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A qualitative investigation into anorexia nervosa: The inner perspective

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Abstract: The ego-syntonic nature of anorexia nervosa (AN) emphasizes how some aspects of this disorder can be highly valuable to patients. To understand the different perspectives that patients with AN hold about their condition, we explored the meanings they attribute to it. Thirty-four AN patients were asked to write a letter to their condition describing what it represents and means to them. Letters were then evaluated using a standardized coding scheme. Three pro-codes resulted to be mostly represented: difference (i.e. feeling different from others because of AN), company (i.e. being protected by the disorder), and identity (i.e. being totally represented by the illness). Some anti-codes were also particularly used: anger/hate, expressing anger toward AN, fear/distress, betrayal/pretend (i.e. feeling cheated by the disorder), and loss/waste (i.e. describing a feeling of life being wasted). In addition to pro- and anti-codes, the ambivalence theme was also well represented. Given the complex adaptive function of this disorder, this study may provide a framework of different perspectives that therapists could refer to and patients could identify with during the therapeutic process toward discovering individual meanings of the disorder.

Subjects: Eating Disorders - Anorexia - Adult; Eating Disorders - All - Adult; Eating Disorders - Binge Eating & Bulimia

Keywords: eating disorders; anorexia nervosa; letters; emotion avoidance

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Secondo Fassino is an MD, psychiatrist and he is the director of the Eating Disorders Center of the University of Turin, Italy. All authors have an extensive experience in the field of Eating Disorders and with this research aimed to expand the knowledge about how sufferers consider their own disorder in order to deliver treatments as individualized as possible.

PUBLIC INTEREST STATEMENT

Recent research on eating disorders (EDs) has focused on the meaning the eating symptoms have to patients. As regards anorexia nervosa (AN), symptoms have a complex defensive function aimed at reducing social threats and therefore a sort of adaptive function.

Benefits from EDs include creating a distance to unpleasant experiences, gaining confidence, feeling different, sense of one's own identity and of control, experience and expression of negative emotions, and avoidance of close relationships.

ED psychopathology may be interpreted as a response to regulate emotional states and to avoid emotions. Therefore, patients often highly value their disorder which turns evident in treatment resistance and dropout.

Letters to AN can be useful to (a) emphasize the importance of listening to patients, (b) have patients begin to talk about their bodily forms of communication, and (c) overcome the challenges represented by establishing a therapeutic alliance with these patients.

1. Introduction

Anorexia nervosa (AN) is a severe disorder of unknown etiology typically occurring during adolescence in females. To date, treatment options that have been proven to be effective are scarce and outcome is unpredictable and frequently poor or chronic with high mortality (Fitzpatrick & Lock, 2011). Ego-syntonicity and ambivalence are central features of AN with affected individuals often placing positive values on their eating problems (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006) and only rarely autonomously seeking treatment (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013).

Over the past years, the meanings of the disorder have been widely debated to further the understanding of AN individuals' unwillingness to change (Vitousek, Watson, & Wilson, 1998). Schmidt and Treasure (2006) proposed a maintenance model for AN according to which such a condition is maintained intrapersonally by beliefs about the advantages brought about by the disorder itself and interpersonally by the responses—both positive and negative—of significant others to patients' condition. Thus, AN would have an “adaptive” function aimed at reducing social challenges and threats (Schmidt & Treasure, 2006).

To date, only a few qualitative studies aimed at unraveling the multiplicity of meanings that AN has to patients. Nordbø and coworkers (2006) investigated this topic highlighting eight constructs which may be involved in generating and maintaining eating-disordered behaviors: security, avoidance, self-confidence, mental strength, identity, care, communication, and death. Ambivalence and reluctance about recovery have been found to lead to a vicious cycle of maintenance of the disorder through self-reinforcement (Abbate-Daga et al., 2013; Vitousek et al., 1998). The way patients relate to their condition has been suggested to be relevant also with respect to outcome and compliance to treatment (Darcy et al., 2010; Federici & Kaplan, 2008).

AN can be highly pervasive and patients tend to mislabel adverse physical and emotional states as feeling “fat” (Fassino, Daga, Pierò, & Delsedime, 2007; Skårderud, 2007). Moreover, people with AN have been shown to be characterized by high levels of alexithymia (Speranza, Loas, Wallier, & Corcos, 2007) which describes an impairment in identifying, expressing, and distinguishing emotions—even from bodily sensations—contributing to hampering recovery and outcome (Speranza et al., 2007). Taken together, these elements may contribute to the focus on bodily experiences of AN individuals as a means of handling emotional, cognitive, and relational problems. This mechanism has been suggested to entail several subjective benefits for those who are affected including sense of identity and control (Espíndola & Blay, 2009), avoidance of unpleasant experiences and close relationships (Krug et al., 2013; Schmidt & Treasure, 2006; Wildes, Ringham, & Marcus, 2010), protection (Serpell, Treasure, Teasdale, & Sullivan, 1999), as well as comfort and distraction from stressors (Tierney & Fox, 2010).

Several lines of research suggest a central role for emotion dysregulation in AN (Skårderud, 2007; Treasure, Claudino, & Zucker, 2010) encompassing emotional awareness, emotion recognition in others, and behavioral regulation when experiencing strong emotions (Racine & Wildes, 2013). Such difficulties tend to be endemic to the AN population and may partially explain patients' tendency to highly value their disorder. In fact, eating problems could represent a way to regulate intense or undifferentiated emotional states and to avoid emotional coping (Wildes et al., 2010).

Although no treatments with proven effectiveness exist for AN, all the aforementioned aspects of this condition can be useful in treatment. In fact, ambivalence has been used in motivational interviewing (Wong & Cheng, 2013), cost-benefit analysis and exploring perspectives are key for cognitive restructuring in cognitive behavioral therapy (Dalle Grave, Calugi, Doll, & Fairburn, 2013), and emotion acceptance behavior therapy (Wildes, Marcus, Cheng, McCabe, & Gaskill, 2014) is grounded on increasing emotion awareness while decreasing emotion avoidance. Moreover, anger (Abbate-Daga et al., 2012) as well as identity (Stein, Corte, Chen, Nuliyalu, & Wing, 2013) have been specifically included in the treatment of AN.

Given the dearth of studies on subjective perceptions of AN, we aimed to qualitatively explore patients' perspective about the meanings of their disorder. According to previous research (Serpell et al., 1999), we asked patients to write a letter to AN, but—differently from previous work—participants were not instructed to address it separately as a friend and as an enemy. Our a priori hypothesis was that patients' letters could mirror their inner complexity toward AN and recovery with most participants reporting both pro- and anti-codes. Relatedly, the overarching rationale of this study was to provide therapists with a starting point not only to work on maintaining factors, but also to foster the therapeutic relationship.

2. Methods

2.1. Participants

Letters were collected from 31 July 2010 to 31 May 2012 at the Day Hospital (DH) of the University of Turin. Patients were approached by their psychiatrist in order to ascertain their willingness to participate in this study. The DH treatment of the University of Turin is focused on psychodynamic psychotherapy delivered daily with an individual and group setting. The DH intervention lasts 6 months and is offered between Monday and Friday from 8:30 am to 3:30 pm to a maximum of 12 patients. In addition to psychotherapy all patients receive: dietetic management and meals (three structured meals: half-morning snack, lunch, mid-afternoon snack), parent counseling, and cognitive behavioral techniques. The treatment team includes psychiatrists, clinical psychologists, registered dietitians, internal medicine physicians, and psychiatric nurses. A full description of the DH treatment can be found elsewhere (Abbate-Daga et al., 2012).

Patients were included in this study who met the structured clinical interview for DSM axis-I disorders (SCID-I; First, Spitzer, Gibbon, & Williams, 1997) diagnostic criteria for AN. The SCID-I was administered by an experienced psychiatrist. Inclusion criteria were: (a) age ranging from 18 to 40 years old; and (b) female gender. Exclusion criteria were: (a) severe medical comorbidity (e.g. epilepsy or diabetes); (b) alcohol or drug dependence; (c) comorbid psychosis.

This study was conducted in compliance with the Declaration of Helsinki and all participants provided written informed consent prior to being included in the study according to the Ethics Committee of the Department of Neuroscience of the University of Turin. Moreover, patients gave permission for quotes of their letters to be used; all letters were kept in patients' clinical charts but a copy of it was given to those participants who required it.

2.2. Measures

Patients were asked to complete this task within the first week after being admitted to avoid treatment bias. The only directions were: "Please think about your disorder and write a letter to it describing what it represents and means to you." The patients were provided with paper and pens to write their letter during the DH hours; they were allowed a maximum of 60 minutes to complete it. In order to make patients feel as free as possible, they were told to use whatever space they preferred (e.g. armchairs and sofas) in the DH; also, they were alone although the researchers could be available immediately if needed. Given patients' marked cognitive control about their disorder we chose not to instruct participants to refer to their condition as a friend or as an enemy; doing so, we aimed to garner as precisely as possible how intertwined and enmeshed their feelings and emotions are in this regard.

2.3. Coding scheme

The coding manual proposed by Serpell and coworkers (1999) was initially adopted. After performing a preliminary analysis on five letters randomly selected, we operationalized an "ambivalence" code in order to capture all statements referring to this aspect (e.g. "I hate AN but I could not live without it"). Therefore, the original codes were modified accordingly and 10 pro-codes and 13 anti-codes were finally identified in addition to ambivalence (Tables 1 and 2).

Table 1. Pro-codes used to evaluate patients' letters

Pro-codes	Description
1. Identity	Used when patients describe themselves as totally represented by their illness; they describe themselves as a whole with AN. "I could not live without you (AN)."
2. Avoidance	For statements describing how the disorder can help patients to avoid some uncomfortable situations. "When I starve I feel allowed to avoid thinking about hurting stuff."
3. Difference	Used to code feeling of being different from others, special or superior because of the disorder. For statements that describe the disorder as something patients are good at or which others cannot do as well. "You (AN) make me feel so special."
4. Control	Used where the disorder appears to provide control or structure to patients' life. "With you (AN) I know exactly what I am going to do and feel next."
5. Denial	For statements that do not consider at all the illness; when patients deny their illness, living as if it never happened. "You (AN) are just a healthy way of living."
6. Gratitude	Used when patients appear grateful to their disorder. "Thank you, AN."
7. Irresponsivity	For statements describing the illness as able to ease patients from their responsibilities in life. "You (AN) are always there for me when I feel I cannot accomplish my goals."
8. Communicate	Used when patients describe their subjective experience of expressing their emotions through their bodies and illnesses; when patients use their illness as communication channel. "Finally my parents got worried about my suffering."
9. Company	For statements involving ideas of being looked after, kept safe, and protected. Used when patients describe the disorder as always there or supporting their life. "Nobody can protect me as you (AN) can do."
10. Addiction/aniolysis	For statements describing how AN can be useful to get relief from anxiety and how patients cannot think about not being ill. "When I starve I feel high and finally in peace."

Table 2. Anti-codes used to evaluate patients' letters

Anti-codes	Description
1. Anger/Hate	Used when patients express their anger towards their illness. "I hate you, AN."
2. Health	Used to code current or future health problems (including bone and fertility problems) considered as a result from the disorder. "I know could not be able to have children one day because of you (AN)."
3. Emotion avoidance	For statements involving ideas of the disorder as silencing patients' feelings and emotions (usually considered as pro). "You (AN) paralyzed my heart and my emotions."
4. Devaluation	Used when patients describe themselves as devaluated by others/themselves because of their disorder. "Because of you (AN) I have been sometimes judges as a freak."
5. Social impairment	Used for statement that describe how AN impaired patients' social abilities and environment, leading to progressive isolation. "I scare people/Nobody wants me as a friend."
6. Shame/take over	Used when patients feel ashamed or taken over by the disorder. Also used to code feeling of not being a person without the disorder. "I feel so ashamed."
7. Fear/distress	Used when patients describe feelings of fear/distress/anxiety towards their illness; "I am afraid of you (AN)/You (AN) are my worst nightmare."
8. Annihilation	Used for statements describing patients who think not to live their lives anymore because of the presence of AN. "I am nothing if I do not have you (AN)."
9. Betrayal/pretend	Used to highlight the aspects of feeling cheated by the disorder, of being aware of its false promises. "You (AN) made me only broken promises."
10. Loss/waste	This code describes a feeling of life being wasted by the disorder and that the disorder has hampered the patient doing things. "I could not enjoy my holidays because of you (AN)."
11. Food obsession	For statements describing patients being tired of thinking about /being controlled by food all the time. "Thinking about food all the time is just exhausting."
12. Others	Used where patient describes the disorders as worrying/hurting other people such as family members. "You (AN) made my parents feel desperate and completely overwhelmed."
13. Emptiness	For statements describing how patients sometimes feel empty because of completely identified with their illness. "I feel nothing if you (AN) are not with me."

No patients refused to participate and letters were rated according to the same coding scheme by two experienced psychiatrists (Enrica Marzola and Carla Gramaglia) and then a cluster analysis on both pro- and anti-codes was performed to evaluate possible associations among different themes. An independent researcher (Giovanni Abbate-Daga) supervised the study and provided credibility checks. We found strong correlations between the two raters with respect to all codes (interrater reliability $r = 0.76$; $p < 0.001$).

It was also counted how many times a certain code was mentioned in every letter. To identify how many individuals showed a specific code, the latter was hence evaluated as dichotomous variable (present/absent).

2.4. Statistical analysis

The SPSS statistical software package was used for data analysis. Descriptive statistics were computed and subsequently, a two-step cluster analysis was performed to gather cases into separate groups of patients with similar characteristics. The assessed variables to group participants were codes considered as dichotomous variables (present/absent).

We performed a first cluster analysis on pro-codes and a second one on anti-codes. In the context of this study, a cluster was conceived as a class or conceptually meaningful groups of feelings about AN that share common characteristics and statistically “aggregate” together. The two-step cluster method is a scalable cluster analysis algorithm designed to handle heterogeneous data-sets (i.e. continuous and categorical variables). The two steps are: (1) pre-cluster the cases into many small subclusters; and (2) cluster the subclusters resulting from pre-cluster step into the desired number of clusters. The log-likelihood distance measure was used, with participants assigned to the cluster leading to the largest likelihood. A defined number of clusters was not defined a priori. Solution was found with the Bayesian information criterion. Then we compared the clusters using the χ^2 test. Significance level was set at 0.05.

3. Results

3.1. Clinical features of the sample

We enrolled a total of 34 partially hospitalized patients diagnosed with AN both subtypes, ($N = 21$ restricting type and $N = 13$ binge-purging type). Patients were all Caucasian and their mean age was 25.62 ± 5.07 years, duration of illness was 9.00 ± 5 years; onset of illness occurred at 16.75 ± 3.07 years, and mean body mass index (BMI) at intake was 16.35 ± 2.59 .

3.2. Pro-codes and anti-codes

Three pro-codes frequently emerged (percentages represent the number of times a code was cited divided for the total number of mentioned codes): (a) 20% of the pro-codes was represented by difference, i.e. feeling of being different from others and special; (b) 16% by company, i.e. ideas of being looked after, kept safe, and protected; and (c) 14% by identity, i.e. used to describe themselves as completely represented by AN and as they could not live without it.

Examining the anti-codes, four were particularly used: (a) anger/hate theme was found to be the most common, representing 30% of all anti-codes, i.e. considered as the expression of patients' anger toward their condition; (b) fear/distress (11%), i.e. used when patients describe feelings of fear, distress, and anxiety; (c) betrayal/pretend (11%), i.e. when feeling cheated by the disorder; and (d) loss/waste (11%), i.e. describing a feeling of life being wasted.

As regards how frequently each code was overall mentioned, anger/hate most commonly emerged ($N = 101$ times), followed by difference ($N = 78$ times) and company ($N = 60$ times).

Table 3. Clusters of pro-codes

	Need for excellence group (N = 12)		Safe-seeking group (N = 10)		Entrenched AN group (N = 12)		χ^2	p
	%	N	%	N	%	N		
Identity	50	6	70	7	100	12	7.79	0.02
Avoidance	41.7	5	0	0	75	9	12.66	0.002
Difference	91.7	11	60	6	75	9	3.06	0.21
Control	41.7	5	0	0	58.3	7	8.45	0.01
Denial	66.7	8	0	0	16.7	2	13.12	0.001
Gratitude	8.3	1	20	2	83.3	10	16.28	0.001
Irresponsivity	58.3	7	50	5	66.7	8	0.62	0.73
Communicate	41.7	5	0	0	33.3	4	5.31	0.07
Company	33.3	4	100	10	83.3	10	13.12	0.001
Addiction/anxiolysis	41.7	5	40	4	41.7	5	0.008	0.99

3.3. Clusters of codes

As regards pro-codes, the cluster analysis identified three clusters of patients. The first group was found to be mainly characterized by difference and denial, the second by company, and the third by identity codes (Table 3). On the other hand, no clusters were found among anti-codes.

3.4. Ambivalence

The ambivalence code represented 6% of all codes: 26 patients out of 34 mentioned the ambivalence theme 47 times.

4. Discussion

With this qualitative study, we aimed to explore the meanings that patients affected by AN attribute to their eating problems and to better investigate their attitude toward AN. Differently from previous work (Serpell et al., 1999), we did not explicitly ask patients to write to their disorder as a friend and then as an enemy in order to let positive and/or negative sides of the disorder spontaneously emerge (Nordbø et al., 2006). Doing so, we operationalized a slightly different coding system since the ambivalence code was frequently represented.

4.1. Pro-codes

Reluctance to seek treatment is a hallmark of AN entailing relevant effects on course and outcome (Abbate-Daga et al., 2013) and both defensive functions (Schmidt & Treasure, 2006) and positive values (Nordbø et al., 2006) of AN have been widely acknowledged as potentially underpinning this phenomenon. In keeping with these findings, we found not only that the positive aspects of AN largely emerged, but also that their distribution could be clustered into three groups.

The first group, named need for excellence, was composed by those patients highlighting the positive values of the disorder especially as a means of being different from others. People with AN have been extensively characterized by low levels of self-esteem not only in the ill-state, but also premorbidly (Brockmeyer et al., 2013) and recovered individuals have been found to exhibit higher self-esteem than those actively ill (Bardone-Cone et al., 2010). Therefore, this result raises the hypothesis that AN itself may represent a way to overcome this feeling of worthlessness contributing to the maintenance of this condition.

A safe-seeking group also emerged with the company code being the most represented one. Our company code is somehow similar to the “guardian” code previously described (Serpell et al., 1999) and refers to the idea of AN representing a friend/caregiver, providing protection and stability. As

previously reported (Serpell et al., 1999), this code characterized the majority of the sample and was expressed by all participants (100%) included in this cluster. For these patients, the eating disorder seemed to represent an attempt to alleviate both threatening feeling of loneliness and maturity fear. Moreover, AN patients often show socio-relational impairments and poor self-confidence and may try to overcome their sense of isolation with the disorder. Further research may want to assess whether these individuals are characterized by harm-avoidant (Kaye, Fudge, & Paulus, 2009) or inhibited (Wagner et al., 2006) personality features.

The third cluster was characterized by multiple meanings representing thus an AN-entrenched and multifaceted group, since 7 codes out of 10 were shared by more than 50% of this subsample. However, the identity code—referring to patients describing themselves as totally represented AN—was mentioned by all participants mirroring indeed the clinical features often emerging in everyday clinical practice. Interestingly, this code was found in the great majority of the whole sample (50% of need for excellence cluster and 70% of safe-seeking cluster) providing further support to the positive value placed on AN by patients (Nordbø et al., 2006) also considering the potential relationship between identity, self-schemas, and eating-disordered behaviors previously suggested (Stein & Corte, 2008).

4.2. Anti-codes

As regards anti-codes, we did not identify any cluster; this finding raises the hypothesis that the negative aspects of AN could be homogeneously distributed among affected individuals without specific subgroups. In fact, the heavy burden of physical and psychological sequelae of the disorder (Treasure et al., 2010) could be somehow shared by all patients, even more so if long-standing like those in this study (duration of illness: 9 ± 5 years).

Negative emotions like anger-hate and fear were frequently reported by this sample providing a qualitatively accurate description of patients' feeling of hopelessness. Since negative emotionality represents a daunting challenge for these patients often impacting on eating behaviors (Racine & Wildes, 2013) therapists should pay close attention to improve patients' awareness of such emotions and consequently encourage more adaptive coping strategies. Interestingly, patients described these negative aspects of AN without being asked to do so (i.e. open letter); future studies are warranted to verify whether such aspects can be useful in treatments as a leverage to enhance motivation to treatments.

4.3. Ambivalence

Patients' ambivalence clearly emerged in this study, with 26 patients out of 34 reporting such perspective. This is in line with previous qualitative research (Colton & Pistrang, 2004; Reid, Burr, Williams, & Hammersley, 2008; Serpell et al., 1999; Williams & Reid, 2010) and it is relevant from a clinical perspective since it has been pointed out how ambivalence and eating-disordered behaviors can be related (Vitousek et al., 1998). Interestingly, it has been suggested that recovery could be promoted by those treatments that help patients finding a balance between the conflicting aspects underpinning ambivalence (Jenkins & Ogden, 2012).

Patients usually battle with AN for several years (Nordbø et al., 2012; Serpell et al., 1999) and recovery is often a lengthy process. This ambivalence code mirrors how difficult the recovery process can be from patients' perspective since it likely challenges all the positive values that patients attribute to AN and that are unwilling to give up (Serpell et al., 1999; Williams & Reid, 2010). This difficulty could be further exaggerated by other peculiar characteristics of AN. In fact, affected individuals are cognitively inflexible (Abbate-Daga, Buzzichelli, Marzola, Amianto, & Fassino, 2014; Tchanturia et al., 2012), highly anxious, and scarcely able to tolerate uncertainty (Frank et al., 2012). Taken together, all these psychopathological elements may play a role in making AN individuals not only ambivalent, but also highly distressed by such uncertainty.

In spite of some strengths, this study suffers from some limitations as well: first, our sample consisted of long-standing patients so our findings could not be fully generalized to other groups of patients; second, the study procedure (open letter task) could have insufficiently stimulated patients' thoughts about their condition. Moreover, these findings have not been correlated with other clinical parameters (e.g. depression, AN stages of change) and no measurement has been made on the usefulness of this instrument with respect to treatment effectiveness.

5. Conclusions

Qualitative studies investigating the subjective aspects of AN have increasingly shed light on the need of taking into account in treatment the peculiar adaptive function of this disorder (Abbate-Daga et al., 2013; Schmidt & Treasure, 2006; Serpell et al., 1999). According to the findings of this study, this therapeutic strategy could have several clinical implications. In fact, given the well-known "adaptive function" (Schmidt & Treasure, 2006) of the disorder, therapists may find it helpful to ask patients—using a letter format—what is the peculiar meaning they attribute to their disorder. Furthermore, considering patients' inner perspective on AN could help therapists avoid a frustrated and rejecting attitude toward these patients by minimizing treatment resistance. Moreover, the lack of instruction on writing to an enemy or to a friend may help patients make their emotions flow freely and overcome some alexithymic traits that are well known in AN (Speranza et al., 2007). Finally, letters may be a useful tool in identifying patients' feelings toward the disorder, helping patients labeling and express their emotions, and fostering the therapeutic relationship through the improvement of patients' satisfaction with therapists (Gulliksen et al., 2012). Further research is warranted to combine qualitative and quantitative assessments to clarify as to whether this approach can be useful in treatment.

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