**Towards Establishing the Role of Family Support in the Treatment of Adults with Anorexia Nervosa**

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Family-based treatment (FBT), developed and manualized by James Lock and Daniel Le Grange, has an indisputable amount of evidence affirming its effectiveness for the treatment of adolescents with anorexia nervosa (AN). But what about young adults? There remains work to be done to be able to answer this question empirically. Studies evaluating FBT in samples of young adults are extremely limited. 1 The average age of adolescents participating in family-based treatment in rigorous FBT trials is roughly 14-15 years.2 As such, whether FBT is effective, and to what degree it works for individuals suffering at older chronological ages are questions that science has only begun to do the work to answer.

Whether FBT is an effective treatment for young adults with anorexia is a reflection of a broader theoretical question about the role of family support and involvement in the treatment of adults with AN. It is worthwhile to remember that the most widely used treatments for adult AN are delivered in an individual format. 3 If one were to seek psychological treatment for AN with no intention or pretense about what to expect, it is highly likely, if not almost certain, that they would be placed in individual therapy where therapeutic family involvement would play a minimal role, or be absent altogether. This is true for both young adults and those further along the age spectrum, and irrespective of the level of family involvement. For instance, a 21 year living in her parent’s home would be likely to be recommended for individual treatment despite her dependence and level of interaction with her parents.

It is unclear as to why individual treatment for AN has prevailed for so long, and continues to be the most commonly used treatment. Decades of evidence suggest that currently available treatments, most of which are individual, are not effective and the evidence supporting these treatments is weak4. Evidence-based standards on the type of treatments that adult with AN should receive do not exist because of the lack of data on effective treatments for these individuals3. This is particularly alarming given the high mortality rates and propensity towards chronicity that is associated with this disease. Clearly, we need to find improved ways to help adults suffering from this illness.

The lack of effective treatments for adults with AN points to the need to critically assess how current treatments are insufficient, and most importantly, what new treatment modalities should be considered and explored further. Borrowing from principles of FBT, the question arises about whether therapeutic family involvement should be considered, and the way in which familial support can be mobilized to improve outcomes.

When considered closely, there are biological, empirical, and theoretical reasons to believe that a paradigm shift towards increased family involvement may improve outcomes.

AN is a psychiatric disease with unique features that differentiate it from other illnesses. AN is unique in that it is one of the only psychiatric problems characterized by what is referred to as “ego-syntonicity,” which refers to the way in which individuals with AN see their symptoms and behaviors as consistent with their fundamental personality and beliefs. This terminology, although old, accurately captures a cardinal and puzzling symptom of this disease, which is the desire to maintain the symptoms and behaviors of AN, and a lack of desire to relinquish them. Individuals with AN are often staunchly opposed to changing their behavior and/or restoring necessary weight, even when faced with compelling medical evidence. Whereas an individual with depression does not want to be depressed, an individual with anorexia most often would prefer to maintain their anorexia and will go to great lengths to do so. Even in those who recognize the need for change and can verbalize the desire for recovery, it is often difficult for them to change their behaviors in accordance with this desire. Individuals with AN often appear to lack insight into the nature and scope of their symptoms. For instance, where it may be easy for others to see the extreme dangers associated with a low body weight, it is not uncommon to see cases where this is rejected by the individual suffering. The lack of awareness about having a psychiatric illness is referred to as anosognosia. This is an important feature to consider because it raises the risk of treatment nonadherence and points to the need for external support. Because AN is characterized by starvation, physiology is affected in a strikingly comprehensive way. Lack of insight, or “anosognosia” and fusion with AN symptoms and behaviors may be caused or exacerbated by gross changes in the brain that occur as a result of starvation. These features have important implications for treatment. An individual who has limited ability to see their disease as problematic, and yet who is physically compromised, is likely going to have difficulty adhering to treatment recommendations despite the medical risk and may need external assistance to do so.

The lack of insight and puzzling propensity to engage in physically deleterious behaviors that affect health in serious ways can be explained by the powerful neurobiological drives that underpin this disease.4 Brain imaging research has allowed us to understand biological reasons that explain why individuals with AN engage in restriction by allowing us to use technology to look inside the brain. Although these symptoms seem puzzling and counterintuitive from the outside, when we observe what is occurring in the brain of an individual in AN, we see that behaviors such as restriction are not at all arbitrary, but in fact are occurring for reason and may actually have a functional purpose for the individual. It is with this information that we have established that this disease is less of a choice than it is a sentence. We now understand that for an individual with AN, stopping these behaviors may be akin to swimming against a powerful current. Imagine that you are swimming in the ocean and suddenly a strong rip tide begins to forcefully pull you away from shore. No matter how hard you try to swim, you are drifting further and further away from shore. You are getting more tired and yet getting nowhere. You give up, recognizing that the current is powerful, and that there is no amount of swimming that can get you back to shore. Providing individual treatment to someone with anorexia may be akin to someone standing on the shore with a loud speaker giving you tips and strategies for how to swim Harder! Faster! More Efficiently against a rip current that is grueling if simply not impossible for you to fight. There’s a slight chance that there are some tips that may get you closer to shore, but it would surely be easier for someone with a boat to throw you a line and tow you back. Assuming that someone with anorexia can fight this riptide with no direct assistance is a risky gamble, and reinforcing the idea of trying on their own by providing individual help, may be misguided especially if there are reinforcements in the form of support standing by eager to provide assistance. This is often the case with family members of individuals with AN; they are desperate to help but have not been given permission nor the appropriate tools to do so. What about allowing the riptide to pull you if you know that you will eventually reach the shore? Research shows that you’d be floating with the tide for five to seven years.5 What will you have missed on shore? What effects will that have had on you? Will you be able to keep your head above water for all that time? Will you survive unscathed? Calling on reinforcements by enlisting understanding, help, and support from family members may avoid prolonged illness, which drastically increases the chances of a good prognosis.6 The metaphorical boat and tow line can look many different ways in recovery, but signifies a more direct approach to support and intervention.

These reasons are not particularly novel or unique to adults. Rather, these are facts that have been known and well documented and that underlie the premise of family involvement in FBT for adolescents. FBT acknowledges that a powerful drive prevents adolescents with eating disorders from making appropriate decisions around food, weight, and eating that are ultimately health-compromising and calls upon parents to be involved to the extent that is necessary to ensure that their adolescents achieve and maintain good health. FBT has demonstrated good outcomes in ability to restore weight and reduce eating disorder cognitions.7 The mechanisms by which this is achieved have not been formally identified, but what distinguishes this treatment from other commonly used treatments is the heavy emphasis placed on familial support.

Let’s return to the question that was originally posed: What about FBT or more broadly, a “family-involved treatment” for adults? It is a sensible question given the evidence in favor of family-based treatments for adolescents and the fact that there are no other effective treatments available for adults with AN. Moreover, we understand that the unique physiological and biological considerations associated with this disease may render individual-focused work insufficient and/or inefficient.

What exactly differentiates an adolescent with AN from an adult with AN? The question is pertinent because the answer elucidates important factors to consider when applying familial support to adults. There are three primary distinctions that can be made between adults and adolescents.8

1. Greater Severity

In a study evaluating differences between young adults and adolescents with eating disorders who presented to an eating disorder program, young adults had higher global severity scores, a longer period of weight loss, greater amounts of total weight loss, and a history of experiencing a greater number of eating disorder behaviors.9  Furthermore, most often, adults have often experienced a protracted course of illness with instances of failed courses of previous treatment.8 Taken together, these data indicate higher levels of severity and the potential for a poorer prognosis due to a longer duration of illness.

2. Access to Family Support

Family support is more variable in adults. Adults may be more financially, emotionally and/or socially independent from family members. However, US census dates suggests that the age at which adults are reaching financial independence has changed. Roughly two-thirds of young adults in their early 20’s receive financial support from their parents. 10 Since it is estimated that 95% of those with eating disorders are between the ages of 12 and 26, it is likely that many adults with AN are still somewhat dependent on their family system. In an article summarizing experiences of working with families of adults with AN, Treasure et al., 2005 note that adult sufferers with severe AN often live with their families or rely heavily on their support.

3. Legal Rights

Persons above the age of 18 are treated differently by our legal system due to their chronological age and regardless of their developmental standing. This has important implications in the treatment of AN due to the developmental stunting that can occur with a protracted illness. A 25 year old with a 10 year history of AN may be developmentally and socially different from someone else of that chronological age. Despite this, legal adults are considered the holders of privilege in the right to consent to treatment and confidentiality .

These considerations help inform the potential benefit and viability of family involvement in adult AN. The greater likelihood of severity inherent in adult AN indicate a need for more comprehensive treatments that includes a family component. Higher levels of severity may further exacerbate physiological and cognitive symptoms that make it increasingly difficult for individuals to make recovery-oriented decisions independently. Severity may also indicate a lack of ability to manage independently and the need for increased support. Given the data we have about availability of familial support, it is likely that a significant portion of individuals suffering from AN have access to familial support in the form of parents, partners, or other loved ones. Higher levels of illness severity in combination with the relatively high access to familial support propagate an argument TOWARDS therapeutic family involvement that could improve outcomes.

The last factor to consider is the issue of consent and legal privilege held by an individual. Legal rights become irrelevant when an individual can agree to familial involvement and see the potential that this may hold. However, due to the factors that characterize AN that were described above, there are commonly situations in which individuals will actively reject or refuse involvement and help from their family members. In situations where there is financial dependence or other leverage held by support persons, those factors can be made use in order to get an agreement for collaboration. These issues related to age of majority, both legally and developmentally, have led experts in the field to recommend that family-based treatment be modified to be more collaborative when being used with young adults.10

Efforts are underway by many clinical research groups across the world to develop, test, and disseminate improved treatments for adults with AN that incorporate a focus on family/carer support. Chen et al., 2010 published a case series detailing outcomes on four young adults who underwent FBT. Modifications were made to the traditional FBT approach in an effort to be more collaborative due to age. Although very preliminary, results were promising with 3/4 achieving weight progress into normative weight ranges. Continued efforts are in process to test a young adult version of FBT. Janet Treasure, Ulrike Schmidt , and others pioneers in the area of carer involvement in the treatment of adults with AN have developed a novel treatment for adults with AN called MANTRA (Maudsley Model of Treatment for Adults with Anorexia), based on a contemporary understanding of the numerous facets underlying AN, and which incorporates familial involvement. 11 Bulik et al. have created U-CAN (Uniting Couples Against Anorexia), a couples-based treatment for individuals with AN and their partners.12 In conjunction with Laura Hill and the Center for Balanced Living, UCSD has developed and is currently testing an intensive family treatment program for adults and their loved ones that combines familial support with neurobiology for a new treatment approach that we are calling NEW-FED. NEW-FED focuses on improving clients’ and families’ understanding of the neurobiology underlying AN and teaching carers and clients strategies and skills to manage symptoms constructively using neurobiologically-based skills.

Given the strong argument in support of therapeutic family involvement, treatment studies are desperately needed to 1) provide empirical affirmation that involving familial support in the treatments of adults with AN is effective, and 2) to elucidate precisely HOW familial support should be mobilized to be most effective in supporting recovery.

“[**Cooperation is the thorough conviction that nobody can get there unless everybody gets there.”**](http://www.wisdomquotes.com/quote/virginia-burden.html)

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