

# Navigating the Transition from Pediatric to Adult Eating Disorder Programs: Perspectives of Service Providers

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## ABSTRACT

**Objective:** This study aims to conduct qualitative research on the perspectives of service providers regarding the transition process from pediatric to adult specialized eating disorder tertiary care programs.

**Method:** Two focus groups with a diverse group of clinicians in pediatric and adult eating disorder programs and five qualitative interviews with clinicians in the community were conducted.

**Results:** Three themes were identified as challenges during the transition process: (1) illness related factors (ambivalence and denial); (2) the interruption of normative adolescent developmental processes by the illness; and, (3) the

impact of decreased parental involvement in the adult compared to pediatric eating disorder programs.

**Discussion:** These themes were compared with empirical evidence on other chronic mental or physical health concerns for the purpose of identifying ways to facilitate a more successful service transition for young adults with anorexia nervosa. Future research and clinical implications are delineated. © 2012 by Wiley Periodicals, Inc.

**Keywords:** anorexia nervosa; service transition; adolescents and families

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## Introduction

Anorexia nervosa (AN) results in significant physical and mental health consequences, especially if left untreated during adolescence.<sup>1,2</sup> Although AN is typically diagnosed in adolescence,<sup>3</sup> the majority of affected adolescents will continue to require treatment for AN as adults.<sup>3,4</sup> Furthermore, late adolescence is a particularly vulnerable period for development of other psychiatric disorders (depression, anxiety, and substance abuse issues<sup>5</sup>) and engaging in high risk behaviors.<sup>5</sup> Despite the clear need for continuing care during this critical

life stage, this is precisely the time when many older adolescents and young adults are faced with an often difficult transition from pediatric to adult services. When exiting child and adolescent services, young people often fail to initiate or follow through with available services in the absence of external pressures from their family,<sup>6</sup> contributing to higher rates of mortality and morbidity.<sup>5</sup>

There has only been one study evaluating the process of service transition (ST) for eating disorders, in contrast to multiple studies regarding ST for other psychiatric and physical disorders.<sup>2,5,7,8</sup> Arcelus et al.<sup>1</sup> studied young adults (ages 16–25 years old) receiving an assessment in an adult eating disorder program (AEDP). They compared individuals who had been previously treated in a pediatric eating disorder program (PEDP, 30% of sample) to those who had not. Patients with previous PEDP treatment had lower self-esteem and greater maturity fears, suggesting the need for specialized interventions to enhance the independence and autonomy of individuals with an early onset of illness as they grow older. Further, this study revealed an apparent lack of coordination between PEDPs and AEDPs, with referrals originating from the family doctor rather than the PEDP.<sup>1</sup>

Treasure et al.<sup>2</sup> reviewed practice guidelines from the UK and Australia and identified an absence of procedures, protocols, and pathways for transition

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from PEDPs to AEDPs. A major challenge during this transition arises from different philosophical approaches influencing service delivery in PEDPs and AEDPs, including differing expectations regarding parental involvement in weight restoration and eating rehabilitation and the degree of responsibility placed on the patient for treatment.<sup>2,9</sup> The importance of therapeutic alliance becomes much more salient as adolescents enter adult services, as they are expected to assume more responsibility for pursuing and engaging in treatment. However, this expectation of increased responsibility is greatly hampered by the profound sense of denial and ambivalence towards treatment that often accompanies AN, even in the face of significant medical complications.<sup>4</sup> Individuals with AN often express ambivalence about adhering to medical and psychological interventions promoting weight restoration and normalization of eating.<sup>10</sup> The adverse effects of ambivalence during ST from PEDPs to AEDPs have not been investigated.

To date, there is a dearth of research on the transition from PEDPs to AEDPs, and there are no studies on the perspective of clinicians. The chief objective of this qualitative study is to develop an in-depth understanding of illness-specific factors, philosophical issues, and organizational challenges affecting the transition from PEDPs to AEDPs for young people with AN. To achieve this objective, the perspective of service providers working with adolescents and young adults with AN in tertiary care and community-based settings were sought through the use of qualitative interviews and focus groups.

## Method

### *Participants*

Service providers were eligible to participate in the study if they had direct experience working with young people transitioning from PEDPs to AEDPs within the last 12 months. A total of two focus groups were conducted with eligible service providers, one at a PEDP and one at an AEDP (both are among the largest tertiary care programs for eating disorders in Canada). We were also interested in capturing the experiences of clinicians treating young people who have exited PEDPs and have not accessed tertiary care services for eating disorders. Therefore, in addition to the two focus groups, we conducted qualitative interviews with a range of service providers, including professionals from community agencies and adolescent medicine pediatricians (specializing in transition age youth). The sample size for qualitative

interviews was determined by whether the data had reached saturation based on guidelines outlined by Strauss and Corbin.<sup>11</sup>

### *Description of Sample*

Information was collected regarding clinicians' years of service, location of service delivery, and professional affiliation. To maintain anonymity of participants, this information was not directly linked to any of the service providers. Years of experience ranged from 2 to 28. In the qualitative interviews, participants included occupational therapists, social workers, and pediatricians specializing in adolescent medicine. In the AEDP focus group, two dietitians, four nurses, two social workers, one occupational therapist, and a psychiatrist participated. A transition worker, a child and youth worker, two social workers, two front-line nurses, and two pediatricians took part in the PEDP focus group.

### *Measures*

For both the focus groups and qualitative interviews, a semistructured interview guide was established to provide standardization through the use of questions consistently used in all interviews. Two skilled interviewers utilized the interview guide for the focus group and the qualitative interviews.

### *Setting and Procedure*

The study received approval from institutional Research Ethics Boards. A letter describing the study was distributed to eligible staff. At the outset of the interviews and focus groups, the investigators obtained consent and reviewed the importance of confidentiality regarding the identity of both the clinician and their patients during the transcription and data analysis phase. The focus groups were 2 h long and conducted at a time that was convenient for staff and did not interfere with clinical demands. The qualitative interviews were 1 h long and conducted in a location and time that was convenient for the practitioner.

### *Data Analysis*

The focus groups and qualitative interviews were audio-taped and transcribed verbatim. Transcripts were reviewed independently by each researcher, and the PI (GD) randomly checked segments of the transcript against the tape to verify accuracy. The research team regularly met to discuss the interview process and to explore the data. Using grounded theory methodology,<sup>11</sup> we analyzed the data in three steps. First, we read the transcripts several times to establish familiarity with the whole data set. An open coding system was inductively developed through line by line analysis of each transcript. Second, constant comparative analysis was used to simultaneously review themes while identifying new areas for exploration in additional interviews with partic-

ipants. In our meetings, the research team discussed their observations and described emerging patterns in the data. The research team continuously discussed similarities and differences in interpretation of transcriptions, and identified discrepancies and divergent views which they processed extensively until consensus was achieved. Once consensus was achieved, the PI developed a coding system for organizing major themes and sub-themes. Finally, an axial coding system was used by linking thick descriptions with major themes.

**Efforts to Maximize Quality of Research**

Established guidelines for qualitative studies<sup>12</sup> were adapted and used to enhance the quality of the research. First, consistent with grounded theory, the PI did not adhere to a specific theoretical model but rather established an interview guide with a broad set of questions that would allow participants to generate issues pertaining to their work with patients undergoing ST from PEDP to AEDP. Second, themes were grounded in thick descriptions and examples from focus groups and interviews. Triangulation, a process of establishing validity, was achieved through the following steps: (1) ensuring that the identified themes were supported by findings in the literature on other mental illnesses and chronic physical illnesses, to provide a credibility check; (2) researchers involved in this study independently analyzed the data but synthesized the results of the whole team in the final analysis; (3) presenting findings to other clinicians working in PEDPs and AEDPs to ensure that they resonated with others in similar positions and with similar experiences.<sup>12</sup>

**Results**

The following three interrelated themes were identified: (1) illness related factors (particularly ambivalence and denial); (2) interruptions to the developmental phase of adolescence (e.g. inability to form social connections, or develop autonomy); and, (3) reduced parental involvement contributing to disengagement from treatment (**Table 1**).

**Theme 1: Illness Related Factors—Denial and Ambivalence**

Participants consistently described the challenges of working with older adolescents and young adults who deny the presence of the illness or express ambivalence about recovery. Given this denial, participants in the focus group from the PEDP all agreed that parents must unequivocally become involved in ensuring that the adolescent patient eats and gains weight. Despite preparations

**TABLE 1. Themes that emerged from the focus groups and qualitative interviews**

Themes	Key Findings
Illness related factors	<ul style="list-style-type: none"> <li>• Denial about the illness hinders young people from being “active” participants in adolescent treatment and during service transition</li> <li>• Ambivalence about change affects therapeutic relationships with clinicians in adult treatment programs</li> </ul>
Illness interrupts normative developmental processes	<ul style="list-style-type: none"> <li>• Starvation affects cognitive abilities, as well as physiological and neurological development</li> <li>• Illness and prolonged hospitalization affects social connections with others</li> </ul>
Parental involvement changes during transition process	<ul style="list-style-type: none"> <li>• Ambivalence coupled with decreased parental involvement during service transition may result in disengagement from adult eating disorder programs</li> <li>• Important to continually involve parents in treatment process regardless of age of patient, although no longer involved in re-feeding process</li> </ul>

by clinicians and parents to facilitate ST, some young adults refuse to participate in treatment when they leave a PEDP. As stated by one of the community practitioners, (C-04)<sup>a</sup>: “most of these patients are saying to us ‘when I’m 18, I am out of here, and I don’t need any care because there’s nothing wrong with me and this is a lifestyle choice.’” Hence, the participants in the PEDP focus group and community clinicians all agreed that the most significant barrier to a successful ST is denial about the illness and ambivalence about recovery in young adults.

Participants in the qualitative interviews emphasized the necessity for parental involvement in re-feeding adolescents who are emaciated and medically compromised. However, these same participants also noted that some individuals refuse or delay seeking assistance for their eating disorder as adults because they perceived themselves as powerless when their parents pressured them into treatment during their adolescence. In the qualitative interviews, all clinicians described difficulties they had engaging adolescents in decision-making since they did not perceive themselves as ill. One health care provider stated (C-06): “It’s like 95% motivation by parents and 5% motivation by the kids. So typically, many of them will do the weight gain and eat to get out [of treatment].”

In the AEDP focus group, participants described patients who were previously in PEDPs as exhibiting less autonomy, independence and responsibility for pursuing, and fully engaging in treatment. These participants described young adults who

<sup>a</sup>The letters in parenthesis denotes the participant’s role, where C, community service provider; A, AEDP service provider; and P, PEDP service provider.

were previously in a PEDP as needing more external control to eat, gain weight and stay in treatment. One participant stated that, (A-01): "I would find myself falling into the parent role sometimes. . . So a lot of convincing, a lot of threatening 'I want to leave' and 'no, maybe you should stay' as opposed to an adult to adult type of relationship where they want to stay in treatment". Participants further described that individuals who have transitioned from a PEDP to an AEDP engage in adversarial interactions with staff where they challenge authority and conceal symptoms. One participant stated, (A-06): "Quite often we have issues around trust. . . because things have been done to them. So, when we say things like well you're really in control of what happens here this is up to you....all that stuff seems so foreign to them so I think it takes longer to develop a therapeutic rapport in a milieu of trust." Another participant stated, (A-03): "I think adults know what they are coming for, usually they have some goals in mind, whereas the kids usually do not have their goals straight yet."

In summary, the first theme that emerged was that denial coupled with ambivalence regarding weight restoration and eating rehabilitation are the most important illness-related factors that interfere with service transition from PEDPs to AEDPs. Although the clinicians in this study agreed with the necessity of parents engaging in the re-feeding process during adolescence, there was consensus that this approach inadvertently results in few opportunities to decrease ambivalence and enhance the readiness of the adolescent for transitioning to an AEDP. As a result, young adults may either completely disengage from treatment or relinquish their responsibility for recovery to professionals and have difficulty establishing a therapeutic alliance with service providers.

### ***Theme 2: Illness Interrupts Normative Adolescent Developmental Process***

Developing AN in childhood or adolescence negatively impacts the adolescent's psychological, physiological, and social development. A service provider from the AEDP focus group noted that, (A-03): "Often times, the teenagers that we see, although they may be chronologically 17 or 18 they're functioning at a much lower level of development, 14 or 15. That can be a challenge as well, if they've been restricting their intake for a long time and their brain has been quite starved. And if they've been in and out of hospital have missed a large part of their adolescence." Clinicians in both the PEDP and AEDP felt that AN affects the cognitive abilities of young people through starvation,

and also prevents young people from achieving psychological maturation. As one participant stated, (A-02): "The kids have been sick from the time that they were 14 coming into this program at 18 or 19. They have missed a significant developmental piece, many of them they just often don't know how to do it, they don't have the skills to do it, to live on their own, to cook themselves lunch or breakfast."

All study participants agreed that young people become increasingly isolated and disconnected from peers because they hide the illness from friends, or cannot sustain connections with their peers when they are in intensive treatment for the AN. This social isolation leads to sustained difficulties forming and maintaining friendships and romantic relationships. Patients who maintain peer connections often find that their friends surpass them academically and have more opportunities to explore issues around sexuality and intimacy. One clinician noted, (C-04): "a lot of their friends, again, just want to move on and it's like 'aren't you done with that yet?' I think a lot of these kids are really isolated". Another participant (A-02) stated that "the fact that oftentimes these young girls are not forming more intimate relationships, so for instance with boyfriends. So, there is also a bit more of a gap from their peers and they feel again a little bit out of the loop". Some AEDP clinicians reported that earlier interruptions to the development of friendships often lead young people to form unhelpful relationships with others whom they meet in treatment, one clinician (A-03) stated that young people often "end up relying on peers, sometimes in unhelpful ways, they rely on other ill peers, other peers with anorexia, people they met in the treatment system, and actually end up quite isolated at times."

In summary, the second theme that emerged is that individuals who develop AN during adolescence experience significant psycho-social delays. These include the adverse effects of starvation and low body weight on cognitive abilities, as well as limited opportunities to form friendships, intimate relationships, and an identity separate from their illness.

### ***Theme 3: Parental Involvement Changes during the Transition Process***

According to the clinicians in this study, families in the PEDP have a higher level of expectation of involvement in the treatment process because they are accustomed to participating in family based treatment. One participant noted: (A-03): "Parental

involvement in adolescent programs is very different when the young person transitions to an AEDP. However, if parents are used to being very much involved and in control of what happens in their child's treatment, it can be quite shocking when they get here and they have a whole lot less control." Participants agreed that ST is extremely challenging for parents when young people refuse to continue with treatment or do not have the skills to manage the illness without parental support. One participant stated, (P-06) "it often comes up in a lot of our sessions, this magical number 18. Parents worry that, sometimes their child will continue to remind them that their 18th birthday is coming up and once they turn 18, everything is going to be different. And that's something we really also work with the parents on, easing their anxiety, putting certain things in place to help with that transition. But it can be really difficult, especially when the young person isn't so keen on getting the services in their community or at a hospital. So it kind of leaves the parents to 'ok what can we do?'"

Clinicians perceived some young people as being concerned about the decline in their parent's involvement in their care during ST. In one of the qualitative interviews, a participant stated, (P-05): "I think there are patients who are a little bit worried about transition because they know that the reason they're actually staying as well as they are is because of this additional external support and I think they're somewhat anxious about what that's going to look like, so it's going to be up to them and they're going to have a choice, and I think they're a bit anxious about not having that kind of external motivation."

In the AEDP focus group, participants unanimously identified changes regarding confidentiality as one of the most significant challenges for parents during ST. One participant stated (A-02): "We have a little more contact with [families] when they're right out of the pediatric system. The families are anxious, they have a lot more questions because they know the system is a bit different, they'll call frequently, they're so worried about their child and want to get involved in the care. And of course because they're in an adult system, we can't give them a whole lot of information, in fact we can't really say anything without the child's consent." The decline in access to information becomes increasingly problematic for families when the person with AN is in crisis. One community practitioner stated that, (C-03) "A parent is much more involved and included in discussions around their child's care up until that child is 18. And there's a great deal of confidentiality still but,

one day a child is 17 and 364 days old and the next day the child could be in an incredible crisis, really, really ill and the parent could no longer access the team in the same way. What parents have told me, and my client is more often the parent in this case, is that they've been cut off and they're terrified and petrified about the well being of their child."

Despite the emphasis on adult responsibility for recovery and policies regarding confidentiality, clinicians emphasized the importance of continuing to involve parents in the treatment process regardless of the patient's age. AEDP service providers all felt that parents must recognize their ongoing influence even though they no longer should be involved in re-feeding. Parental support should be provided to assist the young person to form their own goals for treatment and to become more autonomous. PEDP participants similarly advocated that parents continue to acknowledge the influential role that they play in their child's life even when they leave PEDP, one clinician stating, (P-04): "they are turning 18 and they're going to be transitioned out of our program, but it's usually a time where the thoughts of university or college or moving out of their parents home needs to be talked about. . . parents need to determine whether or not they can support their child, if they feel their child is too ill to go away to university, whether they should stay in the city, whether they should allow them to go away."

Another clinician from the PEDP focus group noted, (P-03): "We do have parents who come to the decision to say to their child 'we will not support you going to university because of your eating disorder, we do not support you living away from home....'" This has been a big issue where parents have gotten together and said even though they're 18 we can still make decisions, we can still have influence over these things." An AEDP clinician shares, (A-05): "When they're in the adolescent system it's 'how are you going to help your daughter to eat, how are you going to make her eat?' And when they come here it becomes much more of a supportive role, so 'how are you going to support your daughter in making the decisions that she needs to make that are in the best interest of her recovery'? So, it's a real shift for families, and it's a difficult one."

In summary, clinicians described ST as a difficult time for parents of young adults exhibiting denial and ambivalence, and lacking the necessary skills to autonomously participate in their recovery. Clinicians identified the philosophical shift from a family-oriented to an adult-focused treatment as profoundly affecting both parents and young adults

during ST. Finally, clinicians in this study strongly advocated for ongoing parental involvement in domains outside of the re-feeding process and in promoting independence.

## Discussion

The chief objective of this qualitative study was to obtain in-depth information about the perspective of service providers working with older adolescents and young adults during service transition from a PEDP to an AEDP. Themes emerging from the data include: (1) the influence of illness related factors such as denial about the illness and ambivalence towards recovery; (2) the effects of the illness on normal developmental processes; and, (3) a decline in parental involvement during ST. There was congruency within and across focus groups and interviews with service providers despite the fact that participants represented both PEDPs and AEDPs in tertiary care and community settings.

### *Illness Related Factors*

Service providers agreed that denial of the adverse effects of the illness and ambivalence toward treatment are barriers to preparing young people to move from PEDP to AEDPs. This finding is consistent with empirical research that consistently demonstrates that ambivalence is a core feature of AN,<sup>13</sup> that motivation influences willingness of patients to engage in treatment and is an important predictor of relapse.<sup>14</sup> Ambivalence has also been found to affect the establishment of a strong therapeutic alliance in patients with AN.<sup>15</sup> Therapeutic alliance is of key importance, as highlighted in a recent qualitative study in which patients with AN identified trust in their relationship with parents and clinicians as a key factor in allowing them to personally address their ambivalence about treatment and in enhancing their willingness to accept assistance.<sup>16</sup>

Ambivalence is not unique to AN, and lack of motivation and ambivalence towards treatment has been identified as a possible contributor to the decreased utilization of adult services by older adolescents and young adults with other chronic medical conditions,<sup>17,18</sup> due to missed or cancelled appointments and disengagement from necessary follow up care.<sup>17</sup> Young adults with substance abuse similarly disengage from adult mental health services when they leave child and adolescent care,<sup>19</sup> due to denial and a cessation in their level

of motivation that was previously maintained by external (parental) factors.<sup>19</sup>

### *Disruptions to Normative Developmental Processes*

During the developmental phase of adolescence, significant brain and cognitive development occurs<sup>20</sup> alongside psychological, social, and familial transformations.<sup>21</sup> During adolescence, young people acquire life skills that enable them to form an identity separate from their families while establishing an affiliation with their peer group. Young people undergoing normative life cycle changes (moving from high school to postsecondary school) without mental health issues experience difficulties making decisions without parental involvement.<sup>22</sup> Physical and mental health problems disrupt normative developmental processes, intensifying reliance of young people on parents for making decisions about important life changes.<sup>23</sup> In this study, clinicians suggested that the adverse effects of starvation on the brain, repeated and prolonged hospitalizations for AN lead to missed opportunities for young people to develop the skills necessary to become autonomous and self-reliant and to make informed decisions about normative life changes without the aid of their parents.

Service providers identified the formation of intimate relationships as being exceptionally challenging for young people with AN. Young people with other mental and physical disabilities also experience social isolation and difficulties forming intimate relationships.<sup>24</sup> Individuals with AN and other chronic illnesses share difficulties achieving psychological maturation<sup>1</sup> and sexual intimacy<sup>24</sup> due to medical and psychological regimens that interfere with the ability to participate in daily activities and social gatherings, resulting in increased social isolation.<sup>24</sup> Young people with AN and other mental and physical illnesses experience high levels of distress about school<sup>24</sup> and generally have low educational attainment.<sup>25</sup> In addition, starvation resulting from AN can lead to impairment of various aspects of cognitive functioning, including memory<sup>26</sup> and problem solving,<sup>27</sup> both of which are necessary for academic achievement.

### *Decrease in Parental Involvement and Decline in the Utilization of AEDP*

This study found that clinicians perceive significant barriers to successful ST when parents no longer have the external influence and legal power to insist that their child seek and stay in an AEDP when they exit a PEDP. This decline in parental power and authority to bring their child to treat-

ment may lead the young person who is already highly ambivalent about treatment to disengage from AEDPs. Along the same lines as AN, in substance abuse programs for young adults, a decrease in social control and external pressures from parents invariably results in non-adherence to outpatient treatment appointments or a complete cessation of treatment.<sup>19</sup>

Fundamental philosophical differences between the pediatric and adult health care system contribute to the significant decrease in parental involvement in the health and mental health of young adults.<sup>24,28</sup> The pediatric health care system places a greater emphasis on the role of the family in the treatment of AN in contrast to the patient-centred approach in the adult system.<sup>24,28</sup> The model of the adult system gives more autonomy (i.e., regarding the management of the illness) to patients and reduces the influence of families.<sup>24,29</sup> This philosophical shift to patient-centred rather than family-centred care appears to be embedded in cultural ideals regarding the importance of achieving independence and autonomy in young adults and policies regarding confidentiality. The patient-centred philosophy for adults with mental health problems can prove particularly challenging for young people who have been unable to develop the necessary skills to achieve independence. Even in the absence of mental health issues, a recent study revealed that emerging adults face significant difficulties achieving autonomy from their families as they transition from secondary to post secondary schools and that the expectations of parents that their children would function independently exceed their child's expectations of themselves.<sup>30</sup> If young people without AN are experiencing complications in transitioning to college and university without parental involvement, it is not surprising that vulnerable and psychologically immature adolescents with AN experience difficulties with expectations by health and mental health systems designed to serve adults with full capacity for autonomous decision making.

The philosophical shift from pediatric to adult health and mental health programs including eating disorders has been identified as a potential barrier to young people experiencing a successful service transition.<sup>9,29</sup> In fact, clinicians in the AEDP focus group argued against the abrupt and legally imposed requirement that young people independently organize and navigate adult treatment programs and manage their illness on their own. In the PEDP focus group, clinicians advocated for interventions that demonstrate to families how they can continue to be involved in assisting with recovery from AN and other salient life transitions without

specifically being involved in the process of re-feeding. This finding is consistent with academic literature regarding the critical role that parents play in assisting young people with important life course changes (e.g., psychological, relational, and academic) that extend beyond the focus on illness, health, and medical care.<sup>7,29</sup>

Perhaps a transition program emphasizing the interdependence between young adults and their families is needed, especially during ST. Alternatively, a gradual cessation of parental involvement in treatment that is not dictated by age but rather readiness to engage in self-management of their illness on the part of the young person is needed during ST. Specifically, an intervention is needed to assist with decreasing parental involvement in the re-feeding process while enhancing the motivation and readiness of young adults to enable them to become responsible for their own recovery. This finding is in line with empirical research that shows that young people's reliance on their parents not only persists throughout adolescence but is intensified for some during young adulthood.<sup>31</sup>

### **Strengths and Limitations**

This study has three salient strengths. First, it is the only study examining transition issues in eating disorders from the perspective of service providers. Second, this study provides a diversity of clinician perspectives by including a range of professional disciplines from various settings, including a PEDP, an AEDP and the community. Third, the research team used several criteria designed to enhance the quality of the research data including ensuring that the findings resonated with other clinicians working with patients during ST.

There are several limitations to this study. It is possible that participants who self-selected to participate in this study were different from those clinicians who elected not to engage in the focus groups and qualitative interviews. Although a diversity of opinions was sought from a varied group of clinicians, this study only includes the perspectives of clinicians rather than patients and families transitioning from PEDP to AEDPs. Another limitation is that the clinicians were reflecting on their previous clinical experience with transitioning youth and their families; therefore their observations may be subject to recall bias. Moreover, the majority of the participants worked in inpatient settings in a large urban area so the findings may not be generalized to outpatients with a milder illness or rural areas where there are fewer resources for patients with AN. We attempted to mitigate this

limitation somewhat by adding qualitative interviews with community-based service providers working with patients with a broader range of severity. Despite these limitations, the results of this inquiry generated significant findings that provide a foundation for future empirical studies.

### **Research and Clinical Implications**

Given the dearth of empirical knowledge regarding ST issues, three lines of further inquiry are recommended. First, a larger, broad-based qualitative study is recommended to gather the perspectives of clinicians who work in a variety of settings (e.g., tertiary care, community based services, and primary care) with transitioning patients and their families in rural and urban areas including underserved communities. This type of qualitative study would further elicit the experiences of young people and their families undergoing ST. Second, longitudinal studies combining both qualitative and quantitative methods need to be undertaken to extrapolate the different pathways that patients take when they leave PEDP and examine questions such as differences between patients based on severity, age of onset, type of eating disorder and comorbidity. Such a longitudinal study would provide the necessary knowledge to establish well-designed interventions for ensuring continuity of care from adolescence to adulthood for AN. Third, randomized controlled trials are required to determine the efficacy and effectiveness of interventions designed to address the illness-related, familial and developmental challenges that arise during the process of service transition.

### **Conclusion**

This qualitative study is based on findings that emerged from focus groups and qualitative interviews with individuals employed in a PEDP, an AEDP and in the community. The findings of this study provide information about how factors associated with AN may interfere with a successful transition from PEDPs. The illness may further interfere with key aspects of psychological maturation, including the development of autonomy, self-reliance, and interdependence. The ambivalence that often accompanies AN and the delay in normative developmental processes may result in disengagement during service transition to an AEDP. The shift from a family-centred to patient-centred approach that usually accompanies the transition

from the pediatric to the adult system leads to a reduction in parental involvement in treatment. It is hoped that a better understanding of the process of transition from PEDP to AEDPs will lead to improved outcomes and quality of life for young people with AN and their families.

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