Controversial issues concerning the concept of palliative care of anorexic patients

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Summary

Anorexia is a grave and often fatal illness. Death rates would undoubtedly be higher if anorexics were not force-fed once their weight became dangerously low. A very important feature distinguishing anorexia from other mental disorders is highly ambivalent attitude of sufferers to their own illness. On the one hand, anorexic individuals seem to accept their progressing malnutrition, which supports suggestions of researchers that egosyntonicity which refers to the patients' sense of the anorexia nervosa being a part of themselves or of their identity, is a fundamental aspect of this disorder. Thus denial and resistance towards treatment, which are frequent among anorexic patients represent their conscious attempts to preserve its egosyntonic symptomatology. On the other hand, a lot of researchers underline destructiveness of anorexia, namely it not only doesn't give happiness, but also restricts the anorexic person's life to one dimension: in this context she/he can't derive satisfaction from another resource than the more and more mechanic, obsessive self-starving, which finally leads to exhaustion and desire for death. Some researchers ask whether anorexic patients can actually make competent decisions about their quality of life. If so, then the decision to refuse therapy may be on a par with other decisions to refuse life-prolonging therapy made by sufferers of debilitating chronic, or acute onset terminal illness. The aim of the article is to answer a question if data concerning the quality of life among anorexic individuals justify a proposition of palliative care over these persons.

anorexia nervosa / quality of life / mortality / egosyntonicity / palliative care

INTRODUCTION

Anorexia is a mental disorder that, along with bulimia, binge eating disorder and obesity, is recognised among eating disorders. According to the Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (DSM-IV-TR) [1], there are four diagnostic criteria for anorexia: (1) refusal to maintain body weight above a minimally normal weight for age and height; (2) intense fear of gaining weight or becoming fat, even though being underweight; (3) disturbance in the way in which one's body weight, size or shape is experienced, for instance an individual can claim that they are fat, even if emaciated; (4) the absence of menstrual cycles i.e. amenorrhea, and loss of libido in men. On the other hand, the tenth revision of the International Statistical Classification of Diseases and Related Health Problems, known under the abbreviated name of ICD-10 [2], gives similar diagnostic criteria for anorexia, yet describes it as anorexia nervosa, and also states that in anorexia a dread of fatness and flabbiness of body contour is an intrusive overvalued idea, making patients impose a low weight threshold/standard on themselves. There is no doubt that the quality of life of anorexic patients is considerably lowered due to
cachexia, and the resulting serious impediment of mental and social functioning of such patients [3, 4, 5, 6]. This is a very significant issue, which has become even more important in the context of the proposal of Heather Draper of the Centre for Biomedical Ethics, The University of Birmingham [7], to replace traditional treatment of anorexic patients with palliative care. The author’s proposal reminds us of the controversy of whether the lack of appetite in cancer patients should be referred to as anorexia (the precise international term to refer to anorexia in cancer is cachexia-anorexia) [8]. Again, researchers who are considering the current proposal, automatically object to suggesting any similarity between a mental (or, according to some researchers, psychosomatic) illness [9] such as anorexia, to a physical illness such as cancer, this time by using the phrase “palliative care”. It should be added here that some studies on anorexia actually mention the “terminal stage” while discussing this disorder, which also brings to mind unavoidable associations with the terminal stage of cancer [10]. Draper’s proposal [7] seems to be controversial enough, in that it cannot be ignored. The problem of an approach of anorexic patients to their own illness is so highly specific that before we can embark on an assessment of the palliative care proposal, we should carefully follow through the researcher’s line of thought, and find out whether her suggestions are justified or not. An important aim of this paper is to present the most important aspects of the quality of life of anorexic patients and to assess the palliative care proposal in the light of the most recent publications on the subject. The most important question that this paper is asking is: Can anorexia, at least in some cases, be called an incurable illness, and if so, would palliative care be an optimum solution of the problem?

Biological consequences of anorexia and reasons for the high mortality rate of anorexic patients

One of the important aspects of anorexia that determines patients’ quality of life consists in the serious physical and mental consequences of this illness. Undoubtedly, the course of anorexia may be moderate (experimenting with diets, moderately distorted perception of the body) or severe (destructive diets, life-long starving of oneself). In the most extreme and chronic cases, such drastic interference in the correct functioning of the body leads to numerous adverse biological changes; with time, the damage to internal organs, teeth and bones becomes irreversible [10]. Joseph A. Silverman [11] lists such biological consequences of anorexia as: hypotension, bradycardia, dizziness, fainting and vascular collapse with a possible fatal effect. On the other hand, Kathryn J. Zerbe [9] mentions the following somatic consequences of anorexia: osteoporosis, anaemia, bradycardia, arrhythmia, sleeplessness and optic nerve atrophy. What is more, anorexic patients are prone to infections and often display effusions and bruises related to capillary permeability [11]. Dolores Moyano et al. [12] mention that a frequent symptom in anorexic patients resulting from malnutrition is the antioxidant status. Some authors point to the fact that there are other, apparently unnoticeable, changes in the bodies of anorexic patients that may actually make their functioning more difficult. Among important medical consequences of weight loss in anorexia, Andreas Karwautz et al. [13] name autophonia i.e. the hyperperception of one’s own voice and breathing, resulting from the patulous Eustachian tube lacking fat tissue. Undoubtedly, the most dangerous consequence of emaciation is cardiovascular disorders [14, cf. 15].

Anorexia is often mentioned as a psychiatric illness, with a high mortality rate [16]. According to Pamela K. Keel et al., a very frequent consequence of eating disorders is premature death [16]. Anorexia is considered to be an illness with the highest mortality rate of all psychiatric illnesses [17]. According to the most recent reports, as many as 4% to 20% patients die [7, 10, 18, 19, 20]. It should also be mentioned here that although short-term catamneses report relatively low mortality rates (from zero to a few percent), long-term catamneses, many years after the occurrence of the illness, show that the mortality rate among anorexic patients is really high [21]. Among the reasons for this high mortality rate in this group of patients, numerous biological and psychological factors are mentioned. The most frequently reported direct causes of death in anorexia are the following ones (all resulting from cachexia and associated electrolytic...
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[20] and cardiovascular [22] disorders): congestive heart failure [23], asymptomatic pericardial effusion [24, 25] and myocardial infarction as a final stage of coronary thrombosis [23]. Some reports also mention sudden deaths resulting from pulmonary embolism and deep vein thrombosis [26]. Other frequent cause of death in anorexia (yet much less frequently compared to cardiovascular diseases) is suicide [16, 17, 20, 22, 25]. Another significant cause of death among anorexic patients is alcohol intoxication [16].

Is anorexia a chronic illness?

The question whether anorexia is a chronic and curable illness has always given rise to controversy, and the answer to it is actually very difficult. This question may refer to both physical and mental aspects of this illness. According to Alessandra Lemma-Wright [27], the recovery rate in anorexic patients fluctuates between 23% and 86%. Jacinta Tan et al. [28], in turn, are of the opinion that up to 25% of anorexic patients never fully recover. Yet, considering the group of surviving patients (as a rule, those individuals who are considered cured), we should ask: - what are the later fates of the surviving patients suffering from anorexia? According to Angel Padierna et al. [4], eating disorders, even if they do not bring fatal consequences, still determine psychological, physical and social aspects of life and tend to become chronic. This is most frequently expressed by periods of remission, alternating with recurrences. Hans-Christoph Steinhausen [29], after the reviewing and analysing 119 descriptions of studies involving 5,590 subjects, concluded that the mortality rate in anorexia is high, but also that from the surviving patients, less than a half managed to recover, a third improved, and a fifth remained chronically ill. On the other hand, the studies of Craig L. Johnson et al. [30] led to the finding that in 50% of the anorexic patients, symptoms subside after 1-3 years and such individuals never require hospital treatment again, while 75%–90% of anorexic patients actually recover. Examining the patients whose health considerably improves, most frequently due to hospital treatment, has led the authors to the conclusion that the cure rate for anorexia is 90%, while the remaining 10% of patients are given unfavourable prognoses, this being chronic illness and/or death. According to Alessandra Lemma-Wright [27], the recovery rate in anorexic patients fluctuates between 23% and 86%. Lucy Serpell et al. [31] are of the opinion that anorexia is a chronic illness with an unknown aetiology and an acute course [32]. Padierna et al. [4] reach similar conclusions. According to Deborah L. Finfgeld [33], both anorexic patients who failed to regain weight, and those who were successful in this respect, experience chronic problems, such as low self-esteem and perceived inefficiency [34, 35]. If we assume that chronicity of anorexia means lingering mental problems, even when there are no external symptoms of anorexia such as cachexia, we should acknowledge the truth of Michael Strober’s [37] statement that anorexia “is a chronic illness in a substantial number of cases” (p. 247).

Reasons for chronicity of anorexia

Undoubtedly, one of the most important reasons for chronicity of anorexia is the illness-specific mechanism of a vicious circle. On the one hand, we can mention a number of psychological factors that undoubtedly lead to anorexic behaviours. These include low self-esteem [34, 35, 38], social anxieties with a particularly heightened sense of shame [39] and general ill-being. We should mention here the endorphin hypothesis, according to which anorexia can be treated as an addiction to increased levels of endorphins, i.e. endogenic opioid substances, which produce a sense of well-being. Such endorphins are released, among others, during physical exercise [40]. On the other hand, anorexia impairs the functioning of the patient in a number of fields of everyday life. Pierre Beumont and Terry Carney [41] list the following psychological consequences of anorexia: dysphoria, irritation, social withdrawal, loss of libido, ruminations and rituals related to eating, reduced concentration and a depressive mood. Researchers emphasise that anorexic patients’ depression is related to their eating disorder in itself. In other words, depression is a consequence of the systemic cachexia [42, 43] or a reaction to treatment and the ensuing weight gain [44]. In the context
of the discussion concerning curability of anorexia, authors present varied opinions as to the degree to which the illness impairs social functioning. Yuval Melamed et al. [45] claim that in spite of the fact that anorexic patients are seemingly capable of rational judgment and functioning, as regards their work or education, while the field of body weight, diet and acceptance of medical care seems to be the only area impaired by the illness, in fact “If one area of the reality testing capability is damaged, most probably all other testing functions are attacked too” [45, p. 622]. An important aspect of anorexia, which undoubtedly impacts on the course of the illness, including persistence of symptoms, is the phenomenon called “egosyntonicity” [28, p. 537; 46, p. 702], which refers to the patients’ perception that the illness is a part of their identity; some authors talk about a phenomenon of the “slim identity” [47, p. 113] of an anorexic person or about the patient’s identity split into two, when one half of the person wants recovery, and the other desires to be ill [17]. Probably, this characteristic of anorexia allows them to recognise it, along with bulimia, among “the most treatment-resistant mental disorders” [48, p. 164], because, as Strober claims, in the first place, patients suffering from chronic anorexia oppose the change [37]. In this context, it seems obvious that mere weight gain does not equal improvement of the patient’s mental condition or actual recovery [45]. Draper [7] emphasises that feeding alone with no psychotherapy may even aggravate the symptoms; Simon G. Gowers et al. [49] think likewise, stating that hospital treatment with extra feeding and no intensive psychological programme can worsen the patient’s condition or even result in their premature death. Findings of the study by Firouzeh Mehran et al. [50], using Osgood’s semantic differential model, have shown that anorexic patients who gain weight but do not undergo any psychotherapy display worsened mental functioning in the sense of perceiving themselves as less worthy than before the treatment. It is not infrequent for such persons to attempt suicide.

Mental functioning of anorexic patients

Elżbieta Nitendel-Bujakowa [38], based on the studies involving thirty-eight anorexic and thirty-eight healthy girls aged between 13 and 21, and using the Polish version of the Gießen-Test (created by Beckmann, Brähler and Richter in 1964 and adapted by Andrzej Januszewski in 1992) has shown that anorexic girls think that they are socially unattractive and unpopular and feel that the others despise and criticise them. Moreover, they consider themselves unable to “get what they want”. Undoubtedly, in this group we deal with distorted and lowered self-perception. Moreover, such people are not interested in their looks, and describe their mood as depressive, while emphasising a lack of self-confidence, self-criticism and suppressing anger. Inhibition in social interactions in these girls, manifesting itself as social anxiety as well as self-restraint in showing feelings and needs, is a characteristic feature of anorexic patients, which is confirmed by both the patients and their parents [38]. The following section of the paper will describe the most important aspects of anorexic patients’ mental functioning.

Firstly, such persons are characterised by low self-esteem and a fear of imposing themselves on others. Not only do they think that they do not deserve to reveal their needs or receive help but they do not even have the right to live [51]. According to Beumont and Carney [41], anorexic persons are convinced that “they do not have the right to live or expect anything” (p. 824). Similar are the findings of Ronald Manley and Pierre Leichner [17] and Walter Vandereycken [52]: anorexic people think that they do not deserve to receive help, and are of opinion that “others can have needs but they can’t” (p. 33). A sense of guilt among such people is “frequent and paradoxical” [41, p. 824]. For instance, they feel guilty when they do not eat and do exercise, and when they eat and do not do exercise [41]. Secondly, anorexic people very often experience both helplessness and hopelessness. Symptoms of anorexia can last for many years, which is why those who suffer from this illness are often afraid that they will never be able to get over its impact on their lives. Studies by Joanna Holliday et al. [53] have shown that anorexic people consider their illness – contrary to the people from their environment, and, less often, therapists [54] – a chronic and highly stressful illness with serious negative consequences. Patients with anorexia are absolutely negative about the
controllability and curability of their illness, contrary to the more optimistic views of other people. Losing friends, gradually lowering educational and/or sports achievements or a limited level of activity, coupled with the experience-based conclusion that recovering will probably be a long and difficult process, may adversely influence the person’s strength to fight the illness and their hope for recovery. In the course of subsequent therapeutic attempts, the patient may repeatedly come to the point when they feel exhausted and are unable to see a chance of health improvement, especially when, as we have already mentioned above, they are “split” inside, and at the same time want and do not want to recover. Clinicians should be aware that this attitude may also result from the patient’s fear that their anorexia is going to “severely punish them for any progress towards recovery” [17, p. 33; 55, p. 258]. In this context, suicidal tendencies may be perceived as an indication of the lost hope for change [17]. Thirdly, anorexic patients are strongly ambivalent as regards their recovery, as they feel the aforementioned egosyntonicity of anorexia. Such ambivalence manifests itself as a fear of treatment, and distrust or even hostility towards doctors and therapists that, according to the anorexic patient, try to “deprive them” [17, p. 34] of certain convictions (being slim is the most important thing) and behaviour (starving oneself) which have been their stress coping mechanisms so far. Fourthly, anorexic people are ambivalent in the assessment of their illness. Numerous researchers point to a tragic situation of an individual with anorexia. Anorexic people live with a permanent fear of putting on weight, which equals failure. They often emphasise that they “would rather die than put on weight” [41, p. 824]. For an anorexic person, being emaciated becomes an obsession, “a target on its own, not a way to achieve happiness” [41, p. 824]. Manley and Leichner [17] share this opinion too: the existence of such people revolves around the subjects of calories, exercise, concerns for bodily shape and weight, and with time becomes reduced to the routine and extremely predictable. In this context, we can understand what Mary Levens had in mind while describing the mental condition of anorexic patients as “devastating emptiness” [56, p. 36]. A clear confirmation of such experience is the following statement of one of the patients: “It’s terrible, but anorexia is the most important thing in my life …” [46, p. 702]; “I can’t stop starving myself. I don’t want to and I wouldn’t be able to” [46, p. 703]. Beaumont and Carney [41] emphasise that anorexic people often feel the urge to punish themselves by strenuous exercise, and if they neglect such practices, they feel “disgusted with themselves and guilty” (p. 824). It seems that to describe the mental condition of anorexic patients, we should quote the title of the text that we have referred to many times in this paper, i.e. Manley and Leichner’s [17] “Anguish and despair”. As Manley and Leichner [17] state, self-injuries and suicidal attempts of anorexic patients spring from deep pain and despair. It should be emphasised, however, that, especially at the onset of anorexia, self-injuries [57, 58] and suicidal attempts are not aimed at taking one’s life [45]. The reason is that, although anorexia brings suffering to an individual, reports of both researchers and anorexic people deny that anorexia is a destructive force. On the contrary, it seems to give a sense of worthiness, power, success and even immortality. Anorexic people are often perceived as “delighted, inspired, joyful, proud and strong” [59, p. 223]. A pioneer of anorexia research, Charles Lasègue was quite surprised to notice a peculiar quality of anorexic patients, that he called “inexhaustible optimism” [52; p. 341, 342]. On the other hand, Grace Nicolle talks about a “specific euphoric state” and “pathological energy” [52, p. 342] in anorexic individuals. Such feelings are illustrated by the following statement of an anorexic person: “When I step on the scales and see that I have lost weight, I feel happy all day” [46, p. 702]. When asked about their condition, an anorexic individual would most frequently say: - “I have never felt better in my life” [52, p. 342] or state: “I don’t suffer, so how can I be ill?” [52, p. 341]. “I’m not ill, so I don’t need help” [52, p. 350]. Anorexic patients treat their illness as their best friend [10]. Undoubtedly, any such individual “defines their ‘self’ by a decision not to eat” [27, p. 39], and in fact considers such behaviour as the only way of their existence in the world [10]. This aspect of anorexia can also be seen in a following statement of an anorexic individual: “Without anorexia, I would be nobody/nothing” [27, p. 39]. According to Margery Gans and William B.
Gunn [10] anorexia is an existential illness, which means that a suffering individual derives a fundamental meaning, satisfaction and the reason to live from losing weight. In the context of all the aforementioned positive aspects of anorexia as perceived by a suffering individual, we can understand the opinion of Malamed [45] that although “patients do not make active suicidal attempts, they remain indifferent to their own self-destructive behaviour” (p. 622). It seems, however, that there comes the time when anorexic people start to consider dying for real (as a result of starving themselves or suicide), thinking that death will be the only solution to get out of the vicious circle in which they are stuck. According to Arthur Crisp, such thoughts appear when the only aim of an ill person is “to have a rest from unending terror and exhaust in a fight to retain their position” [7, p. 132], whereas the word “position” in this context should be understood as “identity”. We should quote here a sentence that illustrates such a situation: “An anorexic person is caught in a cruel trap. They refuse to eat in order to preserve their identity but in order to survive they have to eat, which is felt as a betrayal of themselves” [27, p. 55]. An anorexic patient feels gradually more and more tired of the illness and stops believing that the situation can ever change [28, 53]. As the illness continues, anorexic persons become more and more aware that anorexia will not bring them happiness because a consequence of this illness is being “very lonely and very unhappy” [28, p. 543]. One of the patients described by Gans and Gunn [10] doubted whether she would ever be able to live a normal life even when she returned to her previous weight. She was of the opinion that her reasons for refusal to undergo treatment were both mental (she claimed that putting on weight aroused some unbearable feelings leading to the wish for death) and physical (the person was aware of irreversible damage that emaciation had brought to some of her bodily organs, making her permanently disabled). She claimed that she wanted comfort and peace in a place like a hospice; then she started to make preparations for her own funeral, emphasising that she would not commit suicide, as she knew how deeply affected her family had been by the suicidal death of her cousin.

Findings of the Research on the Impact of Anorexia on the Patients’ Quality of Life

Patients suffering from eating disorders (including anorexia), their relatives and doctors all agree that the illness has a highly destructive impact on physical health, social and family relations, as well as their mood, studies and work [6]. The aim of the study of Padierna et al. [4] was to examine the relationship between the Health-Related Quality of Life – HRQoL in outpatients with eating disorders, and the symptomatology of eating disorders and psychological co-morbidity. The authors examined 197 patients who were subsequently admitted to the outpatients’ clinic for eating disorders (diagnoses: restrictive anorexia, purgative anorexia, bulimia and binge eating). In order to examine various aspects of the Health-Related Quality of Life, the following were used: 36-item HRQoL (Health-Related Quality of Life) questionnaire – SF-36 (Short Form – 36 items – Likert scale with the range of 0 – 100; the higher the result, the better the patient’s condition and their quality of life); EAT-40 (Eating Attitudes Test – 40 items); and HAD (Hospital Anxiety and Depression Scale). It was shown that female patients with eating disorders are much more dysfunctional in many areas of the quality of life (as measured with the SF-36 questionnaire) than healthy women. The greatest negative changes were observed in the following subscales: vitality (energy/fatigue), emotional problems limiting current social functions, social activity and mental health; some less significant but still important changes were observed in the following subscales: health problems limiting physical activity, health problems that prevent the patients from serving their previous social functions, and the general assessment of the patients’ condition (results obtained by Padierna et al. on the questionnaire scales: EAT-40 and HAD were positively correlated with the results obtained using the SF-36). Similar results using the SF-36 questionnaire were obtained by Helen A. Doll et al. [60] and Simone M. de la Rie et al. [61]. As Padierna et al. state [4], the results obtained by his research group are similar to the research findings of Matthias Keilen et al. [3], using the NHP (Nottingham Health Profile), namely, the most significant worsening of the quality of life was observed in the following dimensions: emotional reactions and social alienation,
which corresponds to the mental health dimension in the SF-36 questionnaire. Additionally, the researchers observed a worse functioning as regards life energy (vitality in SF-36) and in the dimension not included in SF-36 i.e. sleeping disorders. Moreover, the researchers discovered disturbances in completing everyday duties because of physical limitations, which correspond to health problems limiting the physical activity in SF-36. Last but not least, anorexic patients experienced greater difficulty in family and social relationships than bulimic patients did. It should be added here that negative changes in emotional reactions of anorexic patients were also observed by Zonnevylle-Bender et al. [62] and Kucharska-Pietura et al. [63]. The studies on the quality of life of anorexic patients [3, 4, 60, 61, 62, 63] confirm the impact of eating disorders on the health-related quality of life in terms of various areas of life unrelated to eating itself. It should be emphasised that purging in anorexia results in significant lowering of the quality of life of an anorexic person (especially in the mental sphere) [4, 64]. Findings of the research on the quality of life of people with eating disorders (including anorexia) have shown that these individuals are distinctly aware that their quality of life is getting worse due to their bad physical condition, as regards their work and everyday activities (moreover – which is a very interesting observation – they complain about particularly severe experiences of physical pain due to a lower pain threshold). Such results are similar to the findings of the studies including schizophrenic patients; still the quality of life of people with eating disorders seems to be lower than among people with advanced depression [61] and panic disorder [65]. It should be added that social functioning of patients does not improve even when the symptoms of their disorder become milder after the completion of treatment [65]. Such results, however, should not discourage clinicians from looking for optimum methods of anorexia treatment, because, as we have already mentioned in this paper, anorexic patients are rather ambivalent than explicitly negative about the prospect of treatment, and it is their tiredness of the illness, not its acceptance, that produces the death wish. We should keep in mind that an important factor in anorexic patients, which may obstruct any motivation to undergo treatment, is anxiety (especially social anxiety) [66, 67]. In the opinion of Anna Banas et al. [5], comprehensive treatment that combines state-of-the-art developments in medicine [68, 69] (especially in pharmacotherapy) and psychotherapy [70], focused on mitigation of the existing anxiety, may be very successful in improving the quality of life of anorexic patients and bring a lasting therapeutic effect.

Introduction of palliative care of anorexic patients: Discussion

In the context of deliberations on chronicity of anorexia and the illness-related suffering, it becomes inevitable to ask a question about the sense of treatment and a possibility to replace it with palliative care. Padierna et al. [4] assess highly the usefulness of the SF-36 tool for measurement of the quality of life of people with eating disorders (it should be added that Suzanne F. Abraham et al. created a 20-item tool for measurement of the quality of life of people with eating disorders: Quality of Life for Eating Disorders (QOL ED), which differentiates finely between people with various types of eating disorders, while the SF-36 questionnaire had no such functions) [71], claiming that the tool “reflects the self-awareness of the lowered quality of life among patients with eating disorders. SF-36 also informs the patients about the impact of the illness on their quality of life” (p. 672). At the same time, the researcher adds: - “Consequently, SF-36 can be a therapeutic tool for using in the patients’ recovery process” (p. 672). At the same time, the author is of the opinion that “Another potential role [for the tool] is indicating a direction and measuring efficiency of palliative methods in treatment of chronically ill patients in order to justify and assess the use of such methods” (p. 672). The researcher that thoroughly examines a palliative care option for some anorexic patients is Draper [7]. She states: - “Without doubt, it is a terrible thing to watch somebody – especially a young person – die, if their life could be easily saved. However, if we want to do justice to the suffering people who can live neither with their illness nor without it, we have to listen intently to their refusal of treatment” (p. 133). Tan and al. [72] emphasise that some of
the patients, especially those who have been battling against anorexia for years, and some mothers of such people are of the opinion that if anorexia becomes chronic and does not respond to treatment, and a suffering person goes beyond a certain critical point, they should be allowed to “leave” [72, p. 641]. Draper [7] tries to establish which point is by asking the following question: “Can an anorexic person withdraw from treatment not because they do not want to eat or feel ‘fat’ but because their quality of life is so low that the therapy is of no use, and at its best brings as many benefits as losses?” (p. 122). Than the author asks: “If a patient refuses to participate in the treatment not because they think that their condition is not severe but because they are tired of the therapy and its side effects, can they choose death?” (p. 131). According to Manley and Leichner [17], “While in treatment, a patient can now and then come to the point when they feel exhausted and no longer able continue their battle against the illness” (p. 33). As Draper [7] says, such difficult cases are not typical, yet “we should bear in mind that some people suffering from anorexia will probably never recover or even be able to live a stable life by maintaining the low but constant body weight” [7, p. 131]. Undoubtedly, when a person suffering from anorexia chooses death, this creates a serious ethical dilemma for their family and people involved in the treatment. Draper [7] suggests that the palliative approach should be applied to patients who have been ill for a very long time (for longer than 1-8 years i.e. the natural cycle of the illness), who have already been force-fed, are critical about making decisions concerning their own lives, are able to see the impact of anorexia on certain aspects of their lives, and whose lives are not at direct risk. According to the researcher, in such cases the refusal of therapy is analogous to “the decision to refuse the life-prolonging therapy in the case of patients suffering from disabling, chronic or acute terminal illnesses; consequently, in such cases palliative treatment could be a justified replacement for the aggressive therapy” (p. 122).

When a patient in full possession of their mental faculties refuses treatment, no matter whether they are terminally ill or just choose to die, a doctor should accept it [7]. Undoubtedly, a suggestive statement is a comparison proposed by Gans and Gunn [10], referring to the difference between a 20-year old woman that is secretly starving herself and a 50-year old woman with chronic anorexia, exhausted by hospital and clinic stays and various medical appointments. Gans and Gunn [10] wonder whether there is a point when clinicians abandon hope that the patient will change their attitude, and have come to the conclusion that they are unable to continue in their treatment attempts that have always proved a failure? They may think in this way:— if no method to fully cure anorexia has been found so far, why should they hope that the next attempt is going to be successful? [10]. Obviously, we can consider sending a patient to a better, private treatment centre, yet the question comes up: who is going to be charged for this? On the other hand, the treatment of a long-term disability of anorexic patients is expensive too [73]. Such questions seem to be highly problematic. Can we really resign from saving lives only because we feel discouraged or we cannot always afford high-level therapy? Should we always do whatever is possible to save somebody’s life? Some researchers openly criticise the concept of palliative care of anorexic patients. Malamed et al. [45] do not doubt that “Anorexia is not an incurable and progressing terminal illness.” (p. 621); frequently, therapy is aimed at partial recovery only, and one must take into account recurrences, especially in chronic cases, but this is actually the reason why clinicians should focus, in the first place, on saving the lives of anorexic patients. The palliative care proposal is also considered disputable by Rosalyn A. Griffiths et al. [44]. They argue that in spite of particular difficulties of anorexia treatment, those who survive are “deeply grateful” (p. 530) to the doctors who have helped them. Gans and Gunn [10] take an even more definitive stand on the issue, by saying that if an anorexic person dies, there will be no chance for recovery whatsoever.

CONCLUSION

The studies have shown that anorexia contributes to the drastic lowering of the patients’ quality of life. Yet, egosyntonicity of this illness makes any effective therapy difficult for both patients and clinicians. Patients that are tired

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with the illness and therapists that are discouraged with the treatment-resistance of anorexia, suggest that in some most difficult and chronic cases, therapy should be ceased and replaced with palliative care. However, when we examine Draper’s [7] statement that at least some anorexic patients can be capable of a rational decision to refuse treatment (even if they are a minority among the suffering individuals), at least two doubts appear. Firstly, as for now there is no tool that would allow studying the rationality of decisions that are made by anorexic patients [46, 74, 75], and, what is more, “Currently used rationality measurement criteria (...) do not identify the aspects that characterize rationality of the treatment related decision-making of anorexic patients” [46, p. 706]. Secondly, some patients will never have a chance to thank their doctors and psychologists for their assistance in the most serious stage of the illness.

Finally, it must be noticed that all suggestions of palliative care in the case of anorexic patients are essentially existential, but state-of-art medical literature suggests that anorexia can be successfully treated, for example by using cognitive interventions. Moreover, a lot of studies were dedicated to neurobiological functioning of anorexic patients. The study of Suchan et.al.[76] revealed that structural alterations in the EBA (extrastriate body area which is located in the lateral occipital cortex) in anorexic patients might be at least in part responsible for the body image distortion in anorexia nervosa. Similarly, Sachdev et.al. [77] showed that the brain processing of an image of self was different in the brains of anorexic patients than in the case of control subjects. When the two groups were contrasted for the differential activation with self vs. non-self-images, anorexic patients did not have greater activation in any region while controls had greater activation than the patients in the middle frontal gyri, insula, precuneus, and occipital regions while thus processing of self-images in anorexic patients is quite discrepant, with a lack of activation of the attentional system or the insula. The authors suggest that such discrepancy may underlie the distortion of self-images by anorexic patients. Thus contemporary medicine has not uttered its ”last word” in this regard.

REFERENCES


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Important dates:
June 2010 ..................... Second Announcement
January 20, 2011 ............ Deadline for abstract submission
March 15, 2011 .............. Notification of acceptance
April 15, 2011 ............... Deadline for early registration

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