Using Technology to Improve Treatment Outcomes for Children and Adolescents with Eating Disorders

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INTRODUCTION

Anorexia nervosa (AN) and bulimia nervosa (BN) are serious psychiatric disorders that constitute an important public health problem in terms of prevalence, cost, morbidity, and mortality.\(^1\)\(^2\) Approximately 13% of young women will suffer from a diagnosable...
eating disorder (ED) in their lifetime. It is just beginning to be understood that disordered eating among young men is far more common than previously believed. Individuals with EDs have elevated mortality rates and high medical costs, and often develop physical and psychiatric comorbidities. Despite the establishment of clinical practice guidelines for effective treatments, dissemination and implementation of evidence-based treatments have progressed slowly, with only a small proportion of affected individuals seeking and receiving treatment. Some of the barriers to treatment include insufficient numbers of adequately trained clinicians, shame associated with the illness, geographic constraints, and substantial costs associated with treatment. These reasons, coupled with the relative rarity of the disorders, have meant that the field has been hampered by a lack of data. This has made treatment development especially challenging and slow relative to other disorders. These difficulties can be summarized as problems of scale, access, and innovation inertia caused by a lack of data.

THE CHALLENGE OF SCALABILITY AND ACCESSIBILITY

The current front-line treatment for adolescents is a specific form of family-based treatment (FBT), which leads to full remission in about 50% of patients initially, outperforming individual approaches in the follow-up phase. Largely a behavioral treatment, it features interventions highly specific to the illness, such as framing progress around weight gain, orchestrating an intense scene around the illness, and a family meal that includes in vivo parental coaching. Given the specificities of the treatment model, specialist training is a necessity. However, training to the level of certification consists of attending a 2-day intensive seminar, with few following up with the required individualized session-by-session supervision on treatment with at least 3 families. Even where this training has been undertaken at an institutional level, the model has not been implemented with fidelity. This inherent lack of scalability is a huge challenge for treatment providers and health systems at a global level.

The net result of these challenges means that most adolescent patients with a diagnosis of AN do not have access to the treatment that is most likely to bring about full and sustained recovery. Thus, the same challenges seen from the point of view of those who have received a diagnosis is a problem of access. The existing disparity between need and availability of specialized treatment for AN is especially alarming given the vital importance of early intervention for maximizing chances of recovery, and the substantial medical and psychosocial consequences if AN persists. Thus, there is an immediate need to invest resources in adapting FBT to be scalable from the perspective of treatment providers and accessible from the perspective of those who need it.

PROBLEMS OF A LACK OF DATA

Although EDs have seen an increase in research interest in recent years, most clinical studies are of adult populations. There are only 7 published randomized clinical trials examining adolescents with AN, totaling just 480 subjects. In BN, few treatments exist that were specifically designed for child and adolescent populations, and extrapolating from treatments of choice for adults (eg, cognitive behavioral therapy) has not proven particularly fruitful, although there are 3 randomized clinical trials examining this population. In AN, there are substantial difficulties associated with conducting research, and among the greatest challenges are the relative rarity of this disorder, and either the resultant lack of statistical power necessary to detect changes, or the time it takes to build adequately powered sample sizes. In a recent review of evidence-based treatments for AN, the authors concluded that relatively little...
innovation has occurred in the past 80 years. Clearly, more data are needed from which to develop treatments that are customized and specifically address the needs of young people.

OPPORTUNITIES IN TECHNOLOGY TO ADDRESS THESE PROBLEMS

The authors developed 3 innovations to address scalability, lack of access, and data-informed treatment innovation. To address these challenges, they turned to concurrent innovations in the field of online education, in the form of massive open online course (MOOC) platforms. In the field of education, MOOCs have successfully delivered specialist top-tier expertise all over the world in a way that is scalable, solves problems of access, and generates data sets sufficient to stimulate genuine innovation in teaching practices. It was the authors’ contention that both these online learning methodologies and the technical platforms on which they were delivered could be leveraged for the purposes of clinical training and the delivery of treatment. Finally, the authors turned to advances in mobile technology, and in particular, smartphones, to first augment, and later deliver, interventions to individuals with EDs who are and are not in formal treatment, respectively.

MASSIVE OPEN ONLINE COURSES

MOOCs represent an emerging methodology in online learning. Some of the defining features of MOOCs that distinguish them from other online learning platforms include that they

1. Rely heavily on video with most material being delivered that way
2. Include a range of assessments that encourage procedural (rather than only declarative or rote) learning
3. Can be data-driven and iteratively enhanced

Some MOOC platforms have leveraged social technology to provide meaningful opportunities for students to collaborate and communicate within a community of learners. These features were leveraged to construct a learning environment ideal for clinical training. One of the defining features of MOOCs that was not used in this case, however, is that they have open, public enrollment.

DEVELOPMENT OF A MASSIVE OPEN ONLINE COURSE-BASED SPECIALIST PSYCHOTHERAPY TRAINING IN FAMILY-BASED THERAPY

The Clinical Training Massive Open Online Course

An online course for FBT was developed on an MOOC platform as part of a US National Institutes of Health (NIH)-funded study to explore the feasibility of improving fidelity to FBT by improving training.

Training was amended to include training modules that specifically target elements of treatment fidelity that influence outcomes. The 12-week course consists of about 6 to 7 lectures, comprising 5 to 6 very short (about 3–4 minutes in length) didactic videos that discuss the treatment model and an accompanying role-play therapy session (or series of short role-played scenarios) with a typical case of AN, prescribed reading, and an assignment. The course is delivered sequentially, with assignments due on Sunday evening and a new lecture delivered every Monday morning. The authors borrowed from concepts of case method teaching to include the kind of clinical information that one would have with a typical AN case (ie, weight chart [with every lecture to track progress], standardized assessments, and intake evaluation report)
to create an immersive clinical experience. Assignments tested clinical decision making: “read this intake evaluation and write down which lab and medical tests you would order for this patient given her history,” and provided the opportunity to step into the shoes of the experts and rate how well the therapist executes a clinician intervention in a segment of video of role-played therapeutic session.

**Pilot Data**

The course was not open or public; participants could only enroll by invitation. In a 6-month period, the authors conducted 3 pilot studies with N = 45 participants, a mix of MD psychiatrists (37%), doctoral-level psychologists (30%), master’s level family therapists (7%), doctoral-level graduate students (22%), and 1 registered dietician (4%). Completion (defined as finishing >80% of videos and assignments) ranged from 40% in the first pilot to 78% in the final. There was a high level of satisfaction with the course overall (85%), the didactic content (100%), the clinical content including role-play videos, and supportive clinical material (80%) and the homework (69%). Not having enough time was the most frequently cited challenge to completing the course (70%). This was also demonstrated by the fact that 76% of participants completed their course obligations on the weekend after 8 PM. Ninety-four percent of participants said they were satisfied with the usability of the interface. Development of the training model was iterative, with feedback being integrated into the next pilot iteration. For example, participants in the first pilot strongly suggested implementing more structure around homework assignments (eg, being due on a consistent day of the week for each lecture, frequent email reminders), and so this was adjusted in the second pilot. In the second iteration, participants suggested more opportunity for discussion of actual clinical cases, and a system of moderated asynchronous clinical discussion was implemented in the third pilot. This system of iterative development led to more innovation in training methods than has been possible in the previous decade of traditional seminar-based training.

**Next Steps**

For the randomized trial, and unlike most studies of online training interventions, the authors will measure clinical outcomes and benchmark against known outcomes from previous trials where standard training has been implemented. They are developing 2 methods of assessing applied knowledge acquisition and clinical skill. Applied knowledge is tested by a written, clinical vignette, and multiple choice-examination, and to measure clinical skill, trainees are required to respond to a series of short, standardized role-played video vignettes as if they were the therapist. The teleconference recordings are then expert-rated using a validated measure of treatment fidelity.10

**DEVELOPMENT OF INTERNET-DELIVERED GUIDED SELF-HELP**

**Background**

Internet-delivered interventions present the opportunity to increase access, reach, reduce costs, and establish sustainable systems for providing care. When linked to in-person medical services, such as monitoring by a pediatrician, online programs may help reduce mental health care disparities for adolescent AN. Internet-delivered guided self-help (GSH) interventions have been successfully implemented among individuals with BN and binge eating disorder, and at a minimum appear to promote symptom reduction beyond a wait list control condition.13–16 There are currently no comparable treatments developed for AN. A fundamental principle of FBT is parental empowerment, making it ideal for dissemination as a GSH approach.
for parents. The authors’ research team developed an Internet-delivered GSH parent intervention derived from FBT for the prevention of AN and early intervention. Pilot data suggested that an Internet-delivered text-based program was feasible to provide, acceptable to parents, and may result in symptom reduction in both those who are at risk of developing AN and those with an ED not otherwise specified. A natural and important extension of this preliminary work was the examination of its utility for parents of adolescents with full AN. The authors ran a case series to answer the question of whether FBT could be adapted and delivered as an online GSH intervention for parents of adolescents with AN. Data gathered in the case series will be benchmarked against a large body of existing data from trials that have examined traditional FBT to gather preliminary information on the efficacy of a GSH approach to FBT (FBT-GSH).

The Intervention

The program consisted of 80 short videos (all <7 minutes in length, average length about 3 minutes) delivered in 10 lectures over 6 months. Incorporating a participatory medicine framework, the authors included 3 25-minute videos featuring an interview with a recovery role model, a former patient successfully treated with FBT for AN. In addition to the videos, materials aimed at empowering parents in the active treatment of their adolescents were uploaded. These included materials that are commonly used clinically such as an ideal body weight calculator (using growth charts as reference tables), a weight chart to allow parents to plot weight progress, and a booklet explaining medical management of AN (produced by the Academy of Eating Disorders). A recipe book produced by parents who have experience of renourishment was also uploaded, and each family was sent a copy of the self-help book “Help Your Teenager Beat an Eating Disorder,” 2nd Edition (Lock & Le Grange, 2014) from which readings were prescribed weekly. Finally, the therapist conducted brief (30-min) check-in meetings with parents over a Heath Insurance Portability and Accountability Act (HIPAA)-compliant video conferencing program. Following the form factor of gold-standard FBT, these meetings were initially weekly, but tapered off to every 2 to 3 weeks during later phases of treatment and finally at monthly intervals for the final sessions. All families had exactly 12 check-in sessions with a certified FBT practitioner.

Rather than provide in vivo coaching as in standard FBT, the assessment capability of the MOOC platform was leveraged to create opportunities for parents to develop skills needed for successfully navigating the renourishment process. In this way, parents were encouraged to adopt an objective observational orientation (Fig. 1), and the data gathered were discussed during the weekly check-in with the therapist.

To ensure that there was no delay before getting treatment, a rolling group format was implemented such that individuals could join the group as soon as they were eligible.

As described previously, the MOOC platform contains a discussion forum that aims to facilitate the establishment of learning communities. In the context of the GSH program, the forum became an asynchronous support group addressing the sense of isolation that parents often report feeling.

Pilot Data

A small case series is currently underway to test the feasibility and acceptability of the intervention. The overall study design was a case series of 20 parents of adolescents (aged 11–18 years) with a diagnosis of AN in the previous 12 months. To allow for benchmarking against data that have been collected from randomized clinical trials at Stanford and University of Chicago, the authors maintained the same inclusion
criteria of weight between 75% to 90% of expected for age and height. Prior to enrollment, all participants must get sign-off from a treating physician to certify that the patient is safe for outpatient therapy and to continue medical monitoring. At the time of writing, 16 families have completed treatment, and while outcomes have not been formally evaluated, there are interim findings for the first 11 families who completed. The parents of N = 20 adolescents were recruited (mean age = 14.8; standard deviation [SD] = 1.9) with a mean % expected body weight (for age and height) of 83% (SD = 5.27%).

Although follow-up data are not available at this time, among the 11 participants who have completed the program, there was a significant reduction in symptoms between baseline and end of treatment. Percent expected body weight for age and height (EBW) increased from a mean of 82.37% (SD = 5.96) at baseline to 97.23% by end of treatment (SD = 7.98) with a large effect size (Cohen d = 1.94). The restraint subscale of the Eating Disorders Examination Questionnaire decreased significantly (with a large effect size of .71).

Again, while only in a position to report interim findings, data suggest that outcomes from this study are within the range of those achieved by comparison FBT trials. For example, the effect size of 1.94 compares favorably to the within subjects change in

Fig. 1. The authors’ research team developed an Internet-delivered GSH parent intervention for the treatment of AN translating therapeutic coaching into meaningful assignments. (Courtesy of Stanford University, Stanford, CA; with permission.)
weight among a pooled dataset of N = 196 adolescents treated during comparison FBT trials that demonstrated a significant weight increase between baseline and end of treatment with a large effect size of 1.2. In addition, 60% of the adolescents met criteria for full remission at end of treatment (defined as weight at least 95% of expected and Eating Disorders Examination Questionnaire global score within 1 SD of published norms). This compares favorably to a rate of about 42% in the Lock and colleagues study and 33% in the Agras and colleagues study.

Although these findings are interim, the authors are optimistic about the success of the study overall. The study appears to be feasible and acceptable to parents, and patient safety considerations appear to be appropriate.

DEVELOPING SMARTPHONE APPLICATIONS FOR THE AUGMENTATION AND DELIVERY OF THERAPEUTIC INTERVENTIONS

Background

Smart mobile technologies offer unique opportunity to dramatically change the landscape of therapeutic intervention. However, as is the case across almost all diagnoses, the amount of available smartphone applications claiming to impart some kind of mental health advantage for their users far outweighs the evidence that confirms such assertions. The first studies on mobile-enhanced therapeutic interventions in EDs, although limited, were promising, although most pertained to short messaging system (SMS) interventions, or ecological momentary assessment. However, 2 reports demonstrated increased adherence to smartphone self-monitoring over paper and pen for recording meals and physical activity.

Food for Thought

The authors first developed a Web application optimized for smartphone called Food For Thought. Developed in the context of a treatment trial for adolescent BN, they created an application in the hope that it would facilitate adolescents’ food and symptom self-monitoring. The application was built using an academic development approach, emulating as close as possible the conventional paper-and-pen format and with great attention paid to encryption and secure hosting. The latter piece necessitated substantial time investment before the application was ready for roll-out with patients but had the advantage of ensuring patient confidentiality. The authors ran a small case series of the first 5 users of the applications and their respective clinicians, demonstrating feasibility and acceptability as well as broad heterogeneity in terms of how it was used. Building an application for research purposes had the advantages of being HIPAA-compliant; however, without a dedicated team to support and update the application, it quickly became outdated.

The Development of Recovery Record

Around the same time, the authors began consulting with an entrepreneur who wanted to build a mobile application to enhance treatment for EDs and facilitate food and symptom self-monitoring. This application was developed using best-practice in person-centered design, soliciting user feedback in rapid, iterative development cycles and implementing current understanding in user engagement. The development process is described in detail elsewhere. The result is a mature and highly acceptable application that has been downloaded by over 300,000 individuals. Although this reach may be modest for most large-scale commercial applications, this kind of reach for an ED service is unprecedented, and, outside the context of only the best-executed and large-scale epidemiologic studies, the dataset it generates is unique.
Most users are young, with the mean reported age being 22 (range = 13–77 years) and about two-thirds of those who provide their age being under the age of 25.

Using Mobile Data to Develop Targeted Treatment for Individuals Not in Formal Treatment

Although the application was originally developed to facilitate evidence-based treatment, preliminary analyses suggested that approximately 46% of application users were not currently in therapy. In addition, approximately 26% of these individuals saw clinically significant symptom improvement after at least 4 weeks of application usage. This overall response rate is comparable to those observed in clinical trials of self-help interventions, although these are not directly comparable. However, a limitation of the application is that it is a “one-size-fits-all” product that does not formally account for the heterogeneity of ED symptoms. Genetic, personality, and neurocognitive data support distinct clusters of ED presentations that also differ according to response to treatment and course, and the authors’ preliminary data strongly suggested that Recovery Record users span the breadth of this spectrum, offering a unique opportunity to specifically engage diagnostic verticals from 1 platform.

Next Steps

In partnership with Recovery Record, the authors obtained a 2-phase Small Business Innovation Grant from NIH to capitalize on this public health opportunity and develop content tailored to the needs of specific user groups according to their symptoms.

The study is nearing completion of its first phase, the aim of which is to confirm the algorithms that were generated by analysis of the first dataset in a prospective design to minimize bias. To date, the authors have recruited N = 1276 individuals and have developed curated content that addresses their symptoms. The authors have completed a patient-centered design process to create content and curated it into 5 distinct programs that incorporate review and feedback on the previous week’s progress gathered on the application, goal setting and skills selection, as well as activities that facilitate psychoeducation. Although they have consulted with service users throughout the process, initial pilot data suggest feasibility and acceptability of the programs. In the randomized controlled trial phase of the project, the authors will test whether the resultant algorithm-generated dynamic programs delivered in an adaptive application will improve outcomes relative to the standard “one-size-fits-all” version.

This methodology represents a data-driven approach to service development for individuals with EDs. There are several reasons to believe that if successful, Recovery Record has the potential to make a substantial public health impact. As the first commercially available smartphone application developed specifically for EDs crossing ages and diagnostic boundaries, it represents an important opportunity for reaching a population that is notoriously difficult to reach. In addition, the incremental cost of delivering tailored intervention components is negligible in comparison to traditional interventions, especially if reach is taken into consideration.

SUMMARY

The authors’ research group at Stanford has sought to tackle the many barriers that face adolescents with EDs and evidence-based service providers with a view to improving clinical outcomes and prevention efforts. In doing so, they have learned that the most successful strategies come from looking outward from one’s psychiatric subspecialty, toward parallel innovations and complementary expertise. The authors
advocate for the development of fruitful partnerships with computer scientists and companies with deep domain expertise in specific technology verticals, as these result in mutually beneficial relationships and the development of services that reflect best practices in both technology and clinical service design. From both perspectives, an emphasis on patient-centered (human-centered) design practice should be adopted to ensure ethics in clinical design thinking at every stage of development.

REFERENCES


