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Severe and Enduring Eating Disorders: Concepts and Management

Paul Robinson

Abstract

The concept of severe and enduring mental illness was introduced in 1999 in order to direct resources to patients suffering from long-term serious disorders, and was suggested for eating disorders in 2009. However, the term is still restricted to patients with long-term psychosis. In this chapter, the concept of severe and enduring eating disorder (SEED) is described and its relevance to anorexia nervosa (AN) and bulimia nervosa (BN) is explored. The recovery curve for anorexia nervosa seems to follow an exponential pattern with an asymptote that approaches but does not meet the horizontal, suggesting that recovery is always possible. Symptoms of AN but not BN seem to worsen after 3 years of illness, perhaps a significant threshold. Symptoms of severe and enduring AN (SEED-AN) are debilitating and longstanding as well as potentially fatal. Symptoms of severe and enduring BN (SEED-BN) are also debilitating, especially in social adjustment. In both conditions, family difficulties are prominent. A clinical approach to SEED is described based on improving quality of life, the recovery approach, (rather than cure) for sufferers and their families is described, although full symptomatic recovery can occur at any stage and clinicians should be alert to the possibility in all patients.

Keywords: anorexia nervosa, bulimia, chronic, severe and enduring, recovery model

1. Introduction

The idea of severe and enduring mental illness (SEMI) extends back to 1999 when the UK Department of Health published the National Service Framework [1]. In it, SEMI was defined as follows:

“People with recurrent or severe and enduring mental illness, for example schizophrenia, bipolar affective disorder or organic mental disorder, severe anxiety disorders or severe eating disorders, have complex needs which may require the continuing care of specialist mental health services working effectively with other agencies.”

Clearly it was intended, rightly, to include non-psychotic disorders such as eating disorders and obsessive-compulsive disorder. Since that time policy has changed, perhaps because of increasing demands on community psychiatric

services due to bed closures and funding restrictions and the most recent definition is very restrictive. In 2018, the National Institute for Clinical and Care Excellence (NICE) [2] released the draft scope for SEMI and stated: “the groups that will be covered are *Adults (aged 18 years and older) with complex psychosis*”. Ruggeri et al. [3] provided two sets of criteria that reflect this tension: 1. Diagnosis of psychosis, 2. Duration of service contact ≥ 2 years, 3. GAF (Global Assessment of Functioning) score, < 50 and a second model only including the latter two criteria, hence including non-psychotic disorders (including eating disorders).

In this context in which access to services could be restricted by psychiatric teams on the basis that the patient did not have a severe and enduring mental illness, the author wrote a book entitled *Severe and Enduring Eating Disorders* [4] partly in an attempt to draw attention to the ongoing major problems experienced by people with long term eating disorders. In this chapter we will examine the SEMI concept as applied to eating disorders, review the symptoms experienced by SEED patients and look at the differences between different eating disorders, which have lasted for many years. In the last section, recommendations for management of SEED will be made.

2. Definitions and concepts

Eating disorders have been fully described in the DSM 5 [5] and these definitions will not be considered here. However, the questions of duration and severity do give rise to controversy and although the term “Severe and Enduring” has been applied to eating disorders [4, 6], the precise length of history and severity required are still undecided.

2.1 Length of illness

This can be approached in a number of ways. One is to ask the question: At what point do eating disorders become significantly harder to treat? This is an important question, because if we knew the answer, we could make all possible efforts to begin treatment before that point. Unfortunately there is rather little evidence to guide us, although it has been suggested [7] that after 3 years of illness, anorexia nervosa may become more intractable. This is based on a randomised controlled study of anorexia nervosa [8] in which patients with a length of history of restricting anorexia nervosa of < 3 years did significantly better in family therapy than patients with a longer history. Another approach is to look at the proportion of patients who still fulfil criteria for the disorder at different times after onset. In **Table 1**, a number of studies in which this proportion is reported are displayed. In each study, the proportion of patients with a “poor outcome” is noted in the 5th column. The proportion includes all deaths, as well as patients with a poor outcome due to reasons other than the eating disorder, so the measure is somewhat flawed. However, the proportion after 9–24 years (average 13.4 years) ranges from 12 to 59%, average 27.9%. This tells us that the proportion of patients initially diagnosed as having anorexia nervosa and who go on to do badly is high, and we can expect around a quarter of patients to follow this course. A more conservative estimate is shown in the 3rd column, namely the proportion of patients still fulfilling diagnostic criteria for anorexia nervosa. The range is from 3 to 37% with an average of 14.4%. The highest estimate in that column, 37% [13] is from a national service which accepted referrals from all over the UK. Hence the severity of disease in patients admitted is likely to be higher and length of illness proportionately longer.

Condition studied	Length of follow-up (years)	Proportion % fulfilling disease criteria	Notes	Poor outcome (ED and other reasons)	Reference
Anorexia nervosa	24	Diagnoses not recorded	Mortality 12.8%	29%	Theander et al. [9]
Anorexia nervosa	9	17	Mortality 11%	59%	Deter et al. [10]
Anorexia nervosa	12	19	Mortality 7.7%, BN 9.5%	39.6%	Fichter et al. [11]
Anorexia nervosa	10	3	Adolescents, no deaths, 5% BN, 23% personality disorder		Herpertz-Dahlmann et al. [12]
Anorexia nervosa	20	37	15% BN, 15% died	36.6%	Ratnasuriya et al. [13]
Anorexia nervosa	15	13	No deaths, 30% binge eating		Strober et al. [14]
Anorexia nervosa	10	6	Community screening, mean age onset 14	27%	Wentz et al. [15]
Anorexia nervosa	18	6	Same cohort as above	12%	Wentz et al. [16]
Average	13.4	14.4		27.9%	

Table 1.
 Follow-up studies of anorexia nervosa.

Without that centre the average proportion fulfilling criteria at average 14 years is 9.14% which may be a more representative figure.

2.1.1 The asymptotic pattern of outcome

Four of the above studies [9–11, 16] provided data on outcome of anorexia nervosa at several time points which allows us to draw a survival curve (**Figure 1**).

This shows that as time goes on, the number of cases reduces and almost, but not quite, reaches the horizontal, that is the curve seems to represent an asymptote. It should be noted that at no time does the curve ever stop falling, although the gradient does flatten, showing that anorexia nervosa can always recover, at any stage. The graph suggests that significant flattening seems to occur between 5 and 10 years, and in that period after diagnosis recovery does become less likely. **Figure 1** also shows the exponential curve that was derived from the data points shown and this also suggests an asymptotic pattern.

2.1.2 Symptoms may increase in severity after 3 years

The proposal by Treasure and Russell [7] that a history of more than 3 years might be accompanied by a decreased responsiveness to treatment was further examined in a study by Gardini [17]. In this audit of routine questionnaires, results in patients with anorexia nervosa with under 3 years history were compared with a group of patients with a history of 3–10 years and a further group with over 10 years duration. A comparable study was performed for patients with a diagnosis of bulimia nervosa and the same durations of illness.

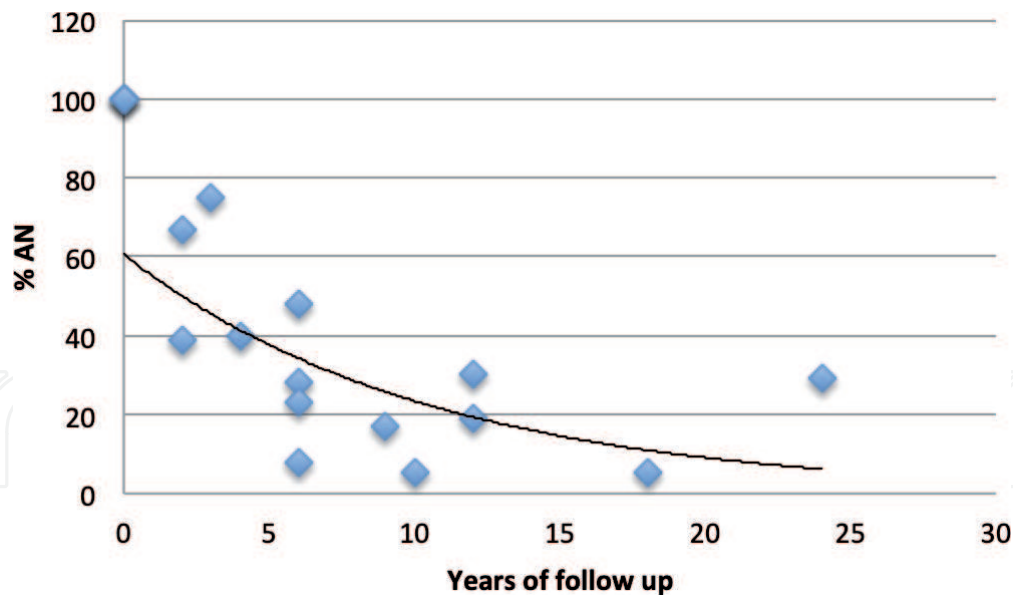


Figure 1. Percentage of participants who fulfilled diagnostic criteria at each assessment from four follow-up studies of anorexia nervosa. The curve is exponential, derived from these data points.

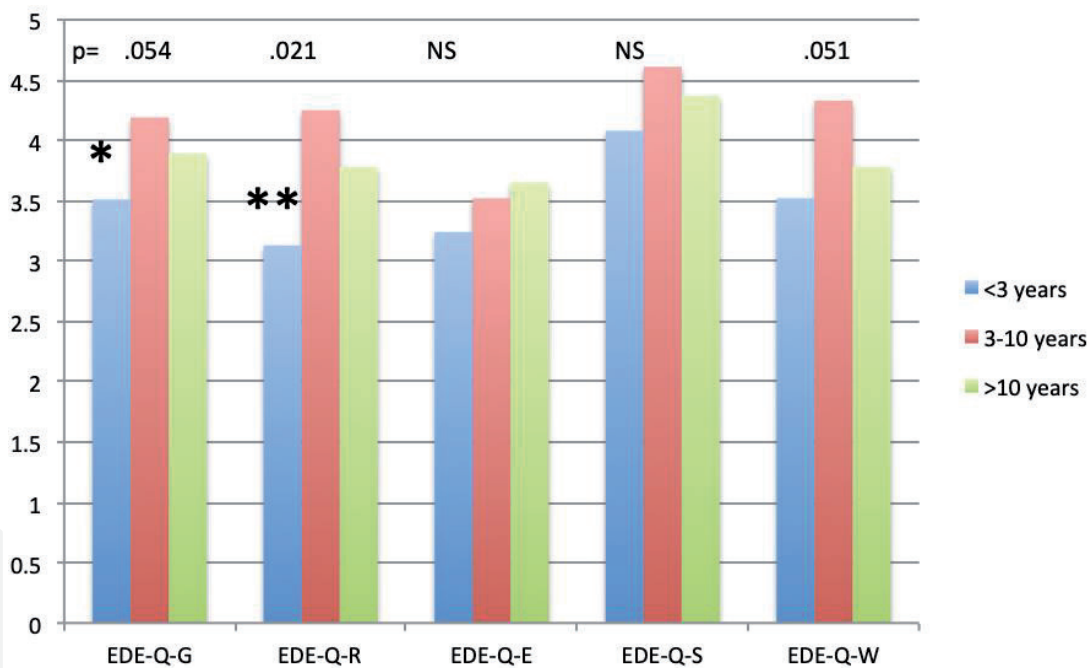


Figure 2. EDE-Q scores in three groups of patients with anorexia nervosa (total n = 87) with length of history of <3 years, 3–10 years and >10 years. The p values derive from a Manova comparing the three length of history groups. *≤3 years group vs. 3–10 year group p = 0.048, **≤3 years group vs. 3–10 year group p = 0.017 (post-hoc tests). EDE-Q-G: global score, EDE-Q-R: restraint, EDE-Q-E: eating concern, EDE-Q-S: shape concern, EDE-Q-W: weight concern.

The results were intriguing. For anorexia nervosa (but not for bulimia nervosa), time had a significant impact on EDE-Q restraint and a borderline significant impact of EDE-Q weight concern and EDE-Q global score. The scores increased between <3 and 3–10 years and then declined after 10 years. The results are summarised in **Figure 2**.

This study provides some evidence for the 3 year threshold proposed by Treasure and Russell [7]. Some eating disorder symptoms significantly increase after 3 years

illness and this could relate to increasing difficulty in helping patients achieve remission. The increased restraint score could reflect increased resistance to the parents encouraging the patient to consume a weight gaining diet, an essential element in family based therapy.

3. Clinical features of SEED

In this section, SEED-AN symptoms [18] will be compared with SEED-BN (unpublished data).

3.1 Physical

In SEED-AN, many participants complained of physical problems, but also denied their seriousness:

“The worst thing is going to be as I am moving in my latter years being osteoporotic but you know what, there are some fantastic tablets today.”

“Osteoporosis was diagnosed but I think it’s controllable ... with Calcium and the right diet, and I think it’s not acute.”

In SEED-BN most participants either did not complain of any physical problem, or felt they were manageable.

3.2 Psychological

In SEED-AN, most participants were depressed, and self esteem was often extremely low:

“I felt like I was a horrible, disgusting, person ... I felt like really ugly and disgusting and dirty and therefore to dress myself in things that made me look pretty would be like, it would be wrong somehow.”

In SEED-BN depression and mood instability were the rule.

“Sometimes I’m just bubbly and happy and in a fun mood and other days I just want to be on my own.”

“I think a lot of it is dealing with your depression.”

3.3 Social

In SEED-AN, social disruption, lack of intimate relationships and social isolation were common.

“I felt I just totally failed and dropped out of life. I was too scared to join up the squash club, I was too scared to socialise with people, I lost all my confidence with job interviews.”

In SEED-BN most participants were not in relationships and were living alone.

“I’ve got some friends that I have online but I haven’t actually met them. Because I feel I can totally fake...see it kind of doesn’t matter what I say because I haven’t met them. Do you know what I mean? Because it doesn’t matter if they disappear, they’re not actually real friends.”

3.4 Family

In SEED-AN, the patient sometimes ended up as their parents’ carer.

“I was sort of left; a lot of the family got married and moved away from home.”

In other cases, difficult relationships improved over time.

“In the last 2 years the relationship with my family has got better. I now have contact with my sister. We often chat on the phone. I don’t really see my brothers or hear from them, I often ask my parents about them, they ask about me.”

In SEED-BN, family difficulties were frequent. Some felt their families did not take the eating disorder seriously. One patient after she had confessed her bulimia to her mother, reported that her mother said *“yeah I used to do it. It’s so stupid. You kind of don’t wanna do that ... ,”* which she did not find helpful. Other patients reported that their families were weight obsessed. When one participant had regained a size 12, a member of her extended family exclaimed *“Oh my God what have they been feeding you? You’re enormous!”*

3.5 Financial

For SEED-AN, patients were often poor, living on benefits without paid work. They also described clinical frugality, in which they had extreme difficulty spending money on themselves:

“I find it very difficult spending money. If you walked into my flat, I’ve got nothing particular there ... just very-very bare. My shoes, I wear them until they begin to fall into pieces.”

For SEED-BN, the illness was often very costly because of the large quantity of food consumed. One patient interviewed was seeing a debt counsellor to manage loans from 5 different lenders: *“I don’t have any savings, and I don’t buy anything nice for myself, I just survive.”*

3.6 Occupational

SEED-AN: These patients often reported being out of work and surviving on benefits. *“I completed 1 year of that (teaching) course and then I had to go into hospital so that came to an end. ... I seemed to lose interest in work and it seemed more important that I planned my meals and my walks.”*

SEED-BN: These individuals were often in work, and some valued the structure of work to help manage their eating disorder: *“I feel that going to work in the morning ‘wipes the slate clean’ if I have binged and vomited the night before.”* Others found that the eating disorder had an adverse effect on work: *“Last summer I had to take a number of months off work due to my eating disorder and depression, and I still struggle to fulfill all my commitments when my mood is low.”*

4. Management

Outcome research in the area of management of SEED is sparse. There are several examples of publications in which clinicians have expressed their opinion in this area [14, 19, 20]. One question that constantly appears in the area of management is what general approach to use. As already discussed full recovery from an eating disorder is always possible although less likely as the years pass. The patient (and the clinician and family) are thus confronted with the question each time therapy is contemplated: Should I go for a full recovery or for the best quality-of-life given that I have a long-term disorder.

From the point of view of the clinician, there may be a moral dilemma. Funding for services may depend on inpatient units being full. This applies to both the public and private health sectors. There may therefore be perverse incentives to admit the SEED patient for a prolonged hospital stay in pursuit of weight gain. Most professionals in charge of an inpatient eating disorders service will be aware of these pressures, and how they sometimes conflict with patient care. Hospital admission is essential in the case of a patient who presents life threatening physical illness. However the likelihood of long-term recovery after prolonged admission in someone with a long illness is probably small and one is left with a suspicion that some SEED patients may be admitted for long periods without much benefit.

4.1 Cure or care?

It seems to the author evident that all patients with SEED to be offered treatment and that fully alleviating disorder. However not all patients benefit from this approach especially if it is provided against the patient's consent and in such cases a harm minimization or recovery approach focused on improving quality of life maybe more humane and helpful.

4.2 The recovery approach

This approach [21] that originated amongst service users in the United States posits that improved mental and physical health can be achieved even though the illness at the root of a person's difficulties cannot be cured. Thus a person with schizophrenia who hears voices, believes he is being bugged and has interpersonal difficulties can still be helped to deal with the symptoms through individual family and social interventions even though medication has had limited impact.

Can a similar approach applied to eating disorders? Here we will go through the different realms indicated by see patients as problematic and identify ways to approach them.

4.3 Medication

The role of medication in the eating disorders is limited and the main group who appear to benefit are those with bulimia nervosa. Antidepressants such as high-dose fluoxetine can be tried with patients who have had at least one evidence-based psychological treatment for bulimia nervosa [22]. Of other drugs olanzapine has been tried in anorexia nervosa [23] and although the evidence is currently weak, some eating disorder specialists believe that the drug reduces anxiety and may have an impact in improving weight gain. Adequate randomised trials are awaited.

4.4 Psychological therapy

Patients with anorexia nervosa and bulimia nervosa are in both quantitative and qualitative studies are found to suffer from depression and anxiety. These difficulties often correlate with the severity of the eating disorder symptoms such as lower weight or frequent bingeing and purging and treatments to reduce those are clearly the preferred approach. However patients with SEED have often received one or more courses of psychotherapy and perhaps one or more inpatient or day patient episodes. In anorexia nervosa there is little evidence that any therapy is better than any other although in bulimia nervosa CBT [24] and some other approaches have been found helpful. In a trial in which two therapies were tested in patients with long-standing anorexia nervosa [6] weight gain was modest but significant and there were significant improvements in depression and eating disorder symptoms. The two therapies were SSCM and cognitive behaviour therapy (CBT). SSCM is Specialist Supportive Clinical Management [25] and is a therapy that can be delivered by mental health staff without psychotherapy training. It mostly addresses eating disorder behaviours and has been used as a control therapy in several randomised trials [6, 26, 27] in which the results were surprisingly good, often doing as well as the more complex therapy being studied. Hence it has earned itself a place in the NICE guidelines [28]. Initially it was designed exclusively for anorexia nervosa and a variant (SSCM-ED) has been used in all eating disorders [29]. SSCM and SSCM-ED have no published manual but a manual for the latter can be obtained from the author of this chapter.

4.5 Physical risk monitoring

This is clearly required in anorexia nervosa of any duration, because without in patients can deteriorate and die from nutritional problems. For bulimia nervosa, the most common serious medical problems are electrolyte disturbances. Who should do the monitoring is a point of debate. When specialist eating disorder services are scarce and expensive, there is an argument for monitoring to be based in primary care. However, the staff in primary care require training in monitoring eating disorders and in what to do when a worrying finding, such as an abnormal ECG, is uncovered. Some general practitioners are reluctant to take on this work, and a possible model in the UK NHS might be to provide funding for primary care staff to provide this service, and a formal link with an eating disorders specialist to provide support and guidance when abnormalities are discovered. Unfortunately, this has not yet been achieved and care is thus often a source of tension between primary and specialist care. Methods for monitoring patients with eating disorders have been documented in MARSIPAN [30] and in Treasure [31]. For monitoring of physical problems which develop over time but do not usually threaten life, such as osteoporosis, the patient and doctor need to decide on whether and how often to monitor the conditions. Some have argued that as the sole effective treatment for osteoporosis due to anorexia nervosa is weight gain, and as we know it will get worse without increase in weight, repeated scans are not required. Others believe that knowing that the condition is deteriorating might provide an incentive to improve weight and secondly alerts patient, physician and family to the increasing possibility of fractures after trivial or no injury.

4.6 Family interventions

Many patients with SEED-AN and SEED-BN describe difficulties with their families as already described. The problems from the family members' point of view are how to respond to a serious eating disorder which does not seem to be getting better, without suffering from depression and other manifestations of stress, and

without inadvertently making the eating disorder worse. For these families, collaborative caring [32] has a lot to offer, and has been shown [33] to result in lower distress levels in carers. Single or multiple family therapy might sometimes be indicated to help resolve some difficulties, although naturally the aim of therapy would be improving family functioning and quality of life, rather than curing the eating disorder, as it is in younger, short history patients [34].

4.7 Social and occupational interventions

As described above, social isolation is commonly described in patients with long term anorexia nervosa and bulimia nervosa. Patients are reluctant to eat with others and may turn down invitations to go out, preferring to stay at home and binge-eat. Attending a day service for treatment can be a first step in re-socialising and help to find appropriate voluntary work or educational courses can also be a useful aid to recreating a social network. Some patients, especially with anorexia nervosa, find that meeting other patients with the same condition can be more acceptable, because they do not need to explain their behaviour to others. However, while this may be helpful initially, it can result in further entrenchment of the eating disorder and if possible, wider social networks should be sought. The help of occupational therapy and nursing staff can be invaluable in this process. If a patient already has a career, or is mid way through a training, the staff can help them reintegrate and request observer status before going back to work or study. For certain occupations, such as dance or athletics, the patient needs to decide whether pursuing the former career is possible without the eating disorder becoming more severe.

5. Summary and conclusions

A substantial proportion of individuals with eating disorder fail to recover either because they have not had early access to treatment, or because they have not responded to such treatment. As time goes on the chances of recovery reduce but they never seem to reach zero, suggesting an asymptotic function underlying the chances of recovery with time. There is some evidence to suggest that over 3 years, anorexia nervosa, but not, apparently bulimia nervosa, may become more entrenched and resistant to treatment. Both conditions, however, profoundly affect quality of life and although the mortality is lower in bulimia nervosa, both conditions are associated with widespread disruption of physical health and psychological, family and social functioning. In long term eating disorders each of these realms require attention from professionals and from other informed individuals in families, who require adequate training and support, and the general public including ex-sufferers and charities such as BEAT. Severe and enduring eating disorders (SEED) should be recognised by the wider psychiatry community as deserving of attention and resources as much as other severe and enduring mental disorders so that the suffering endured by patients and their families as well as the costs incurred by individuals, families and society can be alleviated.

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