

Executive summary

Eating disorders are serious conditions that can cause major suffering for patients and their families. Better knowledge on how eating disorders and treatment of the conditions are perceived may add value to the development of the clinical work. The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) has evaluated the perceptions, needs and desires of patients, family members and health care professionals regarding their experiences with eating disorders. Most of the results presented in this report pertain to anorexia nervosa because the identified qualitative research most often focused on people with that diagnosis.

Findings

The following findings were extracted from systematic reviews judged to have low to moderate concerns for methodological limitations.

Individuals with eating disorders (predominantly anorexia nervosa)

- described life as lonely and isolated with difficulties in relationships and significant health problems, and experienced that the eating disorder had a negative impact on their school or work life
- underlined the importance of a holistic treatment that doesn't only focus on normalization and weight rehabilitation, and a therapeutic alliance that includes room for conversations about thoughts and emotions
- experienced that the recovery process benefited from supportive relationships, hobbies, treatment and an increased understanding for the disease and food.

Health care professionals

- perceived individuals with anorexia nervosa as patients with significant treatment needs who were difficult to establish a therapeutic alliance with

- considered the biomedical model to be helpful for explaining eating disorders and guiding their treatment, as it seemed to reduce the patients' and family members' feelings of guilt
- considered that it was important to establish an alliance with the parents.

Family members

- were significantly negatively affected by the eating disorder, and experienced that the entire family was affected
- experienced lack of support and participation and considered the treatment as too medically oriented.

Background

The Government has commissioned SBU to review the current body of evidence regarding the care of people with eating disorders. Eating disorder diagnoses include anorexia nervosa, bulimia nervosa, binge eating disorder, as well as other specified and unspecified eating disorders. There are currently no Swedish national guidelines in this field.

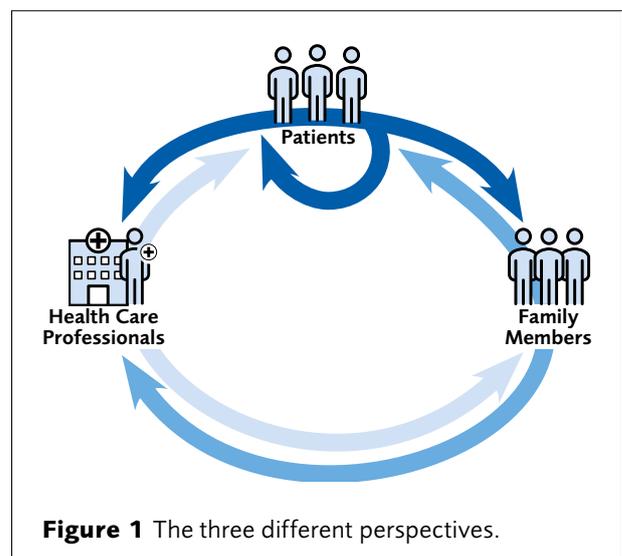


Figure 1 The three different perspectives.

Objective

The objective of this report was to systematically review the available qualitative scientific evidence regarding the perceptions, needs and desires of patients, friends and family members and health care professionals regarding their experiences with eating disorders.

Method

The literature overview was undertaken following the ENTREQ statement and standard methods used by SBU. A systematic literature search covering the period 1990 to 2018 was conducted in international databases (PubMed, PsycInfo, Scopus database, and CINAHL). Systematic reviews of qualitative research published in peer reviewed journals in English, Swedish, Norwegian, or Danish were included in the overview. To be included, the systematic reviews must have investigated experiences, perceptions, needs and/or desires related to eating disorders from at least one of the three perspectives.

Systematic reviews that fulfilled the inclusion criteria were assessed for relevance and quality by at least two researchers independently, using pre-defined protocols. The confidence in the findings was not assessed.

Results

Of the 3082 abstracts identified in the literature search, 17 systematic reviews with low to moderate methodological limitations met our inclusion criteria. A total of 13 systematic reviews reported on the patients' perspectives, 5 on the family members' perspectives, and 3 the health care professionals' perspectives.

SBU's assessment of the qualitative evidence identified three themes that were in common for patients, family members and health care professionals.

The first theme pertained to the use of the *biomedical model* to explain the disorder and guide treatment. Health care professionals felt that the model provided them with the support they needed to define target symptoms and goals for their normalization, while patients and family members felt that the model placed too much focus on the somatic aspects of the disorder and failed to address their psychological distress. The second theme was the patients' *need for control*, which was seen by the family members and the healthcare professionals as a false control where the affected person in fact was controlled and limited by the eating disorder. The third theme was the

importance of a well-functioning *therapeutic alliance*, an alliance that recognise the whole individual and not just the disease, and that also involves family members.

The included systematic reviews included both women and men with eating disorders, but men were under-represented relative to their expected incidence. The included reviews focused mainly on girls and young women with anorexia nervosa or with eating disorders in general, without focusing on a specific diagnosis. None of the identified reviews exclusively evaluated people with bulimia nervosa or binge eating disorder. Few of the systematic reviews contained Swedish or Nordic studies.

Evidence gaps

No reviews addressed the experiences and perceptions of individuals with eating disorders regarding their relationships with their families. No reviews specifically addressed the needs and desires of individuals with eating disorders or health care professionals.

There is a need for methodologically well conducted systematic reviews in which the population is clearly described regarding age, sex and diagnosis. Future systematic reviews should report when in the progression of the disorder data was taken, and the study authors' competence in the field.

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