



## Bilaga 3 Systematiska översikter av kvalitativ forskning som ligger till grund för resultat/Systematic reviews of qualitative research of low and moderate concerns used for results in the present report

Table 1. Included studies in alphabetic order

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Ali et al 2017 [1] Australia	<b>Aim</b> To systematically review the literature on perceived barriers and facilitators of help-seeking for eating disorders.	<b>Informants</b> <b>Patient perspective</b> Diverse groups of people with past or current ED or disordered eating. Most studies were based on community samples (mostly female) via advertisement.  Studies from United states, Australia, Germany, England and Norway published between 2001–2015 (search not restricted by year).	<b>Included studies in total (number)</b> 13 studies  <b>Type of study</b> 3 quantitative 2 mixed 8 qualitative  All included qualitative studies involved interviews, including telephone, semistructured, structured, and in-depth interviews.	<b>Method</b> Followed PRISMA.  <b>Type of analysis</b> Data analysis by Thematic Analysis (TA)	<b>Author's main conclusions</b> Determining the factors that impede or facilitate help-seeking is critical in tackling ED. Reducing stigma and shame and educating people about ED, their impact and available resources is crucial.	<b>Risk of bias</b> Minor

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Bezance et al 2013 [2] UK	<b>Aim</b> To review qualitative studies on the experience of treatment and recovery for adolescents with AN.	<b>Informants</b> <b>Patient perspective</b> Clinical samples (past or current) of adolescent and young adult patients with AN.	<b>Included studies in total (number)</b> <b>Type of study</b> 11 studies, all qualitative or mixed method.  Studies mainly from United Kingdom published after 1950	<b>Method</b> No description of any method to ensure quality of included studies.  <b>Type of analysis</b> Data analysis by Thematic analysis (TA).	<b>**The article lacks a formulated conclusion. The conclusions herein are based on the article's results but have been formulated by SBU's expert.</b> Patients described that access to specialist care was crucial although they reported both positive and negative aspects of specialist treatment, such as family therapy and inpatient treatment. The adolescents emphasised the need to address both psychological and physical aspects of the condition, to be fully recovered. Positive relationships with parents, siblings and friends had an important role in recovery from an ED.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus
De Vos et al 2017 [3] The Netherlands	<b>Aim</b> To identify fundamental criteria for eating disorder recovery according to recovered individuals.	<b>Informants</b> <b>Patient perspective</b> Diagnostically diverse ED-samples (mainly female) who had recovered from an ED.	<b>Included studies in total (number)</b> <b>Type of study</b> 18 studies all qualitative  Final search conducted 4 February 2016. Studies from USA, Australia, Sweden, Canada, United Kingdom, Brazil, Norway and Israel. Search not restricted by year.	<b>Method</b> Followed PRISMA Critical evaluation of studies according to CASP.  <b>Type of analysis</b> Data analysis according to Qualitative meta-analytic approach	<b>Author's main conclusions</b> People who have recovered rate psychological well-being as a central criterion for ED recovery in addition to the remission of eating disorder symptoms. Supplementary criteria, besides symptom remission, are needed to measure recovery.	<b>Risk of bias</b> Moderate  Not reported if two independent researchers conducted the appraisal with CASP

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Duncan et al 2015 [4] Australia	<b>Aim</b> To enhance current understanding of recovery by synthesising the rich body of qualitative evidence examining the phenomenon from the perspective of those who have experienced it.	<b>Informants</b> <b>Patient perspective</b> Samples of recovered patients with AN (although some studies included even other diagnoses).	<b>Included studies in total (number)</b> <b>Type of study</b> 8 studies, all qualitative  Studies published between 2003–2013.	<b>Method</b> Critical evaluation of studies according to CASP.  <b>Type of analysis</b> Data analysis by a Meta ethnographic approach	<b>Author's main conclusions</b> Recovery is described as a dynamic process involving a self-determined search for identity and truth and the repossession of personal control and power. The medicalisation of AN may downplay the wider human and social dimensions by the condition.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus
Eklund et al 2016 [5] Sweden	<b>Aim</b> To describe how eating disorders among adolescents affect family relationships and the family's daily living conditions and to describe the family's experienced need for professional support.	<b>Informants</b> <b>Relatives perspective</b> Diagnostically diverse ED-sample and relatives (mainly parents) of adolescents suffering from an ED.	<b>Included studies in total (number)</b> 15 studies  <b>Type of study</b> 9 quantitative 6 qualitative  Studies published between 2005–2015.	<b>Method</b> <b>Type of analysis</b> Data analysis according to the Integrative method of Whittemore & Knaf1	<b>**The article lacks a formulated conclusion. The conclusions herein are based on the article's results but have been formulated by SBU's expert.</b> The group identity of the family is affected when an adolescent suffers from an ED, and emotional burdens on the family include isolation, and adapting to the situation. Input from health care professionals was crucial for the families. Parents' experiences of the burden of care should take a central place when healthcare professionals discuss treatment options for the affected family.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Espindola et al 2009a [6] Brazil	<b>Aim</b> To organize the body of information available in qualitative studies about the treatment of AN.	<b>Informants</b> <b>Patient perspective</b> Adolescent and adult patients (mainly female) in past or current treatment for AN (some studies had a mixed sample) according to DSM-IV criteria. Two studies also included some participants with no treatment. Two studies included some mothers, but only data from the patients were included in the analyses.	<b>Included studies in total (number)</b> <b>Type of study</b> 15 studies, all qualitative.  Studies published between 1990–2005. Studies from England, USA, Canada, New Zealand, Australia and China.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysed by a Meta ethnographic approach	<b>Author's main conclusions</b> Recovery from AN, as a very complex process, goes well beyond conventional treatment. Self-acceptance, determination, and spirituality are equally important elements.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening
Espindola et al 2009b [7] Brazil	<b>Aim</b> To develop a hypothesis about the nature of AN and how it relates to more effective therapeutic interventions.	<b>Informants</b> <b>Patient perspective</b> Adolescent and adult participants (mainly female) with past or current AN (some studies had a mixed sample) according to DSM-IV criteria.	<b>Included studies in total (number)</b> <b>Type of study</b> 24 studies, all qualitative.  Studies published between 1990–2005.  Studies published in USA, Canada, China, New Zealand, Australia, Israel, Brazil and Spain.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysed by a Meta ethnographic approach	<b>Author's main conclusions</b> Knowledge of patients' efforts to interpret the illness as a part of their own identity and sense of control have a key role in in physician understanding of the disorder by allowing physicians to bring structure to the patients' lives generally and to their help-seeking behaviour specifically.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus.

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Espindola et al 2009c [8] Brazil	<b>Aim</b> To carry out a systematic review on how family members perceive AN and bulimia nervosa patients.	<b>Informants</b> <b>Relatives perspective</b> Family members of a mixed ED sample (mainly adolescent or young adult women with AN). Some studies also included patients, but only data from the relatives were included in the analyses.	<b>Included studies in total (number)</b> <b>Type of study</b> 9 studies, all qualitative  2 studies published 2 articles on the same data, thus the review included data from 7 populations. Studies published between 1990–2006.  Studies published in England, Australia, Israel and China.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysed by a meta-ethnographic approach	<b>**The article lacks a formulated conclusion. The conclusions herein are based on the article's results but have been formulated by SBU's expert.</b> Care provided to patients should include the opportunity of examining and consulting family members, give clarification and information about patient care, and situations involving pathological functioning of patients and their family. Support networks and self-help networks such as meeting with families experiencing similar situations should be considered.	<b>Risk of bias</b> Minor
Fogarty et al 2018 [9] Australia	<b>Aim</b> To examine the experience of women with an eating disorder in the perinatal period: that is during pregnancy and two years following birth.	<b>Informants</b> <b>Patient perspective</b> Mixed ED sample of women that were pregnant or in the perinatal period.	<b>Included studies in total (number)</b> <b>Type of study</b> 12 studies, all qualitative  Studies published later than 1980 was considered.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analyzed by a Meta ethnographic approach.	<b>Author's main conclusions</b> Following a tumultuous pregnancy experience, many described returning to their pre-pregnancy eating behavior and thoughts, which highlights the emotional difficulty of having an ED whilst pregnant, but also points to opportunities for intervention and a continued acceptance of body image changes.	<b>Risk of bias</b> Minor

Author Year Reference Country (first author)	Aim	Informants Perspective (patients, health care, relatives)	Included studies in total (number) Type of study	Method Type of analysis	Author's main conclusions	Risk of bias
Fox et al 2017 [10] UK	<b>Aim</b> To synthesize qualitative studies relating to the caring experience and its impact, thereby gaining an understanding from the perspective of the individuals themselves.	<b>Informants</b> <b>Relatives perspective</b> Most participants were parents, but some studies also included partners and siblings. Most participants had a family member diagnosed with AN, but some studies also included relatives of patients with bulimia nervosa.	<b>Included studies in total (number)</b> 20 studies  <b>Type of study</b> 1 mixed 19 qualitative Studies published later than 1970.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysis based on metasynthesis according to the principles of Noblit & Hare <sup>1</sup> .	<b>Author's main conclusions</b> The ED was found to have a pervasive impact upon family members, mediated by a number of factors. Cognitive appraisals affected the caregiving experience and responses to the individual. The experience of caregiving was continually reappraised leading to a process of adaptation. Most of studies identified unmet career needs.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus.
Medway et al 2016 [11] Australia	<b>Aim</b> To describe patient's experiences of family interventions for AN.	<b>Informants</b> <b>Patient perspective</b> The sample included patients (mainly adolescents) with a current or former diagnosis of AN who had underwent a therapist delivered family intervention. Some studies had a mixed ED-sample. Some studies also included family members, but only data from the patients were included in the analyses.	<b>Included studies in total (number)</b> 15 studies, all qualitative.  Search conducted during November 2015. The search was not restricted by year.	<b>Method</b> Critical evaluation of studies according to COREQ.  <b>Type of analysis</b> Data analysis based on metasynthesis using thematic synthesis according to Thomas & Harden, 2008 <sup>2</sup> .	<b>Author's main conclusions</b> Strength of family-based approaches included support of family understanding and use of the family as a resource for recovery. Addressing a variety of underlying family and individual issues was implicated as an area for improvement.	<b>Risk of bias</b> Minor

<sup>1</sup> Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies. Newbury Park, CA: Sage; 1988

<sup>2</sup> Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8(1), 45. doi:10.1186/1471-2288-8-45

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Salzmann-Eriksson et al 2017 [12] Sweden	<b>Aim</b> To identify and describe factors that promote and impede the relationships between nurses and children, adolescents and young adults who are diagnosed with AN and also to explore and describe how those relationships benefit the patients' process toward increased health and well-being.	<b>Informants</b> <b>Health care perspective</b> A sample of adolescent and adult patients with AN and nurses (both in general and specialised care) in mainly inpatient treatment for AN.	<b>Included studies in total (number)</b> <b>Type of study</b> 14 studies, all qualitative.  Studies published in England, Netherlands, Australia and Norway.	<b>Method</b> Quality of included studies was assessed based on a review template published by Forsberg & Wengström, 2013 <sup>3</sup> and Willman et al., 2006 <sup>4</sup> .  <b>Type of analysis</b> Data was synthesised through the process outlined by Evans, 2002 <sup>5</sup> .	<b>Author's main conclusions</b> Nurses need to be person-centred in their relationships with patients and to have attitudes characterised by presence, genuine commitment and motivation. Nurses are more likely to convey a sense of trust and safety when they communicate with openness and honesty.	<b>Risk of bias</b> Moderate  Not reported if two independent researchers conducted the appraisal with CASP
Sibeoni et al 2017 [13] France	<b>Aim</b> To perform a systematic review of qualitative studies to synthesize the views of adolescents with AN, their parents, and their healthcare providers about its treatment.	<b>Informants</b> <b>Patient perspective, relatives perspective and health care perspective</b> Participants could be patients (younger than 18 years during their disease, AN), their families, or the healthcare professionals caring for them.	<b>Included studies in total (number)</b> <b>Type of study</b> 32 studies, all qualitative.  Studies published between 1990 and 2014.	<b>Method</b> The study complies with the ENTREQ guidelines, which includes critical evaluation of study quality according to CASP.  <b>Type of analysis</b> Data analysed by a Meta ethnographic approach	<b>Author's main conclusions</b> The results underline the difficulty in establishing a therapeutic alliance, the barriers to it, especially the risk that professionals, adolescents, and parents will not converse about treatment; although such a dialogue appears to be an essential component in the construction of a therapeutic alliance.	<b>Risk of bias</b> Minor

<sup>3</sup> Forsberg, C., & Wengström, Y. (2013). Att göra systematiska litteraturstudier [To conduct systematic literature reviews]. Stockholm: Natur & Kultur.

<sup>4</sup> Willman, A., Stolz, P., & Bathsevani, C. (2006). Evidensbaserad omvårdnad: En bro mellan forskning och klinisk verksamhet [Evidence-based nursing: A bridge between research and clinical practice]. Lund: Studentlitteratur.

<sup>5</sup> Evans, D. (2002). Systematic reviews of interpretive research: interpretive data synthesis of processed data. Australian Journal of Advanced Nursing, 20(2), 22–26.

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Sibeoni et al 2017 [14] France	<b>Aim</b> To explore how AN is experienced by adolescents, their families and the health care professionals who provide care for them and to compare their perspectives.	<b>Informants</b> <b>Patient perspective, relatives perspective and health care perspective</b> Study samples included people who had experienced having AN during adolescence (younger than 18 years during their disease), parents of adolescents with AN, and health care professionals with experience in the field of AN.	<b>Included studies in total (number)</b> <b>Type of study</b> 30 studies, all qualitative.  Literature search conducted on 5 March 2014, with an update on 1 September 2015. Studies published between 1990–2015 were included.	<b>Method</b> The study complies with the ENTREQ guidelines, which includes critical evaluation of study quality according to CASP.  <b>Type of analysis</b> Data analysed by a Meta ethnographic approach and follows the procedure of thematic synthesise by Thomas & Harden, 2008 <sup>6</sup> .	<b>Author's main conclusions</b> There were important disparities between three different stakeholders. The adolescents underlined the psychological and emotional aspects of their experience, while the visible state of these patients' bodies impeded the work of the professionals. Treatment of AN in adolescence must integrate both psychological and physical components.	<b>Risk of bias</b> Minor
Stockford et al 2018 [15] UK	<b>Aim</b> To systematically review qualitative studies which have investigated female service users' experiences of recovering from AN.	<b>Informants</b> <b>Patient perspective</b> Study samples of adolescent or adult individuals who had fulfilled DSM-IV or DSM-5 criteria of AN. The majority of informants were recovered or in various stages of recovery during the data collection.	<b>Included studies in total (number)</b> <b>Type of study</b> 14 studies, all qualitative.  Studies conducted in New Zealand, Canada, Sweden, USA, UK, Brazil and Australia.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysed by a Meta ethnographic approach	<b>Author's main conclusions</b> Recovery from AN is experienced as a complex psychological process with many contributing factors. Findings highlight the need to reconsider clinical practice and treatment provision to incorporate the psychological components of self-identity into recovery programs.	<b>Risk of bias</b> Moderate  Lack of information about if the researchers independently conducted the screening and appraisal with consensus

<sup>6</sup> Thomas J, Harden A. Methods for the Thematic Synthesis of Qualitative Research in Systematic Reviews. BMC Med Res Methodol 2008; 8(1):8–45.



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Thapliyal et al 2018 [16] Australia	<b>Aim</b> To more richly understand issues related to gender in EDs and their treatment across relevant qualitative research studies.	<b>Informants</b> <b>Patient perspective</b> Study samples included participants of all ages and genders that had an ED according to current diagnostic schemes. One study also included representatives of organizations and health care practitioners.	<b>Included studies in total (number)</b> <b>Type of study</b> 9 studies, all qualitative.  Studies published between 1980–2017.  Included studies that addressed some aspect of the role of gender or sexual orientation in the treatment of people with ED.	<b>Method</b> Study quality assessed according to CASP and RATS  <b>Type of analysis</b> Data analysis according to principles of Shaw, 2012.	<b>Author's main conclusions</b> Gender issues impact upon the ED experience and require broader consideration in the development and evaluation of ED treatment interventions, including the further development of gender-informed interventions.	<b>Risk of bias</b> Minor
Tierney et al 2013 [17] UK	<b>Aim</b> To synthesise qualitative studies that focused on the perspective of women with an ED in relation to being pregnant.	<b>Informants</b> <b>Patient perspective</b> Women with self-reported or diagnosed ED that were pregnant or had given birth at the time of data collection.	<b>Included studies in total (number)</b> <b>Type of study</b> 7 studies, all qualitative.  Studies published from 1980 and onwards.	<b>Method</b> Study quality assessed according to CASP.  <b>Type of analysis</b> Data analysis by framework analysis (Ritchie et al., 2003) <sup>7</sup>	<b>Author's main conclusions</b> Participants reported vacillating between wanting to do the best for their child, being motivated by social pressures and feeling the need to control their body for self-preservation purposes. This created the inner turmoil they experienced while pregnant.	<b>Risk of bias</b> Minor

AN = Anorexia nervosa; CASP = The Critical Appraisal Skills Programme (CASP) tools; COREQ = COnsolidated criteria for REporting Qualitative research checklist; ED = Eating disorder; mHealth = mobile health; ENTREQ = Enhancing transparency in reporting the synthesis of qualitative research; PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RATS = Qualitative research review guidelines – RATS (Relevance, Appropriateness, and Transparency; TA = Thematic Analysis

<sup>7</sup> Ritchie, J., Spencer, L., O'Connor, W., 2003. Carrying out qualitative analysis. In: Ritchie, J., Lewis, J. (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Sage, London, Thousand Oaks, New Delhi.

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