



# The Role of Pediatric Psychologists in the Transition of Youth to Adult Health Care: A Descriptive Qualitative Study of Their Practice and Recommendations

Marco Bonanno<sup>1,3,5</sup> · David Ogez<sup>2,3</sup> · Claude Julie Bourque<sup>3</sup> · Caroline Laverdière<sup>3,4</sup> · Serge Sultan<sup>2,3,4</sup>

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## Abstract

Transition from pediatric to adult health care setting is a challenge for young patients because of the psychosocial issues they may present that could hinder their commitment to treatment and medical care. Psychologists play a key role in supporting these patients. They intervene with the most vulnerable ones for whom the current transitional practice does not necessarily meet their specific needs and help them to develop an appropriate level of autonomy despite medical condition. To date, few studies have described their clinical practice in this field. This study aimed to gather in-depth information about the elements that characterize their different roles in transition care. Following a semi-structured interviews with ten pediatric psychologists, we conducted a thematic content analysis to identify common themes among participants. The results indicate that the psychologists' practice focuses on four main aspects: assessment, intervention, education, and liaison. Their recommendations point towards a better organization of health care services and a reflection on the best practices in psychology. These results highlight the specific roles that pediatric psychologists play in the transition process within the health care environment.

**Keywords** Transition · Psychologists · Health care system · Young patients · Pediatrics

In the health care sector, transition is defined as the “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum, Garell, Hodgman, & Slap, 1993). Over time, transition has become a specific area of interdisciplinary practice that is

increasingly recognized (Nehring, Betz, & Lobo, 2015). With recent advances in medicine, 90% of youth with a chronic illness have a life expectancy of more than 20 years (Rapley & Davidson, 2010) and will require follow-up or treatment in an adult health care setting. These young people are considered vulnerable, as they are at risk of displaying behaviors of dependency on others, developmental delays, and psychosocial issues (Beal et al., 2016; Rosen, 2004).

In order to address the difficulties encountered by this population, studies aimed to identify barriers in the transition of these adolescents and young adults to the adult health care environment (Stewart et al., 2010). The resulting recommendations highlighted the need to provide coordinated, flexible, and developmentally appropriate services to support their autonomy (Rosen et al., 2003). However, these recommendations have not been systematically implemented (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Group, 2011) and the field of transition care may appear elusive and vague with respect to its approach as a specific practice (Nehring et al., 2015).

The challenges in this field of practice are daunting seeing that all pediatric professionals are expected to develop

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✉ Marco Bonanno  
marco.bonanno.hs@ssss.gouv.qc.ca

<sup>1</sup> Department of Psychology, Université de Sherbrooke, Sherbrooke, Canada

<sup>2</sup> Department of Psychology, Université de Montréal, Montreal, Canada

<sup>3</sup> Sainte-Justine University Health Centre, Montreal, Canada

<sup>4</sup> Department of Pediatrics, Université de Montréal, Montreal, Canada

<sup>5</sup> Hematology-Oncology Division, Sainte-Justine University Health Centre, 3175 Chemin de la Côte Sainte-Catherine, Montreal, QC H3T 1C5, Canada

an additional repertoire of transition and health care skills (Nehring et al., 2015). The current literature recognizes the importance of a discussion around the creation, adjustment, and change of roles and responsibilities in the health care system (Rapley & Davidson, 2010; Stewart et al., 2010). Indeed, the services offered have been described as fragmented and uncoordinated (Institute of Medicine (US) Committee on Disability in America, 2007; Learning Disabilities Association of Canada, 2007). Due to limited evidence, the Agency for Healthcare Research and Quality of the U.S. Department of Health and Human Services (AHRQ, 2013) recently highlighted the difficulty in identifying which interventions would be the most effective in this field.

Pediatric psychologists are an integral part of multidisciplinary teams in which they play an important role because of their function in evidence-based client assessment and intervention, as well as in team consultation and liaison (Crosby, Lynch-Jordan, & Slater, 2010; Spirito et al., 2003; Willen, 2007). They have highly relevant expertise related to the developmental and behavioral aspects of the transitioning population such as treatment adherence and patient–caregiver communication (Kichler, Harris, & Weissberg-Benchell, 2015). They also conduct research and are involved in health policies related to the preparation and implementation of transition programs (Gray, Resmini, et al., 2015).

Despite all of these competencies, few studies have been conducted on the role of psychologists in the transition process. To our knowledge, only one research, based on an online questionnaire administered to 100 psychologists, seems to address this issue (Gray, Monaghan, Marchak, Driscoll, & Hilliard, 2015). The study, using primarily a quantitative approach, provided a list with the corresponding percentage of three general roles, the type of population served, and barriers psychologists may face in the field of transition. The findings showed that their involvement resulted in clinical interventions with adolescent and young adult, often in collaboration with other members of the multidisciplinary team and, indirectly, through the participation in research projects or as consultants to research teams. In particular, psychologists were called upon to promote adherence to treatment and to assess transition readiness in youth.

However, we lack details on the elements that characterize the different roles and responsibilities held by psychologists in the transition to adult health care and the former study did not collect recommendations to improve psychologists' practice. This is an important issue that deserves further investigation. Firstly, given the limited information we have on this subject, it is important to collect information on the practice of psychologists in the field of transition with an inductive methodology in order to make a description of practice through their own views. This approach could allow unexpected, unknown, and new aspects in this field to

surface, independent of what is already known on the subject (Patton, 2002). Secondly, current transition practices often assume that patients have a certain level of competence and do not address the specific needs of the most vulnerable youth (Herzer, Goebel, & Cortina, 2010). They are patients who may present mental health symptoms, physical disabilities for whom the normal developmental stages expected in the adolescent period are compromised or slowed down, or those with cognitive difficulties. However, research has shown that psychologists in the health care system could meet this need (Palermo et al., 2014). Then, the development of an appropriate level of autonomy has been shown to be an important factor supporting the transition process (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Nonetheless, the medical condition limits and delays the normal process toward autonomy. In this context, psychologists' practice may promote and develop the autonomy of the youth during the transition process (Bailey, O'Connell, & Pearce, 2003). It is thus important to collect information on what psychologists do when they deal with this process, and their views on what should be done.

The main objective of this study was to describe the professional practice of hospital pediatric psychologists in the transition for young people with a chronic or degenerative disease to adult health care, as they themselves perceive it. Using a small qualitative sample, we specifically aimed to (1) describe some of the actions, tasks, and competencies developed by psychologists in the field of transition that characterize their specific roles, (2) to collect information on the impact of these actions on the target population, as recommended by Gray, Monaghan et al. (2015), and (3) to collect their suggestions for improving their clinical practice in the future.

## Methods

This study was part of the doctoral undertaking of the study's principal investigator, a clinical psychologist who has been working in the field of medical psychology in hospitals for more than 15 years.

A qualitative methodology using a thematic content analysis and a descriptive inductive approach was chosen with this group of professionals (Braun & Clarke, 2006). Based on a constructivist epistemological framework (Ponterotto, 2005), this approach was appropriate to meet the objectives of the study, as its aim was to describe and explore a phenomenon in order to better define it, with observations collected from a small group of key informants (Patton, 2002). Particularly, this approach allowed obtaining rich data on various topics expressed by the participants themselves. It also allowed to reach exploratory objectives of the study with a limited number of participants, and let unexpected

and new elements surface from an in-depth discourse (Malterud, Siersma, & Guassora, 2016; Ponterotto, 2005).

The participants of this study were psychologists from a tertiary pediatric academic hospital (TPH), and its affiliated rehabilitation center (RC), in Canada. The reason for limiting data collection on one site is related to limitations in resources for data collection and to avoid interpretation bias due to deviation effects between different institutional cultures.

After approval from the ethics committees, this research project was presented to psychologists from both institutions during a professional meeting. We also sent an internal email to potential participants to inform them of the study. Participants were recruited according to two principles of qualitative research: internal diversification and empirical saturation (Pires, 1997). Eligibility was based on the following inclusion criteria: to speak French; to be a licensed psychologist; to work or have worked for at least 1 year in the last 10 years with youth (14 years of age and older) with a chronic or degenerative condition. No exclusion criteria were imposed. Based on the fact that the principal investigator (MB) was affiliated to the same institution as the respondents, potential participants were randomly selected from the list of 48 psychologists employed at TPH and RC to ensure neutrality in the selection. They were contacted by telephone to validate their availability, the inclusion criteria, as well as their interest in participating in the study. Out of 12 participants meeting the inclusion criteria, 10 agreed to participate and were invited to sign a consent form. Recruitment continued as interviews began at a rhythm of about one interview every 4 weeks. Empirical data saturation was reached after eight interviews as redundancy was noticed in all the sub-categories of themes identified, but two extra participants were included to ensure good coverage of the results, bringing the number of participants up to 10. In all, seven clinical health psychologists and three neuropsychologists were interviewed. All the participants were female. This was mainly due to the fact that about 98% of psychologists working in the TPH and RC were women and the mode of selection did not allow for adjustment of the sample in terms of gender representativity.

Psychologists from both institutions are represented in the group, as well as both training profiles (six Ph.D. and four M.Sc./M.A.). They all worked with a pediatric population and they cumulated in total past and present experiences in 15 medical subspecialties. The participants had an average of  $10 \pm 6$  years of experience in transitioning youth to adult health care settings and their seniority was  $15 \pm 8$  years on average. They spent an average of 52% of their working time in assessment work and 48% in carrying out interventions with patients.

Participants were invited to take part in a 1-h individual interview that was led by the principal investigator and

audio recorded. Demographic information was collected from participants before the interview. Each participant was interviewed once at their office following a semi-structured interview grid comprising two main questions that assessed respectively the participants' role and suggestions regarding the field of transition. These questions were thought of and discussed within the research team at the start of the project. They were developed based on interviews in other studies examining the role of other professionals in the field of transition (Fair, Albright, Lawrence, & Gatto, 2012; Geenen, Powers, & Sells, 2003). This interview grid was adapted to the objectives of the study and aimed to generate the discourse in a non-directive way to allow participants to approach topics around the transition in the way they wished. Each question and sub-question were asked to the participants allowing them to elaborate their answers (Table S1). All interviews were transcribed.

## Data Analysis

Interview data were analyzed inductively using thematic content analysis. Thematic analysis aims to identify, analyze, and present patterns (themes) in the data collected during the research interviews (Boyatzis, 1998). We proceeded with a three-step content analysis following the recommendations of Miles, Huberman, and Saldana (2013), which included data reduction from the transcripts, identification of themes and categories, drawing, and conclusions.

The process of coding and organizing the transcripts was computer assisted with Qualitative Data Analysis (QDA) Miner software (Provalis Research, version 5). First, the transcripts were divided into several paragraphs, then into sentences to bring out meaningful units based on the research questions. A code grid, which was created on the basis of the first three interviews, was revised throughout the analysis process. At the beginning of the analysis, the codes were mainly descriptive of the participants' interview content. As the interviews occurred, these were progressively grouped and interpreted to highlight the participants' roles and recommendations. Thematic categories of a more interpretative nature were to be created.

Meetings amongst the co-researchers of the study were conducted to optimize the internal validity of the study. The purpose of these meetings was to discuss the codes and themes and to improve or clarify them. Following the coding of the first interviews by the principal investigator in order to ensure the credibility of the approach, we included confirmation of the thematisation process and a detailed documentation of thematisation steps. In this regard, the first three interviews were coded by an independent external co-investigator to ensure the reproducibility of the coding originally carried out by the principal investigator (allowing for inter-judge agreement). In accordance with

the constructivist paradigm of the study (Ponterotto, 2005), this procedure was done not using any type of quantitative measure of agreement but mostly to refine code definitions and the final structure of the coding tree. All discrepancies were resolved through discussion between analysts until consensus was reached. All remaining transcripts were coded with the validated codebook. Citations were identified for each of the themes. Some excerpts from the transcripts are presented as quotes in the results in order to bring out and highlight the issues raised by participants.

## Results

This study wanted to highlight the roles of psychologists in the transition practice in describing their actions and competencies, their impact on the population served, and to collect suggestions for improving their clinical practice. Accordingly to these aims, the inductive analyses used allowed to present the results in two principal sections: the transition practice and the recommendations to improve transition.

### Transition Practice

The interviews highlighted the participants' representation of their transition practice, which is based on four main aspects: (1) assessment, (2) support interventions, (3) education and information activities, and (4) interprofessional collaboration and liaison (Fig. 1).

#### Assessment

The participants reported they may be called by various team members to establish the cognitive profile of youth to highlight the difficulties and limitations that may impact the process of transition to adulthood. Depending on the needs, they may decide to evaluate a patient several times

in order to gain an accurate portrait of his or her cognitive or socio-affective profile (strengths and difficulties) before transferring to adult healthcare.

The doctor refers the patient to us at the end of their treatments in order to evaluate their cognitive profile. Sometimes, we can see that the patient has a delay that will worsen, so we can expect stagnation with respect to the development of the patient's capabilities, we can foresee how it will be difficult for him. (P2)

Most psychologists in this study believe they have specific expertise in "assessing normal and pathological development" and socio-emotional aspects, which enable them to give their opinion on the transfer readiness of patients. In particular, these professionals assess transition needs based on the history of the young person and the difficulties caused by the medical condition. Suggestions are provided to the team regarding the most opportune time to plan the transfer to the adult health care sector.

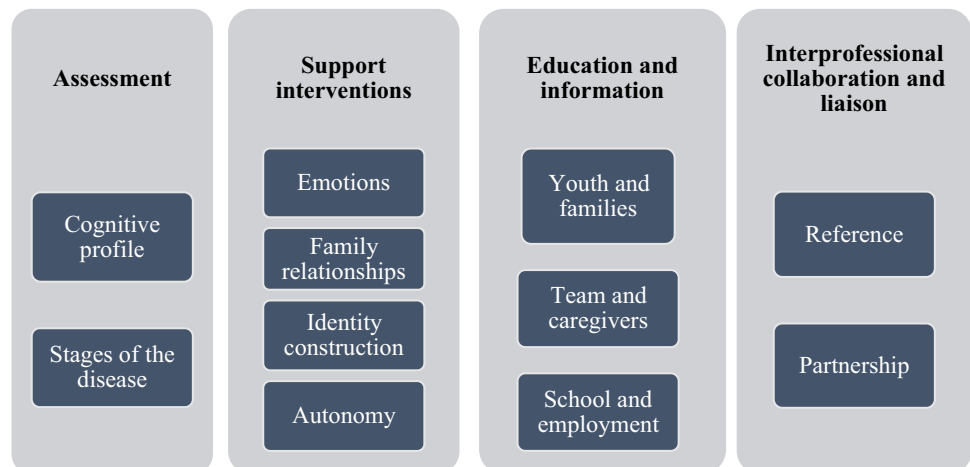
#### Support Interventions

Participants highlighted the importance of supporting young patients in exploring emotions and social relationships that may be challenging in their lives. This work aims to give meaning to the experience, with respect to the medical condition, according to the stages of life expected for their age.

This support around the disease is at the heart of the psychologists' interventions and allows the patients, despite the decline they endure due to the disease, to continue to pursue their expected development for their age in terms of their objectives and projection towards the future. (P1).

According to participants, transitioning to an adult health care environment can carry a significant emotional burden for youth. This is due to the detachment process that is

**Fig. 1** Aspects of transition practice addressed by pediatric psychologists



required of youth with respect to leaving the pediatric setting. It also includes the physical limitations, the awareness of outlook limitations as well as the losses they will have to face during their life. Psychologists thus help reduce feelings of insecurity and fear related to the change of environment and allow for a better adjustment to these limitations.

I think it is first and foremost an emotional support with respect to their expectations of the adult health care setting, their anxieties, and regarding their relationships, social and family issues, and their difficulties with respect to their studies, workplace, and love life; all that it can entail on an emotional developmental level. (P1)

Psychological support was said to be able to promote the search for a new balance in family relationships. This allows patients to better adapt to the different structure of the services offered in the adult health care setting, and to become aware of his or her own abilities and needs. Psychological work was believed to allow young people to become aware of the emotional and physical changes they are experiencing that are caused by adolescence and their medical condition. By offering an “intimate and safe” space, the psychologist helps in youth’ identity construction by allowing youth to know themselves better.

My interventions focus on knowing oneself, trying to get the patient to discover himself enough to be aware of who he is, of what is important, of what makes him happy, unhappy, and to try to see what are the big areas of vulnerability that concern him, what are the strengths. (P10)

Psychological interventions targeting autonomy can reinforce these young patients to express their needs, to take steps without parental help, to seek support for medical needs, and to make decisions accordingly. The psychologists reported being able to support patients in exploring possible choices in different aspects of their lives such as continuing education or choosing work.

### Education and Information

One of the roles described by participants is to favor awareness of the psychosocial issues related to a chronic or degenerative medical condition to patients, teams, and external individuals who are involved in patient’s lives (e.g., teachers, employers). This is necessary, for example, in youths with neuromuscular disorders who may have learning disabilities or for brain tumor survivors who may find it difficult to acquire and use social skills. Psychologists can promote a better understanding among patients and their families of the cognitive sequelae caused by illness and treatment, and they can suggest strategies for improving medication

management. They help young people express their needs during medical appointments and meet with parents to provide information about services offered in the adult health care setting.

It helps to describe to the youth his new reality so that he is aware of how things are in adulthood. With your new doctors, it’s not them that call, it’s you that has to call. Your doctor won’t run after you to find out if you completed your analyses. That’s why I talk about the importance of knowing one’s disease, knowing one’s body, and being able to take it into account. (P8)

Most psychologists in the study sensitize teams to the challenges experienced by youth in the transition process by explaining some aspects of their psychological functioning, according to the individual’s stage of life and medical condition, and by highlighting the individual’s needs. In the school environment or with employers, psychologists can explain the long-term sequelae caused by the medical condition that impact the day-to-day functioning of the patient. This knowledge transfer is guided by the direct assistance of psychologists in the environment in setting up an intervention plan or providing recommendations that explain the youth’ limitations.

At school, what we still unfortunately hear often is: “but he is no longer sick, so it can’t be related to that.” So we have to educate and explain that it happens at the brain level. So our role is to educate. (P2)

### Interprofessional Collaboration and Liaison

To facilitate the transition to adult health care, the psychologists reported advising and referring the young patients to the most appropriate resources and, if necessary, working in collaboration with medical caregivers who have an intermediary role to facilitate the exploration of needs in pediatric patients. Psychologists can facilitate contact between patients and the available resources in the adult sector by providing adequate references to meet their support needs, while trying to aid continuity. They also described how they build bridges with external agencies to ease their integration into the labor market. Most participants in the study also collaborate and engage with other caregivers to promote young people care in the adult sector and to set up services that are needed. In some cases, in order to improve youth collaboration during the transfer process, psychologists may organize or partake in joint meetings between caregivers from pediatric and adult health care settings.

We contacted the adult health care center and asked to have a meeting so we could explain to the youth what the services are, how it works. There were several caregivers there and it helped to illustrate where the

patient was [with respect to her care plan] and what her needs were. She was also able to discuss her fears, her concerns and her needs, and we came up with a plan of action as a group that was going to be developed. (P5)

## Recommendations to Improve Transition

The participants' recommendations for improving the transition process were grouped into four broad areas as a result of the qualitative analysis (Fig. 2). These proposals concern: (1) the adult health care setting, (2) a cooperation between the pediatric and adult health care settings, (3) the pediatric health care setting, and (4) psychologist practice.

### Adult Health Care Setting

According to the participants, caregivers in the adult health care setting should have better knowledge of pediatric diseases and of their long-term impact on patients. This would allow them to have a clearer understanding of the work and challenges involved in the transition from pediatric to adult health care for youth and for the pediatric teams. Participants also felt that adult health care settings should also offer systematic support for young people leaving pediatrics. The reason lies in the presence of a psychological fragility in this population largely caused by the treatments they receive that can have long-term effects on different parts of their lives, such as their fertility, autonomy, or organizational capacity, across family and work environments. These aspects tend to be specific to pediatrics and are not often present in most patients who become sick as adults.

So the adult patient in question would have access to this service because the effects on the functioning of our clientele is experienced at the educational level, but in the adult patient, it's at the professional and family level. The patient who finds himself with huge cognitive impairments, I can say that he'll find the

work-family balance difficult, as well as the morning routine, all the autonomy that it takes to make a budget, to do the shopping, school, day-care, meals. (P2)

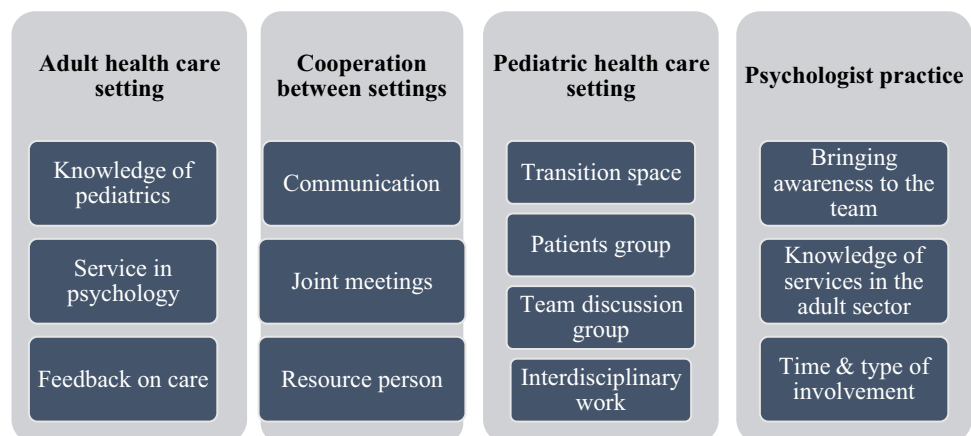
Pediatric psychologists view that feedback from the adult health care setting on the transferred young patients would also be an effective way to adjust and better target pre-transfer interventions, particularly for those who are most vulnerable.

### Cooperation Between Settings

Communication between caregivers in pediatric and adult health care settings is an important component for a successful transition. To support this, the two settings must generally deliberate to find better ways to maintain interventions and transfer information. Setting up joint meetings between caregivers from both settings would help improve the effectiveness of the proposed transition approaches by personalizing interventions based on the specific challenges faced by each young patient. Participants also stressed the importance of having a reference person, regardless of their background, who can bridge the gap between the different institutions. This person could also make sure to put in place resources needed for optimal support, particularly for youth that would be deemed most vulnerable.

We worry for certain patients because we wonder: "How is he going to set up appointments, ensure that his follow-ups are in place, or arrange for transportation?" So maybe in the beginning or in some cases where patients have more important limitations, there should be someone acting as a coordinator, because I find that patients are left to themselves in this respect. (P5)

**Fig. 2** Recommendations made by psychologists to improve transition practice



## Pediatric Health Care Setting

In the study, some psychologists suggested that there should be a separate physical space in pediatric health care settings in which caregivers could propose targeted interventions to prepare youth for the different set-up of services offered in the adult health care setting. In this “geographically determined” space, the team could propose specific activities for their patients and common procedures for the caregivers involved with this population. This could include an evaluative component as well as interventions aimed at preparing patients for transfer.

Shouldn't there be a space dedicated to the specificity of the transition? Yes, adolescence is part of childhood but it is also part of adulthood. Could we not come up with a branch that could ease the transition into the jungle of adulthood, that would allow for contemplation, that would give the patient time, with a clear beginning and end because as it is now, it's not clear. (P3)

The setting up of discussion groups for young people, which could be organized in the hospital or via social media, would facilitate transfer preparation through shared experiences. These groups could help connect young patients who feel more comfortable expressing their needs among peers rather than talking about it individually in the office of a psychologist. The creation of discussion groups among professionals in pediatric health care settings may also be an effective means of developing better practices for transition and can better help define professional interventions.

I think we should have a working committee that should precisely look at: “When should we begin to think about transition? What aspects should be addressed? What are the available resources? When should we start talking about it with the young patient? What are the steps to take? Who does what?” (P5)

The support objectives targeted in transition work could also be improved through joint interventions and concerted interdisciplinary actions in order to promote the autonomy of patients.

## Psychologist Practice

The participants recommended that psychologists be more involved in team meetings to bring awareness to caregivers about the psychological needs of youth in transition. This would help improve the understanding of the psychologist's role among the caregivers and would allow caregivers to identify and refer the most vulnerable patients to psychological consultations at the appropriate time.

I think that raising the awareness of caregivers about what this period represents emotionally for these patients. It would allow us to reach more patients who would ultimately benefit from a follow-up and who are very vulnerable in this transition period. (P1)

It was also deemed important for psychologists to know more about the services offered in the adult health care setting in order to adapt interventions and to appropriately refer to available resources. According to the participants, psychologists must better assess the timing and relevance of their involvement based on the specific transition needs of each patient. The participants are looking for clear criteria to guide action.

I wonder. Do patient and their families need me as a psychologist for their transition to the adult health care center? I don't know, I wonder. I think that for me, in the patients I see, there are some for whom at this stage I am no longer the meaningful person who is important in their journey. So it would be to better know when my role would be desirable and to be there for them at that time. (P6)

## Discussion

The present study updated the psychologists' practice of transition from the pediatric to the adult sector, as perceived by these caregivers, and collected for the first time their recommendation in this field. Particularly, the results made it possible to specify some elements and characteristics of their different roles and the impact of their actions in their clinical practice.

Following a qualitative method on interview content, these results allowed detailing, deepening, and characterizing some of the general fields of practice of psychologists in the transition showed by Gray, Monaghan et al. (2015), specifically the clinical care and leadership involvement roles. The results of our study show that these two fields of practice are encompassed by four specific areas (i.e., assessment, support, education, and liaison), which form the core of the recommendations on the skills required and the development of the best practices in pediatric psychology (Palermo et al., 2014; Spirito et al., 2003). It is only recently that the field of transition has been introduced in the “Crosscutting Knowledge Competencies in Pediatric Psychology” (Palermo et al., 2014). However, very little detail is given about the skills required. Some of the themes that emerged from the participants' interview content can help better define them.

One of the main tasks required of psychologists is to conduct the biopsychosocial assessment of children and adolescents in order to better understand coping behaviors with respect to health problems (Palermo et al., 2014). In

these patients, medical treatment is sometimes associated with cognitive difficulties that make the transition to the adult health care sector more challenging (Kuhlthau et al., 2015). This study highlighted that the expertise developed in pediatric psychology is very specific and makes it possible to support the transition in a way that is congruent with the needs of these patients which are not often met by current transition practices (Herzer et al., 2010).

Autonomy and identity construction among young adults takes up an important part in the support interventions conducted by psychologists. Achieving autonomy is a core developmental task of adolescence (DiClemente, Hansen, & Ponton, 1996; Hui & Tsang, 2012). However, the medical condition can be an obstacle to its development in the transition process (Schwartz et al., 2011). This can be explained by some factors such as: (1) the decrease in social interactions (Wray-Lake, Crouter, & McHale, 2010); (2) the long-term dependent relationship that exists between patients and their natural and professional caregivers (Bailey et al., 2003) and (3) the overcompensation by the caregivers for the difficulties faced by these patients (Sarrazin, 2012). The pediatric psychologists interviewed have sought to support youths in their steps regarding their educational and professional choices, and allowing a better management of their medical condition. This activity can help young patients better negotiate their transition into the adult health care setting based on their needs (Bailey et al., 2003). It also improves their commitment and adherence to treatment by facilitating self-organization and self-regulation (Ryan & Deci, 2008), and by supporting and empowering them in their choices (Moller, Deci, & Ryan, 2006).

Transition support also involves accompanying youth in building their identity. This process can be hindered by the presence of a medical condition because these young people, unlike their peers, must also incorporate their chronic condition and body image into their self-concept (Michaud, Suris, & Viner, 2004; Taddeo, Egedy, & Frappier, 2008). This lack of integration would be responsible for the difficulty that some youths have in adhering to the medical recommendations necessary for a successful transfer to the adult sector (Michaud et al., 2004). The psychologist's interventions can promote youths' identity development with the disease through a process of both adaptation and illness differentiation with respect to their health status.

Some of the participants' recommendations were consistent with existing guidelines in this area: promoting continuity in the provision of psychological services in the adult health care setting, appointing a resource person who could promote the cooperation between the two settings, introducing discussion groups for youths (Canadian Association of Pediatric Health Centres, 2016; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Rous, Myers, & Strickin, 2007).

Other recommendations, which are more innovative in this field and specific to the clinical practice of psychologists, deserve to be mentioned. Participants insisted that it is important to get feedback on patients who have been followed by psychologists and have transitioned to an adult health care setting. As the lack of feedback is a widespread problem in clinical psychology (APA Presidential Task Force on Evidence-Based Practice, 2006), feedback in this field has not yet been formalized. Its use in the clinical practice of transition appears as a fundamental piece of action, as it could reduce errors, improve decision-making, and assess progress in transition interventions.

Young people could also benefit from a specific transition space that would be dedicated to them. Such places are being designed in the health care sector and take different forms, including physical spaces and consultation clinics for adolescents or clinical days for youths with a specific disease (Amaria, Stinson, Cullen-Dean, Sappleton, & Kaufman, 2011; Grant & Pan, 2011; Sawing et al., 2015). This recommendation is in line with the idea that commonly seen barriers to a successful transition is the lack of a structured transition program (Michaud et al., 2004), and the difficulty of professionals to reflect on their own attachment to the child they have supported and seen grow (Michaud, Suris, & Viner, 2007). The participants' proposal to bring more awareness to the care team about transition issues could respond to this issue.

Likewise, participants questioned the optimal moment for the psychological care of the young adults but also the relevance of a systematic involvement throughout the transition. This questioning confirms the necessity of a multidisciplinary consultation among caregivers in order to prioritize interventions according to the specific needs of each youth (Nehring et al., 2015). In addition, in the health care field, some administrative constraints still prevail as reference criteria at the expense of individual developmental needs. In this context, referring a patient to a psychologist may be at odds with the psychologist's mandate, as it does not address the transition as a process requiring an assessment and preparation from a psychosocial perspective but rather to an institutional need (Paone, Wigle, & Saewyc, 2006). Interestingly, this study indicated that psychologists could usefully focus on populations that are particularly vulnerable to transitioning to the adult sector (e.g., cognitive limitations, issues related to autonomy) and for which existing data already suggest important difficulties in preparing for transition to adulthood (Beal et al., 2016).

We need to acknowledge some limitations of this study. Firstly, data were collected in single health facility and therefore restricts the applicability of the results to other health care settings. Secondly, our methodological choice of favoring heterogeneity in sample responses and common themes prevented the exploration of differences between groups of



participants. Yet, we noted that neuropsychologists, when compared to clinical psychologists had further explored their role in addressing the cognitive limitations of accompanied youths and aspects relating to education and information. Importantly, the results are limited to the psychologists' point of view and bear no information on the perception of the psychologists' role by the other members of the team or of the clientele served. Finally, we cannot rule out selection bias. For example, the fact that only women participated in the study may have influenced the formulation or over-representation of some themes, or prevented other themes from surfacing.

## Conclusions and Recommendations for Practice

This study shows that the role of pediatric psychologists in the work of transitioning young people to the community consists of activities of evaluation, intervention and education, and information and liaison with other caregivers. The detailed description of each of these activities could serve as a base in view of complementing the Crosscutting Knowledge Competencies requested in Pediatric Psychology in the field of transition (Palermo et al., 2014). Firstly, it would be important to prioritize evaluation, intervention, and support during the transition process with the most vulnerable patients. Secondly, to foster patient's autonomy, psychologists should be favoring a gradual separation of parents and other professional caregivers. Thirdly, the psychologists could better educate health care providers on issues of autonomy of patients with chronic or degenerative disease and raise awareness of the difficulties of letting patients go. Fourthly, they could promote youth identity development as a balance between the normal steps expected for their age and the challenges of their medical condition. Finally, psychologists should find ways to obtain some feedback on patients who have transitioned to an adult health care setting to monitor their own activities regarding transition.

Future research could address these recommendations to develop integrated interventions to prepare youths for transition and change current work practices. If the themes found in this research are replicated in other institutions, they may lead further adjustments that research could then evaluate. The recommendations of professionals themselves, as collected here, are probably a central aspect when considering improving services for the transition of youth to adult health care.

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## Compliance with Ethical Standards

**Conflict of interest** The authors Marco Bonanno, David Ogez, Claude Julie Bourque, Caroline Laverdière and Serge Sultan declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Human and Animal Rights** All procedures were in accordance with the ethical standards of the institutional research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

## References

- Agency for Healthcare Research and Quality (AHRQ). (2013). Transitions care for children with special health needs. *Evidence-based practice center technical brief protocol*. Retrieved from <http://www.effectivehealthcare.ahrq.gov>.
- Amaria, K., Stinson, J., Cullen-Dean, G., Sappleton, K., & Kaufman, M. (2011). Tools for Addressing Systems Issues in Transition. *Healthcare Quarterly*, 14(3), 72–76.
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Group, T. C. R. A. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182–200. <https://doi.org/10.1542/peds.2011-0969>.
- APA Presidential Task Force on Evidence-Based Practice. (2006). Evidence-based practice in psychology. *The American Psychologist*, 61(4), 271–285. <https://doi.org/10.1037/0003-066X.61.4.271>.
- Bailey, S., O'Connell, B., & Pearce, J. (2003). The transition from paediatric to adult health care services for young adults with a disability: An ethical perspective. *Australian Health Review*, 26(1), 64–69.
- Beal, S. J., Riddle, I. K., Kichler, J. C., Duncan, A., Houchen, A., Casnellie, L., ... Corathers, S. D. (2016). The associations of chronic condition type and individual characteristics with transition readiness. *Academic Pediatrics*, 16(7), 660–667. <https://doi.org/10.1016/j.acap.2016.06.007>.
- Blum, R. W., Garell, D., Hodgman, C. H., & Slap, G. B. (1993). Transition from child-centered to adult health care systems for adolescents with chronic conditions: A Position Paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14, 570–576. [https://doi.org/10.1016/1054-139X\(93\)90143-D](https://doi.org/10.1016/1054-139X(93)90143-D).
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks: Sage Publications.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Canadian Association of Pediatric Health Centres. (2016). *A guideline for transition from paediatric to adult health care for youth with special health care needs: A national approach*. Retrieved from <http://ken.caphc.org/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care>.
- Crosby, L., Lynch-Jordan, A., & Slater, S. (2010). The role of psychologists in improving health outcomes for youth with chronic

- conditions. *American Psychological Association (APA). Children, Youth, and Families Office (CYF News)*. Retrieved from <https://www.apa.org/pi/families/resources/newsletter/2010/08/summer.pdf>.
- Davis, A. M., Brown, R. F., Taylor, J. L., Epstein, R. A., & McPheeters, M. L. (2014). Transition care for children with special health care needs. *Pediatrics*, *134*(5), 900–908. <https://doi.org/10.1542/peds.2014-1909>.
- DiClemente, R. J., Hansen, W. B., & Ponton, L. E. (1996). Adolescents at risk. In R. J. DiClemente, W. B. Hansen & L. E. Ponton (Eds.), *Handbook of adolescent health risk behavior* (pp. 1–4). New York: Plenum Press.
- Fair, C. D., Albright, J., Lawrence, A., & Gatto, A. (2012). The pediatric social worker really shepherds them through the process: Care team members' roles in transitioning adolescents and young adults with HIV to adult care. *An International Interdisciplinary Journal for Research, Policy and Care*, *7*(4), 338–346.
- Greenen, S. J., Powers, L. E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, *32*(3), 225–233.
- Grant, C., & Pan, J. (2011). A comparison of five transition programmes for youth with chronic illness in Canada. *Child: Care, Health and Development*, *37*(6), 815–820. <https://doi.org/10.1111/j.1365-2214.2011.01322.x>.
- Gray, W. N., Monaghan, M. C., Marchak, J. G., Driscoll, K. A., & Hilliard, M. E. (2015). Psychologists and the transition from pediatrics to adult healthcare. *The Journal of Adolescent Health*, *57*(5), 468–474. <https://doi.org/10.1016/j.jadohealth.2015.07.011>.
- Gray, W. N., Resmini, A. R., Baker, K. D., Holbrook, E., Morgan, P. J., Ryan, J., ... Hommel, K. A. (2015). Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflammatory Bowel Disease*, *21*(7), 1641–1651. <https://doi.org/10.1097/MIB.0000000000000419>.
- Herzer, M., Goebel, J., & Cortina, S. (2010). Transitioning cognitively impaired young patients with special health needs to adult-oriented care: Collaboration between medical providers and pediatric psychologists. *Current Opinion in Pediatrics*, *22*(5), 668–672. <https://doi.org/10.1097/MOP.0b013e32833c3609>.
- Hui, E. K. P., & Tsang, S. K. M. (2012). Self-determination as a psychological and positive youth development construct. *The Scientific World Journal*, *2012*, 1–7. <https://doi.org/10.1100/2012/759358>.
- Institute of Medicine (US) Committee on Disability in America. (2007). Health care transitions for young people. In M. J. Field & A. M. Jette (Eds.), *The future of disability in America*. Washington, DC: National Academies Press.
- Kichler, J. C., Harris, M. A., & Weissberg-Benchell, J. (2015). Contemporary roles of the pediatric psychologist in diabetes care. *Current Diabetes Reviews*, *11*(4), 210–221. <https://doi.org/10.2174/1573399811666150421104449>.
- Kuhlthau, K., Luff, D., Delahaye, J., Wong, A., Yock, T., Huang, M., & Park, E. R. (2015). Health-related quality of life of adolescent and young adult survivors of central nervous system tumors: Identifying domains from a survivor perspective. *Journal of Pediatric Oncology Nursing*, *32*(6), 385–393. <https://doi.org/10.1177/1043454214563752>.
- Learning Disabilities Association of Canada. (2007). *Putting a Canadian face on learning disabilities (PACFOLD)*. Retrieved from <http://www.pacfold.ca/>.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>.
- Michaud, P. A., Suris, J. C., & Viner, R. (2004). The adolescent with a chronic condition. Part II: Healthcare provision. *Archives of Disease in Childhood*, *89*(10), 943–949. <https://doi.org/10.1136/adc.2003.045377>.
- Michaud, P. A., Suris, J. C., & Viner, R. (2007). *The adolescent with chronic condition: Epidemiology, developmental issues and health care provision*. Retrieved from <http://www.who.int/iris/handle/10665/43775-sthash.yetUHKBO.dpuf>.
- Miles, M., Huberman, A. M., & Saldana, J. (2013). *Qualitative data analysis. A Methods sourcebook* (3 ed.). Thousand Oaks: Sage.
- Moller, A. C., Deci, E. L., & Ryan, R. M. (2006). Choice and ego-depletion: The moderating role of autonomy. *Personality and Social Psychology Bulletin*, *32*(8), 1024–1036. <https://doi.org/10.1177/0146167206288008>.
- Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing*, *30*, 732–747. <https://doi.org/10.1016/j.pedn.2015.05.030>.
- Palermo, T. M., Janicke, D. M., McQuaid, E. L., Mullins, L. L., Robins, P. M., & Wu, Y. P. (2014). Recommendations for training in pediatric psychology: Defining core competencies across training levels. *Journal of Pediatric Psychology*, *39*(9), 965–984. <https://doi.org/10.1093/jpepsy/jsu015>.
- Paone, M. C., Wigle, M., & Saewyc, E. (2006). The ON TRAC model for transitional care of adolescents. *Progress in Transplantation*, *16*(4), 291–302. <https://doi.org/10.1177/152692480601600403>.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3 ed.). Thousand Oaks: Sage Publications.
- Pires, A. P. (1997). Echantillonnage et recherche qualitative: Essai théorique et méthodologique. In J. Poupard, J.-P. Deslauriers, L.-H. Groulx, A. Laperrrière & R. Mayer, & A. P. Pires (Eds.), *La recherche qualitative. Enjeux épistémologiques et méthodologiques* (pp. 113–169). Montreal: Gaëtan Morin Editeur.
- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *52*(2), 126–136. <https://doi.org/10.1037/0022-0167.52.2.126>.
- Rapley, P., & Davidson, P. M. (2010). Enough of the problem: A review of time for health care transition solutions for young adults with a chronic illness. *Journal of Clinical Nursing*, *19*(3–4), 313–323. <https://doi.org/10.1111/j.1365-2702.2009.03027.x>.
- Rosen, D. S. (2004). Transition of young people with respiratory diseases to adult health care. *Paediatric Respiratory Reviews*, *5*(2), 124–131. <https://doi.org/10.1016/j.prrv.2004.01.008>.
- Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., Siegel, D. M., & Medicine, S. F. A. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, *33*(4), 309–311.
- Rous, B., Myers, C. T., & Strickin, S. B. (2007). Strategies for supporting transitions of young children with special needs and their families. *Journal of Early Intervention*, *30*(1), 1–18. <https://doi.org/10.1177/105381510703000102>.
- Ryan, R. M., & Deci, E. L. (2008). A Self-determination theory approach to psychotherapy: The motivational basis for effective change. *Canadian Psychology*, *49*(3), 186–193. <https://doi.org/10.1037/a0012753>.
- Sarrazin, C. (2012). À propos de l'autodétermination des personnes présentant une déficience intellectuelle. *Journal of Human Development, Disability, and Social Change*, *20*(3), 93–101.
- Sawing, K. J., Rauen, K., Bartelt, T., Wilson, A., O'Connor, R. C., Waring, W. P., & Orr, M. (2015). Transitioning adolescents and young adults with spina bifida to adult healthcare: Initial findings from a model program. *Rehabilitation Nursing*, *40*(1), 3–11. <https://doi.org/10.1002/rnj.140>.
- Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011). A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic

- health conditions. *Child: Care, Health and Development*, 37(6), 883–895. <https://doi.org/10.1111/j.1365-2214.2011.01282.x>.
- Spirito, A., Brown, R. T., D'Angelo, E., Delamater, A., Rodrigue, J., & Siegel, L. (2003). Society of pediatric psychology task force report: Recommendations for the training of pediatric psychologists. *Journal of Pediatric Psychology*, 28, 85–98.
- Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., ... Guenther, S. (2010). Transition to adulthood for youth with disabilities: Evidence from the literature. *International Encyclopedia of Rehabilitation*. Retrieved from <http://cirrie.buffalo.edu/encyclopedia/en/article/110/>.
- Taddeo, D., Egedy, M., & Frappier, J.-Y. (2008). Adherence to treatment in adolescents. *Paediatric & Child Health*, 13(1), 19–24.
- Willen, E. (2007). Collaborative practice consultation and collaboration in the care of children and families: The role of the pediatric psychologist. *Journal for Specialists in Pediatric Nursing*, 12(4), 290–293. <https://doi.org/10.1111/j.1744-6155.2007.00123.x>.
- Wray-Lake, L., Crouter, A. C., & McHale, S. M. (2010). Developmental patterns in decision-making autonomy across middle childhood and adolescence: European American parents' perspectives. *Child Development*, 81(2), 636–651. <https://doi.org/10.1111/j.1467-8624.2009.01420.x>.