CONSUMER’S PERCEPTIONS OF EATING DISORDER TREATMENT SERVICES IN AUSTRALIA

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ABSTRACT

Objective: The purpose of this study was to partially replicate a Dutch study which investigated the quality of received eating disorder treatment as perceived by consumers. Method: An online questionnaire was completed by 135 members of various eating disorder foundations within Australia, ranging in age from 18 to 53 years. Results: Results highlighted the importance that patients place upon being taken seriously whilst in treatment, and being treated by a professional who is perceived to be trustworthy, interested and honest. A comparison between current and former consumers also revealed that former consumers of services place a higher level of importance on gaining an understanding about eating disorders, and learning to understand that they have a problem. Conclusion: These findings could be used to improve upon the current treatment practices of clinicians working with individuals with eating disorders in Australia and Internationally. The presenter will discuss this findings and their relevance internationally.

Key words: Treatment, Australia, Perceptions, therapy

Consumer’s Perceptions of Eating Disorder Treatment Services in Australia

Throughout the past 25 to 30 years, significant advancements have been made within the field of psychology regarding the development and implementation of empirically supported eating disorder treatments (1). Recent research suggests that family-based therapy is currently the most effective form of treatment for adolescents with AN (2), although Cognitive Behavioural Therapy (CBT) can be used as a suitable alternative for older patients (3). CBT is also considered to be an effective form of treatment for sufferers of BN and BED (4-6) with further research suggesting that Interpersonal Therapy (IPT) may also help to alleviate BN and BED symptoms (7, 8).

Despite extensive research highlighting the effectiveness of empirically supported treatments, eating disorders continue to have a poor prognosis (9). AN has the highest mortality rate of any psychiatric disorder (10), with 5 to 20 percent of patients dying of starvation, suicide and other related causes (11). Although the outcome of other eating disorders is somewhat more favourable by comparison, patients with BN and BED are still largely affected by a range of adverse medical consequences (12), and are still at an increased risk of self-harming and suicide (13). In order to improve
the prognosis of eating disorders, it is essential that researchers evaluate the overall quality eating disorder treatment; as such knowledge may lead to improvements within current treatment practices.

When evaluating the quality of treatment for any psychiatric disorder, it is important to ascertain the opinions of current and former patients (14). Prior to the 1980s, the patient’s only role was that of a passive recipient, as they were thought to be incapable of making logical decisions regarding their own treatment needs (15). In more recent years however, there has been a noticeable shift towards encouraging patients to become active participants, who are involved in all aspects of mental health care (16). This shift is partially due to a recognition that patients can be particularly insightful when evaluating treatments for mental illness, as their opinions are derived from their individual experiences and expectations (14). This shift towards a more participatory model has shaped government policy worldwide, including the National Standards for Mental Health Services (17), which state that patients have the right to be involved in the planning, implementation and evaluation of mental health services.

Despite a recognition of the importance of involving consumers in the evaluation of mental health services, patient involvement in the evaluation of eating disorder treatments has been described as a neglected area of research (18, 19). There are a number of studies worldwide that have explored the experiences and expectations of patients in order to evaluate the overall quality of eating disorder treatments (18, 20-24), but no similar study to date has been conducted within Australia. Gaining insight into patient perceptions of quality of eating disorder treatment practices within Australia is important; as such knowledge could contribute to the development and implementation of more effective treatment regimes. It is therefore the purpose of this study to partially replicate a study by de la Rie, Noordenbos, Donker and van Furth (2008), in order to evaluate the quality of eating disorder treatments via patients’ expectations, within an Australian sample.

De la Rie, Noordenbos, Donker and van Furth (2008) studied perceptions of the quality of eating disorder treatments in a sample of 158 current eating disorder patients, 148 former eating disorder patients, and 73 therapists from specialised eating disorder centres in the Netherlands. This study highlighted the similarities and differences, between therapist and patient perceptions on what factors are important within the eating disorder treatment process. Whilst therapists believed that it is extremely important to focus on eating disorder symptoms and behavioural change, patients believed that it is more important to focus on the therapeutic relationship as well as thoughts, feelings and self-esteem. Despite these differences, both therapists and patients valued a number of the same factors, including “trust in the therapist”, “being respected”, “being taken seriously” and “being able to talk about eating behaviours”. This study also revealed slight differences when comparing the opinions of current versus former patients, as current patients valued “being accepted as you are”, whereas former patients valued “learning to take your own responsibility”.

METHOD

Participants

The sample consisted of 131 females (97.04%) and 4 males (2.96%) who ranged in age from 18 to 53 years ($M = 27.56$, $SD = 7.82$). The mean age for females was 27.52 years ($SD = 7.75$) and the mean age for males was 29.00 years ($SD = 10.99$). Although few males responded to the questionnaire, they were still included in the study as their responses did not differ greatly from the responses of female participants. With regards to personal experiences of an eating disorder, 53.33% of participants ($N = 72$)
indicated that they had experienced either AN (N = 54, 40.00%), BN (N = 17, 12.59%) or EDNOS (N = 1, .74%), and 46.67 % of participants (N = 63) indicated that they had experienced a combination of 2 or more eating disorders as follows; AN and BN (N = 32, 23.70%), AN and EDNOS (N = 18, 13.33%), BN and EDNOS (N = 4, 2.96%), or AN, BN and EDNOS (N = 9, 6.67%). Furthermore, 62.96% of participants (N = 85) reported that they were currently suffering from an eating disorder, 34.07% of participants (N = 46) reported that they were former sufferers, and 2.96% of participants (N = 4) chose not to indicate their current eating disorder status. For the purposes of this study consumers refers to those having received treatment for an eating disorder.

Measures

The participants were required to complete a 15 to 20 minute online, self-report questionnaire regarding experiences of eating disorder treatment (part A), and expectations of eating disorder treatment (part B). The questionnaire contained a total of 145 open-ended and multiple items, although not every item was relevant to every participant.

Part A of the questionnaire was derived from the work of Newton, Robinson and Hartley (1993), and contained questions regarding demographic information, experiences whilst first seeking help for an eating disorder, the helpfulness of treatments received, and overall coping and treatment satisfaction levels.

Part B of the questionnaire contained an adaptation of the original Questionnaire for Eating Problems and Treatment (QEPT) developed by de la Rie, Noordenbos, Donker and van Furth (2008). It also contained opened ended questions regarding general expectations of treatment, treatment preferences, and suggestions to improve upon treatment.

Procedure

The online questionnaire was made available to over 6000 members and contacts of various eating disorder organisations around Australia. The type of media (email, newsletter or web page) used to inform members about the study, was dependent on the organisations standard methods of communicating with members. Prior to commencing the questionnaire, individuals were informed that participation was both voluntary and anonymous. One hundred and fifty-five questionnaires were returned indicating a response rate of less than 2.58%, however it is assumed that not all members would have been eligible to participate. Of the 155 questionnaires that were returned, 20 were excluded from the data analysis due to grossly incomplete answers (N = 17), age limitations of the survey (N = 2), and no personal experience of an eating disorder (N = 1).

RESULTS

Expectations of Treatment

Table I presents the 10 most important criterion for high quality eating disorder treatment as indicated by 85.19% of participants (N = 115). Participants rated the original 64 criterion on a 5-point-likert scale (1: Not important at all, to 5: Very important), thus higher means are indicative of more important criterion as perceived by participants.
As displayed in Table I, participants thought that it was most important to be taken seriously whilst in treatment. Participants also thought that it was extremely important to be able to trust their therapist, to be treated by a therapist who was interested in their case, to be treated by a therapist who truly listened to them, and to be treated by a therapist who is honest. Participants also perceived support and respect to be of high importance to eating disorder treatment, as well as trust from ones therapist, and being able to talk about ones thoughts and feelings.

Table II presents the 10 least important criterion for high quality eating disorder treatment as indicated by 85.19% of participants ($N = 115$). As a result of the 5-point Likert scale (1: not at all important, 5: extremely important), scores below 3 are indicative of criterion that are not important, a score of 3 is indicative of criterion that is neither unimportant nor important, and scores above 3 are indicative of criterion that are still important to the majority of participants but to a lesser extent than other criterion.

As displayed in Table II participants thought that it was not important to be able to talk about religion whilst in treatment. Participants also indicated that it was not important to restore weight first before focusing on other problems, to take part in role plays as part of treatment, to receive standardised treatment, and to keep an eating diary. Participants thought that it was neither important nor unimportant to know how long treatment would take. Furthermore, participants thought that it was only somewhat important to focus of weight recovery while in treatment, to include music, drawing or drama as part of treatment, to talk in groups, and to participate in compulsory parts of treatment.

Comparing the Expectations of Current and Former Consumers

Due to severe violations of normality, in addition to unequal sample sizes, Mann-Whitney $U$ tests were used to assess the differences between current ($N = 73$) and former ($N = 42$) sufferer’s ratings of the 64 treatment expectation criterion. Despite extreme deviations from the normal curve, a visual inspection of the relevant histograms indicated that distribution of scores for each variable was similar between groups.

The Mann-Whitney $U$ tests indicated that participant’s ratings of 4 out of the original 64 criterion differed significantly between those who identified themselves as current sufferers and those who identified as former sufferers. Table III presents the results of the Mann-Whitney $U$ tests.

As shown in Table III former consumers placed a higher level of importance on being able to talk about ones thoughts, and being able to tell ones story than did current sufferers. As compared to current consumers, former consumers also thought that it was more important that patients learn to understand that they have a problem, and that patients are provided with information or an explanation about eating disorders. By Cohen’s (1988) conventions these effects can be described as “small” to “medium”.

DISCUSSION

The purpose of the study was to partially replicate a Dutch study in order to further explore the quality of eating disorder treatments as perceived by both current and former patients. Consistent with the research findings of de la rie, Noordenbos, Donker and van Furth (2008), participants within this current study thought that it was extremely important to be taken seriously, to be able to talk about
thoughts and feelings, and to have a therapist who is trustworthy, respectful, and supportive. Participants in the study further emphasised the importance of being treated by a therapist who listens, and who is truly interested, when being treated for an eating disorder.

Participants indicated that it was not important to be able to talk about religion whilst in treatment, or to partake in role-playing as part of treatment. Furthermore, participants indicated that it was not important to receive standardised treatment, to keep an eating diary, or focus on restoring weight first before focusing on the psychological aspects of the condition. These findings may suggest a dislike for treatment that focuses only on the physical aspects of the disorder, whilst neglecting the individual needs of the client. This finding may also be partially attributed to the high levels of treatment resistance found in patients with AN, as their goal of weight loss contradicts the primary treatment goal of weight gain (25).

In contrast to the findings of de la Rie, Donker and van Furth (2008), this study revealed no differences between the treatment expectations of current and former patients with respect to “being accepted as you are” and “learning to take your own responsibility”. Small differences however, were found with regards to former sufferers believing that it was more important to be able to tell ones story, and to talk about ones thoughts. As compared to current sufferers, former sufferers also thought that it was more important to gain an understanding about eating disorders, and to learn to understand that one has a problem. These latter differences indicate that an individual may need to recognise that they have a psychiatric disorder and understand the consequences of their condition before they are able to fully recover.

When interpreting the results of this study however, there are a number of limitations that should be noted. Firstly, the sample size within this study is considerably smaller than in other studies of a similar nature (18, 20, 21, 24). Secondly, the utilisation of a convenience sampling method can be somewhat problematic when generalising the results. Lastly, the current study was based solely upon participants’ perceptions of eating disorder treatments, and although the primary purpose of this research was to gather the opinions of patients, this factor should remain salient when interpreting the results.

Despite these limitations, the findings of the current study suggest that patients with eating disorders respond better towards empathetic professionals who are able to demonstrate high levels of respect, trust, and concern for their client. The findings of the current study also suggest that patients are more likely to be satisfied with their treatment experience if they receive treatment that is tailored to their individual needs.

Due to the dislike that participants expressed towards treatment that focuses on the physical aspects of the disorder, further research could examine the discrepancies between patient’s perceptions of treatment, and the actual effectiveness of. Such research could be useful as it would shed light on when it would be beneficial to take the patients opinions into consideration, and when to overlook their opinions for the benefit of their physical and psychological health.

**TABLES**

<table>
<thead>
<tr>
<th>Table I</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptive Statistics for the Ten Most Important Treatment Criterion (N = 115)</strong></td>
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<tr>
<td>Treatment Criterion</td>
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<table>
<thead>
<tr>
<th>Treatment Criterion</th>
<th>Mean</th>
<th>SD</th>
</tr>
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<tbody>
<tr>
<td>Being able to talk about religion</td>
<td>2.23</td>
<td>1.40</td>
</tr>
<tr>
<td>Restoring weight first before focusing on other problems</td>
<td>2.28</td>
<td>1.14</td>
</tr>
<tr>
<td>Role-playing as part of treatment</td>
<td>2.32</td>
<td>1.24</td>
</tr>
<tr>
<td>Receiving standardised treatment</td>
<td>2.34</td>
<td>1.23</td>
</tr>
<tr>
<td>Keeping a(n) (eating) diary</td>
<td>2.53</td>
<td>1.31</td>
</tr>
<tr>
<td>Knowing how long treatment will take</td>
<td>3.00</td>
<td>1.13</td>
</tr>
<tr>
<td>Focus on recovering weight</td>
<td>3.05</td>
<td>1.13</td>
</tr>
<tr>
<td>Music, drawing or drama as part of treatment</td>
<td>3.07</td>
<td>1.46</td>
</tr>
<tr>
<td>Talking in groups</td>
<td>3.07</td>
<td>1.32</td>
</tr>
<tr>
<td>Participating in compulsory parts of treatment</td>
<td>3.21</td>
<td>1.25</td>
</tr>
</tbody>
</table>

Table III

Results of the Mann-Whitney U Tests Comparing the Treatment Expectations of Current and Former Sufferers (N = 115)

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Mean Rank</th>
<th>Former</th>
<th>Current</th>
<th>U</th>
<th>z</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Explanation or information about eating disorders”</td>
<td>61.56</td>
<td>55.95</td>
<td>1120.00</td>
<td>-2.53</td>
<td>.01</td>
<td>.24</td>
<td></td>
</tr>
<tr>
<td>“Learning to understand you have a problem”</td>
<td>66.57</td>
<td>53.07</td>
<td>1173.00</td>
<td>-2.27</td>
<td>.02</td>
<td>.21</td>
<td></td>
</tr>
<tr>
<td>“Being able to tell your story”</td>
<td>64.50</td>
<td>54.26</td>
<td>1260.00</td>
<td>-2.02</td>
<td>.04</td>
<td>.19</td>
<td></td>
</tr>
<tr>
<td>“Being able to talk about thoughts”</td>
<td>63.07</td>
<td>55.08</td>
<td>1320.00</td>
<td>-1.96</td>
<td>.05</td>
<td>.18</td>
<td></td>
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</tbody>
</table>

Note: Significance (two-tailed); z statistics have been corrected for ties.
References