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PITFALLS IN ANOREXIA NERVOSA RESEARCH: THE RISK OF ARTIFACTS LINKED TO DENIAL OF ILLNESS AND METHODS OF PREVENTING THEM

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SUMMARY

One of the most serious problems faced by researchers studying eating disorders is denial of illness in individuals with anorexia nervosa. Importantly, the term "denial" not only has different meanings, but in the case of anorexia nervosa its very nature still remains obscure. It is not even known whether it is deliberate or unintentional. Denial of illness in anorexic patients has serious consequences for evaluation of the reliability of information obtained from those individuals. Indeed, the most frequently used screening questionnaires, such as the Eating Attitudes Test (EAT) (Garner & Garfinkel 1979) and the Eating Disorder Inventory (EDI) (Garner et al. 1983), may not reflect the psychological state of the subjects due to distorted responses. The objective of this review article is to elucidate, at least in part, the nature of denial of illness in anorexic individuals and, importantly, to present methods for direct or indirect measurement of this variable. The authors emphasize the detrimental effect of denial of illness on the quality of information obtained from the patients and the notorious unreliability of self-report data. The final part of the paper contains suggestions as to methods of bypassing the pitfalls associated with the influence of denial of illness on the results of studies involving anorexic individuals; for instance, it is recommended that one should build an honest and trustful relationship with the patient. Last but not least, the focus is placed on the potential of experimental psychology, which offers tools producing robust data, resistant to deliberate distortion by patients.

Key words: *anorexia nervosa – methodological pitfalls – denial of illness – self-report measures*

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INTRODUCTION

The well-known book "Assessment of Eating Disorders" (Mitchell & Peterson 2008), which provides a detailed specification of all the prerequisites for an accurate diagnosis of patients with eating disorders, contains a short, half-page-long section entitled "Assessment challenges and clinical skill". That section is devoted to the obstacles facing researchers in the process of making a diagnosis, and the authors emphasize difficulties associated with patients denying or downplaying their disorder. According to Vitousek et al. (1991), "the challenge of getting eating disorder clients to tell us what they think and feel - and the difficulty of trusting them when they do - have long figured prominently among the concerns of clinicians and researchers who work with this population". Similarly, Bruch (1978) observed that "it is exceedingly difficult to get objective statements about how anorexics feel". Indeed, those individuals tend to be extremely secretive about their private experience (Vitousek et al. 1991).

Denial of illness in patients suffering from eating disorders, and especially their restrictive forms, has been known for a very long time. Back in the 19th century Lasegue (1873) noted that an individual with anorexia nervosa "is not ill pleased with her condition, notwithstanding all the unpleasantness it is attended with" (cited in Vandereycken 2006a). According to Halmi (1974), denial occurs in 80% of anorexic individuals, which makes them different from other eating disordered patients. The term "denial" used in works on eating disorders has lost its original psychodynamic meaning with the development of the various schools of psychological thought.[1] Vitousek et al. (1991) defined it as "any consciously or unconsciously motivated omission, concealment, or misrepresentation of behavior or internal experience". According to these researchers, in the case of patients with anorexia nervosa it would be more appropriate to use the word "distortion" because of its narrower sense (rejection of a discernible truth), but they decided to continue with the former term as it has been consistently adopted by researchers in this context for years.

Based on her research of the attitudes of anorexic patients to their illness, Bruch observed that the most readily recognizable symptom of anorexia nervosa is the patient's denial that she/he is too thin. While in DSM-IV-TR (2000) the third diagnostic criterion of anorexia nervosa was "denial of the seriousness of the current low body weight" in DSM-V (2013) the word "denial" was removed and the criterion was redefined as a "persistent lack of recognition of the seriousness of the current low body weight" (see also Vandereycken 2006a).

[1] Originally, denial was conceived of as one of the defense mechanisms in psychoanalysis, related to psychological repression. Denial is a falsification of reality in which one refuses to acknowledge certain facts in order to escape the negative thoughts and feelings that they might otherwise bring about

THE NATURE OF DENIAL OF ILLNESS IN EATING DISORDERS

There is no consensus among researchers as to the nature of denial of illness in anorexia nervosa. Some claim that denial is a consequence of conscious reasoning; for instance, Vitousek et al. (1998) propose that "the dominant clinical interpretation of denial and resistance in anorexia nervosa is that they represent conscious and instrumental attempts to preserve its egosyntonic[2] symptomatology". While patients with anorexia nervosa are sometimes too rashly labeled as "manipulative" they can indeed take recourse to manipulation to attain a specific purpose. In such situations, they are likely to pursue their goals through deception, coercion, or deceit, ignoring the goals or needs of others. Vitousek et al. (1991) termed such behavior "the instrumental version of denial" (cf. Vandereycken's notion of "tactical deception" 2006b) in light of the fact that although individuals with anorexia nervosa know that their behavior is irrational and pathological, understand that they are emaciated, and are aware of their fear of gaining weight, they still refuse to provide their "inquisitors" with enough information to "indict" them. In contrast, Hebebrand et al. (2004, see also Vandereycken 2006a) believe that denial is not a fully intentional process and suggest that the term should be replaced by the phrase "lack of concern about the physiological and psychological consequences of underweight". In turn, according to Merskey (1995), anorexia nervosa involves "either conscious or unconscious production of symptoms and the denial of a problem". Therefore, it may take the form of either simulated illness, deliberate self-damage, or blissful indifference (Vandereycken 2006a) in the face of emaciation and possible death.

The debate concerning the nature of denial of illness in anorexia nervosa translates into how researchers define the nature of the disease itself. Melamed et al. (2003) classify anorexia nervosa among psychotic illnesses, similarly to Bruch (1978), who used the term "delusion" for the phenomenon of feeling fat in individuals with anorexia nervosa in spite of her/his obvious emaciation. However Casper (1987) criticized that approach, pointing out that it does not explain, e.g. the patient's frequent mirror gazing, combined with the admiration of her/his wasted body, which indicates some awareness of reality (cf. Bruch's notion of "self-deceptive training" 1978, see also Vandereycken 2006a). In summary, an individual with anorexia nervosa "perceives the reality but disavows its meaning: she 'knows' she is too thin in the eyes of others, but in her own eyes it 'feels' different. Except for this disavowal, all other reality-testing functions remain intact" (Vandereycken 2006a). Probably that is why Casper (1987) opposed considering anorexia nervosa as a psychotic illness. According to Casper et al. (1981), even patients with very severe anorexia nervosa are fully aware of their emotional state, mood swings, loneliness, and low self-esteem, but although they can visually perceive their wasted body, they do not feel emaciated themselves. This led Giles (1985) to the conclusion that in anorexia nervosa self-perception is not determined by perceptual disturbances, but rather by denial of illness; interestingly, more intense denial of emaciation is accompanied by greater overestimation of one's body size.

Any endeavor to explain the phenomenon of denial seems to trigger a series of further questions. For instance, Tan et al. (2003a) proposed egosyntonicity as the factor responsible for denial of illness in anorexia nervosa, as patients consider treatment to be tantamount to abandonment of their identity. Indeed, anorexic individuals believe that it is not necessary or even especially desirable for others to be extremely thin (Vandereycken 2006a). The question arises as to whether such a belief is a symptom of egocentrism or the consequence of recognition of the irrationality of one's own fears and desires (Vitousek & Hollon 1990). A similar problem emerges if one attempts to elucidate denial of illness in anorexic patients with the notion of dissociation. This condition can be most succinctly captured with a patient's words: "the person in the mirror is not me, but someone else" and is characterized by body detachment, indifference to pain, and self-depreciation, which is typical of, e.g. self-harming and suicidal patients. However, if one approaches denial of anorexia nervosa from the perspective of dissociation, the question is whether the patient is "blind" to some aspects of reality or perhaps does not want to see them?

Vandereycken (2006b) acknowledged that denial of illness may be attributed to different causative factors, which may be helpful in elucidating this phenomenon. He made a distinction between:

- Unintentional or only partially intentional denial; and
- Deliberate denial.

The first type of denial is attributable to:

- anosognosia (a deficit of self-awareness that results from physiological damage to brain structures);
- limited insight due to overvalued ideas that may be placed on the continuum between obsessions and delusions;
- narrowed consciousness, i.e. dissociation from one's body in the sense of indifference to hunger signals;
- attempts to preserve or enhance self-esteem, as part of a coping strategy with an overwhelming fear of being nobody and of being weak and ineffective (i.e., "pseudo-identity" Vandereycken 2006a).

The second type is associated with:

- avoidance of the consequences of acknowledging the illness, such as treatment and stigmatization;
- self-determination related to the protection and/or enhancement of self-esteem (e.g. pride) and battle for control (e.g. need of independence) (see Figure 1).

[2] Egosyntonicity – in the case of anorexia nervosa this term refers to the patient's belief that the illness is part of herself/himself or of her/his identity (Tan et al. 2003a)

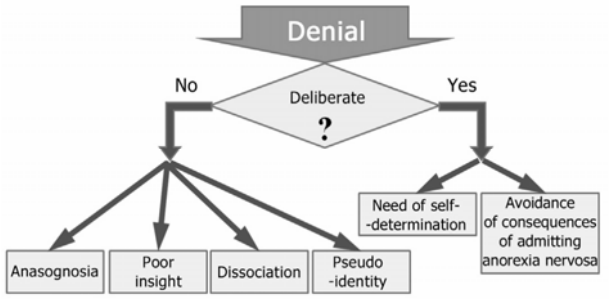


Figure 1. Causes of denial of illness in anorexia nervosa

It should be noted that Vitousek et al. (1991) added yet another form of denial, that is, the desire to meet the expectations of others (e.g. the researcher): individuals suffering from anorexia nervosa may say what they think appropriate in a given situation rather than what they really feel. Although this aspect does not seem to be fully consistent with denial of illness, at least in some cases it may have important ramifications for the evaluation of data from anorexic patients.

THE INFLUENCE OF DENIAL OF ILLNESS ON THE RELIABILITY OF DATA OBTAINED FROM ANOREXIC PATIENTS: THE RISK OF ARTIFACTS

Denial of illness by individuals with eating disorders has serious consequences for the amount and reliability of information obtained from them. First of all, it is very difficult to elicit information from such persons. Denial of illness obviously concurs with reluctance to help-seeking, which has been corroborated by the results of several studies. Hoek (1993) estimated that of all cases of anorexia nervosa in the Netherlands only 43% were detected by the general practitioner or the family physician, and only 34% were finally admitted to a mental institution. Another retrospective study conducted in the Netherlands showed that out of 108 current and past patients with anorexia nervosa, 72% denied there was anything wrong in the early months or years of their illness (Noordenbos 1992). In turn, the Dutch Association for Anorexia and Bulimia Nervosa, which regularly conducts online surveys of people with eating disorders, published the results of a poll asking the question: "Who was the first person to whom you told you have an eating disorder?" Out of 2742 respondents, 31.1% answered "a friend", 25.7% – "nobody", 13.7% – "my mother or father", 11.3% – "my partner", 6.1% – "someone else", 5% – "a health care professional", 3.7% – "my sister or other family member" and 3.5% – "the family physician" (cited in Vandereycken 2006b). It should be noted that "nobody" was the second most popular response.

As far as the reliability of information obtained from patients with eating disorders is concerned, Vitousek and Manke (1994) claim that "anorexics may resort to deliberate, instrumental distortion in self-report when it suits their purposes to do so". According to Faunce (2002), "self-reported data, as a source of information regarding cognitive processes in anorexics and bulimics, are notoriously unreliable". Similarly, Vitousek and Orimoto (1993) observed that patients with eating disorders tend to deliberately distort their responses in self-reporting measures and are therefore considered "unreliable" (Vitousek et al. 1991), "unsatisfactory" (Vitousek et al. 1991), or "poor" (Vitousek et al. 1991) informants. Obviously, this dramatically decreases the reliability of self-report studies involving patients with eating disorders. Unfortunately, this methodological "trap" (Vandereycken 2006a) is usually overlooked in studies of patients with eating disorders (Shaw & Garfinkel 1990). According to Vandereycken (2006a), in the case of patients with anorexia nervosa "all research relying solely on self-reporting can have a questionable reliability and/or validity". The results of the Eating Attitudes Test (EAT) (Garner & Garfinkel 1979), a screening tool for eating disorders, which has been adapted to many languages, may be highly distorted due to denial (Vandereycken & Venderlinden 1983). Vitousek et al. (1991) even claim that researches have to do with regular underestimation of results by individuals with eating disorders. In particular, tests with high face validity, such as the above-mentioned EAT, as well as the Eating Disorder Inventory (EDI) (Garner et al. 1983), and especially its scales Drive for Thinness, Bulimia, Body Dissatisfaction, are vulnerable to underreporting (Williamson et al. 1995, Vandereycken 2006a). Obviously, there is also a positive side of this phenomenon. For instance, Garner (1991), who observed considerable underreporting by patients with eating disorders in EDI results, proposed that such data should be treated as valuable information about the patient's psychological state and motivation for treatment at the time of testing. Unfortunately, such inferences as to the distortion of questionnaire results can be made only if external observer data are available in addition to self-reported information (Vandereycken 2006a).

It should be stressed that while raw data obtained in studies of patients with eating disorders may indeed contain very important information (such as responses to the questions asked by the researcher), it is often contaminated (Tadeusiewicz 2000). Therefore, it is of utmost importance to ensure high quality data by eliminating "noise" (Tadeusiewicz 2000) consisting of mistakes and methodological artifacts. As self-reported data from individuals with eating disorders are likely to be artifacts associated with denial of illness, they may lead to invalid conclusions if one does not undertake sufficient measures to increase reliability. It is difficult, or indeed impossible, to make inferences about, e.g., cognitive schemas in eating disordered patients, because one would have to exclusively depend on information whose quality cannot be verified: "the strategy of relying on (patient) self-reports to validate a construct whose operation is intended to explain these self-reports becomes increasingly circular unless additional referents can be provided to demonstrate schematic processing" (Segal 1988, see also Dobson & Dozois 2004).

STUDIES ON DENIAL OF ILLNESS IN PATIENTS WITH EATING DISORDERS

Direct studies on denial of illness

Despite the fact that the literature reporting studies on patients with eating disorders is very rich, few researchers have addressed the methodological problem of the effect of denial of illness on the reliability of the results obtained by means of self-report measures (Vitousek et al. 1991, Vandereycken 2006a). Unfortunately, the available tools used for investigating the patient's insight into her/his illness in psychoses and for examining denial in somatic diseases (e.g. cancer) are not suitable for anorexia nervosa, which is in many ways a peculiar disorder (Greenfeld et al. 1991).

Vandereycken and Vanderlinden (1983) were the first to investigate this issue. They found that 13 out of 40 patients with anorexia nervosa who took the EAT at admission to hospital scored below the diagnostic threshold (30) for that eating disorder. A similar study was carried out by Newton et al. (1988), who tested 66 subjects referred to a clinic for assessment of an eating disorder. Persons who obtained low scores on the EAT (so-called "deniers"), were more often diagnosed with anorexia nervosa and had a lower weight at testing in comparison to subjects scoring higher (so-called "admitters"). Along these lines, Pryor et al. (1995) have defined denial as:

- meeting the DSM-IV criteria for anorexia nervosa;
- scoring within or below the normal range in the following three EDI scales: Drive for Thinness, Bulimia, and Body Dissatisfaction.

Using these criteria, they found that 27.6% of a population of 105 anorexic subjects referred to an eating disorders clinic were deniers. Interestingly, the deniers did not differ significantly from the admitters in terms of age at onset, length of time in treatment, or mental and physical condition 1 year after initial evaluation. It was also noted that the deniers were arrogant or at least viewed themselves as superior to other people, who they thought weak and succumbing to bodily instincts. This observation was corroborated by the fact that the admitters exhibited bulimic symptoms more often than the deniers. Therefore, it is possible that denial of illness concurs with restrictive anorexia nervosa, which imparts a sense of self-mastery to the patient. This is consistent with the proposal that individuals with anorexia nervosa deny illness because they feel special, while bulimic patients conceal symptomatology because of a sense of shame (Vitousek et al. 1991).

Indirect studies on denial of illness

Recently, denial of illness in anorexia nervosa has also been conceptualized as "precontemplation" – the first stage of change in the Transtheoretical Model of Change (TMC) (Prochaska 1979, Prochaska & DiClemente 1983, 1984, Prochaska et al. 1992), with the other stages being contemplation, preparation, action, maintenance, and termination. In this stage individuals are not aware of their problem or underestimate it, and do not intend to modify their behavior in the near future. Sometimes they may undertake some efforts to change as a result of persuasion or pressure of others, but such efforts are discontinued as soon as the pressure disappears and the individuals relapse into their previous behavior. Patients can be evaluated in terms of their stage using the Stages of Change Algorithm (SCA). A version of SCA adapted for the study of patients with eating disorders was used in 51 hospitalized patients with anorexia nervosa, with 23.5% of them being classified to the precontemplation stage (Blake et al. 1997).

Instruments testing motivation to change, which can identify the precontemplation stage, may also play a major role in indirect research on denial of illness in eating disorders. The University of Rhode Island Change Assessment Scale (URICA) (McConnaughy et al. 1989) is a 32-item self-report questionnaire for determining the patient's stage of change. Its version adapted for research of eating disorders was used in a study involving 88 women, including 29 anorexic outpatients (Hasler et al. 2004). It was found that fewer self-referred patients were in the precontemplation stage than those who were referred by others; furthermore, precontemplation patients exhibited a lack of engagement in continuing treatment. In turn, the Readiness and Motivation Interview (RMI) (Geller & Drab 1999) is a semistructured interview that addresses readiness and motivation over the past 2 weeks. It includes all diagnostic items from the Eating Disorder Examination (EDE) (Cooper & Fairburn 1987), such as cognitive symptoms, restriction, bingeing, compensatory strategies, and one additional item (restraint over eating). For each symptom, this instrument assesses readiness and motivation status, and the extent to which change is for internal versus external reasons. Precontemplation patients are defined as those who do not see the symptom as a problem or are not interested in any kind of change. Geller et al. (2004) studied 57 anorexic patients and reported that precontemplation scores were correlated with a lower likelihood of accepting hospitalization and a higher likelihood of dropping out of treatment. It should be added that Geller et al. (2013) developed the Readiness and Motivation Questionnaire (RMQ), a self-report symptom-specific version of the RMI that can be used to assess readiness to change across all eating disorder diagnoses. Another important tool designed to evaluate readiness to recover in anorexia nervosa is the Anorexia Nervosa Stages of Change Questionnaire (ANSOCQ) (Rieger et al. 2000). It is a self-report instrument consisting of 20 items concerning weight, shape, eating behavior, etc. Respondents mark their responses on a five-point scale where "1" corresponds to precontemplation and "5" to maintenance. Some items refer directly to precontemplation, e.g. "My fear of becoming fat is not excessive". A study of 44 hospitalized patients with anorexia nervosa conducted

by means of ANSOCQ found that 9.1% of them were in the precontemplation stage. Furthermore, two modifications of ANSOCQ have been developed. The Bulimia Nervosa Stages of Change Questionnaire (BNSOCQ) (Martínez et al. 2007) is designed to assess readiness to recover from bulimia nervosa. In addition to the areas evaluated by ANSOCQ, it has a separate section with items related to bulimic symptoms, namely binge eating and compensatory behaviors. In turn, the Eating Disorders Stages of Change Questionnaire (EDSOCQ) (Ackard et al. 2009) can be applied to patients with anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified. The Motivational Stages of Change for Adolescents Recovering from an Eating Disorder (MSCARED) (Gusella et al. 2003) is a simple, short scale to be completed by the patient or another person (e.g. parent or clinician). One item tests whether the patient in the precontemplation stage: "Other people think I have an eating disorder, but I don't". In a study of 34 persons with eating disorders (including 15 anorexia nervosa outpatients), 29.4% of them were in the precontemplation stage; that group also exhibited body image disturbances. The Attitudes towards Change in Eating Disorders (ACTA) (Beato-Fernández & Rodríguez-Cano 2003) is a self-rating instrument containing 10 items pertaining to precontemplation, e.g. "I am not ill, I only do not want to be fat". After testing 186 women with eating disorders (outpatients, including 48 subjects with anorexia nervosa), all ten items were assigned to the same factor.

Nordbø et al. (2012) studied reluctance to recover in patients with anorexia nervosa using a phenomenological, descriptive, and qualitative study design (Moustakas 1994) with elements of grounded theory (Strauss & Corbin 2008). In-depth phenomenological interviews were conducted with 36 anorexic women. Seven core obstacles were found to interfere with their wish to recover: "perceiving judgements", "feeling stuck", "feeling distressed", "denying illness", "eating", "gaining weight", and "appreciating the benefits". Nordbø et al. (2012) concluded that the wish to recover was a fundamental motivational requirement for becoming ready to change.

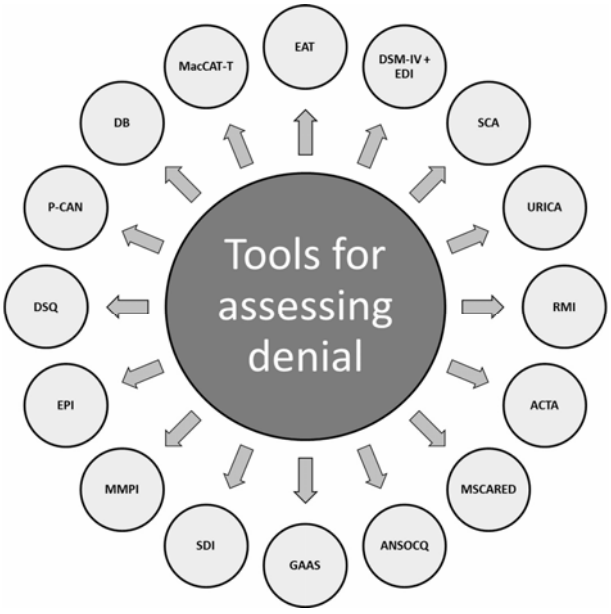
In contrast to URICA, RMI, ANSOCQ, MSCARED, and ACTA, which assess motivation and readiness to change based on TMC, the Decisional Balance Scale (DB) (Cockell et al. 2002) and the Pros and Cons of Anorexia Nervosa Scale (P-CAN) (Serpell et al. 2004) are based on analyzing benefits and burdens in anorexia nervosa. DB is a self-report questionnaire consisting of 30 items that can be rated on a 5-point Likert scale where 1 is "not at all true", and 5 is "completely true". DB contains three subscales: benefits, burdens, and functional avoidance. The benefits subscale lists 8 items dealing with self-control, being very thin, and striving for perfection. The burden subscale consists of 15 items dealing with social isolation, negative affect, and loss of energy. The functional avoidance subscale has 7 items reflecting the way that anorexia nervosa helps to avoid dealing with adverse emotions, challenges, and responsibilities. Cockell et al. (2003) used this instrument in a study of 80 female anorexic inpatients. It was found that relative to individuals in precontemplation, those in the contemplation stage reported more disadvantages of anorexia nervosa (higher burdens) and more insight regarding how anorexia nervosa helps to avoid negative feelings (i.e., higher functional avoidance). The Pros and Cons of Anorexia Nervosa Scale (P-CAN) (Serpell et al. 2004) is another self-report instrument measuring positive and negative aspects of anorexia nervosa. It was derived from thematic analyses of therapeutic letters of patients suffering from this disorder (Serpell et al. 1999) and gives insight into the perceived pros and cons of the patient's illness. P-CAN has 10 subscales: six of them are pro-anorexia (safe/structure, appearance, fertility/sexuality, fitness, communicate, emotions/distress, and specialness) and the remaining four are con-anorexia (trapped, guilt, hatred, and stifles emotions). Each item has five possible answers "agree strongly", "agree moderately", "neither agree nor disagree", "disagree moderately", and "disagree strongly". Serpell et al. (2004) suggests that the strength of the pro-subscales was related to the severity of anorexia nervosa. A study of 233 women with anorexia nervosa revealed that P-CAN is a useful tool for the measurement of attitudes towards AN and offers insights into the maintenance of the disorder. Additionally, Serpell et al. (2003) found significant differences between the P-CAN scores of children/adolescents and those of adults; namely, younger patients have a tendency to score lower on some subscales ("specialness", "stifles emotions", and "trapped"). The benefits and burdens subscales of DB can be viewed as equivalent to the pros and cons of P-CAN.

To enable the application of P-CAN to individuals with bulimia nervosa, some subscales dealing with bingeing and purging were added to the Pros and Cons of Eating Disorders Scale (P-CED*)* and the term "anorexia nervosa" was substituted by "eating disorder" (Gale et al. 2006).

Another interesting review of research on motivation to change in eating disorders was published by Hoetze (2013), who analyzed 15 studies investigating the psychometric properties of different assessment tools of motivation to change in eating disorders These instruments can be divided into those assessing the stages of change according to the TMC (6 instruments: RMI, ANSOCQ, BNSOCQ, EDSOCQ, MSCARED, RMQ) and those evaluating decisional balance (3 instruments: DB, P-CAN, P-CED). Overall, the psychometric properties of those instruments appeared to be satisfactory to good.

One should also mention other tools that indirectly test denial of illness in eating disorders. Engel and Wilms (1986) constructed a scale for patients and therapists measuring the degree of motivation, including the "pressure of suffering" (acceptance of help which results from the awareness of suffering) and "understanding and feeling of being ill" (the rational and emotional awareness of illness). Unfortunately, the psychometric properties (reliability and validity) of this instrument were not determined due to an insufficient

number of patients tested. Yet another measure in this field is the Goldberg Anorectic Attitudes Scale GAAS (Goldberg et al. 1980), which contains a "denial of illness" factor with four items, e.g. "Yes, I did lose some weight but not enough for everybody to get as worried as they did". A follow-up study on 105 patients with anorexia nervosa showed that the weaker the denial intensity, the greater the weight gain. The Self-Disclosure Index (SDI) (Miller et al. 1983) is designed to investigate willingness to share one's feelings and thoughts with others. Respondents are asked to provide information about how much time they spend talking to others about their habits, anxiety, traits they dislike in others, etc. Unfortunately, this instrument has not been applied in studies of eating disordered patients. Still, it should be borne in mind that it might represent a pitfall for researchers as the evaluation of self-disclosure itself is dependent on the honesty of the interviewed subject (Vandereycken 2006a). Another similar measure, the Self-Disclosure Scale, has not been used on patients with eating disorders to date, either (Vandereycken 2006a).



Legend: ACTA – Attitudes towards Change in Eating Disorders, ANSOCQ – Anorexia Nervosa Stages of Change Questionnaire, DB – Decisional Balance Scale, DSM-IV – Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, DSQ – Defense Style Questionnaire, EAT – Eating Attitudes Test, EDI – Eating Disorder Inventory, EPI – Eysenck Personality Inventory, GAAS – Goldberg Anorectic Attitudes Scale, MacCAT-T – MacArthur Competence Assessment Tool for Treatment, MMPI – Minnesota Multiphasic Personality Inventory, MSCARED – Motivational Stages of Change for Adolescents Recovering from an Eating Disorder, P-CAN – Pros and Cons of Anorexia Nervosa Scale, RMI – Readiness and Motivation Interview, SCA – Stages of Change Algorithm, SDI – Self-Disclosure Index, URICA – University of Rhode-Island Change Assessment Scale

Figure 2. Direct and indirect tools used for assessing denial

Other indirect methods of investigating denial of illness involve so-called "lie scales" in instruments such as the Minnesota Multiphasic Personality Inventory (MMPI) (Hathaway & McKinley 1943), the Eysenck Personality Inventory (EPI) (Eysenck & Eysenck 1963), and the Defense Style Questionnaire (DSQ) (Bond 1992).

Furthermore, the identification of denial of illness may be facilitated by tools for the assessment of a patient's capacity or competence to make treatment decisions, e.g. the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (Grisso & Appelbaum 1998). At the beginning of the test, the patient is shown a script that contains information on the disorder (i.e., anorexia nervosa) and treatment options. Subsequently, the researcher conducts a structured interview using a three-point scale to mark her/his own evaluation of such aspects of the patient's attitude toward illness as understanding, reasoning, and appreciation of illness. In a study by Tan et al. (2003b) 8 out of 10 patients with anorexia nervosa exhibited an understanding of the disorder, its consequences, and treatment options. Unfortunately, according to Melamed et al. (2003) "hard-core[3] patients are even capable, after months or years of hospitalizations, of intellectualizing that they are too thin and of quoting which exact dietary regimes they should follow. Thus, in competency testing procedures, they often score normally, while in reality, their daily behavior regarding nutrition is inappropriate".

The instruments discussed above are also shown in Figure 2.

METHODS OF OVERCOMING DENIAL OF ILLNESS

According to Vandereycken (2006a), "a crucial element in denial assessment is the inherent conflict of perception between patient and health care professional". This problem concerns the issue of social desirability, which is a well-known notion in psychology. The tendency to "fake good" or to present oneself in socially favorable light becomes particularly pronounced in the case of questions of personal nature. The research method itself may play a major role; for instance, during an interview the patient may be very embarrassed talking about the symptoms of anorexia nervosa, which in turn may result in "face to face" denial (Vandereycken 2006a). Furthermore, the more the interviewer persuades the patient to make confessions (Vandereycken 2006b), the more the patient resists a "sick role" (Vandereycken 2006b). Therefore, it is recommended that investigators should be authentic (Hope et al. 2011, Wright & Hacking 2011, Abbate-Daga et al. 2013) and as gentle as possible in interviewing eating disordered patients (Mitchell & Peterson 2008). On the other hand, self-report questionnaires afford more privacy while answering questions, which may translate into greater honesty of responses (Wolk et al. 2005, see also Fairburn & Beglin 1994, Black & Wilson 1996, Mitchell & Peterson 2008).

[3] Those who very strongly resist treatment

Finally, of utmost importance is the patient's trust in the researcher, as well as an appropriate explanation of the nature of the illness to the patient. As Vandereycken (2006b) aptly put it, "we can trust these patients as far as they can trust us". Very good results may be achieved by a combination of competence and empathy (Vandereycken 2006b, Mitchell & Peterson 2008). Abbate-Daga et al. (2013), who selected and analysed 71 articles concerning resistance to treatment and change in anorexia nervosa, formulated the following conclusion: "Treating resistant patients is a long and winding road entailing inevitable multiple problems in the therapeutic alliance. A secure and firm relationship and the avoidance of premature interpretations and arrogant approaches are both effective elements in fostering a positive therapeutic relationship".

METHODS OF OBTAINING RELIABLE INFORMATION FROM INDIVIDUALS WITH EATING DISORDERS AND ELIMINATING THE DENIAL OF ILLNESS EFFECT

Researchers have been looking for ways to "bypass" (Vitousek et al. 1991) the pitfalls associated with the influence of denial of illness on the data obtained from patients with eating disorders. Some have proposed that studies should focus on recovered subjects, who could frankly talk about their experiences of illness, or on persons who do not undergo treatment, especially in clinics, as treated patients are likely to exhibit so-called "captive mentality" (Vitousek et al. 1991) and firmly oppose any attempts at gaining insight into their internal world. Researchers also advise the use of third-person questions, which tend to be perceived as less threatening than direct questions to the patient. Finally, it has been suggested that the role of the researcher should be kept separate from that of the therapist: patients are likely to be more honest if they are confident that the interviewer is an "outsider" with respect to their therapy (Vitousek et al. 1991), and thus their responses will not affect the course of treatment. On the other hand, some patients may take advantage of the fact that the researcher (in contrast to the therapist or medical personnel) does not know their condition, and manipulate their answers. In turn, the proposal to reward patients for honest answers (usually with certain privileges during hospitalization) is questionable both on ethical and methodological grounds as nobody can guarantee that such an approach will increase the openness of patients.

Other interesting research alternatives are behavioral techniques, e.g. self-confrontation with mirror or videotape images or feeling one's own arm to realize how thin it is. In recent years, in response to the controversy over the use of self-report instruments for eating disorders, some researchers have suggested the use of techniques derived from experimental cognitive psychology, which are "less transparent" (Vitousek & Hollon 1990, Faunce 2002) or "nonobvious" (Vitousek & Hollon 1990) to the subjects as compared to the traditional questionnaires or interviews, and are thus "uncontaminated" (Vitousek & Hollon 1990) by the subjects' concern for their weight or other aspects of eating disorders, including the fear of opening oneself up. Such techniques, which are aimed at "determining what one really thinks and feels, or what one's thoughts are now focused on, are much more objective and reproducible. They are based on computer measurements of subtle changes in reaction times or involve processing of material presented below the threshold of conscious perception" (Krejtz & Sędek 2001). Such techniques include the Stroop color-naming task (e.g. Dobson & Dozois 2004) and the dot-probe task (e.g. Shafran et al. 2007). Also the Repertory Grid has been successfully used in studies on eating disordered individuals (Fransella & Button 1983), even though this tool does not measure reaction times.

CONCLUSIONS

Testing individuals with an eating disorder is always daunting not only for the researcher, but also for the subjects. Thus, one should make sure that the efforts of both parties are not wasted by eliminating the adverse effects of denial of illness on data.

The presented review of the literature shows that denial of illness, which is commonplace in anorexia nervosa, may lead to unreliable data obtained from the patients. To prevent such methodological artifacts, researchers have developed a number of methods directly or indirectly identifying denial of illness in those individuals. More reports have been devoted to indirect tools, and especially those designed to evaluate the patient's readiness and motivation to change, wish to recover, perceived benefits and burdens of the illness, and engagement in continuing treatment.

Thus, it is recommended that some less transparent methods of assessing the psychological state of the patient be used along with self-report instruments. As Mischel aptly observed (1981, cited in Vitousek et al. 1991), "we may find that we stand to learn a great deal from our subjects if we can begin to ask them the right questions in the right ways".

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Małgorzata Starzomska was involved in gathering literature for the preparation of the manuscript and in preparing the manuscript;
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References

1. *Abbate-Daga G, Amianto F, Delsedime N, De-Bacco C & Fassino S: Resistance to treatment and change in anorexia nervosa [corrected]: a clinical overview. BMC Psychiatry 2013; 13:294.*
2. *Ackard DM, Croll JK, Richter S, Adlis S & Wonderlich A: A self-report instrument measuring readiness to change disordered eating behaviors: the Eating Disorders Stage of Change. Eat Weight Disord 2009; 14:66-76.*
3. *Beato-Fernández L & Rodríguez-Cano T: Attitudes towards change in eating disorders (ACTA). Development and psychometric properties. Actas Esp Psiquiatr 2003; 31:111-9.*
4. *Black CMD & Wilson GT: Assessment of eating disorders: Interview versus questionnaire. Int J Eat Disord 1996; 20:43-50.*
5. *Blake W, Turnbull S & Treasure J: Stages and processes of change in eating disorders: Implications for therapy. Clin Psychol Psychother 1997; 4:186-91.*
6. *Bond M: An empirical study of defensive styles: The Defense Style Questionnaire. In Vaillant GE (ed): Ego mechanisms of defense: A guide for clinicians and researchers, 127-158. American Psychiatric Press, Inc., Washington, DC, 1992.*
7. *Bruch H: The golden cage. The enigma of anorexia nervosa. Harvard University Press, Cambridge, MA, 1978.*
8. *Casper RC, Offer D & Ostrov E: The self-image of adolescents with acute anorexia nervosa. J Pediatr 1981; 98:656-61.*
9. *Casper RC: The psychopathology of anorexia nervosa: The pathological psychodynamic processes. In Beumont PJV, Burrows GD & Casper RC (eds): Handbook of eating disorders. Part 1: Anorexia and bulimia nervosa, 159-169. Elsevier, Amsterdam - New York, 1987.*
10. *Cockell SJ, Geller J & Linden W: The development of a decisional balance scale for anorexia nervosa. Eur Eat Disord Rev 2002; 10:359-75.*
11. *Cockell SJ, Geller J & Linden W: Decisional balance in anorexia nervosa: capitalizing on ambivalence. Eur Eat Disord Rev 2003; 11:75–89.*
12. *Cooper Z & Fairburn CG: The Eating Disorder Examination: a semistructured interview for the assessment of the specific psychopathology of eating disorders. Int J Eat Disord 1987; 6:1-8.*
13. *Diagnostic and statistical manual of mental disorders, 4th Edition, text revison (DSM-IV-TR). American Psychiatric Association, Washington, DC, 2000.*
14. *Diagnostic and statistical manual of mental disorders, 5th Edition (DSM-V). American Psychiatric Association, Washington, DC, 2013.*
15. *Dobson KS & Dozois DJA: Attentional biases in eating disorders: A meta-analytic review of Stroop performance. Clin Psychol Rev 2004; 23:1001-22.*
16. *Engel K & Wilms H: Therapy motivation in anorexia nervosa: theory and first empirical results. Psychother Psychosom 1986; 46:161-70.*
17. *Eysenck HJ & Eysenck SBG: The Eysenck Personality Inventory (EPI). Educational and Industrial Testing Service, San Diego, 1963.*
18. *Fairburn CG & Beglin SJ: Assessment of eating disorders: Interview or self-report questionnaire? Int J Eat Disord 1994; 16:363-70.*
19. *Faunce GJ: Eating disorders and attentional bias: A review. Eat Disord 2002; 10:125-39.*
20. *Fransella F & Button E: The „construing" of self and body size in relation to maintenance of weight gain in anorexia nervosa. In Darby PL, Garfinkel PE, Garner DM & Coscina DV (eds): Anorexia nervosa. Recent developments in research, 107-16. Alan R. Liss, New York, 1983.*
21. *Gale C, Holliday J, Troop NA, Serpell L & Treasure J: The pros and cons of change in individuals with eating disorders: a broader perspective. Int J Eat Disord 2006; 1:394-403.*
22. *Garner DM, Olmstead M & Polivy J: Development and validation of a multidimensional eating disorder inventory for anorexia nervosa and bulimia. Int J Eat Disord 1983; 2:15-34.*
23. *Garner DM & Garfinkel PE: The Eating Attitudes Test: An index of the symptoms of anorexia nervosa. Psychol Med 1979; 9: 273-9.*
24. *Garner DM: Eating Disorder Inventory-2 Manual. Psychological Assessment Resources, Odessa, FL, 1991.*
25. *Geller J, Drab-Hudson DL, Whisenhunt BL & Srikameswaran S: Readiness to change dietary restriction predicts outcomes in the eating disorders. Eat Disord 2004; 12:209-24.*
26. *Geller J, Brown KE, Srikameswaran S, Piper W & Dunn EC: The psychometric properties of the Readiness and Motivation Questionnaire: a symptom-specific measure of readiness for change in the eating disorders. Psychol Assess 2013; 25: 759-68.*
27. *Geller J & Drab DL: The Readiness and Motivation Interview: A symptom specific measure of readiness for change in the eating disorders. Eur Eat Disord Rev 1999; 7:259-78.*
28. *Giles GM. Anorexia nervosa and bulimia: An activity-oriented approach. Am J Occup Ther 1985; 39:510-17.*
29. *Goldberg SC, Halmi KA, Eckert ED, Casper RC, Davis JM & Roper M: Attitudinal dimensions in anorexia nervosa. J Psychiatr Res 1980; 15:239-51.*
30. *Greenfeld DG, Anyan WR, Hobart M, Quinlan DM & Plantes M: Insight into illness and outcome in anorexia nervosa. Int J Eat Disord 1991; 10:101-9.*
31. *Grisso T & Appelbaum PS: MacArthur Competence Assessment Tool for Treatment (MacCAT-T). Oxford University Press, Sarasota, 1998.*
32. *Gusella J, Butler G, Nichols L & Bird D: A brief questionnaire to assess readiness to change in adolescents with eating disorders: its application to group therapy. Eur Eat Disord Rev 2003; 11:58-71.*
33. *Halmi KA: Anorexia nervosa: demographic and clinical features in 94 cases. Psychosom Med 1974; 36: 18-26.*
34. *Hasler G, Delsignore A, Milos G, Buddeberg C & Schnyder U: Application of Prochaska's transtheoretical model of change to patients with eating disorders. J Psychosom Res 2004; 57: 67-72.*
35. *Hathaway SR & McKinley JC: Manual for the Minnesota Multiphasic Personality Inventory. Psychological Corporation, New York, 1943.*
36. *Hebebrand J, Casper R, Treasure J & Schweiger U: The need to revise the diagnostic criteria for anorexia nervosa. J Neural Transm 2004; 111: 827-40.*
37. *Hoek HW: Review of the epidemiological studies of eating disorders. Int Rev Psychiatr 1993; 5:61-74.*
38. *Hoetzel K, von Brachel R, Schlossmacher L & Vocks S: Assessing motivation to change in eating disorders: a systematic review. J Eat Disord 2013; 1:38.*
39. *Hope T, Tan J, Stewart A & Fitzpatrick R: Anorexia nervosa and the language of authenticity. Hastings Cent Rep 2011; 41:19-29.*
40. *Krejtz I & Sędek G: Pitfalls of unconscious processing of emotional content [In Polish]. In Ohme RK, Jarymowicz M & Reykowski J (eds): Automatisms in processes of information processing, 135-152. Institute of Psychology, Polish Academy of Sciences, Higher School of Social Psychology, Warsaw, 2001.*

41. Martínez E, Castro J, Bigorra A, Morer A, Calvo R, Vila M et al.: Assessing motivation to change in bulimia nervosa: the bulimia nervosa stages of change questionnaire. Eur Eat Disord Rev 2007; 1:13-23.
42. McConnaughy EA, DiClemente CC, Prochaska JO & Velicer WF: Stages of change in psychotherapy: A follow-up report. Psychotherapy 1989; 26:494-503.
43. Merskey H: Malingering, self-damage and anorexia nervosa. In Merskey H (ed): The analysis of hysteria. Understanding conversion and dissociation, 91-111. Gaskell, London, 1995.
44. Miller LC, Berg JH & Archer RL: Openers: Individuals who elicit intimate self-disclosure. J Pers Soc Psychol 1983; 44:1234-44.
45. Mitchell JE & Peterson CB: Assessment of Eating Disorders. The Guilford Press, New York, 2008.
46. Melamed Y, Mester R, Margolin J & Kalian M: Involuntary treatment of anorexia nervosa. Int J Law Psychiatry 2003; 26:617-26.
47. Moustakas C: Phenomenological research methods. Sage, Thousand Oaks, CA, 1994.
48. Newton T, Butler N & Slade P: Denial of symptoms and self-report in eating disorders. Br Rev Bul Anor Nerv 1988; 2:55-9.
49. Noordenbos G: Important factors in the process of recovery according to patients with anorexia nervosa. In Herzog W, Deter HC & Vandereycken W (eds): The course of eating disorders. Long term follow-up studies of anorexia and bulimia nervosa, 304-323. Springer Verlag, Berlin-Heidelberg, 1992.
50. Nordbø RHS, Espeset EMS, Gulliksen KS, Skårderud F, Geller J & Holte A: Reluctance to Recover in Anorexia Nervosa Eur Eat Disorders Rev 2012; 20: 60-7.
51. Prochaska J: Systems of psychotherapy: A transtheoretical analysis. Dorsey Press, Homewood, IL, 1979.
52. Prochaska JO & DiClemente CC: The transtheoretical approach: crossing traditional boundaries of therapy. Dow Jones-Irwin, Homewood, IL, 1984.
53. Prochaska JO, DiClemente CC & Norcross JC: In search of how people change: Application to addictive behaviour. Am Psychol 1992; 9:1102-14.
54. Prochaska JO & DiClemente CC: Stages and processes of self-change in smoking: Toward an integrative model of change. J Consult Clin Psychol 1983; 51:390-5.
55. Pryor TL, Johnson T, Wiederman MW & Boswell DL: The clinical significance of symptom denial among women with anorexia nervosa: Another disposable myth? Eat Disord J Treat Prev 1995; 3:293-303.
56. Rieger E, Touyz S, Schotte D, Beumont P, Russell J, Clarke S et al.: Development of an instrument to assess readiness to recover in anorexia nervosa. Int J Eat Disord 2000; 28:387-96.
57. Segal ZV: Appraisal of the self-schema construct in cognitive models of depression. Psychol Bull 1988; 103:147-62.
58. Serpell L, Neiderman M, Haworth E, Emmanueli F & Lask B: The use of pros and cons of anorexia nervosa (P-CAN) scale with children and adolescents. J Psychosom Res 2003; 54: 567-71.
59. Serpell L, Teasdale JD, Troop NA & Treasure J: The development of the PCAN, a measure to operationalize the pros and cons of anorexia nervosa. Int J Eat Disord 2004; 4:416-33.
60. Serpell L, Treasure J, Teasdale J & Sullivan V: Anorexia nervosa: Friend or foe? A qualitative analysis of the themes expressed in letters written by anorexia nervosa patients. Int J Eat Disord 1999; 25:177-86.
61. Shafran R, Lee M, Cooper Z, Palmer RL & Fairburn CG: Attentional bias in eating disorders. Int J Eat Disord 2007; 40:369-80.
62. Shaw BF & Garfinkel PE: Research problems in eating disorders. Int J Eat Disord 1990; 9: 545–55.
63. Strauss A & Corbin J: Basics of qualitative research. Techniques to developing grounded theory. Sage, Los Angeles, CA, 2008.
64. Tadeusiewicz R: Ways and pathless tracts of statistics in scientific research [In Polish]. In Statistics for scientific research, 43-50. StatSoft, Krakow, 2000.
65. Tan JOA, Hope T & Steward A: Anorexia nervosa and personal identity: The accounts of patients and their parents. Int J Law Psychiatry 2003a; 26:533-48.
66. Tan JOA, Hope T & Steward A: Competence to refuse treatment in anorexia nervosa. Int J Law Psychiatry 2003b; 26:697-707.
67. Vandereycken W: Denial of illness in anorexia nervosa – a conceptual review: Part 1 Diagnostic significance and assessment. Eur Eat Disord Rev 2006a; 14:341-51.
68. Vandereycken W: Denial of illness in anorexia nervosa – a conceptual review: Part 2 Different forms and meanings. Eur Eat Disord Rev 2006b; 14:352-68.
69. Vandereycken W & Vanderlinden J: Denial of illness and the use of self-reporting measures in anorexia nervosa patients. Int J Eat Disord 1983; 2:101-7.
70. Vitousek KB, Daly J & Heiser C: Reconstructing the internal world of the eating disordered individual: Overcoming denial and distortion in self-report. Int J Eat Disord 1991; 10:647-66.
71. Vitousek KB & Hollon SD: The investigation of schematic content and processing in eating disorders. Cog Ther Res 1990; 14:191-214.
72. Vitousek KB & Manke F: Personality variables and disorders in anorexia nervosa and bulimia nervosa. J Abnorm Psychol 1994; 103: 137-47.
73. Vitousek KB & Orimoto L: Cognitive-behavioral models of anorexia nervosa, bulimia nervosa and obesity. In Dobson KS & Kendall PC (eds): Psychopathology and cognition, 191-234. Academic Press, San Diego, 1993.
74. Vitousek KB, Watson S & Wilson GT: Enhancing motivation for change in treatment-resistant eating disorders. Clin Psychol Rev 1998; 18:391-420.
75. Williamson DA, Anderson DA, Jackman LP & Jackson SR: Assessment of eating disordered thoughts, feelings, and behaviors. In Allison DB (ed): Handbook of assessment methods for eating behaviors and weight-related problems, 347-386. Sage, London, 1995.
76. Wolk SL, Loeb KL & Walsh BT: Assessment of patients with anorexia nervosa: Interview versus self-report. Int J Eat Disord 2005; 37:92-9.
77. Wright KM & Hacking S: An angel on my shoulder: a study of relationships between women with anorexia and healthcare professionals. J Psychiatr Ment Health Nurs 2012; 19:107-15.

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