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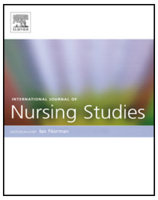

Review

The lived experience of anorexia nervosa in adolescence, comparison of the points of view of adolescents, parents, and professionals: A metasynthesis

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A R T I C L E I N F O

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ABSTRACT

Background: Anorexia nervosa in adolescence has been increasingly documented in numerous quantitative and qualitative studies. Qualitative research, which focuses on subjective experience, is a well-established method to deepen our understanding and provide new insights about specific diseases.
Objective: We conducted a metasynthesis of qualitative studies to explore how anorexia nervosa is experienced by adolescents, their families, and the health professionals who provide care for them and to compare their perspectives.
Review methods: Five databases (Medline, PsycINFO, CINHAL, EMBASE, SSCI; 1990–2015) were systematically searched for qualitative studies reporting participants' views about anorexia nervosa. Article quality was assessed with the Critical Appraisal Skills Program (CASP). We used thematic synthesis to examine and summarize the topics found in the articles selected and develop their central themes.
Results: We included 30 articles from seven different countries. Two domains of experience were inductively developed from the analysis: (1) *constructs and beliefs about* etiological theories of anorexia nervosa, and (2) the experience of the disease from the points of view of adolescents, parents, and healthcare providers.
Conclusions: We found important disparities between the three 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. These difficulties shed new light on the stakes of treatment of anorexia nervosa in adolescence, which must integrate both its psychological and physical components.

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What is already known about the topic

- More and more qualitative studies about anorexia nervosa in adolescents are published exploring the lived experience of the skateholders — adolescents, parents and healthcare providers-
- A previous metasynthesis explored the meaning of anorexia nervosa from the patients' point of view and concluded that anorexia nervosa is a part of the patient's identity.
- So far, neither qualitative studies, nor qualitative synthesis have explored the similarities and disparities about how anorexia is experienced by adolescents, their families and the health professionals who provide care for them.

What this paper adds

- We conducted a systematic review of qualitative papers to gather and compare these three perspectives in order to highlight their similarities and disparities.
- We found that healthcare providers focus on the visible signs of anorexia nervosa while adolescents focus on their psychological state and their emotions.
- To establish an early therapeutic alliance, healthcare professionals need to cope with feeling stunned by the appearance and condition of the body of these adolescents with anorexia nervosa and try to pay attention to the psychological and emotional state of these adolescents.

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1. Introduction

Anorexia nervosa is a severe disease characterized by a distorted body image and restricted food intake that leads to severe weight loss; it affects mainly adolescent girls and young women. As increasing numbers of scientific studies examine different aspects of anorexia nervosa, our understanding of this disease progressively improves. Anorexia nervosa begins most often during adolescence (Le Grange and Loeb, 2007). Its clinical aspects have been well documented (Herpertz-Dahlmann, 2015) from both the psychiatric (Brand-Gothelf et al., 2014; Godier and Park, 2014) and somatic perspectives (El Ghoch et al., 2014). Much has been learned about its biologic correlates (Kontis and Theochari, 2012), and numerous risk factors and etiological models have been described (Rikani et al., 2013), in particular, sociocultural, developmental, and pathophysiologic (Clarke et al., 2012). Psychopathological models have also been developed in numerous studies (Damiano et al., 2015).

At the same time, over the past two decades, the number of publications reporting qualitative research in psychiatry has grown. Qualitative research seeks to deepen our understanding of complex issues through the subjective experiences reported by patients, family members, and health professionals. Qualitative studies about anorexia nervosa in adolescence explore the subjective understanding and the lived experience of the disease from several perspectives. These studies are usually conducted with small samples and in specific contexts. We chose to conduct a metasynthesis in order to transform initial findings from original qualitative studies into decontextualized results more abstracted and generalizable (Atkins et al., 2008; Finfgeld-Connett, 2010; Thomas and Harden, 2008). Metasynthesis is a type of systematic review of the literature of qualitative studies on a subject (Noyes and Lewin, 2011). Aiming to “achieve analytical abstraction at a higher level, by rigorously examining the overlapping elements among studies” (Morton et al., 2010), it has a twofold objective: to summarize the existing publications on a given subject and to open new interpretive pathways by their comparison and joint analysis (Tong et al., 2012).

Espíndola and Blay (2009) published a metasynthesis about the *meaning of anorexia nervosa* from the patients' point of view, both adolescents and adults. Their analysis of 24 articles led them to conclude that anorexia nervosa is a part of the patient's identity. They considered only articles from the perspective of patients, while other qualitative studies – included in our metasynthesis – have explored the experience of parents and healthcare providers as well. Crossing the perspectives of adolescents, parents, and health professionals helps us to understand their shared representations of the disease. In recent years we have conducted several qualitative studies exploring the intersecting viewpoints with young adults with anorexia nervosa (Gorse et al., 2013), childhood obesity (Lachal et al., 2013) and adolescents who have attempted suicide (Lachal et al., 2015).

Thus, we decided to conduct a metasynthesis of qualitative studies exploring how anorexia nervosa is experienced by adolescents, their families, and the health professionals who provide care for them. Our main objective in this metasynthesis was to gather and compare these three perspectives in order to highlight their similarities and disparities. This article does not focus on the point of view of participants about treatment in anorexia nervosa, a recurrent topic in qualitative studies and one for which we conducted a specific metasynthesis (Sibeoni et al., 2016). The latter’s results underlined the difficulty in establishing a therapeutic alliance and its barriers, especially the risk that professionals, adolescents, and parents will fail to hold a real conversation about treatment, even though such a dialogue appears to be an essential component in constructing a therapeutic alliance.

2. Methods

2.1. Study design

This metasynthesis relies on the model of meta-ethnography (Atkins et al., 2008) and follows the procedures of the thematic synthesis described by Thomas and Harden (2008). It complies with the ENTREQ guidelines (Tong et al., 2012).

It consisted of six successive stages:

a. Definition of the research question, the subjects, and the types of studies to be included.
b. Identification and selection of the studies.
c. Assessment of the quality of the studies selected
d. Analysis of the studies, identification of their themes, and the translation of these themes between the studies.
e. Generation of the themes of the analysis and structuring of the synthesis.
f. Writing of the synthesis in two parts: one descriptive, in the Results section, which presents and defines the themes, and the other analytic and reflexive, in the Discussion section, which suggests and develops new ideas drawn from the descriptive review.

2.2. Search strategy and selection criteria

The study took place from March 2014 through September 2015. Five databases – Medline, PsycINFO, CINAHL, EMBASE, SSCI – were systematically searched with algorithms specific to each one. Keywords (referring to anorexia nervosa, adolescence, and qualitative research) were both free-text and thesaurus terms, preliminarily selected by the research group after reviewing the keywords used in key articles and literature reviews. We performed the literature search on March 5; 2014; with one update on September 1; 2015 (Table 1). The complete search strategy for each database is available in the supplemental material (Table S1).

We included only articles in English (as nearly all of these studies are now published in English) that used a qualitative methodology, were published between 1990 and 2015 (because qualitative health research has developed mainly over the past 25 years), and examined the experience of the people involved in anorexia nervosa during adolescence — patients with anorexia nervosa (younger than 18 years during their disease), parents, and healthcare professionals. We excluded all papers that used either a quantitative methodology. We also chose to exclude the mixed studies because the interest of the results of these studies is found in the link they offer between quantitative and qualitative data. Extracting only the qualitative data to integrate it into our metasynthesis would distort the results of these initial studies.

Table 1
Result of search strategy for each database.

Database	Dates	Result
CINAHL Plus (EBSCO Publishing) [1981-]	01/01/1990 to 09/01/2015	512
Embase (Ovid) [1974-]	01/01/1990 to 09/01/2015	275
Medline (PubMed) [1948-]	01/01/1990 to 09/01/2015	63
PsycINFO (EBSCO Publishing) [1800-]	01/01/1990 to 09/01/2015	57
SSCI (Web of Science) [1956-]	01/01/1990 to 09/01/2015	806

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