of my well-being [to go to an adult setting].” (Charles, MP)

“I think we just don't really know what to expect. In our minds, it'll be no big deal.” (Camilia, MP)

“It seems relatively simple, and it isn't necessarily a big traumatic change.” (Bruce, MP)

Many MPs still rely heavily on their parents, mainly their mothers: “Uh, maybe you'd better ask my mother about that” (Charles, MP). However, some pediatricians begin to encourage their patients, in their meetings, to gradually develop more independence, and this is something young people perceive: “Dr. O'Connell talks to me, he addresses questions at me, because he knows it's me. Sometimes my mother will break in because I don't have anything more [to say].” (Fleur, MP)

Once in an adult setting, patients underscored the lack of a program for developing self-management skills and the fact that they were unprepared.

“I would have liked to be more informed when I was 17, and make a kind of adjustment, slowly but surely learning how to manage my illness, rather than just ‘Boom!’ when I turned 18.” (Leah, AP)

These patients were disappointed at not being asked to become more involved in their pediatric healthcare:

“It's important that we get involved in our own case management [...] I find that at St. Justine's [the children's hospital]...you don't have to do anything.” (Liam, AP).

However, some patients (2 out of 3) seemed to have benefited from an existing transition preparation program called TRACC (for patients with Crohn's disease and ulcerative colitis).³⁵ In TRACC, one day is dedicated to preparing 14-18 year olds and their parents for the transition through therapeutic education workshops, testimonials and discussions with peers. They appreciated this approach.

“There was a dinner and then some activities. I met a lot of people who have Crohn's disease [...], I really enjoyed it.” (Leah, AP)

The parents revealed how different teenagers prepared for the transition differently. Some prepared in the final months leading up to the transfer, but others only learned at our meetings that there could be discussions to help them prepare for the transfer.

“It was the gastroenterologist who told us, but we were meeting with him for the last time. Now we're waiting. We have no resources, there's no-one we can call.” (Michael, parent)

“For the parents, for example, I find that it generates insecurities.” (Beckie, parent)

Interviewer: “Because normally St. Justine doesn't treat any patients over the age of 18...”

Helen: “Oh my God!” (Helen, parent)

One mother, summing up the concerns of other parents, also expressed doubts about how transfers are organized and stressed a real need for support.

“Why don't they make the transition early, perhaps making the transfer one year before the file [is transferred], so that we'll have a chance to meet with them, while we're still being supervised here? There could also be a nurse or social worker to talk to parents.” (Lucy, parent)

Although some parents indicated that they want to develop their child's independence, such efforts may get pre-empted by a well-meaning desire to be there for their child.

“I have to be ready to let him go to appointments alone, but it's hard! In [pediatric] care I played a leading role, but now I'll be more like a good listener.” (Vivian, parent)

Parents have difficulty letting go of the exceptional care experience received in pediatrics, as well as their easy access to a nurse clinician when they need to talk. They expect to lose this privileged relationship in adult medicine:

“What I liked about the children's hospital was the nurse. Her name is Amelia. Oh, that lady! As soon as you have a question or something happens, you call her, and she answers. She makes you feel safe.” (Adeline, parent)

“When my daughter began treatment in an adult setting, she decided to take charge of everything. I found myself in a total vacuum, and she didn't tell me what was going on, either.” (Beckie, parent)

“Around here I have a sense of relief, I feel like it's a five-star service, really. I'm running out of time, and he's going to be in a jungle of adults.” (Helen, parent)

The AHPs discussed the informal rules they and their colleagues have established for the transfer.

“They transfer them under two conditions: if they are 18 years old and the patient is stable.” (Dr. Sussex, AHP)

“Theoretically, the agreement we had with the team at Ste. Justine is that the team should give the nurses' contact information, but this doesn't seem to be what's happening.” (Dr. McCarthy, AHP)

One of the nurses also spoke about the new standards recently established for managing new cases, which also addressed parents' concerns.

“In fact, the people we receive [because sometimes the file isn't sent to us], we don't wait for them to be seen before contacting them. We call them, we give them our contact information so that... they'll have someone to call.” (Emma, nurse)

Much like the parents, the AHPs try to develop independence in their young patients, but not without encountering some resistance from the parents.

“Sometimes, when I see that their umbilical cord being cut, I tell them, ‘Next time, Jonathan, you'll come alone, okay?’ And then I see the mother panicking!” (Dr. Sussex, AHP)

Finally, all the AHPs reported that, in general, the transition works quite well.

“Generally speaking, it isn't a big problem.” (Dr. Sussex, Gastroenterologist)

“They're not afraid to go to the hospital and be like adults there.” (Emma, AHP)

“Then they're lost. But all of the patients referred here are lost, whether it's a transition or a new patient.” (Dr. McCarthy, AHP)

Following the transition, young adults underscored the importance of becoming more independent, and how the physicians helped them in that process.

“[The doctor] told us: ‘I don't mind your parents coming with you...but you have to be able to understand what's going on, able to make your own decisions.’” (Emily, AP)

The young adults emphasized the impact of these changes on their parents and were even able to perceive certain benefits.

“My mom was more out of control, because she knew she no longer had it.” (Emily, AP)

“Sometimes, I just feel like I want to be alone with my doctor so that things will go faster...because my mother is really emotional right now.” (Liam, AP)

Like their AHP colleagues, the PHPs underscored many issues related to patients exercising independence in their health care and the maturity of some patients. The result is often poor adherence to treatment plans and increased reliance on parental support. Each professional tried to

address this situation, but there was no universal program for preparing the transition.

“It’s still difficult at our level to get them talking, to get them involved in choice of treatment.” (Dr. Hedley, Pediatric Gastroenterologist)

“Changing the established care relationship is a complex undertaking. They’re still highly dependent on their parents, since they all live with their parents. And we’re used to a three-way relationship.” (Dr. Richardson, PHP)

This group also identified human resource limitations affecting their ability to establish a structured transition process: physicians have to prepare the file transfer on their own. Thus, despite attempts like TRACC to standardize the process, sometimes these professionals do not have the time to develop the file as much as they would like.

“In fact, TRACC usually includes a pre-established form, but I’m often too busy to complete it.” (Dr. O’Connell, PHP)

Post-transfer period

First, APs report some difficulties in their initial contact with health services. These problems seem to be related in part to becoming more independent, or to a lack of control over the disease.

“I hadn’t understood the treatments. I hadn’t understood that I could have other attacks, because in my mind I was adhering to the treatment, so there was no problem.” (Leah, AP)

“When I had a stomach-ache, at 17-18... 19 years [i.e. post-transfer], I would tell my Mom and she’d make an appointment. She took steps.” (Liam, AP).

“It took me four tries before I could reach someone at the appointment centre and know that they had a nurse for people with IBD. ...] My mother had kind of left me on my own, saying, ‘You have to start getting involved....’ I have an envelope where I’ve organized all my papers, prescriptions and scans.” (Leah, AP)

“She basically told me, ‘If you have an attack on purinethol, it means that your treatment isn’t working. We’ll check together to see what we can give you.’ It made me think, ‘Well, I have to understand [my illness].’” (Emily, AP)

Among the parents, experiences differed, no doubt based on their child’s personality and temperament. Some parents only heard about things when something went

wrong: “I heard about it when there was a problem” (Beckie, parent). Other patients demanded their parents’ presence: “You’re coming with meeeee!” (Adeline, parent).

Interestingly, the healthcare professionals were dealing with a backlash against close pediatric supervision, as their patients were feeling somewhat liberated.

“At the children’s hospital they’re fully taken care of. They receive medication, they’re given blood tests, they cry, they rebel. And then they get here, and they say: ‘At last we’re out of it.’” (Dr. Sussex, AHP)

Peer support program for better transitions

This section presents participants’ perceptions of the idea of an accompanying patient program.

Among MPs, we noted a clear lack of interest in this critical period in their care, and therefore little interest in what they could get from a peer support program.

“[Would we be interested in having an accompanying patient?] Asking the question like that... it’s because we don’t know what to expect.” (Bruce, MP)

“I think I’m in the process of being transferred to the Montreal [General] Hospital.” (Adrian, MP)

“The way it’s presented, it’s an extremely complicated transition, but I’m not sure about that. I think the consensus is that it appears to be relatively simple.” (Bruce, MP)

In APs, there is a need to be able to see oneself in the future, to see that it is possible to have a satisfying life plan, even if they have the disease. This involves meeting people who are living with the same disease. Some have even been able to meet older patients, which they found reassuring.

“When I had my attack when I was 11, they put me in a room with a 19-year-old girl experiencing a Crohn’s attack. I was reassured to see that she was still alive at 19 and living [a normal life].” (Leah, AP)

One of the added values underscored by APs is the importance of having a better understanding of life with the disease, and this comes from being able to talk with an accompanying patient.

Emily: “It seems like there’s no one who really understands.”

Liam: “But no, you can’t, not until you’ve been through it yourself.”

Leah: “You haven’t experienced it...”

Liam: “Forget that!”

Emily: “[...] It's more like meeting someone and you're not afraid to say: ‘Look, I go to the bathroom 3 times a day.’”
(Emily, Leah and Liam, APs)

The participants also pointed out some of the challenges in setting up such a program, particularly concerning the taboo around the disease and the way the project is presented:

“It'd be better to have small groups [...] that would eliminate the stress or embarrassment.” (Emily, AP)

On the other hand, the parents seemed very interested in the idea of an accompanying patient.

“There's no one better placed to help you than someone who's been through the same thing.”
(Vivian, parent)

“As long as your stomach doesn't hurt like that... you can't understand.” (Beckie, parent)

“They understand what the other person is going through.” (Adeline, parent)

The participants also mentioned the value of parents being in contact with an accompanying parent.

“We might not dare ask the nurse, but we would ask another parent. As if I were asking a friend.”
(Adeline, parent)

Concerning the idea of an online discussion forum, the AHPs raised a number of concerns about patient-to-patient contact.

“We could have a kind of discussion forum, [but] we have to be careful, because there are people with Crohn's disease who are very sick.” (Dr. Sussex, AHP)

One of the physicians had already asked patients to intervene with other patients. But such initiatives remain exceedingly rare.

“I said, ‘Listen, feel very free to say no. But when situations come up where we need to talk to a young person about an ostomy, would you agree to call them?’ She agreed.” (Dr. McCarthy, AHP)

In the end, despite some initial misgivings, the AHPs said that certain aspects of the disease could be more easily addressed by accompanying patients, effectively acknowledging the limits of their ability to understand life with inflammatory bowel disease.

“I often tell them: ‘I know I don't understand, because I don't have the disease, and I don't know what it is to have chronic pain, or to run around trying to find a bathroom in Montreal.’” (Dr. Sussex, AHP)

Physician PHPs had several questions about the idea of an accompanying patient, particularly in terms of the maturity of their minor patients and the ethical issues around working with them. However, some of them raised the idea of this kind of support for families after they have received the diagnosis.

“I'm not sure that, at that age, young people are available enough to provide this type of support.”
(Dr. Hedley, PHP)

“We have to be careful, because some young people could get involved romantically with or abuse the younger ones. They really need to be closely supervised.” (Dr. Wilson, PHP)

“It would be a good idea to offer this type of support to families when they receive the diagnosis. That would reassure the parents, as well as the young person, to see that things can go well.” (Dr. O'Connell, PHP)

Discussion

Patients who have not yet been transferred to an adult care setting are generally unconcerned about the challenges ahead. This is largely due to the self-absorbed nature of adolescence,^{36,37} especially in terms of their illusion of invincibility, and the personal fiction that they are not governed by the same rules as other people. Moreover, the patients we met all had an illness that was generally well controlled by their treatments, so a young person could completely ignore his or her illness and need for care. Similarly, we were able to show that pediatric services do not provide resources to help young patients develop self-management skills.³⁸ And, contrary to what we found in the literature, patients' emotional attachment to their pediatric setting^{11,39-41} and anxiety around establishing a new therapeutic alliance^{42,43} did not appear to represent major issues among the adolescents we met.

In contrast, APs acknowledge that their understanding of the disease is limited at the time of transfer. Their greatest challenge at that time is losing a therapeutic alliance and needing to build another in a new setting.^{11,39-43} As previously documented by Fair *et al.*⁴⁴ and Paine *et al.*,⁴⁵ issues related to maturity and adherence to therapy generated instability in symptom control, driving their patients to take greater control of their health.

In parents the transition is known to provoke considerable anxiety,⁴⁶ and this is also the case for parents of young people with IBD. They become insecure when they lose direct contact with the care team, which characterized the therapeutic relationship (a three-way relationship) in pediatrics,³⁹ especially since they find that their children are unable to independently manage the required care.⁴⁶ Some of the parents of adolescents became very emotional about their anxiety over the change in care setting.

Much like McLoughlin *et al.*,⁴⁷ we noted that health care professionals perceive the need to have additional resources dedicated to the transition, since logistical, administrative and procedural issues impede a continuum of care. They were also concerned that patients from the pediatric setting have insufficient knowledge of the disease, maturity and independence.

One new finding of this study is that young patients in pediatric settings generally lack interest in their transition. As a result, they fail to see the value of a peer support program beginning in the pediatric setting. However, APs are much more interested in such an intervention. Having already faced the initial challenges of adjusting to adult life with a chronic disease, they are more inclined to accept peer support. Moreover, for parents in a pediatric care setting, preparing for the transition through conversations with parents of APs or with APs is seen as a potentially very positive way to calm their anxieties and see themselves in an anxiety-provoking unknown. In this context, a peer program could take the form of a family sponsorship, in which a young AP could provide support, primarily to the parents at first but then gradually helping the young person as the need arises. Having built a relationship of trust with the parent, the accompanying patient will be able to more easily intervene with the young person. Such a model would make it possible to respect and adapt to each person's needs during the transition period, which may occur at any time between the ages of 15 and 25 years.

Limitations of the study

Participation in this study (by both adults and adolescents) was limited by the educational obligations of most of the participants. Examination periods at school, the cyclical nature of academic semesters and holidays limited the number of times enough patients could be recruited to hold a focus group. There were even times when we had to conduct individual interviews. Since no differences were found between the data obtained via interviews or focus group, it is likely that the inhibition felt by some participants was the same with both methods.

Embarrassment about the disease also deterred people from participating. Some young people were uncomfortable discussing their condition with strangers.

Another limitation was that we had two specialized centres in our study, which may have produced a population with a higher proportion of complex cases requiring this level of care. However, it should be noted that children with IBDs are followed in specialized pediatric centres.

Conclusion

The pediatric transition is a key step in the care pathway of YSCHNs, allowing them to gradually manage their health problem more independently. During this period, a peer support program appears to have positive impacts, and would be appreciated if it could evolve over time. In the pediatric environment it is mainly the parents who can benefit from such a program, and as the young people mature, a peer can help them meet more needs and manage their health problems more independently. Drawing on this approach, professionals, patients and parents are carrying out co-construction work and implementing a program. An assessment of this program will help ensure that everyone's needs are being taken into account and met.

Acknowledgements

The co-authors thank Nadine Magali-Ufitinema for her help through this project and Jim Kroening for his significant rereading, which helped bring greater clarity and focus to the article. We would also want to express our deepest appreciation to the participants for making this project possible.

References

1. World Health Organization. The world health report 2002 - Reducing Risks, Promoting Healthy Life. In. Genève: WHO; 2002:248.
2. Omran AR. The Epidemiologic Transition: A Theory of the Epidemiology of Population Change. *The Milbank quarterly*. 2005;83(4):731-757.
3. Van Cleave J, Gortmaker SL, Perrin JM. Dynamics of obesity and chronic health conditions among children and youth. *JAMA*. 2010;303(7):623-630.
4. Halfon N, Newacheck PW. Evolving notions of childhood chronic illness. *JAMA*. 2010;303(7):665-666.
5. Michaud P-A, Suris JC, Viner R. *The adolescent with a chronic condition : epidemiology, developmental issues and health care provision*. Genève: World Health Organization; 2007.
6. Society of Pediatric Nurses. SPN Position Statement: Transition of Pediatric Patients into Adult Care. 2016. <http://www.pedsnurses.org/p/cm/ld/fid=57&tid=28&sid=1545>.
7. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of

- the Society for Adolescent Medicine. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*. 2003;33(4):309-311.
8. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*. 1993;14(7):570-576.
 9. Pyatak EA, Sequeira PA, Whittemore R, Vigen CP, Peters AL, Weigensberg MJ. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with Type 1 diabetes. 2014;31(12):1615-1624.
 10. Perry EE, Zheng K, Ferris ME, Torres L, Bickford K, Segal JH. Invited Manuscript Poster on Renal-Related Education American Society of Nephrology, Nov. 16–21, 2010 Adolescents with Chronic Kidney Disease and Their Need for Online Peer Mentoring: A Qualitative Investigation of Social Support and Healthcare Transition. *Renal Failure*. 2011;33(7):663-668.
 11. Gray WN, Resmini AR, Baker KD, et al. Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflammatory Bowel Diseases*. 2015;21(7):1641-1651.
 12. Wong LHL, Chan FWK, Wong FYY, et al. Transition Care for Adolescents and Families With Chronic Illnesses. *Journal of Adolescent Health*. 2010;47(6):540-546.
 13. Fernandes SM, Fishman L, O'Sullivan-Oliveira J, et al. Current practices for the transition and transfer of patients with a wide spectrum of pediatric-onset chronic diseases: results of a clinician survey at a free-standing pediatric hospital. *International Journal of Child & Adolescent Health*. 2010;3(4):507-515.
 14. Sebastian S, Jenkins H, McCartney S, et al. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: Differing perceptions from a survey of adult and paediatric gastroenterologists. *Journal of Crohn's and Colitis*. 2012;6(8):830-844.
 15. Gray WN, Maddux MH. Current Transition Practices in Pediatric IBD: Findings from a National Survey of Pediatric Providers. *Inflammatory Bowel Diseases*. 2016;22(2):372-379.
 16. Gray WN, Monaghan MC, Gilleland Marchak J, Driscoll KA, Hilliard ME. Psychologists and the Transition From Pediatrics to Adult Health Care. *Journal of Adolescent Health*. 2015;57(5):468-474.
 17. Kovacs AH, McCrindle BW. So hard to say goodbye: transition from paediatric to adult cardiology care. *Nat Rev Cardiol*. 2014;11(1):51-62.
 18. Carroll M, Coward S, El-Matary W, et al. *Impact des maladies inflammatoires de l'intestin au Canada*. Toronto2018.
 19. Fondation canadienne des maladies inflammatoires de l'intestin. *Le fardeau des maladies inflammatoires de l'intestin au Canada*. Toronto2008.
 20. Falvo DR, Holland B. *Medical and psychosocial aspects of chronic illness and disability*. Sixth edition. Burlington, MA: Jones & Bartlett Learning; 2018.
 21. Streit U. Divers types d'événements, leur impact et les stratégies de coping. In: Frappier J-Y, ed. *Lectures - Croissance, développement, vieillissement - MMD 1228*. Montréal: Université de Montréal; 2014.
 22. Lazarus RS. *Stress, appraisal, and coping*. New York: New York : Springer Pub. Co.; 1984.
 23. Lazarus RS. Emotions and Interpersonal Relationships: Toward a Person-Centered Conceptualization of Emotions and Coping. *Journal of Personality*. 2006;74(1):9-46.
 24. Lazarus RS, Launier R. Stress-Related Transactions between Person and Environment. In: Pervin LA, Lewis M, eds. *Perspectives in Interactional Psychology*. Boston, MA: Springer US; 1978:287-327.
 25. Stringer ET. *Action research*. Fourth edition. ed. Thousand Oaks, California: SAGE; 2014.
 26. McNiff J. *Action research : all you need to know*. Los Angeles: SAGE; 2017.
 27. Bazinet C. Modèle Pomey de co-construction en partenariat. In. Montréal: Chaire de recherche en évaluation des techniques et des pratiques de pointes: Engagement des citoyens et des patients dans la transformation des organisations de santé; 2018.
 28. Pomey M-P, Efanov JI, Arseneault J, et al. The Partnership Co-Design Lab: Co-constructing a Patient Advisor Programme to increase adherence to rehabilitation after upper extremity replantation. *The Journal of Health Design; Vol 3, No 1 (2018): Patients as co-designers to improve the quality of care*. 2018.
 29. Yin RK. *Case study research : design and methods*. 5 edition.. ed. Los Angeles (CA): SAGE; 2014.
 30. Patton MQ. *Qualitative research & evaluation methods : integrating theory and practice*. Fourth edition.. ed: Los Angeles : SAGE; 2015.
 31. Van der Maren J-M. Méthodes de recherche pour l'éducation éducation et formation. Fondements. In: Chicoutimi: Bibliothèque Paul-Émile Boulet de l'Université du Québec à Chicoutimi; 2015: Accès direct http://classiques.uqac.ca/contemporains/Van_der_Maren_jean-marie/methodes_recherche_education/methodes.html <http://ariane.ulaval.ca/cgi-bin/recherche.cgi?qu=a2535263>.
 32. Fereday J, Muir-Cochrane E. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. 2006;5(1):80-92.
 33. Crabtree BF, Miller WL. *Doing qualitative research*. 2nd ed ed. Thousand Oaks, Calif: Sage Publications; 1999.

34. Boyatzis RE. *Transforming qualitative information : thematic analysis and code development*. Thousand Oaks, CA: Sage Publications; 1998.
35. Lévesque D. En bref: Le Tracc. In: Association des gastroentérologues du Québec; 2015:2.
36. Elkind D. Egocentrism in Adolescence. *Child Dev*. 1967;38(4):1025-1034.
37. Papalia DE, Feldman RD. *Psychologie du développement humain*. 8e éd.. ed. Montréal: Montréal : Chenelière/McGraw-Hill; 2014.
38. Fishman LN, Barendse RM, Hait E, Burdick C, Arnold J. Self-management of older adolescents with inflammatory bowel disease: a pilot study of behavior and knowledge as prelude to transition. *Clin Pediatr (Phila)*. 2010;49(12):1129-1133.
39. Fernandes SM, Khairy P, Fishman L, et al. Referral Patterns and Perceived Barriers to Adult Congenital Heart Disease Care: Results of a Survey of U.S. Pediatric Cardiologists. *Journal of the American College of Cardiology*. 2012;60(23):2411-2418.
40. Hilliard ME, Perlus JG, Clark LM, et al. Perspectives From Before and After the Pediatric to Adult Care Transition: A Mixed-Methods Study in Type 1 Diabetes. 2014;37(2):346-354.
41. Maddux MH, Ricks S, Bass J. Patient and Caregiver Perspectives on Transition and Transfer. *Clinical Pediatrics*. 2016;56(3):278-283.
42. Porter JS, Graff JC, Lopez AD, Hankins JS. Transition From Pediatric to Adult Care in Sickle Cell Disease: Perspectives on the Family Role. *Journal of Pediatric Nursing*. 2014;29(2):158-167.
43. Bashore L, Bender J. Evaluation of the Utility of a Transition Workbook in Preparing Adolescent and Young Adult Cancer Survivors for Transition to Adult Services: A Pilot Study. *Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses*. 2016;33(2):111-118.
44. Fair CD, Sullivan K, Dizney R, Stackpole A. "It's like losing a part of my family": transition expectations of adolescents living with perinatally acquired HIV and their guardians. *AIDS patient care and STDs*. 2012;26(7):423-429.
45. Paine CW, Stollon NB, Lucas MS, et al. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. *Inflammatory Bowel Diseases*. 2014;20(11):2083-2091.
46. Hilderson D, Moons P, Van der Elst K, Luyckx K, Wouters C, Westhovens R. The clinical impact of a brief transition programme for young people with juvenile idiopathic arthritis: results of the DON'T RETARD project. *Rheumatology (Oxford, England)*. 2016;55(1):133-142.
47. McLoughlin A, Matthews C, Hickey TM. "They're kept in a bubble": Healthcare professionals' views on transitioning young adults with congenital heart disease from paediatric to adult care. *Child Care Health Development*. 2018;44(5):736-745.