CREATING A CURRICULUM FOR EATING DISORDER RECOVERY PATIENTS AND THEIR SUPPORT NETWORK

A PROJECT REPORT

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ABSTRACT

CREATING A CURRICULUM FOR EATING DISORDER RECOVERY PATIENTS AND THEIR SUPPORT NETWORK

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For someone with an eating disorder, the significant and positive role of the family in the recovery process cannot be underestimated. There is a need for an environment in which both patients and loved ones can learn and unite together during this difficult process of recovery. A critical problem in the field of eating disorder research is a lack of nutrition-focused curriculum structured specifically for loved ones who want to support a patient with an eating disorder. The purpose of this project is, therefore, to create an Eating Disorder Recovery curriculum in which patients and their support network learn alongside of one another. Specifically, this curriculum will follow a 4-week plan focused on the therapeutic and nutrition components of recovery with goals to both educate and unite patients and their support network during the process of recovery.

ACKNOWLEDGEMENTS

This project is dedicated, first and foremost, to all the patients I have worked with over the years and to the promise I have always made to them and to myself to continue my research and keep searching for new and creative ways to improve the recovery process as much as I can.

I would also like to thank all my committee members, especially Dr. Reiboldt, for their confidence in my work and career and for sticking by me throughout the years.

Finally, I must thank my husband, Ryne, for his unending and unconditional support of all that I do. No matter where he is in the world, I always feel his love.

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CHAPTER 1

INTRODUCTION

For someone with an eating disorder, the significant and positive role of the family in the recovery process cannot be underestimated. Parents, spouses, siblings and a close support network can make a world of difference for someone who is struggling with an eating disorder, especially as they work towards recovery (Cockell, Zaitsoff, & Geller, 2004). Recovery work takes patience and presents many challenges for the support network that now must learn about the complexities of an eating disorder and navigate the world of Eating Disorder Treatment. Just as the individual with the disorder experiences intense fear, personal hardship, and emotional angst throughout the illness and recovery, so too do those who support them. It can be torturous to have an eating disorder but it can also be difficult to care deeply for someone who does.

There are so many unanswered questions about the disorder and how a patient's support network can help their suffering loved one. During treatment, alongside a multidisciplinary team of healthcare professionals, a patient will also likely work with a therapist and dietitian. These team members have a unique opportunity to learn and dig deeper into the patient's life to find their individual needs and the nuances of their disorder. They are able to co-mingle and take that information to teach the patient's support network to learn how to better care for them through the recovery process (Cohn, 2005). During the treatment process, families may benefit from a "support team day" where family members and loved ones in the recovery program can come together and learn how to support and care for their eating disorder diagnosed member. The curriculum at this "support team day" could be delivered in such a way that the support network learns and patients can feel understood and supported.

Evidence shows patients need clinical and social support throughout the process of recovery (American Dietetics Association, 2006). This project thus aimed to unite the therapeutic and dietetic components of Eating Disorder Recovery in order to provide a meaningful learning experience for the support networks of eating disordered patients.

Statement of the Problem

While the field of Eating Disorders is certainly extensive, much of the information available has been directed exclusively towards either parents or patients; there are scant evidence-based resources for both patients *and* their support network to learn together. Furthermore, much of the information is also directed towards parents of adolescents with eating disorders with less focus on spouses, close friends, relatives and parents of adult patients who also may be main influences. Studying the effects of "co-mingling learning" for family members and adult patients to learn and be supported together through recovery will broaden the spectrum of eating disorder education.

The current problem is the lack of a curriculum focused on all types of loved ones who want to support a patient with an eating disorder. There is a need for an environment in which both patients and loved ones can learn together and unite during this difficult process. Therefore, having a structured, generalized curriculum for use in an Eating Disorder Treatment Facility may help to educate, motivate and support all those affected in the life of someone recovering from an eating disorder (i.e., their support network).

Purpose Statement

The purpose of this project was, therefore, to create an Eating Disorder Recovery curriculum in which patients and their support network learn together. Specifically, this curriculum followed a 4-week plan focused on the therapeutic and nutrition components of

recovery with goals to both educate and unite patients and their support network during the process of recovery.

Project Objectives

The objectives of this directed project were to:

1. review relevant literature and identify topics for an Eating Disorder Recovery Curriculum used to teach patients and their support network;
2. review related curriculum used to teach patients and/or their support network about Eating Disorder Recovery;
3. develop an effective educational curriculum for the support networks of each patient to better understand the process of Eating Disorder Recovery and for the patients to feel supported by and learn alongside of their support network; and,
4. develop and implement evaluation tools in order to assess the adequacy and effectiveness of the group program.

Definition of Terms

Anorexia nervosa: A serious, potentially life-threatening eating disorder characterized by self-starvation and excessive weight loss (National Eating Disorder Association [NEDA], 2004b).

Binge eating disorder (BED): A type of eating disorder not otherwise specified and is characterized by recurrent binge eating without the regular use of compensatory measures to counter the binge eating (NEDA, 2004b).

Bulimia nervosa: A serious, potentially life-threatening eating disorder characterized by a cycle of bingeing and compensatory behaviors such as self-induced vomiting designed to undo or compensate for the effects of binge eating (NEDA, 2004b).

Eating disorder not otherwise specified (EDNOS): This category is frequently used for people who meet some, but not all, of the diagnostic criteria for anorexia nervosa or bulimia nervosa. For example, a person who shows almost all of the symptoms of anorexia nervosa, but who still has a normal menstrual cycle and/or body mass index, can be diagnosed with EDNOS. A sufferer may experience episodes of binging and purging, but may not do so frequently enough to warrant a diagnosis of bulimia nervosa. A person may also engage in binging episodes without the use of inappropriate compensatory behaviors; this is referred to as binge eating disorder (NEDA, 2004b).

Support team day: One day a week at an eating disorder treatment facility where loved ones of those receiving treatment for an eating disorder may come to attend groups run by therapists and dietitians. The purpose of this day is to bring together patients and their loved ones, have them learn about recovery together and create a supportive environment for all those involved.

Family-based therapy: Also known as the Maudsley Approach or simply FBT, family-based therapy sees the parents of the ill person as the best ally for recovery. In this evidence-based approach, parents are seen as the most committed and competent people in the patient's life and therefore best qualified to find ways to fight the illness, to regain healthy weight, and end unhealthy behaviors (Lock & LeGrange, 2012).

Limitations

The greatest limitation to this directed project was the lack of prior research in the field on eating disorder curricula aimed specifically at teaching a patient's support network. With its emphasis on how patients and their support networks learn and recover together, this project thus

represents an original and inaugural approach that would, as such, require further efficacy testing and corroboration.

Assumptions

The underlying assumption to this project was that patients would want to invite their support network to family day so that they might gain more understanding of eating disorders and better offer support. Furthermore, the curriculum topics and delivery methods were identified and chosen with the assumption that they were non-biased and would be the most beneficial to the patients.

CHAPTER 2

REVIEW OF LITERATURE

Purpose Statement and Objectives

The purpose of this project was to create an Eating Disorder Recovery Curriculum in which patients and their support network learn together. Specifically, this curriculum followed a 4-week plan focused on the therapeutic and nutrition components of recovery with goals to both educate and unite patients and their loved ones during the process of recovery. The objectives of the directed project were to, first, review relevant literature and identify topics for an Eating Disorder Recovery Curriculum used to teach patients and their support network; second, to review related curriculum used to teach patients and/or their support network about Eating Disorder Recovery; third, to develop effective educational curriculum to help the support network increase their knowledge and understanding regarding Eating Disorder Recovery and for patients to feel supported and learn with their loved ones; and, lastly, to develop evaluation tools to be used upon implementation to assess the adequacy and effectiveness of the group program.

Types of Eating Disorders

Eating disorders have the highest mortality rate of any mental illness (Arcelus, Mitchell, Wales, & Nielson, 2001). An eating disorder consists of a variety of symptoms that fall into roughly four diagnostic groups, including anorexia nervosa, bulimia nervosa, binge-eating disorder and eating disorder not-otherwise specified. There are many commonalities and differences among the different diagnosis groups. People of all ages, weights, races, and socioeconomic status can develop eating disorders (Hudson, Hiripi, Pope, & Kessler, 2007; Wade, Keski-Rahkonen, & Hudson, 2011).

Recovery Process

Recovery from an eating disorder can take a variety of treatment forms. Depending on the severity of the disorder, the patient will meet certain diagnostic criteria that place them at the proper level of care to fit their needs. Available levels of care range from least to most severe, including outpatient care, intensive outpatient hospitalization, partial hospitalization, residential treatment and inpatient hospitalization (NEDA, 2004a).

Support During Recovery

Regardless of a given patient's level of care, having a support system is crucial for recovery (Tiller et al., 1997; Treasure, Schmidt, & Macdonald, 2010). Support systems may include the patients' parents, siblings, spouse, friends, or extended family. It is important for the treatment team members to have a good idea of who is included in the patients' support network so they can better treat the patient and involve this supportive group.

Brown and Geller (2006) conducted a study on how "supportive statements" are interpreted by patients. In this study, participants were given common scenarios that occur during interactions with someone with an eating disorder and then asked how they would respond. The responses were separated into categories: unsolicited opinion, demanding, concerned, cautious, encouraging, and jealous. Eating disordered patients viewed the responses labeled as "cautious" and "encouraging" the most helpful. These two "helpful" categories represented only 13% of the total responses given, while 87% of the responses were viewed as being "unhelpful." In other words, seemingly supportive statements were almost always interpreted by eating disordered patients as negative and unhelpful, a fact that highlight the conflict between the positive intentions of potential support networks and the complex realities of individuals who suffer from eating disorders. Due to the complexity of eating disorders, it is

therefore imperative for support system members to be included in the recovery process so they may learn how to help their loved ones without their messages being misinterpreted (Brown & Geller, 2006).

What Recovery Means

Being "recovered" from an eating disorder has a variety of interpretations. Peterson and Rosenvine (2002) conducted research regarding what a patient believes are the most important factors of recovery. Some of those factors include: acceptance of oneself, having interpersonal relations, problem solving abilities, and body satisfaction, which were not entirely dependent on eating disorder behaviors being present. Cohn (2005) conducted a study that asked parents of children with eating disorders to rank their most important aspects of recovery. Team treatment, self-care, communication and responsibility are among the top eight. Responsibility includes the patient being responsible for their own actions as well as the parent taking on the task to get their child treatment and learn about the disorder and how to help. Furthermore, parents provided other parents with advice such as: "Don't make food an issue," "Avoid numbers…," "Improve my own feelings about my body to stop the cycle" (Cohn, 2005).

Other aspects to recovery are based on clinical standards including weight restoration, proper laboratory value recuperation, cessation of eating disorder behaviors (binging, purging, restricting, over-exercising, among others less common) and absence of medical issues such as bradycardia, low blood pressure, orthostatic and hyperglycemic episodes (NEDA, 2004).

Body dissatisfaction. Many patients report body dissatisfaction as one contributing factor to their eating disorder (Peterson & Rosenvinge, 2002). Although this is only one superficial factor in a multi-factorial, complex disease, learning body acceptance is crucial to recovery. Learning this acceptance can be explained through the Metabolic Set-Point Theory of

Homeostasis (also known as set point theory), which states that the body has a natural tendency to maintain a specific weight and will adjust internal body processes accordingly. If body weight goes above or below the set-point range, metabolism will speed up or slow down to stabilize weight (Costin, 2007). An important example of this theory was a study conducted by the *American Journal of Clinical Nutrition* involving overweight women, which found that calorie restriction did alter resting metabolic rate (RMR) during times of reduced food intake. However, once energy balance was restored, RMR returned to normal even for those who experienced significant weight loss (Weinsier, 2000). With increased knowledge of set point theory, patients may thus gain a better understanding of weight management and realize that weight is not as easy to manipulate and maintain as previously believed. This acceptance, as well as some other learned tools, may help to improve body image.

Acceptance of food. Throughout eating disorder recovery, in addition to improved body acceptance comes healthier perceptions of food (Bjork & Ahlstrom, 2008). Juarasico, Forman, Timko, Butryn, and Goodwin (2011) created a Food Acceptance and Awareness Questionnaire to measure acceptance about food related thoughts. A sample group of 463 participants completed the questionnaire that measured their ability to regulate eating despite urges and cravings and desire to maintain internal control over eating thoughts. They found that higher scores indicated greater acceptance of motivations to eat. Similarly, Tribole and Resch (2012) created a concept called Intuitive Eating in which one learns to create a healthy relationship with food, mind, and body. This practice helps one realize that health and self-worth do not change merely because a so-called "bad" food was eaten. Indeed, Tribole and Resch's work has now become the backbone of many Eating Disorder Recovery professionals' philosophy.

Family meals. Not only is it important to rework the patients' and loved ones' views of

food, it is important to look into the environment in which they are eating. A recent study (Hammons & Fiese, 2011) found that teenage girls who regularly eat meals with their families can develop healthier eating habits and avoid eating disorders. The study surveyed 2,516 adolescents at 31 Minnesota schools, collecting information on how often students ate with their families, their body mass index (BMI), as well as their eating behaviors and feelings concerning the connectedness of their family. Researchers concluded that those who ate 5 or more family meals per week were less likely to resort to extreme dieting measures such as binge eating, vomiting, or the use of diet pills to control their weight. The same held true 5 years later when the teens were surveyed again.

Although the positive benefits of family and communal meals are clear, meal times with eating disorder patients often become a battleground where loved ones may feel scared and clueless about how to create the right environment. To address this issue, Robinson, Strahan, Girz, Wilson, and Baochie (2013) studied families receiving family-based therapy and coaching for 6 months. Over time, parents' self-efficacy increased significantly, and they felt more and more confident in and knowledgeable about their role in helping their children through recovery. Likewise, adolescents' eating disorder symptoms, as well as their depression and anxiety, all decreased, as did the impact of symptoms on their parents. Future research can be focused on how these findings would transfer to different family groups as well as adult patients. Family-based therapy largely focuses on family mealtimes and "refeeding" the patient back to proper nourishment. Learning how to create a positive family mealtime is a vital skill to discuss and develop.

Support Network Involvement

How parents respond to anorexia is thought to influence its progress and there is

increasing recognition that parents can be valuable resources for helping with recovery (Cohn, 2005). There are limited studies conducted on spouses and other loved ones' involvement in recovery, as compared to parents of persons with eating disorders. Involvement in recovery involves the reacting, acting and maintaining aspects of the recovery process (Honey & Halse, 2005). Many studies have found that expressed emotion (EE) effects adherence to treatment and the outcomes of anorexia. This EE is modifiable by family-based interventions (Treasure, Schmidt & Macdonald, 2010), for loved ones to learn what is helpful and what is not.

Curriculum

Diverse Audiences

When creating a curriculum of any kind, it is most important to have the audience in mind (Costin, 2007). Treatment facilities often have diverse populations as research shows this disease is no longer being stereotyped as only affecting White demographics or those of higher socioeconomic status (Becker, 2007). Patients and their loved ones all have unique socioeconomic, educational, racial, and gender backgrounds and experiences in prior treatment (Treasure et al., 2010). In fact, many times the one and only thing that patients may seem to have in common with one another is their eating disorder.

As a result of this diversity, learning abilities also vary from individual to individual. The National Adult Literacy Survey shows that a majority of adults operate at around an eighth grade reading level (DuBay, 2013). Therefore, to make sure all groups are equally served and administered to, educational material and group discussions have to be adaptive and stay on a neutral, yet informative level.

Eating disorder patient needs. People with eating disorders have their own learning needs and challenges. Patients can often be easily agitated, anxious, or upset when specific

numbers such as height, weight, or calorie amounts are discussed in eating disorder information (Treasure et al., 2010). It is, therefore, important to structure the material so as to not agitate or trigger the patients. This encourages patients to be open to and learn the information being presented instead of becoming anxious or worried about numbers. Although specific numbers may often be used to create context and give examples, it was important to bear in mind that they can often do more harm than good in this kind of environment.

The National Institute for Health and Clinical Excellence (NICE) guidelines developed recommendations for the treatment of specific eating disorders, including therapies such as Cognitive Behavioral Therapy (CBT), Dialectical Behavioral Therapy (DBT) and Family-Based Therapy (FBT). In fact, research shows that some therapy types may be specific to the different eating disorders present. For example, CBT has a better outcome with those having bulimia (Treasure et al., 2010). FBT, meanwhile, is evidence-based proven only for anorexic adolescents. This therapy type mainly focuses on re-feeding the patient and restoring weight using the primarily the parents' own intuition. FBT has a strong weight and food focus to get the patient to gain weight quickly and steadily, with the parents seen as the experts in helping their child. This is different than what would be discussed at the "support team day," where the support network would simply be learning about the disorder, and allows for more flexibility in patient needs regardless of diagnosis. In order to most effectively meet the needs of patients, it is, therefore, imperative to create curricula adapted to specific therapies. To date, a curriculum for eating disorder recovery patients and their support network—the focus of this project— has not been developed.

Summary

When developing a curriculum, individuals with eating disorders have a variety of needs

to consider. It is important to understand the factors that are used to indicate that a patient is in recovery and create a sense that the patient, as well as their "loved ones," may have different definitions of what being "recovered" means. Two accepted commonalities indicating recovery include improved body dissatisfaction and acceptance of food. To help with this acceptance of food, it is important to look in depth as to what the "family meal" is and how to successfully eat together in harmony. Research has shown how important it is to not only eat with loved ones with eating disorders but also to be involved in the therapeutic learning of the recovery process itself (Cockell et al., 2005). Due to the diversity of the eating disorder population, it is essential to create a curriculum that meets the needs of everyone involved—patients as well as their support network—and that provides for *all* groups to meet together. While therapeutic curricula on the general topic of eating disorders do exist, a curriculum of this nature is certainly lacking.

CHAPTER 3

METHODOLOGY

Introduction

The purpose of this project was to create an Eating Disorder Recovery Curriculum in which patients and their support network learn together. Specifically, this curriculum followed a 4-week plan focused on the therapeutic and nutrition components of recovery with goals to both educate and unite patients and their loved ones during the process of recovery. The objectives of the directed project were to, first, review relevant literature and identify topics for an Eating Disorder Recovery Curriculum used to teach patients and their support network; second, to review related curriculum used to teach patients and/or their support network about Eating Disorder Recovery; third, to develop effective educational curriculum to help the support network increase their knowledge and understanding regarding Eating Disorder Recovery and for patients to feel supported and learn with their loved ones; and, lastly, to develop evaluation tools to be used upon implementation to assess the adequacy and effectiveness of the group program.

Prospective Participants

The groups benefiting from this curriculum were adult eating disordered patients (ages 18-65) and their respective support networks. Support networks included parents, spouses, siblings, children (over the age of 12), extended family members, and friends of the patients. This curriculum is appropriate in a treatment center for patients at any level of care (inpatient-outpatient) in a group setting.

Program Development

There were four phases involved in the development of this Eating Disorder Recovery Curriculum, each stemming from the four project objectives. The first phase involved conducting a thorough review of literature to identify a target audience and people involved in the recovery process. The second phase involved establishing goals of the curriculum and creating objectives to achieve these goals. The third phase moved to identifying and selecting key topics to be addressed for each of the four sessions in the curriculum. Finally, the fourth phase involved developing the curriculum and evaluation tool to be used to test the effectiveness of the curriculum by the patients and their support network.

Curriculum Design

The curriculum was implemented in a group setting at an eating disorder recovery facility. Optimal eating disorder recovery utilizes a multidisciplinary approach (Costin, 2007), so having the group led by dual leaders—a Registered Dietitian and a Family Therapist—was most beneficial. The 4-week program (one course per week) was designed to be engaged from beginning to end; however, due to the fact that many patients enter and leave the recovery center at different times, each lesson had the flexibility to be taught as a distinct module.

Curriculum Topics

The weekly topics were selected based on research of eating disorder recovery.

Aspects to Recovery

Some of the most pertinent research that contributed to the topics was taken from studies by Cohn (2005) and Peterson and Rosenvine (2002), in which patients, family members, and eating disorder professionals were asked to rank what aspects of recovery were most important. The highest ranked aspects among all of those groups were: positive body images, understanding

the disorder and contributions to its development, restoration of weight, decrease in behaviors, ability to eat "normally" and positive coping skills.

Verbal Support

Tiller et al. (1997) studied the most effective ways to support patients with eating disorders and how to give effective feedback. It was, therefore, helpful for loved ones to know the appropriate way to speak to and give support to their loved one in order to communicate a positive message.

Dietary Support

Lastly, Tribole and Resch (2012) created a philosophy for eating disorder recovery using the ideas of Intuitive Eating. This way of eating strays from the typical diet-mindedness of modern society and normalizes many foods without categories of "good" and "bad" foods. The patients' support networks were encouraged to learn more about these eating practices and ideas to help incorporate into home life when the patients return. Beginning to practice intuitive eating occurs once a patient is fully weight restored and has significant decrease in eating disorder behaviors such as purging or restricting. However, support network members can learn the basic ideas and how to support their loved one toward a version of this goal that works for them.

Curriculum Topics Chosen

All of the different aspects of recovery, ways to support loved ones, and specific eating styles for recovery helped shape the four topics below used in the curriculum. Current curriculum models offered from NEDA only contain materials focused on either males or females and discuss what eating disorders are, warning signs, how to seek help, and how to promote positive body image. While this information is helpful with basic eating disorder

information whether a person is in recovery treatment or not, it differs from the proposed curriculum here in that the curriculum of NEDA is less in depth and focused on dietary recovery.

Using the curriculum models above, current research findings, and specific aspects that are important for recovery, the curriculum topics selected were as follows: Set-Point Theory and Body Image (Costin, 2007; Weinsier et al., 2000), Intuitive Eating and "All Foods Fit" Philosophy (Matheiu, 2009; Tribole & Resch, 2012), Family Meals (Collins, 2005), and Food Boundaries (Lock & LeGrange, 2012). By engaging with this curriculum, those in the support networks not only became more educated about the process of eating disorder recovery, they also learned how to give proper, more positive verbal support to their loved ones. The eating disordered patients and their support networks were able to learn together to ensure proper interpretation and clarity of these vital topics.

Curriculum Evaluation

An evaluation tool was included at the end of each session to evaluate the lesson's overall effectiveness. A participant evaluation form was created to obtain feedback from both the patients and their support networks regarding overall content discussed, triggering information, sufficient time length to process information, and overall impressions of the group. The evaluation forms were used to adjust lesson plans, change the wording of information, and improve discussions during group time.

An expert panel, which consisted of the researcher's committee and Registered Dietitians from the University of California San Diego, reviewed the content and format of the curriculum, evaluated its overall effectiveness, and provided important feedback for future research.

Summary

After extensive research, a curriculum was developed to allow eating disorder patients and their loved ones to learn together about eating disorder recovery. A dietitian, who specializes in eating disorders, led the male and female adult groups. The target population was age 18-65. The groups were run as part of a "support team day" in an eating disorder treatment center. The 4-week curriculum covered topics on Set-Point Theory and Body Image, Intuitive Eating and the "All Foods Fit Philosophy," Family Meals, and Food Boundaries Do's and Don'ts. An expert panel of dietitians and scholastic professionals evaluated the curriculum for content and overall effectiveness.

CHAPTER 4

RESULTS

Introduction

The purpose of this project was to create an Eating Disorder Recovery curriculum in which patients and their support network learn together. Specifically, this curriculum followed a 4-week plan focused on the therapeutic and nutrition components of recovery with goals to both educate and unite patients and their support network during the process of recovery.

Meeting the Objectives of the Project

The four main objectives stated at the beginning of this project were to:

1. review relevant literature and identify topics for an Eating Disorder Recovery Curriculum used to teach patients and their support network;
2. review related curriculum used to teach patients and/or their support network about Eating Disorder Recovery;
3. develop an effective educational curriculum for the support networks of each patient to better understand the process of Eating Disorder Recovery and for the patients to feel supported by and learn alongside of their support network; and,
4. develop and implement evaluation tools in order to assess the adequacy and effectiveness of the group program.

These four objectives were accomplished with the completion of this project. Available research and curriculum were reviewed, relevant literature analyzed and assessed, educational material for eating disorder patients and their support network were created to increase knowledge and understanding of Eating Disorder Recovery, and an evaluation tool was developed to evaluate the adequacy and effectiveness of the program. During the review of

literature, four key areas were identified as being the most fundamental for both patients and loved ones to learn together and better understand the process of Eating Disorder Recovery. The 4-week curriculum was built to correspond to a once weekly family visitation day. On this day, the support network of patients at a recovery program came to visit and took part in a 1-hour group session. These four topics and their corresponding curriculum can be found in Appendix A.

The lesson plans were structured to fill a 1-hour time gap and structured to provide relevant information while also allowing time for discussion and processing during the course of the sessions. Since the majority of the patients could read at only an eighth grade level—and their support networks came from a variety of different backgrounds—it was important to convey the written material in a way that everyone could understand (DuBay, 2013). Much of the recovery was individualized; therefore, every lesson provided time for patients to speak directly to their support networks and share their own thoughts on each topic.

An evaluation form was created to help gather comments and feedback from the learning group. The questionnaire asked evaluators to rate the curriculum topic, adequacy of content, degree of triggering information for patients, and relevancy for treatment, and solicited overall thoughts on the themes that were learned. Extra space was provided at the end of the evaluation form for additional comments.

Program Review

The review committee for this study, which included therapists and dietitians in the eating disorder field, reviewed the curriculum and provided feedback on the evaluation form provided (Appendix B).

Their observations and remarks were positive and revealed that the curriculum was well-structured, effective, and easy to understand. Furthermore, all reviewers thought the information was appropriate for the audience.

CHAPTER 5

DISCUSSION AND CONCLUSION

Introduction

The purpose of this project was to create an Eating Disorder Recovery curriculum in which patients and their support network learn together. Specifically, this curriculum followed a 4-week plan focused on the therapeutic and nutrition components of recovery with goals to both educate and unite patients and their support network during the process of recovery.

Discussion

Literature Review

Research clearly confirms that having a support system is crucial to eating disorder recovery (Tiller et al., 1997; Treasure et al., 2007). In turn, however, members of a support network may try to offer support that, however well-intended, will often be misunderstood and misinterpreted as negative and unhelpful by eating disorder patients (Brown, & Geller 2006). It is, therefore, important to educate the support network on how to properly communicate with their eating disordered loved one to remain effective (Cohn, 2005). Currently, there is scarce curriculum available that is nutrition-based and meets the needs of both support networks and eating disorder patients. This directed project aimed to address this crucial issue.

Curriculum topics for this project were chosen based on reports from patients and eating disorder professionals as to what criteria is most important to them (Cohn, 2005; Peterson, 2011). Some of those factors included: acceptance of oneself and food, quality of interpersonal relations, problem solving abilities, and body satisfaction, which were not entirely dependent on eating disorder behaviors being present. Four curriculum topics in this project were created

following more research into these areas that were the highest relevance to recovery. More topics could surely be added that support the topics already chosen.

A major challenge for this project was the lack of already-published nutrition curricula built for such a broad audience. It was also challenging to find specific research on what nutrition topics were best suited for eating disorder patients and their effectiveness. Many topics are based more on the preferred practices among eating disorder practitioners and their perceived effectiveness. Furthermore, it was vitally important to ensure that the curriculum itself was both specific enough to be educational but also remain at an eighth grade learning level in order to allow for the wide range of support network members and patients (DuBay, 2013; Treasure et al., 2010).

Reviewers' Input

Reviewers gave positive comments regarding the curriculum, reporting that they agreed with the topics chosen and observed a high level of relatability among patients and support networks to the lessons. Lessons were rated highly for their smooth flow; however, comments were raised about the length of group work and questioning, suggesting that conversations could be stretched longer to allow for more in-depth discussions and interactions with the educational materials. This could certainly be permitted at the discretion of the group leaders based on their own abilities and allowances of the group time. Finally, reviewers suggested that the number and scope of topics could be increased, which can definitely be done with further research.

Conclusions

In conclusion, this curriculum allows for adult eating disorder patients and their loved ones to learn about topics in eating disorder recovery together. In light of common miscommunications between patients and their support networks, as well as proven effectiveness

of having educated support for eating disorder treatment, this curriculum would be useful for any treatment center or outpatient provider to use. Indeed, all curriculums must serve a large population and allow for patients and their support networks to learn together.

Recommendations for Future Research

More research and studies are needed to determine specifically which nutrition topics would be most useful to educate support networks and patients together. The curriculum topics in this particular project were gathered based on those criteria we currently know are important to recovery, but there are likely many more topics that could be addressed based on the same criteria. The research on what specific kind of nutrition education is most helpful for patients and support communities is lacking, which lent to the challenge of determining what curriculum to implement in this project.

More research could also be conducted in the effectiveness of the topics discussed here in this project and their potential effects on recovery and treatment. Patients and support networks could comment on their experiences learning together and specify if there was interest in learning separately from each other or even not at all. It would also be particularly interesting to see how the group curriculum might have influenced retention rates in treatment and satisfaction with the program.

Summary

Patients recovering from eating disorders require an incredible amount of support and care from a team of individuals, which includes doctors, nurses, dietitians, therapists, and psychologists. Some of the most important people during a patient's recovery are the patient's support network itself, including not only parents, but also siblings, spouses, friends, and extended family.

While attending a 4-week recovery treatment program that incorporated a novel curriculum based on patient and support network co-mingling and co-learning, participants gained a better understanding of how to support each other and work together towards a successful recovery.

APPENDICES

APPENDIX A

EATING DISORDER RECOVERY CURRICULUM

WEEK 1 LESSON

INTUITIVE EATING

Introduction

Today's discussion is about our Dietary philosophy here at our clinic. A few common phrases you may hear often are there are no "good" foods or "bad" foods, or, in other words, "All Foods Fit." It's important to have a non-judgmental approach towards our food choice. Judgments cause certain positive or negative emotions to become attached to whatever food or person that is being discussed. If you eat a so-called "bad food" it may cause one to feel "bad" for eating it and, as a result, cause guilt or shame. If one has very strict food rules but then eats a "bad" food, they may feel the need to have certain balances to eating the "bad" food, such as restricting food entirely, increasing exercise to "earn" the bad food, or purging. In this lesson, we want to work to take the power away from these "good" and "bad" food—they are just food!

No one food item is going to cause automatic weight gain or health issues. Therefore, we use the "all foods fit" approach and ultimately allow ourselves to eat with true balance, variety and moderation. It's important to take away strong feelings towards food to help decrease eating disorder behaviors and increase normal eating.

Question to ask group: What do people think about the dietary approach? How close is this approach to what you practice in your family/friend unit?

Question to ask group: Can anyone explain what Intuitive Eating is?

Body

Intuitive eating is a process-based approach that ultimately teaches patients how to have a healthy relationship with food, wherein patients become the expert of their own bodies. Patients learn how to trust their ability to meet their needs, are able to distinguish between physical and emotional feelings, and develop body wisdom.

Instructor Note: It may be good to split up the group to allow each group to read a section of the Ten Principles of Intuitive Eating. They can read each principle, discuss it briefly, and then share with the group.

Handout: The Ten Principles of Intuitive Eating

1. Reject the diet mentality. Throw out the diet books and magazine articles that offer you false hope of losing weight quickly, easily and permanently. Get angry at the lies that have led you to feel as if you were a failure every time a new diet stopped working and you gained back all of the weight. If you allow even one small hope to linger that a new and better diet is lurking around the corner, it will keep you from staying free enough to rediscover "intuitive eating."

2. Honor your hunger. Keep your body biologically fed with adequate energy and carbohydrates; otherwise, you can trigger a primal drive to overeat. Once you reach a point of excessive hunger, all intentions of moderate, conscious eating become fleeting and irrelevant. Learning to honor this natural, biological signal sets the stage for rebuilding trust with yourself and food.

3. Make peace with food. Call a truce, and stop the food fight! Give yourself unconditional permission to eat. If you tell yourself that you cannot or should not have a particular food, it can lead to intense feelings of deprivation that builds into uncontrollable cravings and, often, bingeing. If you eventually "give in" to your forbidden food, eating is experienced with such intensity that it usually results in overeating and, consequently, an overwhelming feeling of guilt.

4. Challenge the Food Police. Scream a loud "No!" to thoughts in your head that declare you are "good" for eating under 1,000 calories or "bad" because you ate a piece of chocolate cake. The food police monitor the unreasonable rules that dieting has created. The police station is housed deep in your psyche, and its loud speaker shouts negative barbs, hopeless phrases, and guilt-provoking indictments. Chasing the food police away is a critical step in returning to intuitive eating.

5. Respect your fullness. Listen for your body signals that tell you that you are no longer hungry. Observe the signs that show that you are comfortably full. Pause in the middle of eating a meal or a food and ask yourself: How does the food taste? What is your current fullness level?

6. Discover the Satisfaction Factor. The Japanese have the wisdom to promote pleasure as one of the goals of healthy living. In our fury to become and stay thin and healthy, we often overlook one of the most basic gifts of existence, that is, the pleasure and satisfaction that is found in the eating experience itself. When you eat what you really want in an environment that is inviting and conducive, the pleasure you derive from it is a powerful force in helping you feel satisfied and content. By allowing yourself to experience this for yourself, you will find that it takes much less food to decide you have had enough.

7. Honor your feelings without using food. Find ways to comfort, nurture, distract, and resolve your issues without using food. Anxiety, loneliness, boredom and anger are emotions we all experience throughout life. Each has its own trigger and each has its own appeasement. Food will not fix any feelings; it merely provides comfort for the short term, distracts from the pain, or even numbs you in the food hangover. But food will not solve the problem. If anything, eating out of emotional hunger will only make you feel worse in the long run. You ultimately have to deal with the source of the emotion, as well as the discomfort of overeating.

8. Respect your body. Accept your genetic blueprint. Just as a person with a size 8 shoe would not expect to realistically squeeze into a size 6, it is equally as futile and uncomfortable to have the same expectation with body size. But most importantly, respect your body so that you feel better about who you are. It is hard to reject the diet mentality if you are unrealistic and overly critical about your body shape.

9. Exercise/Feel the difference. Forget about training for the military; just get active and you will start to feel the difference. Shift your focus to how it feels to move your body, rather than the calorie-burning effect of exercise. If you focus on how you feel from working out—that feeling of being energized and ready for the day—it can make a difference between rolling out of bed for a brisk morning walk or hitting the snooze alarm. If you wake up and your only goal is to lose weight, you will likely not feel as motivated to achieve your goal.

10. Honor your health. Make food choices that honor your health and taste buds while making you feel well. Remember that you do not have to have a perfect diet to stay healthy. You will not suddenly develop a nutrient deficiency or gain weight from one snack, meal, or day of eating; it is what you eat consistently over time that matters. Progress, not perfection, is what counts.

(Reference: Tribole, E. & Resch, E. (2012). *Intuitive Eating: A Revolutionary Program That Works. 3r^{d} Edition*, New York: St. Martin's Griffin.)

Instructor Note:
Create discussion and ask questions after each principle. Record both patients' thoughts and how the support network manages to relate. This is a good time for patients to realize they are not alone since many loved ones may, in fact, struggle with at least one or more of the ten principles, even if they do not suffer from an "eating disorder."

Closing

Intuitive Eating is the "last step" towards a more normal eating style and, while it takes a lot of practice, it can be achieved. Through work with a dietitian and support through therapy, eating disorder patients can become the intuitive eater they truly want to be.

Note: A handout of the Ten Principles above will be given to patients and their loved one allowing them to follow along and participate.

WEEK 2 LESSON

SET-POINT THEORY AND BODY IMAGE

Introduction

Many patients report body dissatisfaction as one contributing factor to their eating disorder. Although this is only one superficial factor in a multi-factorial, complex disease, learning body acceptance is crucial to recovery. Learning about set-point and various self-esteem building techniques can begin to improve body dissatisfaction slowly over time. It is important to note that research shows some eating disorders have a stronger neurobiological effect on body image and that these therapy types may have varying effects depending on the individual.

Body

Body acceptance can be explained through the Metabolic Set-Point Theory of Homeostasis (also known as Set-Point Theory). This theory states that the body has a natural tendency to maintain a specific weight and will adjust internal body processes accordingly. If body weight goes above or below the set-point range, metabolism will speed up or slow down to stabilize weight. A study conducted by the American Journal of Clinical Nutrition involving overweight women found that calorie restriction did alter resting metabolic rate (RMR) during times of reduced food intake. However, once energy balance was resumed, RMR returned to normal even for those who experienced significant weight loss. With increased knowledge of set point theory, patients may gain a better understanding of weight management and realize weight is not as easy to manipulate and maintain as previous believed.

Questions to ask group: What are people's thought's about the set point theory? How does that affect your prospective on weight manipulation?

Instructor Note: Read through Essentials to Build Body Esteem. Have different people read the different points and discuss briefly on thoughts and opinions.

Handout: Essentials to Build Body Esteem

To begin, accept what is not in your control:

1. Body size. Accept your body's genetic predisposition. All bodies are wired to be different sizes. Regardless of efforts to change it, over time your body will fight to maintain or resume the shape it was born to be. You may force your body into sizes and shapes that you prefer, but you can't beat Mother Nature without a tremendous cost.

2. Developmental changes. Understand that all bodies change developmentally in ways that are simply not in your control through healthy means. You may positively influence changes of puberty, pregnancy and lactation, menopause, and aging by living a balanced healthy lifestyle, but you will not "control" these changes, no matter how much you try.

3. Bodies need food. Never "diet." Hunger is an internally regulated drive and demands to be satisfied. If you limit the food needed to satiate hunger completely, it will backfire, triggering preoccupation with food and ultimately an overeating or compulsive eating response. You may lose weight in the short run, but 95% of weight that is lost through dieting is regained, plus added pounds. Dieters who go off their diets only to binge are not "weak-willed." They are mammals whose built-in starvation response has kicked in—both physically and psychologically—and is pursuing what has been denied to be them. Scientific evidence of this fact has been available since the early 1950s, but most people are not aware of the biologically predictable, counterproductive results of "dieting."

Then, focus your attention and energy on what is within your power to achieve:

4. Satisfy hunger. Satisfy your hunger completely, with plenty of variety. Include foods from all different food groups and learn to balance all of your body's needs.

5. Move your body. Healthy amounts of movement can do amazing things. It is important to do things you enjoy as well as be sure you are properly fueled with hydration and nutrition.

6. Be consistent. Understand that if you eat balanced and maintain an active lifestyle over time, your best, natural weight will be revealed. Set a goal to eat balanced and be active. Don't be swayed by whether or not this makes you thin. Healthy, well fed, active bodies are diverse in size and shape, from fat to thin and everything in between. Don't let anyone tell you otherwise, not even your doctor, who may be caught in unhealthy cultural myths about weight.

7. Choose awesome role models. These people should reflect a realistic standard against which you can feel good about yourself. If the "Ugly Duckling" had continued to compare herself to the ducks she'd still be miserable, no matter how beautifully she developed.

8. Values matter! Maintain your integrity as a human being. In spite of advertisements seducing you to believe that "image is everything," Never forget that how you look is only one part of who you are. Develop a sense of identity based on all the many things you can do, the values you believe in, and the person that you are deep inside.

9. Become media savvy. Educate yourself about the hidden power of advertisements. Advertisers spend tons of money on strategies specifically designed to make you feel there is something wrong with you. Why? If they first advertise an unrealistic standard of beauty that leaves you feeling deficient by comparison, a product that promises to improve your condition is an easy sale. Don't be "sold" this bill of goods.

10. Promote the Message. Encourage your friends and co-workers to join you in developing a healthy, realistic body image. Use the collective energy your group would have spent on hating your bodies to make the world a better place. Help the next generation to develop healthy body image attitudes and learn positive lifestyle habits too.

(Reference: Kater, K. (2004). *Real Kids Come in All Sizes; Ten Essentials Lessons to Build Your Child's Body Esteem*, New York: Broadway Books Random House)

Instructor Note: After going through the worksheet lead the group in a closing exercise.
Teaching the counterproductive effects of "dieting" for weight loss

There are five basic needs for physiological life: food, water, sleep, air and warmth. When considering the need for sleep and fluids, a lively discussion of personal experiences reveals that predictable consequences occur for everyone when these vital needs are not fully satisfied, especially over several days or longer:

1) a gradually increasing preoccupation with and craving for what is rationed;
2) an increasing difficulty concentrating on anything else;
3) a growing irritability, self-centeredness and/or depressed mood; and,
4) when restraints are lifted, a powerful urge to make up for what was missing (i.e., to "sleep in" or guzzle liquid). It might take several days of wanting a more than usual amount of sleep before balance is restored.

Instructor:

"Do you think the same thing would happen if you didn't get enough air to breathe? Let's try it! I think you could all benefit from going on a little 'air diet.' I think you have been breathing entirely too much, and your cheeks are too richly colored and rosy. You know, the latest style is to have a kind of gray or blue tone to your skin, and oxygen is what gives our cheeks that rosy glow. Yes, I think you all would be better looking if you cut back on your oxygen so your face coloring would be a bit drabber. Of course, you will need some air to live. But surely you could cut back. Won't it be worth it to have the 'right look'?"

Activity:

Each person is given a straw to breathe through while plugging their nose until the predictable consequences 1-3 (above) are apparent.* When "cheating" occurs, the teacher may chide students for "not having enough willpower." When participants are allowed to "go off" their "diet," they inevitably (and maybe dramatically) "gulp" big mouthfuls of air. This primes them for a meaningful discussion of why weight loss diets are not effective.

When satisfaction of any of our basic needs is limited by external forces or rules, the results are reliable.Dieting for weight loss promotes obsession and preoccupation with food and compulsive or binge eating when the diet is stopped. Symptoms often continue over time, and increase with increased dieting. Over time, dieters lose touch with their internal hunger regulatory system, and normal eating becomes increasingly difficult. Regained weight, often with added pounds, is a natural and predictable outcome.

*(Precautions should be taken for participants with asthma or other lung disorders.)

Closing

Discovering and accepting Set-Point is helpful to improve body image and body satisfaction. We pointed out things that you can and cannot change within your body and the consequences of trying to change that. It takes a long time to improve body image but is possible over time. While people with Eating Disorders very commonly report body dissatisfaction it is not uncommon for non-eating disordered people to report similar thoughts. These comments can benefit all participants to create a positive body environment.

WEEK 3 LESSON

FAMILY MEALS

Introduction

Meal times can be very emotional experiences when one is eating with someone with an eating disorder. There may be anger, anxiety, even tears. Today we will be going through what your meal times look like in an attempt to try and create as positive of an environment as possible through patients' recovery process.

To discuss with group: It is important to remember as we are discussing this topic that we are not trying to provoke shame or blame in the patient, as if it were their "fault" that meal times are not the same as they were in the past. Our goal is to show that there are ways that *everyone* can improve to help make meal times a more positive experience.

Body

Each patient and their support network will group together to fill out the worksheet to then discuss with the group.

Instructor Note: Allow for 20-25 minutes to fill out worksheet. While groups are working, walk around the room to answer questions and promote conversation within the groups based off their answers to ensure details.

Worksheet: Family Meals

1. Who do you typically eat meals with? (During the week and during the weekend)

2. Where do you typically eat? (During the week and during the weekend)

3. What is typically being done while everyone is eating? (During the week and during the weekend)

4. Who makes the meal or decides what to eat?

5. How much time is spent at the table? Does everyone stay the whole time or do people leave when they are finished?

6. What is the "vibe" of the meal? What do you think creates the "vibe?"

7. Draw a picture of what your typically meal looks like? Create the eating space, write where people sit, create the mood by drawing faces/draw emotion.

8. What things do you enjoy about meal times in the past AND currently?

9. What things do you think could be improved?

10. Create one change that you would like to make to help improve meal times?

Instructor Note: At the end of the time allowance, ask for volunteers to share their answers to the various questions. Take note of different discussions and answers you heard as you were walking around the room to encourage less vocal group members to speak. This will help to involve all the support network groups as some may be more confident with group sharing than others, although everyone is capable of sharing good information.

WEEK 4 LESSON

FOOD/DIETARY BOUNDARIES

Introduction

Instructor: "Research shows that parents' interpretation of their child's illness changes how they help them. That is why everyone is here: to learn. While you may hear many commonalities between patients or disease types each patient also has their own needs. When it comes to meal times, everyone has different challenges. There are different things that cause anxiety or fear, different food rules and different eating disorder behaviors. We want to allow this time to gain more in-depth insight into your loved one's disorder with food and create some guidelines about where they are capable of being pushed and where there needs to be compromise. We will work to create current boundaries around eating scenarios to help be as supportive as possible."

Question to ask group: Has anyone in the support network noticed something they have tried to do to help their loved one but found that it only made things worse?

(Wait for someone to answer or give an example.)

Instructor: Do you know why that message was misinterpreted?

(*Ask a few groups to share.*)

Body

Break into patient and support network groups to fill out the worksheet. Have the support network fill out the sheet with how they think patient would respond while the patient fills out his/her own worksheet separately. Then have the support networks and patients compare answers and create boundaries for the different scenarios. Finally, share responses to compare and contrast in order for the support networks to see all the similarities and differences between patients.

Worksheet: Food Boundaries

Respond to the following scenarios or questions.

1. How would you feel about going to a restaurant? What would make you feel comfortable? What would make you feel uncomfortable?

2. Write out your top ten foods that cause fear, anxiety, or urges for eating disorder behaviors. Where are you at in your relationship with those foods?

3. How do you feel when others talk about food? Diet? Exercise? How often does your support network discuss these topics? When would it be ok or not ok to talk about them?

4. How do you feel about eating in front of others? Extended family? Friends? Random people?

5. Do you care if certain people talk about your eating disorder? When would it be ok or not ok?

6. How do you feel about someone saying, "You look great!" or, "You look so healthy!"?

7. What are some of your favorite foods? How comfortable are you with eating them?

8. How do you feel about eating during the holidays? How would you like to handle them in this moment?

9. How much structure/support do you need to meet your meal plan goals?

10. Name any other personal triggers that were not covered.

Now that all the questions have been answered, use responses to create some boundaries/guidelines to help guide the support network.

For example: If calories written on the menu are particularly difficult for the patient, a guideline could be, "No restaurants with calories on the menu right now."
Or, if talking about food is difficult for a patient, a guideline could be no food talk at the table.

Instructor Note: Walk around the room to observe responses to questions and resulting food boundaries to ensure they are appropriate and that the support network is also getting to add input (not just the patient dictating rules). Direct issues that seem to require deeper individual discussion or that create too much conflict to family therapy.

Closing

Does anyone have an example of responses that were different than what they expected? What boundary do you feel is most helpful?

(It is important to remember that the patients' responses to the questions will likely change over time. Continued communication and even repetition of this exercise will allow for continued proper support and maintenance of these food boundaries.)

APPENDIX B

SAMPLE CURRICULUM EVALUATION FORM

SAMPLE CURRICULUM EVALUATION FORM

Evaluator's Name: _____ Date: _____

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Content					
1. The topics were appropriate for the audience.					
2. The curriculum was easy to understand.					
3. The content was accurate and reflects current knowledge.					
4. The curriculum was free of typographical or spelling errors.					
Usability/Functionality					
5. Each lesson was an appropriate length.					
6. Instructor notes and lessons were easy to follow.					

Additional Questions

7. Any specific comments related to the curriculum content?

8. Any specific comments related to the curriculum usability/functionality?

9. What are the major strengths and weaknesses to the curriculum?

10. Any additional comments?

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