Adolescent Eating Disorders: Recovery-Oriented Programming for Residential Treatment

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KEYWORDS

Introduction

Eating disorders (EDs) are mental illnesses characterized by a persistent disturbance in eating or eating-related behaviour which leads to physical and mental impairments.¹ EDs can develop in individuals of all ages; however, the most common age of onset is adolescence.² While the recovery model of care is becoming a widely applied concept in mental health settings,³ it is rarely integrated into ED treatment. Recovery-oriented practice reflects a strength-based model of care designed to empower individuals to take control of their own journey in (re)establishing a meaningful and purposeful life despite their mental health challenges.³ A number of frameworks have been established to describe recovery, but most have been developed for adult populations; and it has been argued that these approaches do not directly translate to the youth experience of mental illness and recovery.⁴ Frameworks developed for adolescent recovery to date have been modified from adult models and, despite the ethos of empowerment and self-determination inherent within the recovery model, youth models are informed primarily by health care practitioners instead of the adolescents themselves.⁵ Therefore, the application of recovery-oriented services to adolescents with EDs is challenging due to the lack of ED-specific recovery-oriented services and the lack of a recovery framework developmentally appropriate for adolescents. This paper describes the successes and challenges of developing and delivering recovery-oriented services to adolescents with severe EDs – a population vastly under-represented in the recovery literature.

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Treatment Setting

The Adolescent Eating Disorders Residential Program (EDRP) at Ontario Shores Centre for Mental Health Sciences (Ontario Shores, Whitby, Ontario, Canada) is the first publicly-funded residential treatment for adolescents with EDs in Ontario. It opened in October 2014 and provides services to 12-18 year olds in Ontario with the most severe, chronic and/or complex EDs. Teens are eligible for the EDRP even if they suffer from other co-occurring disorders, including substance use disorder, which excludes them from many other ED treatment programs which tend to focus solely on the primary diagnosis, the eating disorder. Likewise, having an ED excludes teens from most substance use programs. Programs in both areas expect alleviation of any co-occurring psychiatric disorders prior to treatment. This leads to a catch 22 experience. (Teens must have had their ED treated and in remission to qualify for a substance use program, but they cannot get treatment for their ED until they have been treated and are in recovery for their substance use disorder). Referrals into the EDRP are made by other treatment programs that have been unable to provide treatment that supports and results in recovery.

In order to best provide a full spectrum of recovery-oriented services, the EDRP is staffed by an interdisciplinary team. The staff complement includes three social workers, a behaviour therapist, an occupational therapist, a dietitian, a recreational therapist, three child-and-youth workers (mix of part-time and full-time), a psychologist, a psychiatrist, a mix of 11 full-time and part-time nursing staff who provide 24-hour care, and a clinical team leader. The program has dedicated access to a pharmacist, a nurse practitioner, and a peer support specialist. Most teens are assigned one of the social workers as their family therapist, though they can also be matched with other staff more skilled in an area of need. For example, a teen with a developmental-delay may be assigned to the behaviour therapist for a more behaviour-driven approach. Regardless of who takes the lead, all team members are integrated into the treatment experience to meet all of the teens’ recovery needs.

Recovery Framework

Despite the absence of a recovery model specific to adolescents, the development of the EDRP involved concerted efforts to integrate known recovery philosophy and recovery-oriented practice principles into delivery of program services. The peer support specialist was pivotal in this process, educating the team and advocating from the patient perspective.

The Mental Health Commission of Canada’s Recovery-Oriented Practice Guidelines were not published until 2015. At the program’s inception, the EDRP adopted Mancini’s framework of the recovery paradigm,6 which was considered most appropriate for an adolescent population. The framework is based on self-determination theory, which suggests that people will achieve their goals and wellbeing if their basic human needs (autonomy, competence and relatedness to others) are met. Mancini presents a hypothetical continuum of recovery-oriented practice that is a three-tiered model,
moving from 1) controlling, to 2) traditional (paternalistic) medicine, to 3) recovery-oriented service delivery, or essentially from a primarily provider-driven program to a primarily client-driven program. The model describes the defining characteristics of the program regulatory mechanisms, associated practices (role of medication, individualization, care planning, client-driven approach, consumer feedback mechanisms, role of choice, and implicit treatment focus) and the impact on a client’s self-regulation for each tier of the model. In the development of EDRP service programming, every effort was made to move from the traditional to recovery-oriented services, while adjusting services to be developmentally appropriate for adolescents. The following sections detail how the EDRP used the Mancini recovery framework as a guide to develop recovery-oriented services for adolescents with severe EDs.

Program Regulatory Mechanisms
A prominent feature within Mancini’s theoretical continuum that ultimately guides program practice is the notion of program regulatory mechanisms – the extent to which rewards or sanctions are used to manage client behavior. Regulatory processes determine the way in which a program runs via policies and procedures, therapeutic interventions, medication and documentation practices, etc. These program regulatory mechanisms outline the way in which expectations and norms are maintained. For example, a controlling environment would punish undesired behaviours, while a traditional medical program would provide rewards for desired behaviours. In contrast, the recovery-oriented programing in the EDRP focuses on non-contingent strategies, shifting the teens’ motivation from one that is extrinsic to one that is intrinsic in nature. In this way, behaviours are regulated by providing choice and autonomy rather than being contingent on rewards and punishments. The teens are provided opportunities for decision-making and experimentation with treatment options. They are afforded positive risk-taking opportunities and may make mistakes, experience consequences, and learn how to deal with failure, problem solve, and persevere, all in a safe environment. This helps the EDRP to avoid 'institutionalizing' the teens; and the goal is a return to their home community where the expectation is that the teens manage themselves independently.

Associated Practices

The non-contingent regulatory mechanisms within recovery-oriented practice are applied to seven different associated practices described in the recovery framework and are outlined below.

Role of Medication
Unlike traditional programs where medication is emphasized and adherence may be rewarded, the EDRP integrates medication within treatment; however, it is not mandatory or associated with incentives. The program has also leveraged the pharmacist’s expertise to provide a robust pharmacological education component to help guide the teens (or their family members) to make informed decisions that will best suit each unique set of circumstances. The unit pharmacist meets with the teens and their families individually to discuss both continuing and newly-prescribed medications
to ensure genuine informed consent. Although in some cases medication is strongly recommended, it ultimately becomes the teen’s and/or parents’ decision whether to take it or not. With a pharmacist dedicated to the program, medication is personalized to each teen based on individual needs, rather than mandated via a single protocol applied to all program attendees. Medication is constantly evaluated as part of the treatment plan, and changes are made as needed.

**Individualization**

In traditional ED treatment programs, services may follow relatively strict protocols regarding food consumption and therapeutic intervention with little room for individualization. The EDRP is committed to supporting the teens whenever possible to make decisions that lead to autonomy. For example, although meals are mandatory (because adequate nutrition is a basic necessity of life), meal plans are developed by the dietitian with the teen present to voice their perspective. There is no standard protocol on what a meal looks like for a teen; rather, the meal is determined by the individual’s stage of recovery, personal preferences, and familial and cultural norms. More challenging meals, such as those high in carbohydrates, are introduced at a pace and time consistent with the teen’s level of readiness. Teens are viewed as their own experts and as such, are encouraged to make decisions for themselves. Guidelines rather than absolute rules are provided for all program functions, such as refueling needs after physical activity, bathroom precautions after admission, levels of physical activity, emotional regulation, crisis prevention, unaccompanied leave from hospital, etc.

**Care Planning**

Traditional ED program care planning includes setting goals related to caloric intake and symptom stabilization. Although these are important clinical features, moving toward recovery-oriented care planning, the EDRP encourages teens to set goals, aimed at rebuilding the skills they need to re-establish their 'normal' teenage life and reintegration into the community. Therefore, goals may be related to the ED, but they may also encompass goals important to adolescent life experience, such as leisure and social-related endeavours. The EDRP staff is mindful of the teens’ self-expressed best interests and wishes as a central component of the treatment plan. Work with the teens and their families begins prior to admission in order to establish their treatment goals and readiness for change. The teens’ and families’ goals are constantly re-assessed, to ensure they are achievable and that sufficient progress is being made.

Unique to the EDRP is the inclusion of an occupational therapist and a recreational therapist on the team, who work with the teens to develop the skills needed to return to their communities. These include returning to school and developing an age-appropriate leisure life, social skills, and friendship networks. Another role unique to the EDRP is that of the behaviour therapist, who may work closely with teens and their families to determine ways to approach a behavioural goal. For example, if the goal is to end a particular behaviour, the behaviour therapist and teen would collaboratively develop a step-by-step plan to fade the unhelpful behaviour, track progress, and re-adjust the approach, if needed. Family therapy is heavily integrated in care planning in order to ensure that the parents are part of the support plan.
**Client Driven Approach**
Contrary to traditional, clinician-driven programs, the EDRP’s motto is: “Nothing about you, without you,” meaning, the teen is invited to be present for any discussions related to their treatment and able to make decisions regarding aspects of care. Teens and their families are also invited to participate in weekly clinical rounds. This practice is not common in Ontario. Teens and their families may register for the Ontario Shores ‘Health Check’ online patient portal to obtain secure online access to parts of their clinical charts. This initiative promotes accurate and mindful charting by staff, using recovery-oriented language.

**Consumer Feedback Mechanisms**
Along with traditional hospital feedback mechanisms such as the patient experience survey, the EDRP has other avenues to provide feedback to ensure teens and their families can voice their concerns and opinions. When teens and their families participate in clinical rounds, it gives them the opportunity to provide feedback on their care plans. Additionally, the teens attend a weekly community meeting that is led by a teen volunteer. A minimum of two staff members also attend. The purpose of the meeting is to make announcements that affect the program and address any issues the teens may have with their environment, unit rules, guidelines with which they disagree, suggestions for activities, etc. Minutes are taken and reviewed with the staff leadership for action. Some of the suggestions from the teens have involved unit processes, and staff and management are open to exploring opportunities for change. For example, the teens are divided into two groups for meals: Group 1, whose members need more support, enter the kitchen first, as they may require additional support and take longer to prepare their meals. Group 2, whose members are further along in their treatment and need less support, enter once Group 1 has sat down at the table. During a community meeting, the teens suggested to switch that process and alternate between Group 1 and Group 2 entering the kitchen first, reasoning that sometimes the teens in Group 2 get anxious waiting for Group 1 to finish their preparation. This idea was implemented the following day and trialed for a few weeks. At the review point for this process, the teens agreed that the idea did not benefit the teens that needed more support. The teens and staff then agreed to return to the original process of Group 1 entering first then Group 2. Importantly, the teens were part of the full process from feedback to trial to evaluation and final decision making. This example illustrates the value of feedback and incorporating the teen voice into practice, not only to optimize the treatment experience, but to emphasize to the teens that their voice is important and is heard.

**Role of Choice**
Teen choice is strongly valued in the EDRP, which has adapted concepts from the Choice and Partnership Approach (CAPA) Model. Care is taken to ensure that the 'choices' are age appropriate and that the teen is given proper support from clinicians and family members, when indicated, to make well-informed decisions. Upon referral to the program, each teen and their family meet with staff from the EDRP to complete a
'choice-interview' adapted from the CAPA model. One of the main goals is to allow the teens and their families to make an informed choice about whether the EDRP suits their needs and for the staff to decide if they have the resources to provide appropriate services. Teens are provided with numerous choices throughout their admission to the EDRP, which includes collaborative planning of goals, meals and activities. It should be noted that not all treatment decisions are left up to the teen. For example, it is mandatory for teens to maintain caloric intake, though they are involved in the planning of how this happens and consider the consequences of their inability to meet this requirement.

**Implicit Treatment Focus**
The focus of the EDRP is promoting recovery, which differs from traditional programs that are focused on maintaining medical stability. As previously discussed, each teen defines their personal recovery journey, and the treatment team supports the achievement of these deeply personal goals. A recovery plan may or may not follow psychiatric criteria for the disorder; rather, the focus is on individual goal achievement, readiness to change and discharge planning.

**Impact on Client’s Self-Regulation**
According to the recovery framework developed by Mancini, the type of program (controlling vs. traditional vs. recovery-oriented) dictates the impact of treatment on the individual’s self-regulation and other recovery outcomes by influencing one’s motivational profile, attitudes towards self and autonomous functioning.

**Motivational Profile**
Ideally, recovery-oriented programming promotes the development or strengthening of internal motivation. EDRP staff work with the teens prior to their admission to establish their motivations before reaching the program and to develop pros and cons to help heighten the teens’ motivational awareness. EDRP staff work to shift the teens toward, or to maintain, the teens’ internal motivation by acknowledging their autonomy and choice when it comes to goal setting and care planning. At times, teens may not be ready to work on their ED right away and may want to focus on other goals, which is an accepted reality of this approach. Supporting this choice at the beginning has actually strengthened the therapeutic relationship.

**Attitudes Towards Self**
Recovery-oriented practice promotes self-determining attitudes, unlike traditional practice models, which promote self-worth contingent on achievement. As previously described, the EDRP allows considerable choice and the ability to experiment and potentially fail without punishment, criticism or rejection, hence learning that their self-worth is independent of successes. Teenagers are developmentally driven to express themselves; and the program does not suppress their inclination to do so. Self-worth is addressed specifically in group and individual therapy sessions.
Autonomous Functioning
A clinician-driven environment tends to result in dependency, where the EDRP – a client-driven, recovery-oriented program – strives for the teens to achieve as much independence as developmentally appropriate, with a goal of community reintegration. For example, many individuals with EDs, particularly those with purging subtypes, struggle to control their impulses while in the bathroom. In a traditional treatment environment, individuals may be on supervised bathroom precautions indefinitely. In contrast, the policy in the EDRP is that the teens are on supervised bathroom precautions for their first 48-hours post admission, after which time the team meets with the teen to determine whether or not precautions need to continue. The teens are not sheltered from their struggles and are given ample opportunity to overcome them with staff support, within an honesty-based system. The flexibility in allowing teens to formulate their own solutions and eventually reduce or eradicate purging behaviours tends to increase their confidence when dealing with other difficulties outside of symptomology.

Another example of autonomous functioning is the EDRP’s approach to meal time. In traditional programs, the teens are given a meal tray, which includes foods that have been portioned and prepared for them. This does not allow them to develop the skills to effectively prepare their own meals, which is a very important challenge that many people with EDs face in the community; and the lack of these skills can often lead to relapse. At the EDRP, the teens prepare their meals in a fully stocked and functioning kitchen, learning how to properly portion food and serve themselves. The teens eat at a kitchen table with other residents and staff for a family-style meal, which is less institutionalized than the traditional hospital-style meal tray.

Program Considerations that Support Recovery-Oriented Practices
A couple of noteworthy initiatives have facilitated the delivery of recovery-oriented services in the EDRP.

Space Design
Despite being located in a tertiary mental health hospital, efforts have been made to design a unit that looks and feels as non-institutional as possible to provide a space supportive of recovery. The EDRP has twelve private bedrooms that the teens are encouraged to personalize during their stay. There is no nursing station, but instead mobile computer stations for documentation to avoid creating barriers between staff and residents. There is a large dayroom and a courtyard for social and individual activities and a fully functioning kitchen so residents can acquire skills related to food preparation and consumption. The EDRP also has a classroom with a teacher from the local school board so the teens can continue with their studies, minimizing the disruption of the hospitalization on their academic achievement.

Recovery High School
Recovery colleges have been recognized as an important driver of individual recovery from mental illness. The EDRP developed and implemented Recovery High School, a
developmentally appropriate adaptation of the recovery college model, to offer the
EDRP’s teens the opportunity to have choice and variety when it came to their
treatment sessions. Co-designed therapeutic ‘courses,’ which include individual, family
and different group therapies as well as social and recreational activities are offered to
help them (re)build skills and confidence. Much like regular high school, Recovery High
School has mandatory, elective and selective courses; and teens have to complete
volunteer hours (a requirement of the Ontario Secondary School System). Recovery
High School operates throughout the calendar year, and it is divided in 6-8 week-long
semesters.

Peer Support
As with most recovery-oriented programming, peer support is featured as a prominent
vehicle for practice change and advocacy for the teen voice on the EDRP unit. The peer
support specialist is an integral part of the interdisciplinary team. This is a fulltime paid
role established at Ontario Shores and is designed to support teens using expertise
gained from lived experience with mental illness and navigating the mental health
system. With the EDRP’s long-standing dedication to co design in every aspect of the
program, the peer support specialist has been uniquely qualified to provide consultation
and to work directly with teens to develop and expand key aspects of their treatment.
For example, the peer support specialist was able to identify the organization’s current
means of obtaining feedback from teens as developmentally inappropriate. Specifically,
by engaging with the teens, it was noted that young people do not fill out feedback
forms. In addition, it was shared that the teens did not want to discuss issues they were
having at the facility by phoning the ‘Patient Experience Department’ and engaging with
an individual they had never met. As a result, the peer support specialist created a
developmentally appropriate mechanism for feedback, in the form of frequent face-to-
face communication.

In addition, the peer support specialist is able to interact with each teen regarding
shared experience of determining how to have body acceptance in a weight obsessed
world. Peer support and peer support groups provide validation of thoughts and
feelings about the experience of participating in treatment for this often poorly
understood area of mental health. Ideally, the peer support specialist provides role
modelling opportunities for the teens to raise questions, assert themselves and act with
the goals of improving sense of self, confidence, and control.

This position has proven to be invaluable. For example, some clinical staff have noted
that, at times, teens do not want to talk to their social worker. However, they will open
up and engage with the peer support worker who can offer a perspective, support and
hope of someone who experienced the challenges and successes of the recovery
journey first-hand.

Challenges and Opportunities

The EDRP has made great strides toward providing developmentally appropriate
services that adhere to recovery principles; however, a number of challenges were
noted. Despite the lack of an adolescent-specific recovery framework, efforts were made to be creative and adapt an adult framework to the population by combining other models, such as the CAPA and Recovery College models, and Mancini’s Continuum of Recovery, in order to adequately meet the teens’ needs. Anecdotal feedback from teens has revealed that in general: a 'one size fits all' approach to treatment is disempowering: they want to be treated and feel like a 'regular teen' rather than a 'mental patient;' and they don’t want to feel overly sheltered, though sometimes they need guidance and support from adults. The EDRP has adjusted the regulatory processes to tailor both treatment and rules to optimize recovery for each individual; designed a de-institutionalized environment, as much as possible within the limits of provincial healthcare legislation; supported teens to take risks and learn from their mistakes; and fostered shared power between adult and adolescent that is specific to developmental context. The EDRP strives to support teens while enabling them to access professional experience with mental illness. In this way, the program blends together both the professional and lived experience lenses to optimize and customize the clinical treatment experience while also supporting one’s personal journey of recovery.

The model implemented by the EDRP has effectively addressed many of the concerns of teens on general units. Nonetheless, the comments made by the teens highlight the need for a single recovery framework developmentally appropriate for adolescents. Inherent in the development of a theoretical model of recovery for adolescents is the corresponding translation of theory into practice. The MHCC has conducted extensive work in preparing their 2015 guidelines regarding recovery-oriented practice. Two noteworthy dimensions of their practice guidelines are that services and practice should be responsive to needs across the lifespan and occur within the context of one’s life.\(^3\) Future research regarding adolescents and recovery should build upon these important guidelines to further develop recovery-oriented practice, specifically for adolescent service users.

While every effort has been made to embody recovery, the EDRP is limited by the differing (and sometimes conflicting rules) of what is legally mandated for the inpatient hospital setting. The province has strict rules about inpatient units regardless of type (i.e. intensive care units vs. psychiatry units, etc.) that are designed to ensure best practices. This translates into mandatory staffing, safety, and infection control practices that can sometimes present challenges when creating a recovery-oriented environment. For example, the televisions on all the inpatient units in the hospital are required to be contained in a protective case that results in an 'institutionalized' feeling and discourages their use. A recovery-oriented approach consists of pushing back against these institutionalizing practices.

Another challenge is related to how clinicians have been trained to communicate in hospital settings, which tends to be authoritarian and prescriptive. In a recovery-oriented environment, clinicians need to communicate more collaboratively with service users. For new staff, it can take time and support to learn a recovery-oriented approach. Additionally, health care providers tend to be risk averse, and prioritize safety above
recovery pursuits. This can negatively affect positive risk taking and overshadow residents as they move towards self-determination. Taking small, calculated risks that allow teens to move towards recovery needs to override potential or hypothetical risks. There is no such thing as a completely risk-free environment; a sterile, safe environment comes with the risk that people will regress rather than recover because they never get the opportunity to try to stand on their own two feet.

Conclusions

Even with the limitations and the work it took to become more recovery-oriented, the lessons learned about the usefulness of taking a collaborative approach makes returning to a more traditional approach unthinkable. The recovery-oriented approach applied to the EDRP has fostered a therapeutic milieu where power and decision-making are shared between the teens, the family and the treatment team, which enhances self-determination and empowerment. As a result, personal recovery is possible.

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References