

Transition Age Youth with Eating Disorders: Clinical guidelines and interventions for effectively working with emerging adults and their families in various settings

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Literature Review: Transition Issues in Mental Illness & Eating Disorders

- Introductions
- Clinical Examples
- Literature Review and Overview of Models of Transition
- Clinical Examples
- Small group work
- Q and A

Introductions

How many of you...

- Work with children and adolescents with eating disorders?
- Work with adults with eating disorders?
- Work with individuals across the lifespan?

Work in...

- Hospital based settings
- Community organizations
- Private Practice
- School Based settings
- Other

Hopes and Expectations

Literature Review

Mental illnesses and Young Adulthood

Transition issues and Mental Health

Young adulthood and Mental Health

- Research demonstrates that mental illnesses commonly have their onset in adolescence (Cappelli, Vloet, O'Neil, 2012).
- Some illnesses become severe and persistent contributing to psychological impairment in older adolescents and young adults (ages between 16-25) (McGony et al., 2006).
- Young adults with mental illnesses are a vulnerable group: They are at an increased risk of engaging in high risk behaviours, dropping out of school and failing to achieve important developmental tasks associated with young adulthood (Health Canada, 2002).

Literature on Transition Issues in Mental Health

- Lack of continuity of care between adolescent and adult mental health services is an important issue that warrants greater attention because.....
 - When young people exit child and adolescent mental health services, they are at risk of delaying access to necessary adult treatments.
 - They may also have difficulties forming a therapeutic alliances with adult clinicians, especially if they perceive them as using approaches that are not developmentally appropriate.
 - Issues with treatment engagement are the most pronounced with this age group.

(Sigh, 2010; Gulliver, Griffiths, and Christensen, 2010)

Treatment Engagement: Barriers to Help Seeking in Young Adults

Gulliver et al. (2010) reviewed articles on barriers and facilitators to help seeking behaviours in older adolescents and young adults with mental illnesses.

Identified the following barriers:

- Fears of being stigmatized for having a mental illness and needing services.
- Poor mental health literacy -lacking knowledge about mental health symptoms.
- Preference for self reliance over dependency on professionals for assistance.

Identified the following facilitators:

- Positive *past* experiences with professionals.
- Encouragement from others to pursue treatment.

Barriers to Engaging young people with eating disorders:

What are some of the barriers to engaging adolescents/young adults in treatment for the eating disorder?

What are the facilitators of engagement for adolescents/adults in treatment for eating disorders?

Barriers and Facilitators to Engaging young people with eating disorders:

What are some of the barriers to engaging adolescents/young adults in treatment for the eating disorder?

- Ambivalence (pros and cons of change are similar)
- Adaptive functions of the illness
- Pride associated with thinness and control over appetite
- Body image difficulties and fears of weight gain

Facilitators:

- Use of collaborative therapeutic style
- Confidentiality and Trust building

Literature review on Transition Issues in Eating Disorders

Transitioning: Eating Disorders

In a review article written by Treasure et al. (2005), a number of barriers were identified in the U.K. as adversely affecting the transition to adult ED programs.

- Community Mental Health Teams lack the skills required to manage young adults with eating disorders especially when they also have co-morbid diagnoses.
- Different philosophical treatment approaches may be challenging for young people who are severely ill, unable to take responsibility for controlling/managing their illness.
- Families who have been involved in providing care to their affected child find the transition to adult care extremely difficult as they are often excluded from assessments and treatment process.

Transitioning: Eating Disorders

Winston, Paul and Juanola-Borrat (2011)

- Different expectations of service providers regarding parental involvement in the management of the illness.
- Older adolescents are more likely to experience challenges when undergoing vertical transitions (from child and adolescent to adult eating disorder programs)
- Young adults experience frequent problems when undergoing horizontal transitions (emergency wards to general mental health programs to EDPs).

Qualitative Research

- Qualitative study on the barriers and facilitators of a successful transition process from pediatric to AEDPs from the perspective of expert clinicians (Dimitropoulos et al., 2012).
- Conducted 2 focus groups and qualitative interviews with expert clinicians from pediatric and adult eating disorder programs and in the community in Southern Ontario.

Main Findings:

Theme 1:

- Denial about the illness hinders young people from being "active" participants in adolescent treatment and during service transition.
- Ambivalence about change interferes with the establishment of a therapeutic relationship with clinicians in adult treatment programs.

Illness related factors are important barriers that should be targeted to assist young people to accept a transfer of care to adult providers specializing in eating disorders

Main Findings:

Theme 2:

- Prolonged starvation and emaciation affect cognitive abilities, as well as physiological and neurological development.
- *Important for adult care providers to consider* how to facilitate autonomous decision making and independence in young people whose illness has interrupted their development.

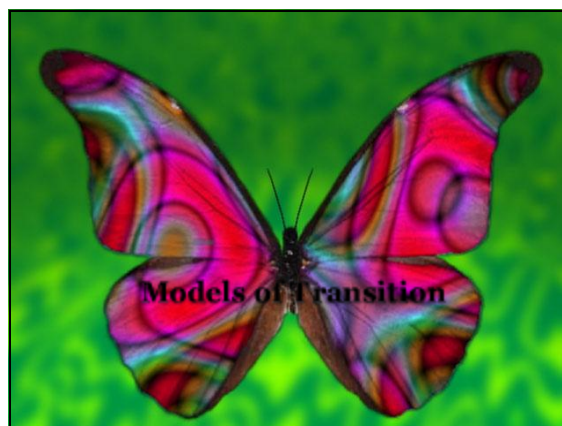
Main Findings

Theme 3:

- A decrease in parental involvement in adult treatment settings has dire consequences for young people who are unable to take responsibility for the management of their illness.
- Important for adolescent and adult providers to identify ways to:
 - better prepare families for the transition and transfer of care; and,
 - maintain parental involvement in domains outside of the refeeding process.

Perspective of Service Providers

- In the second article published by our group (Dimitropoulos et al., 2012b), the recommendations for facilitating a seamless transition of care for young people with Eds included:
 1. family-based interventions that permit parents to learn about how to support young people to become more independent in managing their illness.
 2. social skills groups to help young people become more responsible for their recovery.
 3. linkages with post-secondary schools and employment centres to help facilitate integration to life post-treatment.
 4. clinicians work collaboratively with primary care physicians to provide shared care to people with EDs.



Little Evidence

- Multiple interventions likely needed
- Unlikely that solution is 'one size fits all'
- Difficult to follow patients after transfer
- People want to get started on interventions, don't want the delay of a study
- Difficult to have a concurrent control group who get no intervention

What Do Young People Need To Transition?

- Knowledge
- Increased self-management skills
- Independence skills
- Self-advocacy
- Maturity

Reiss, Pinzon 2005; Blum 1993; Kaufman 2005

What Do Young People Need To Transition?


Impact of their condition on:

- Health & wellness
- Sexuality & Reproduction
- Social life
- Independent living

Paone, 2000

Our local problem...

- Clinic and personnel dependent
- Event as opposed to process
- No formal or hospital-wide approach
- Lack of consistency among clinics
- Lack of coordination and collaboration



Models of Transition

Skills	Knowledge	Transfer
Transition clinics	Peer	Shared management
Graduation		

Conclusion

- Many approaches to transition
- Not an event
- Shared management
- Important to keep the needs of the teen and family at the front
- Just recognizing transition leads to change

• Clinical Examples:

Kate's story – October 2008

- 18 y 3 months, referred by family doctor
- Type 1 diabetes diagnosed at 12 years of age; developed restricting type AN within months
- Successfully treated as inpatient and outpatient at pediatric program

Kate's story – October 2008

- Eating dysregulated with restriction, overeating & SBE
- Diabetes management gradually worsening
- BMI 20.2
- Seeking help to normalize eating, work on body image distortions

Request for Medical Records...

May 12, 2007

Dear Dr. ---:

Kate was seen today in her regular clinic appointment. Overall things are going well. She continues to struggle with body image issues and we focused on that today. She has been snacking more, perhaps related to her insulin. Her endocrinologist plans to switch her to a pump in a few weeks, so that should be helpful in terms of this evening snacking. Things are going well at home and at school and I will see her in follow up in two weeks.

Treatment Plan

- Individual CBT
- Focus on both eating and diabetes management
- Stress and time management
- Periodic meetings to include her mother
- ↑ endocrinologist & diabetes educator

Dear Diabetes, June 2009
 I don't know how else to explain what we have other than a love hate relationship...I hate that you mess up my life...you make me so different from everyone else...I can't be spontaneous with my friends...most of the time it's easier to pretend that you don't exist.
 I love that if I don't give myself insulin, you make it easy for me to lose weight. I feel irritable and sore and tired, but I guess everything comes with a price.
 I don't know how willing I am to accept that you exist.

2009-2011

- Worsening diabetes management
- Fasting
- Binge-eating
- Fluctuating weight

- Day Hospital treatment x 2

2012: now 22 years old

- Mother and family frightened and angry
- Support parents to set clear expectations about diabetes management and medical monitoring
- Frequent emergency room visits and brief hospitalizations
- Worsening situation after moves in with boyfriend

Another example

Small Group Discussion:

Divide up into smaller groups, identify the barriers and facilitators for effectively transitioning young people and their families in your province.

- Are there unique, illness-specific barriers that you have observed in your clinical practice?
- What barriers have you identified that may be specific to your province or the Canadian context?

Questions and Discussion