Challenges in Making the Transition Between Pediatric and Adult Eating Disorder Programs: A Qualitative Study From the Perspective of Service Providers

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There is scant research regarding the transition from pediatric to adult eating disorder programs. This study aims to increase understanding of the factors that impede or facilitate successful service transition for individuals with anorexia nervosa moving from pediatric to adult eating disorder programs. Participants included service providers representing pediatric and adult eating disorder programs, in addition to community treatment providers in

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The following themes were identified: a) readiness, not age, should determine service transition; and b) implementation of interventions for facilitating transition from pediatric to adult eating disorder programs including appropriate medical follow-up. These findings delineate various factors that may help facilitate or interrupt a seamless and coordinated transition from pediatric to adult eating disorder programs.

Anorexia nervosa (AN) is a mental illness that results in significant medical and psychosocial consequences (Arcelus, Bouman, & Morgan, 2008). A subgroup of adolescents will continue to have AN into adulthood requiring them to make the transition either to an adult eating disorder program (AEDP) or a general mental health program (GMHP; Arcelus et al., 2008; Treasure, Schmidt, & Hugo, 2005). Problems with service transitions (ST) for young people with chronic physical ailments and mental illnesses such as AN occur as a result of numerous organizational and policy-related barriers (Kaufman & Pinzon, 2007; Singh, 2009; Winston, Paul, & Juanola-Borrat, 2012). Treatment philosophies may differ between the pediatric and adult health care system with an increasing emphasis on the individual rather than the family context (Kaufman & Pinzon, 2007; Winston et al., 2012). Moreover, patient-centered care may inadvertently lead to the exclusion of parents in adult treatment, which can pose unique problems for young people who have yet to establish the skills to navigate the health care system without parental support (Baldock, 2010; Dimitropoulos, Tran, Agarwal, Sheffield, & Woodside, 2012). To date, there is a dearth of empirical research on the issues that arise during ST for young people with AN and their families.

During the last 30 years, policy makers, researchers, and clinicians have been advocating for the establishment of seamless, coordinated, and collaborative transitions for young people moving from pediatric to adult programs for an array of chronic disabilities, and physical and mental health issues (American Academy of Pediatrics, 2000; National Centre for Youth with Disabilities, 1995). Transitioning has been conceptualized as a “planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-centered health care systems” (Blum et al., 1993). Universal models of ST (Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006; While, Forbes, Ullman, Lewis, Mathes, & Griffiths, 2004) and disease/illness specific transition interventions have been devised for vulnerable adolescents with cancer (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011); organ transplants (LaRosa, Glah, Baluarte, & Meyers, 2011); and, developmental disabilities (Lawrence, Alleckson, & Bjorklund, 2010). ST from child and adolescent mental health services to adult mental health services has garnered more attention in the last few years (Singh, 2009).
The policies governing confidentiality and other legal-ethical issues in adult tertiary care settings differ from pediatric care (Baldock, 2010; Winston et al., 2012). In Western societies, there is an emphasis on individual rights and patient autonomy (Baldock, 2010) in health and mental health programs. Health care policies clearly delineate the professional responsibility of clinicians to protect the confidentiality of patients and a duty to respect patient decisions regarding treatment (Baldock, 2010). However, these policies may be problematic for young people when families are accustomed to having access to information about the young person’s treatment plan (Baldock, 2010). As a result, carers of people with AN often experience an abrupt disconnection from health care providers during service transition (Treasure et al., 2005).

To date, there is minimal research on service transition issues of young people with AN. This study seeks to redress this gap in the literature by aiming to develop an increased understanding of the perceptions of clinicians regarding the factors that impede and facilitate an effective transition from a PEDP to an AEDP.

METHOD

The study received approval from the Research Ethics Board of the University Health Network in Toronto, Canada. Eligible participants were clinicians and community practitioners specializing in eating disorders and working in a large city. Two focus groups were conducted (one in a PEDP and one in an AEDP) in addition to five qualitative interviews with professionals from outside of these programs (two occupational therapists, one social worker and two adolescent medicine pediatricians). The following participants were involved in the AEDP focus group: two dieticians, four nurses, two social workers, one occupational therapist, and one psychiatrist. In the PEDP focus group, participants included: a transition worker, a child and youth worker, two social workers, two front line nurses, and two pediatricians. The focus groups were 2 hours long and the qualitative interviews were 1 hour in length. The same semi-structured interview (developed by the first author, G.D.) was used in the focus groups and with the participant clinicians.

Established guidelines for qualitative research studies were used to maximize the quality of the research (Elliott, Fischer, & Rennie, 1999). The following steps were employed to achieve triangulation: a) each researcher independently analyzed the data and only themes that reached consensus by the team were included; b) the research team examined how the themes were supported by findings in the literature on other mental illnesses and chronic physical illnesses, in order to provide a credibility check; c) the research team presented the findings to the participants of the focus groups and the qualitative interviews for their feedback and d) the findings were
presented to other clinicians specializing in eating disorders and transition age youth to ensure that the results resonated with their experiences of working with patients and their families.

Data Analysis
The focus groups and qualitative interviews were audio-taped, and transcripts analyzed using grounded theory methodology to identify major themes and sub-themes. Transcripts were reviewed independently by two members of the research team and the first author (GD). The research team met weekly to discuss the themes that were emerging from the focus groups and interviews and the transcribed tapes. Using grounded theory (Strauss & Corbin, 1998) we analyzed the data in three steps. First, the research team reviewed the transcripts independently and inductively developed an open coding system reviewing line by line, paragraph by paragraph, and the interview as a whole. Secondly, using constant comparative analysis, we reviewed the focus groups/interviews immediately after they were transcribed to identify themes and areas that have not previously been considered in the development of the interview guide. Upon the completion of the two focus groups and all of the qualitative interviews, the research team independently and then through consensus identified similar themes that permeated the data. Consensus about including a theme was achieved if a theme was present in one focus group and four of the five qualitative interviews. Finally, the first author developed a coding system for organizing and linking thick descriptions to the major themes and sub-themes identified.

RESULTS
The following themes emerged from the qualitative interviews and focus groups: a) readiness, not age, should determine service transition for adolescents and young adults with AN; and b) interventions for individuals with AN and their families for improving service transition, as well as the need for appropriate medical follow-up.

Theme 1: The Timing of the Transition—Determined by Readiness and Not by Age
The participants in the PEDP focus group and all the participants in qualitative interviews emphasized the need for developing a conceptualization of transition that was not restricted to age but instead based on readiness of the patient and the family to leave the adolescent treatment setting. In contrast, those who took part in the AEDP focus group did not identify the timing of ST from child and adolescent programs as a problem. A community clinician
stated that transition occurs whether (C-01),1” the client . . . [or] the families are ready for it . . . Because it means the family has to let go of a lot of control and sometimes they have to do that very reluctantly. It may not be a birth date that makes the difference.” Another community clinician similarly believed that transition should occur:

... irrespective of the age of the child. You think about what would go on with someone with leukemia at age 20, I wonder if it would be so harshly rigid as it is with eating disorders?! I think we get caught up a lot in trying to get the person with an eating disorder to take more responsibility for their illness and they’re often trying as hard as they can and they really could use a more supportive, fluid process if that could be something everyone could agree on. (C-03)

A clinician in the PEDP focus group similarly criticized the overly rigid cutoffs for transition:

Who defines what adolescence is? They talk about it being the storm and the strife of life but it goes right up until maybe 24, 25, for some people 30. . . . The pediatric system has defined the age of 18 when in fact, developmentally, some people don’t finish their adolescence until they’re 30. (P-03)

The data generated from the PEDP focus group and the qualitative interviews pointed to clinicians challenging the organizational and policy expectation that young people exit pediatric care when they turn a certain age, typically 18 in Canada. In fact, the clinicians in the PEDP focus group and participants in the qualitative interviews all argued for greater flexibility regarding the timing of ST, which should be dictated by the psychological needs and readiness of the young adult and their families.

Theme 2: Interventions for Patients and Families to Improve Service Transition

The participants in both focus groups and qualitative interviews generated comments which constitute the second theme. They provided recommendations for facilitating a successful transition for young people and their families from PEDPs to AEDPs. Specific recommendations from focus groups and interviews included: a) family interventions to prepare young people and their families for life course changes prior to and preceding service transition; b) interventions that assist young people with psychological and developmental changes and the integration of self-management skills to

1 The letters in parenthesis denotes the participant’s role, where C = community service provider, A = AEDP adult service provider, and P = PEDP pediatric service provider.
facilitate a seamless transition; and c) coordinated medical follow-up for young people prior to them leaving the PEDP or immediately after the occurrence of ST.

FAMILY INTERVENTIONS TO FACILITATE ST

The participants in the focus groups and qualitative interviews generated innovative ideas for family-based interventions. The participants advocated for approaches whereby therapists work with parents to gradually decrease their role in re-feeding, while increasing their supportive role external to eating and weight restoration. Participants in both focus groups and qualitative interviews unanimously supported the establishment of family interventions incorporating information about the changing roles of parents in caring and supporting their loved one with AN. Participants in the AEDP focus group identified the importance of educating parents about the differences in family therapy in the pediatric and adult system and developmentally appropriate ways of supporting a young adult. A participant from the AEDP shared:

Family therapy takes on a different feeling . . . when they're in the adolescent system it's how are you going to help your daughter to eat . . . 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 are in the best interest of your recovery. (A-O5)

Participants in the PEDP focus group and qualitative interviews also advocated for a new family therapy approach or intervention designed exclusively for the parents that specifically addresses developmental issues, and acknowledges the ways in which AN interrupts physiological, biological, and psychosocial growth and development. One participant in a qualitative interview shared (C-01): “I think the family support around the families letting go is quite significant if people could have that without necessarily their daughters being involved in care. The families get something independently of their kids that might be helpful.” Another participant stated, (C-03): “I know that what the moms love is education and information, about what their rights are, what the parameters are and maybe the possibility of doing . . . a family Maudsley method of treatment . . . Transition Maudsley groups.” Participants across the focus groups and interviews acknowledged the necessity of parents continuing to monitor eating, especially when the teen or young adult is medically compromised.

INTERVENTIONS FOR YOUNG ADULTS TO HELP FACILITATE SERVICE TRANSITIONS

Participants in both focus groups and in the qualitative interviews all agreed that interventions need to be established to assist with fostering greater
Independence and autonomy in young people. A participant from the AEDP echoed the concern that young people have been robbed of the opportunity to become autonomous due to developing the illness at a young age and the long illness course. This person shared: “the kids have been sick from the time that they were 14. . . . They have missed a significant developmental piece . . . they don’t have the skills to do it, to live on their own, to cook themselves lunch or breakfast, to find housing” (A-04). To address the lags in development, a participant in the qualitative interview suggested that, “Different groups for them, some social skills groups or independence around meal preparation and shopping because parents do all of that. So absolutely, I think for that age group it would be useful to do it, before they hit the adult system” (C-06). Participants in the focus groups and qualitative interviews also suggested that groups be offered to assist young people with other life transitions, including starting post secondary school and moving out on their own. In fact, participants in the PEDP focus group noted that all young people, regardless of having AN, require support with life transitions. One pediatric focus group participant argued that “there is increasing recognition that 18–24 is . . . itself a developmental stage” (P-04) requiring clinicians to think differently about how they work with young adults.

All of the participants in the PEDP focus group and qualitative interviews advocated for interventions to assist young people to develop skills for managing their illness on their own. One clinician stated that:

. . . self management might end up being one of the biggest helpful tools.
. . . Self management moves people along a continuum of change and possibility, it at least gets people thinking about taking care of themselves and maybe actually taking some action to do that. . . . A lot of what the adult model does really fits in very nicely with a self management kind of approach. In that people learn the skills that they need to get better from their eating disorder as opposed to the pediatric system where it’s really the parents who are the main drivers. (C-05)

Coordinated Medical Follow-up During Service Transitions

Participants all concurred that young people need to be referred to a family physician during or immediately after they leave PEDPs. The participants in the PEDP focus group acknowledged that patients and their families are often reluctant to work with a family physician in the community while they are being seen in a specialized eating disorder program due to a strong attachment to the treatment team and concerns about fragmenting their treatment. However, challenges arise for patients and families when they leave the pediatric system and they lack accessible and appropriate medical care. The participants in the qualitative interviews all agreed that family physicians are reluctant to accept older adolescents and young adults with
AN because they perceive this population as difficult to engage in treatment. For example, one participant noted that family physicians often decline to work with young patients who are ambivalent and, therefore unwilling to adhere to medical advice, stating:

It can still be hard to find a family doctor who is interested in taking on someone with an eating disorder, because doctors prefer to take care of patients who want to get better and who might therefore be somewhat motivated. . . . If you’re a family doctor and you’re watching somebody killing themselves, that’s difficult. (C-05)

Another participant agreed, stating, “I have clients, who I can’t get a doctor to see them. They’re without medical care. That is a general issue but these are people who are identified as difficult to treat, nobody wants to treat them and finding a doctor is impossible” (C-01). Another clinician bluntly summed up the difficulties, “I think it is a lot easier to get a family doctor when you’re 12 and cute than when you’re a sullen 18 year old recovering from an eating disorder” (C-04).

Consistent with the PEDP focus group and the qualitative interviews, participants in the AEDP focus group identified the enormous challenges that arise for families when their child with AN no longer has access to medical care in the PEDP. As raised by one clinician “We do not offer that ongoing contact and that horrifies the parents. They have to try and find care for their kids and accessing care is very, very difficult. . . . So this is a huge cultural shift for the parents and they are absolutely certain that their kids are going to die” (A-05).

Participants in both focus groups and the qualitative interviews all argued for the provision of training for pediatricians and family doctors regarding the medical complications that often accompany AN. One participant emphatically stated that,

We have an obligation to help provide some of that training or information to family doctors. So on the one hand I think we need to be looking at what the family doctors know and I think one of the ways that we could be doing that is actually sharing care much more often with family doctors when we are seeing patients and following them in our clinics. . . . We will share the monitoring with the family doctors so that they can become knowledgeable about what are the things that they need to be monitoring. . . . Let’s keep you involved in the care of the patient so that they become more knowledgeable and so that they know what’s been happening with the patient and therefore can much more easily transition. (C-04)

In summary, study participants identified three types of interventions for promoting a seamless service transition. First, participating clinicians
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recommended family-based interventions that permit parents to learn about how to support young people to become more independent in managing their illness. Second, participants recommended interventions directed at young people, teaching them how to become responsible for their own recovery from AN. Thirdly, participants suggested that clinicians work collaboratively with primary care physicians to provide shared care to patients with AN.

DISCUSSION

Five qualitative interviews with clinicians in the community and two focus groups with clinicians working in a PEDP and an AEDP in a large city in Ontario, Canada were conducted. For the most part, there was consistency across the focus groups and qualitative interviews with respect to the themes generated. One notable difference is that the AEDP focus group participants did not consider the issue of age determining readiness for transition. Clinicians in the AEDP may be less acutely aware of the issue of readiness for ST since they do not have to identify services for their patients who may not be prepared developmentally for the change. Instead, they accept referrals from young people, and work with individuals from across the life span (i.e., age range of 17–70).

Theme 1: Flexible Service Transition Plan Based on Readiness, as Well as Age

The participants in the pediatric focus group and the qualitative interviews suggested that chronological age (typically 18 in North America) should not be the primary criterion used to determine readiness for exiting pediatric care for AN. The participants strongly recommended that a developmental perspective and an assessment of the psychosocial needs of the young person and their families should be considered before precipitating a service transition to AEDPs. Researchers investigating other medical and psychiatric disorders have similarly advocated that clinicians use a wider age range and a comprehensive assessment plan based on the developmental and psychosocial maturity of the patient to help determine the appropriate time for referral to adult services rather than a unitary cut-off age (Webb et al., 2010). Some researchers have proposed that ST from Child/Adolescent Mental Health Services to Adult Mental Health Services correspond with life changes such as starting post-secondary school and finding employment (Munoz-Solomando, Townley, & Williams, 2010; Nishikawa, Daaleman, & Nageswaran, 2011). Other researchers have suggested that discussions about ST occur on an ongoing basis beginning with the onset of diagnosis and continuing throughout adolescence and young adulthood (While et al., 2004).
The recommendation of using a more fluid definition of adolescence appears to be in keeping with a new developmental stage between the ages of 18–25 that has been coined “emerging adulthood” (Arnett, 2007) and consists of five distinct features including: identity explorations, the age of instability, the self-focused age, the age of feeling in between, and the age of possibilities (Arnett, 2002; Arnett, 2007). Emerging adulthood is characterized as a period whereby young people experience some of the most significant transitions in their lives including the first formation of intimate relationships, building meaningful links with a social network, moving from secondary to post-secondary school and transitioning from education to employment opportunities and then a career (Arnett, 2002). Chronic illnesses and disabilities may interrupt identity explorations and intensify the sense of instability that young people experience while at the same time reducing opportunities to achieve vocational and academic success (Arnett, 2007). Hence, the finding from this qualitative study that the developmental needs of young people with AN be at the forefront when planning a transition is supported by a wealth of literature on transitioning for other chronic illnesses and a theoretical model regarding a new proposed developmental stage labeled emerging adulthood.

The suggestion that developmental and family readiness rather than age be used to determine when to initiate a transition to an AEDP may not be feasible given illness-related factors and economic constraints limiting the availability of clinical resources (Van Staa, Van Der Stege, Jedeloo, Moll, & Hilberink, 2011). Illness-related factors such as a persistent denial about AN and ambivalence about engaging in treatment may lead to the clinical impression that adolescent patients are ill prepared for a service transition because they are non-compliant with psycho-social treatments including normalizing their eating and gaining weight. Readiness for transition should encompass more than adherence to medical regimens, nutritional plans, and restoration of weight.

Theme 2: Facilitating Seamless Transition to AEDP

FAMILY-BASED INTERVENTIONS FOR FACILITATING SERVICE TRANSITIONS

All the participants in this qualitative (both focus groups and interviews) study recommended developing family-based interventions that decrease involvement of parents in the re-feeding process while relinquishing more responsibility for eating and weight restoration to the young adult. Participants suggested a range of interventions (family therapy and parent educational/support groups), but all agreed that the treatment needs to be tailored to the unique developmental stage of transition age youth. One suggestion was to establish groups for parents that combine support and education regarding changing roles within the family and the interruption of
the illness to salient developmental tasks. Another suggestion was a recommendation for a modified version of the Maudsley Model of Family Therapy (Family Based Therapy; Lock & Le Grange, 2001). Research has demonstrated that this form of family based therapy is efficacious in achieving weight restoration for younger adolescents with a shorter duration of illness (Lock & Le Grange, 2001) and in this group of patients is superior to individual therapy based on 1 and 5 year follow up studies (Eisler et al., 1997; Russell, Szmukler, & Eisler, 1987). This model of family therapy is being adapted for older adolescents and young adults. In fact, a small case series of family-based therapy (FBT) in young adults demonstrates that this intervention is acceptable, feasible, and effective in facilitating weight restoration in young adults (Chen et al., 2010). The description of the intervention as outlined in this article recommends that the therapist establish a more collaborative relationship with the young person while engaging them in discussions about identifying behavioral strategies for promoting eating rehabilitation and normalized eating. A further adaptation of FBT for young adults is that some individual sessions are offered in the final phase of treatment.

**Interventions for Young Adults to Facilitate Service Transitions**

The majority of the clinicians participating in this study advocated for the development of psycho-social treatments for young people with AN, with a focus on teaching self-management skills. Clinicians and researchers in the field of eating disorders may consider adapting the Chronic Disease Self-Management Program (CDSMP), which has been established for individuals with a range of chronic illnesses (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). Influenced by Bandura’s Social Cognitive Theory, the CDSMP seeks to build the capacity of individuals by teaching skills of mastery and self-efficacy. The use of such a self management model during service transition for health and mental health issues and disabilities was examined in a systematic review by Crowley, Wolfe, Lock, and McKee, (2011). Crowley et al. (2011) found that interventions jointly delivered by pediatric and adult health care providers that focus on patient education about self-management skills contribute to improved outcomes. Based on the empirical evidence available regarding the effectiveness of interventions for other chronic illnesses or conditions (Lorig et al., 2001; Rose et al., 2008), a Chronic Disease Management Program designed for AN and delivered jointly by those working in PEDP and AEDP is recommended.

**Coordinating Medical Follow-Up During Service Transitions**

This qualitative study found that lack of availability and inadequate training of family physicians seriously impedes seamless service transition to AEDPs. The insufficient education of primary care physicians is a pervasive problem that has been identified in the literature on ST with other chronic physical
ailments, mental health issues, cancer, and disabilities (Daaleman & Elder, 2007; Nathan et al., 2011; Suris, Akre, & Rutishauser, 2009). In addition to the lack of specialized training with respect to specific diseases such as AN or Type 1 diabetes, researchers have advocated for the education of primary care physicians regarding the unique developmental issues that arise for young adults and adolescents with serious illnesses (LaRosa et al., 2011). Achievement of improved training and knowledge dissemination to primary health providers should contribute towards mitigating the fragmented service characteristic of our current health care systems, as young people will have access to services with well-trained health professionals in a variety of settings.

Clinical and Research Implications

The findings of this study provide directions regarding clinical care to young people and their families during transition from pediatric to AEDPs. Irrespective of age of onset and illness severity, every young person and their family should be engaged in transition planning to ensure that they are adequately prepared to exit care in a pediatric eating disorder treatment setting, and that proper linkage with appropriate medical and psycho-social services in an adult health care system have been established. It is common for older adolescents/young adults with AN to require parental support while they become more responsible for managing their own general health and illness related difficulties. Varying levels of family support may be needed to assist young people in their decision-making process regarding how, when, and where to access adult care for health and mental health issues. Parental support groups are suggested that educate parents about the long term illness course, emerging adulthood, and how to support without taking over recovery. Young people and their families may further benefit from a transition model of family based therapy for AN. A transition model of family therapy may build on the family based therapy for young adults described above (Chen et al., 2010) but include additional elements such as: a) working with the parents and the emerging adult to address developmental issues pertaining to the protracted nature of this illness; b) incrementally shifting the responsibility of eating and weight gain from the parents to the young adult by assisting the latter to develop self management skills to direct their own recovery; and c) encouraging parents to become involved in assisting the young adult to achieve tasks associated with adulthood such as building connections with their social support network, and achieving vocational and academic goals.

Future research into transition issues for AN is strongly needed including randomized controlled trials to identify the efficacy of self-management models for AN and family based treatments for emerging adults. Health service research is further recommended to evaluate the effectiveness of shared models of care or specialized transition eating disorder programs in
addressing the physical, psychological, and familial needs of young people with AN and their families. The development and evaluation of clinical guidelines for determining readiness and preparedness for transitioning from adolescent to adult eating disorder programs is needed.

Strengths and Limitations

This study has a number of strengths. First, it is one of the only studies which elicits the perspectives of clinicians regarding the impediments to facilitating service transition from pediatric to AEDPs. Second, this study provides a diversity of clinician perspectives including from a PEDP, an AEDP, and the community. Third, we took several steps to maximize the quality and credibility of our data, carefully checking that the themes generated resonated with other clinicians working with the population of interest, a step which increased our confidence in the validity of our findings.

There were also several limitations to this study. First, by design the study included only clinician perspectives, and future studies would also benefit from eliciting the perspectives of patients and families undergoing ST. Second, the findings may have limited generalizability outside of inpatient settings in large urban centers. We acknowledge that our focus groups only included service providers from tertiary care programs, however we attempted to mitigate this bias by including qualitative interviews with community-based service providers working with outpatients with a broader range of illness severity. There may also have been other regional and institutional factors that influence the findings, although we believe that most general themes would be widely applicable to other health care systems. For example, the specific age of ST in Canada is typically 18 years. Although this age may vary, the general theme of needing to account for developmental factors other than age in ST is likely to be universal. Despite these limitations, the results of this inquiry generated significant findings that provide a foundation for future empirical studies.

CONCLUSION

The findings from this qualitative study reveal that the process of service transition from PEDP to AEDP for adolescents and young adults with AN is affected by a number of factors. Service providers in PEDPs, AEDPs, and from the community generated several recommendations for facilitating a successful transition. Specifically, service transition should not be based on the age of the patient, but rather on their readiness to move to an AEDP. Further research regarding family-based interventions and self management models for young adults and their families is strongly recommended. Finally, the results of this study underscored the need for the development of a model of shared care between specialized programs and primary care practitioners.
REFERENCES


