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Mental Health Practice: evidence & practice

Exploring the factors that affect quality of life in women with severe and enduring anorexia nervosa

Laura Schut, Karen Margaret Wright and Jean Ellen Duckworth

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Abstract

Background Anorexia nervosa is a severe psychiatric disorder characterised by starvation and malnutrition. In severe and enduring anorexia nervosa, individuals may be unable to overcome their persistent ruminations about their weight, food intake and body shape, so interventions may be required that focus on quality of life rather than each manifestation of the condition

Aim To identify which factors are responsible for a reduced quality of life in people with severe and enduring anorexia.

Method Constructivist grounded theory was used. Eight women with severe and enduring anorexia were interviewed.

Findings Data relating to quality of life issues to define four theoretical categories: connective tissue; suffering, but not in silence; one step forward, one step backwards; and best friend, best enemy. Four key messages appeared from the data: recognise suffering as a continual affect for people with severe and enduring anorexia, and that it reduces their quality of life, largely due to its inextricable link with the person's identity; recognition of the 'adaptation versus rejection of the anorexic grip', a cyclical process; recognising the effects of severe and enduring anorexia on family and friends; and the need for an approach which recognised that we need to adjust our perspective on care to one that is more assertive, rather than one that relies upon requests for help'.

Conclusion Education for nurses, patients and family, assertive outreach treatment, the use of therapy dogs and the establishment of structured days including social and family activities are recommended.

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Keywords

Anorexia nervosa, assertive outreach, eating disorders, mental health, mental health therapies, patient outcomes, patients, professional, quality of life

Background

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association 2013) defines anorexia nervosa as a 'severe psychiatric disorder characterised by starvation and malnutrition, experiencing an intense fear of weight gain, a high prevalence of coexisting psychiatric conditions, marked treatment resistance or no response to treatment, frequent medical complications, and a substantial risk of death'.

Roux et al (2013) identified that the prevalence of anorexia in women aged between 11 years and 65 years in non-clinical population ranges from 0 to 2.2%, with a lifetime prevalence of 0.3% among men. Only around 50% of these patients will fully recover from anorexia (Royal College of Psychiatrists 2019) and there is a mortality rate of between 10% and 15% (Brown and Mehler 2015). Residual issues are likely for many (Harbottle et al 2008) and around 20% will relapse and go on to develop severe and enduring anorexia (Thornton et al 2016)

This study aimed to consider the quality of life of women with severe and enduring anorexia residing in a serious eating disorder unit in the Netherlands. This unit uses a model which is replicated across the UK and much of Europe and aligns with the National Institute for Health and Care Excellence (NICE) (2017) guidance, as well as the Dutch Guidelines for Eating Disorders (GGZ Standaarden 2017). Inpatient care is largely focused on weight restoration using carefully monitored refeeding protocols for physical stabilisation – particularly if electrolyte abnormalities, cardiac arrhythmias, indications of organ failure or dehydration are identified – with an aim to restore patients' weight by providing structured, symptom-focused treatment, monitoring their physical status and using psychological therapy (NICE 2017, Bargiacchi et al 2019). Such treatment is often challenging for individuals to tolerate, so their quality of life may be significantly affected (Touyz and Hay 2015).

Severe and enduring anorexia nervosa

There are no formal criteria for severe and enduring anorexia, although it has been suggested that it is better defined by a person's use of services, rather than a list of criteria (Robinson 2014). Hay and Touyz (2018) suggested a duration of >3 years, whereas Wonderlich et al (2020) suggested that treatment resistance and a person's readiness for change might be a more reliable measure. Anorexia is typically driven by a motivation for thinness rather than recovery-focused activities, so it can effectively reinforce an individual's resistance to change. All participants were identified as experiencing 'severe and enduring anorexia nervosa' because the terms 'chronic' and 'treatment resistant' are viewed negatively by people with the condition, and this may negatively affect their motivation for recovery (Broomfield et al 2017). Therefore, we [have coined the term 'anorexic grip', which describes this experience in a way that is acceptable to these patients while recognising the hold that their condition has over them, to the extent that it slows, interrupts or prevents their recovery.

Severe and enduring anorexia causes significant 'suffering' and can be seen as a burden to others, thus negatively affecting an individual's social and family life (Striegel-Moore et al 2008, Touyz et al 2013, Robinson 2014, Wonderlich et al 2020). Social isolation and dissatisfaction occur in multiple areas of their

lives and relationships, affecting their financial and social status (Touyz et al 2013), potentially leading to social and physical health issues.

The treatment of anorexia focuses on an individual's physical and psychological recovery. More positive treatment outcomes have been reported in younger women (Lock 2015, Agras et al 2017), so such individuals rarely meet the threshold for severe and enduring anorexia (Touyz et al 2013). However, those with long-term experiences may be unable to overcome their persistent ruminations about their weight, food intake and body shape, which are frequently overwhelming (Touyz et al 2013). Therefore, such complexity requires different and sustained interventions (Touyz and Hay 2015) which focus on the person's quality of life, rather than attempting to treat every manifestation of the condition (Strober 2010, Williams et al 2010).

Severe and enduring anorexia occurs as a result of complex co-occurring conditions. Such examples are the other conditions that occur as a result of long-term malnourishment: perfectionism and osteoporosis, but this is well known and the text which follows also provides further insight, and involves obsessive thoughts about one's body image, food intake and weight that leads to reduced psychological and social well-being (Touyz et al 2013, Wonderlich et al 2020). Serious neuropsychological dysfunction can occur as a result of long-term malnutrition (Robinson 2014), as well as multiple life-threatening physical issues such as cardiac arrhythmias and renal dysfunction (Brown and Mehler 2015).

In the Netherlands, approximately 20 % of the people diagnosed with anorexia develop a severe and enduring condition (Steinhausen, 2002). (GGZ Standaarden 2017) [although only those most severely affected by their condition receive treatment from serious eating disorder units. Furthermore, the enduring nature of the condition, alongside the recognition that full recovery is rarely possible, led us to consider that partial recovery, with a quality of life that enables independent living and survival, may be a more realistic goal for many people.

In the Netherlands, people with anorexia receive group therapy often led by experts by experience (rivierduinen.nl, ggnet.nl/amarum, altrecht.nl). Two serious eating disorder units offer inpatient treatment for severe and enduring anorexia, based on the principles of specialist supportive clinical management (SSCM) (Touyz et al 2013, McIntosh 2015, Jordan et al 2020). SSCM aims to improve motivation and enhance their quality of life to aid recovery from core anorexia pathology (Touyz et al 2013). SSCM approaches include physical care, psychoeducation and psychotherapy to enhance people's confidence and engagement in treatment. To date, there has been limited research into quality-of-life issues for people experiencing severe and enduring anorexia, and none in the Netherlands that used a qualitative approach only.

Aim

The aim of this study was to identify which factors are responsible for a reduced quality of life in people with severe and enduring anorexia. The objectives were:

- » To provide new insights into the life experiences of people diagnosed with severe and enduring anorexia.
- » To apply this new knowledge to acquire a deeper understanding of the illness.

- » To empower people with severe and enduring anorexia, as well as their family members and friends, to improve their social integration.
- » To identify strategies for improving the quality of life for women with severe and enduring anorexia.

Method

Constructivist grounded theory methodology was used, which places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants (Charmaz, 2006: p. 130). This approach enabled both participant and researcher perspectives (Charmaz 2006, 2017, 2020), since the lead researcher was a clinical nurse lead within the service. This choice considered possible ethical issues regarding the fact that potential interviewees might feel obliged to participate in the study because of their familiarity with the lead researcher. Therefore, ethical approval was sought, memo writing and frequent debriefing with the research team were undertaken to reduce the risk of coercion and bias.

Semi-structured interviews were conducted and recorded in a private room within the inpatient unit. Memos enabled reflection on observations made following the interview and these were considered at the point of analysis. Regular research supervision and debriefing assured fidelity of the methodology and strengthened the credibility of the inductive constructivist grounded theory.

A literature review was undertaken after the interviews to protect the study against bias based on previous research, and so that any new issues raised during the interviews could be included. The interviews were semi-structured, with questions that were developed further to include constructs and topics derived from the participants' perspectives. These are known as 'sensitising concepts' because they sensitise the researcher to areas of potential inquiry (Charmaz 2006).

Recruitment and participant characteristics

The study focused solely on women who experienced severe and enduring anorexia, so purposive sampling was used from within a 15-bedded hospital serious eating disorder unit, because grounded theory does not require a representative sample, but rather that people are recruited because of their experience of the phenomena and there is a notable lack of research on this population. The participants met the following criteria:

- » Diagnosed with anorexia for >7 years or longer.
- » Received a minimum of one common treatment such as guided refeeding in an inpatient setting, family therapy, cognitive behaviour therapy, from an eating disorder specialist therapist.
- » Over the age of 18 years.

After interviewing eight women, it was deemed that the data saturation point had been reached, since no new findings were emerging (Charmaz 2006), so no further participants were invited to take part in the study. The eight women who participated in the study were aged between 20 years and 43 years, with an average age of 34 years. All of the participants had been diagnosed with anorexia, five of whom had of the 'purging' type, while the other three had the 'restrictive' type. The length of time in treatment ranged from 6 years to 20 years, with an average of nearly 11 years in treatment, and all the participants had co-occurring

conditions. Six participants had a co-occurring diagnosis of a personality disorder, one participant had been diagnosed with autistic spectrum disorder and the remaining participant had been diagnosed with social phobia. Of the eight participants, half were in employment, and one was a student. Sadly, one participant – ‘Sandy’ – died before the publication of this study.

Data collection and analysis

The data analysis occurred simultaneously with the data collection, employing a process of constant comparison at each stage (Charmaz 2006). All interviews were transcribed verbatim and were pseudonymised. The document files were then stored in a password-protected MAXQDA software program.

Initial line-by-line coding of the data created ‘sets’ which were re-read repeatedly, and meaningful words or sentences were identified as *in vivo* codes (Charmaz 2006). Once the data had been split into broader categories, these were labelled ‘early groups’ before the data was organised according to the situational and social contexts.

Early focused coding was used during the iterative process, and theoretical codes developed. At each stage of the process, the data set was scrutinised first by the lead researcher [Q LS?]A. Yes) and then two other researchers, thus generating the properties of each theoretical category. Here, Charmaz’s approach follows that of Glaser (1978) which enables the theoretical significance to emerge, using axial coding and establishing the ‘coding family’ when expanding on the theoretical codes to frame findings without being too rigid (Charmaz 2006, 2017, 2020). This approach enabled coherent and comprehensive analysis.

Ethical considerations

Ethical approval was granted by the ethics committee of the University of Central Lancashire] and by the ethics committee of the Erasmus University the Netherlands

Findings

Data relating to quality-of-life issues were organised to define four theoretical categories and several properties associated with each of these. It was recognised that there was some overlap between these categories. Table 1 shows the theoretical categories and their properties.

Table 1. Theoretical categories and their properties

Theoretical category	Properties
Suffering, but not in silence	» Staying childlike » Being seen as a psychiatric patient » Self-image » ‘Addictive’ behaviour
One step forward, one step backwards	» Guilt and shame versus recovery and success » Innocence
Connective tissue	» Maintaining severe and enduring anorexia » Contacts and connections with others » Anorexia as a conductor
Best friend, best enemy	» Personification of anorexia

- » Blame attribution
- » Alignment to **therapists**

Suffering, but not in silence

This theoretical category presents four properties which identify how people with severe and enduring anorexia interact and construct behaviours to maintain involvement with their social world. The women disclosed that 'staying childlike' and 'being seen as a psychiatric patient' negatively influenced their self-image and 'addictive' behaviour. The women engaged with their social world through complex psychological processes, where they interpreted and gave meaning to interactions. For example, Sarah identified how she adopted a childlike approach to avoid rejection from but paradoxically entering the grip of the anorexia when she said that she would always be 'the girl with the eating disorder', a position which reduced her quality of life.

The next property related to coping with stigma and the concept of 'being seen as a psychiatric patient'. The participants considered themselves mentally ill or that society judged them to be mentally ill. The property of 'being the psychiatric patient' negatively affected their quality of life and thus influenced their daily functioning. The following participant quotes underpinned this property:

'I am not normal, I do things which aren't healthy, I walk like a fool, that's why I think I don't have the right to talk about it. I am not a holy person.' (Mariah)

'They treat me as a person with brain damage because of the anorexia.' (Sophie)

Thirdly, in exploring self-image, several participants described the development of self-hate and a negative self-image, which resulted in the loss of their unique personality and often felt 'burdensome' to them. One participant reported that she felt 'robbed' of her identity:

'I think that I've lost a part of my identity as a person, as Sophie, the eating disorder took a part of my identity, I do things I don't want to do but I have to.' (Sophie)

Finally, the fourth property, addictive behaviour, identified certain psychological and physical influences, which were comparable with experiences seen in substance misuse, such as obsessive exercise, binge eating followed by vomiting, although it is explicitly not the same as addictive behaviour. This caused a strengthening of, and dependency on, their severe and enduring anorexia, which also reduced their quality of life. Together, the four properties identified how the participants established and maintained their social circle through their condition. Sandy spoke about the burden of addiction to anorexic behaviours that made her feel like dying:

Interviewer: 'When was your eating disorder the strongest and how did it affect you?'

Sandy: 'Yeah, that's when I wanted to die...I was a slave, I wasn't in charge anymore, didn't dare to stand up, was afraid of everything. I was so tired, when I get out of my bed, the only thing I did was give attention to my eating disorder habits. I had to eat, vomit, eat, vomit, that's how my days passed.'

One step forward, one step backwards

There are two properties in this theoretical category: Innocence; Guilt & shame versus recovery and success.

The analysis revealed several core eating disorder beliefs and internal conflict among the participants. The properties of 'innocence' and 'guilt and shame versus recovery and success' appeared through a weight gain-weight loss continuum. They felt their anorexia controlled them and that they were stuck in a cyclical process where there was a delicate balance between 'guilt and shame' and 'the fear of weight gain'. Guilt and shame was associated with weight gain, weight loss, and is also strongly related to the anorexic voice which tells them to be lazy and to feel dirty if not given into, for example, exercise. Such conflict was a barrier to recovery.

Subsequently, the property of 'innocence' was revealed, which linked with the 'staying childlike' property revealed in the previous theoretical category and added to the factors that diminished participants' quality of life. For example, one participant assumed an innocent position by describing their anorexia as a 'puppeteer' and metaphorically blaming it in an attempt to stay in contact with her family, who were excluded by the condition:

Amy: 'If I remember it well, and the puppeteer, he rules the play.'

Interviewer: 'He directs everything?'

Amy: 'Yes, he takes care of the tragedy, and he also ties up my family and loved ones, he forces them to watch the play about my life, completely powerless.'

In the second property, multiple themes were explored, such as '**guilt and shame**' versus '**recovery and success**'. One participant felt that she had 'surrendered herself' to her condition:

'I feel very bad and guilty when I haven't done enough exercise and also fear, fear of gaining weight, the fear of getting fat, the fear of being rejected and even a piece of disgust over myself, I can feel that. Like I am really dirty, like I literally cannot be with myself. Thus, in order not to feel that scale of things, I surrender to the [eating disorder]. It is like a system, a mechanism.' (Sophie)

Connective tissue

'Connective tissue' explored the communication in the context of human contacts 'through' the SEED-AN condition, the category contains several properties and functions through the properties. The term is a metaphor for communication through the eating disorder condition.) Three properties were revealed in relation to the theoretical category of connective tissue: maintaining severe and enduring anorexia; contacts and connections with others; and anorexia as a conductor.

Communication issues were caused by the women's 'obedience' to their anorexia, and their wish to break free from it. The analysis revealed they frequently had complex, emotional and dynamic relationships with healthcare professionals and people in their social circle, as well as with the severe and enduring anorexia itself. One factor that enhanced quality of life and offered a reciprocal relationship was their therapy dog . which was allowed on the unit and provided companionship, comfort and did not judge them:

‘The dog pulls me out of the house. That’s a big difference. It’s firstly, let’s go outside and later, let’s eat. Instead of, like a fool, walking to the kitchen and survive through the eating disorder.’ (Sandy)

The fragile balance of relationships with other people and with their anorexia determined the first property of ‘maintaining the severe and enduring anorexia’, whereby social contacts were maintained through the condition. For example, one participant found that her anorexic voice which made sense to her:

‘The eating disorder solves it’ (Sandy)

The second property, ‘contacts and connections with others’, was both facilitating and eroding of their quality of life. Anorexia provided one participant with ‘connections’, but the opposite was observed for many participants, in that social contacts were excluded, resulting in isolation and a reduced quality of life, except when connecting with others experiencing severe and enduring anorexia .

‘My eating disorder is the main thing in having fewer social contacts, I am always “busy in my head”, with everything related to eating, I avoid social situations, and contacts which are supposed to be fun, but they are not.’ (Fiona)

‘Anorexia as a conductor’ was the third property identified, and it referred to the interfering power of the severe and enduring anorexia, as well as participants’ futile attempts to distance themselves from it. For example, one participant stated:

‘That is why [the anorexia] directs everything, even if I want to do something else. I am exhausted, too weak.’ (Amy)

Best friend, best enemy

This theoretical category was explored through the operationalisation of three properties. Firstly, the property of ‘personification of anorexia’, whereby severe and enduring anorexia was often seen by participants as a constant companion, despite its controlling nature. One participant referred to her condition as ‘a sniper’ . The excerpt from Sarah can be interpreted as a burden that she experiences: *‘It is a sniper who approaches me slowly and before I knew it, it was ingrained in my life’* (Sarah).

The second and the third properties found were ‘blame attribution’ and ‘alignment to therapists’, both of which maintain the severe and enduring anorexia. The SEED-AN condition is rejected by the community which implicate a strengthening of the dependency upon services and therapists. For example, one participant blamed her condition for the way she is treated by others:

‘As long as people know that I have anorexia, I see a difference in the way they look at me. Then, there will be judgment and prejudice and a distance right away. And I noticed that, in my direct social environment, they do not see me as the Sophie I was before I became ill, that was a long time ago. And now, they always treat me as a patient. And still, they treat me as a person with brain damage because of the anorexia.’ (Sophie)

For another participant, one nurse enabled her to feel accepted and to express herself:

‘Particularly in contact with the nurses, like before, I only wanted to talk with a few of them. But then, a new nurse started working, she gave me the feeling that I was welcome to share my story with her and the other nurses. That was so very important to me. And now, I talk to every nurse, discussing my problems. They are really interested in my story.’ (Fiona)

Discussion

The findings of this study provide a deeper understanding of how quality of life is affected by severe and enduring anorexia, including its effects on individuals’ identities and social circle. The many co-existing conditions required for a diagnosis of this condition further lower their quality of life, as do the necessary interventions (Bamford and Mountford 2012, Touyz et al 2013, Robinson et al 2015). Findings were compared with existing knowledge on the subject, and confirmed what is already known about severe and enduring anorexia from previous empirical research, and aligned with clinical guidelines (GGZ Standaarden 2017, NICE 2017). The social and psychological effects of severe and enduring anorexia on the participants’ quality of life determined the theoretical categories of the study. Four areas of impact emerged: changes in personality, the reality of the experience on the person, issues around communication and the alliance between the participants, their workers and their families.

While healthcare professionals often avoid using the term ‘suffering’ in practice, it is clear that these participants did suffer. The women were ‘suffering in silence’, except when a therapeutic relationship enabled authentic and compassionate expression (Wright 2010, 2013, Robinson 2014). Therefore, healthcare professionals should recognise suffering as a continual affect for people experiencing severe and enduring anorexia that reduces quality of life, due to its inextricable link with the person’s identity.

Despite progress being made in both Dutch and UK guidelines (GGZ Standaarden 2017, NICE 2017), challenges remain. A therapeutic alliance requires shared decision-making, but when the severe and enduring anorexia is ‘in control’, the perspectives of the patient and healthcare professional are not aligned (Wright 2010, 2013, Strober 2010). The women were unable to relinquish their disorder because treatment meant ‘surrendering’ their identity, thus detrimentally affecting their quality of life due to the ‘anorexic grip’. They existed [he risks and the conflict between the mind and the body (Malson 1998). Their quality of life is often reduced by the psychological conflict that they experience due to their condition, since it paradoxically offers them comfort and a sense of identity, but also harms them. Additionally, exercise dependence and intake restriction are controlling, destructive and challenging to withdraw from, not unlike an addiction, although anorexia is not an addiction in itself (Klein 2004, Barbarich-Marsteller et al 2011). Consequently, it was recognised that there was a cyclical process of ‘adaptation versus rejection of the anorexic grip’ because of the strive to adapt in the context of rejecting the one thing that they find offers them solace – the severe and enduring anorexia.

Severe and enduring anorexia can result in significant cognitive impairment resulting in dissonance and altered perceptions, enabling the anorexia voice to become stronger than the nurses’ and perpetuates the

‘one step forward and one step backwards’ scenario, as individuals attempt to move forward but are pulled back by the anorexic voice. The perpetual guilt and shame, alongside feeling powerless to resist the severe and enduring anorexia, was exhausting for participants. Therefore, providing therapy which is compassionate and challenges cognitive processes, such as cognitive behavioural therapy (CBT), is crucial (NICE 2017, Mitchell et al 2020). Uninformed nurses can fall into the unhelpful position of colluding with the patient’s distorted perceptions. Wright (2010) stated that establishing and maintaining therapeutic relationships can be increasingly challenging where there is disagreement about goals and therapeutical objectives. After all, nurses and patients live in a complex society influenced dieting, body size, and food intake (Wolfe and Gimby 2003). Gaining insight into the patient’s perspective enables professional, insightful and empathic responses.

It is also important to recognise the adverse effects on family and friends due to the lack of services for them, so psychoeducation should involve family and significant others. Shared decision-making enables the person experiencing severe and enduring anorexia to have some choice about treatment providers. In the Netherlands, each patient has a personal healthcare manager who is responsible for all the healthcare processes of the patient, and an assertive outreach model – the Flexible Assertive Community Treatment (FACT) model (www.f-actnederland.nl) – has been developed in recognition of the need for a more assertive outreach approach. By using the model, patients are able to stay in their personal environment which positively affects their sense of independence and empowerment rather than one that relies on requests for support.

The ‘childlike’ consequences of the experience – both physically and in terms of a psychological dependency on others, including the anorexia itself – creates a complex interpersonal dynamic that may be better aligned to focusing on quality of life, rather than recovery. It is a fine balance between prescriptive meal-planning, nurturing recovery, compassionate care and the need to promote independence in those who, when offered the choice, would choose their anorexia over their care plan, thus surrendering to the ‘anorexic grip’. Wright (2010) suggested that this is not unlike healthy parenting for nurses who nurture to promote eventual independence.

Limitations

This study was of a small group of women experiencing severe and enduring anorexia and serious psychiatric comorbidities in one serious eating disorder unit in the Netherlands. Within such a rich and in-depth qualitative study this is not unusual, and it seemed that the saturation point had been achieved. Ideally, other sources such as participants’ partners and family members would be included; however, time and resources considerations did not enable this.

Recommendations for practice

Four main messages emerged from the findings of this study:

- » Recognise suffering as a continual affect for people experiencing severe and enduring anorexia, and that it reduces their quality of life, largely due to its inextricable link with the person’s identity,
- » Recognise the cyclical process of adaptation versus rejection of the anorexic grip.

- » Recognise the effects of severe and enduring anorexia on an individual's family and friends.
- » Recognise the need for an approach to care that is more assertive and reaches out, rather than one that relies on requests for support.

This was a small study that has revealed some areas where **healthcare professionals, including nurses**, can aim to enhance the quality of life of this population, for example by raising awareness, providing more appropriate services and recognising therapeutic approaches that were deemed acceptable to the participants in this study.

Conclusion

This study identified how the quality of life of eight women in a serious eating disorder unit was affected by their severe and enduring anorexia. The study found that women experiencing this condition exhibit complex relationships and social interactions which create an identity that is inextricably linked with their diagnosis and is therefore challenging to move away from. We have named this the 'anorexic grip'. Guilt, fear, alienation from others and dependency on the anorexia all reduced patients' quality of life and resulted in barriers to their recovery.

Implications for practice

Six recommendations for nursing practice are made:

- » It should be a requirement for preregistration nurse education to include information about eating disorder.
- » Assertive outreach interventions, such as the FACT model, should be used.
- » Psychoeducation should be offered to patients and family.
- » It is important to establish a structure to patients' days that includes their social contacts and hobbies.
- » Family-orientated meetings should be held with patients' family members and significant others.
- » The possibility for therapy dogs to be present in all serious eating disorder units should be considered.

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