

SUMMARY OF KEY FINDINGS

Introduction

In October and November, 2012 the National Eating Disorders Association sent an email to everyone in its database inviting participation in an online, confidential, consumer survey about their experiences with eating disorders and their treatment. More than 2,000 individuals voluntarily participated. We received responses from those who suffer personally from eating disorders, those with family members who have been diagnosed with eating disorders and family members who have lost a loved one as a result of an eating disorder.

We are very grateful to those of you who participated in this survey. The large number of responses provided us useful insight as explained in greater detail below.

NEDA* and Optum®** partnered to administer the survey and jointly reviewed and analyzed the data. To ensure the survey and its evaluation were unbiased, we also engaged an independent survey firm, American Viewpoint, out of Alexandria, Virginia to validate the survey, collate the findings and identify response themes of note.

The following points summarize the findings:

- The results of this survey are not meant to represent the public at large or even the eating disorders public at large. Instead, the results of this survey are instructive in broad terms of the attitudes of those with an eating disorder as well as the attitudes of those with a loved one who has or had an eating disorder.
- The survey questions were presented in an unbiased manner.
- Two-thirds of the respondents with an eating disorder reported other psychiatric conditions that concern them. The same is true of those respondents with a loved one living with an eating disorder.
 - The most common conditions were anxiety and depression.
- From a list of consequences, family tension related to the eating disorder was rated as having the most significant impact on the lives of respondents in all three groups.
- Among those with an eating disorder, 60% indicated they were not currently in treatment, while 52% of those with a family member with an eating disorder indicated their family member is currently in treatment.
- The length of time a person has been in treatment varied widely, with 36% having been in treatment 1-5 years, and 34% having been in treatment more than 5 years.
- Relapses were common with 89% of those with an eating disorder indicating they have relapsed. Family members similarly reported their loved one relapsed in 79% of the cases. Ninety percent of those who lost a loved one indicate that the person had recovered at some point, but relapsed.
- The types of care received varied widely with many individuals receiving multiple types of care.
- Treatment success was a multi-faceted goal and varied substantially among respondents.
 - Notably, reduction in preoccupation with food and weight, stable nutrition and acceptance of body image, all took priority over stable weight as a desired treatment outcome.

- Respondents indicated a number of experiences helped them or their loved one achieve their goals including psychotherapy and the relationship with their clinician.
- In a list of factors interfering with treatment, cost of care and insurance limitations interfered with success most often.
- Pluralities, if not majorities, of all three groups wanted a multidisciplinary team.
- The majority of all three groups wanted their clinicians to have years of eating disorder experience, the ability to deal with multiple psychological conditions, and certification in eating disorders.
- In response to questions about the factors that contributed to a positive treatment experience, all of the attributes of the treatment listed in the survey were deemed important.
 - The level of comfort with the provider of care topped the list for both individuals with an eating disorder and loved ones of eating disorder patients.
 - The ability to reach their clinician promptly was considered important.
- In rating the usefulness of different treatment settings (inpatient, residential, outpatient, etc.), respondents indicate the desire for a combination of settings.
 - Although all treatment settings were rated highly, residential and out-patient settings received the highest ratings.
- Respondents indicated that a variety of program elements and disciplines included as a part of treatment was important.
- Finally, in terms of information that would be helpful for patients and families in making provider and program decisions, a number of factors were rated highly, particularly clinician's years of experience, credentials and cost.

This was an opinion survey intended to offer guidance for further inquiries to experts and providers of care. It was not intended to be a scientific study.

We believe that these findings will be useful in a number of ways:

1. To inform a small panel of clinicians and researchers about the consumers' view of success factors related to treating eating disorders and desired treatment outcomes, with the possible result of focusing future research and consensus statements,
2. To begin to identify from a consumer perspective some of the important programmatic treatment elements and the criteria for success.
3. To educate benefit administration and providers of the consumer perspective and needs and to encourage accommodation of their needs.

Once again, we sincerely thank those who responded to the survey, and trust that your efforts will positively impact care for those suffering from eating disorders.

Sincerely,

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***About NEDA**

NEDA supports individuals and families affected by eating disorders, and serves as a catalyst for prevention, cures and access to quality care.

****About Optum®**

Optum® is a leading information and technology-enabled health services business dedicated to helping make the health system work better for everyone. Optum® (www.optum.com) comprises three companies – OptumHealth®, OptumInsight® and OptumRx® – representing more than 35,000 employees worldwide who collaborate to deliver integrated, intelligent solutions that work to modernize the health system and improve overall population health.

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