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How Do People with Eating Disorders Experience the Stigma Associated with their Condition? A Mixed-Methods Systematic Review.

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How Do People with Eating Disorders Experience the Stigma Associated with their Condition? A Mixed-Methods Systematic Review.

Background: Public opinion research shows that eating disorders (EDs) are a major target of stigmatisation. To understand the implications of this stigma, research investigating how stigma is experienced by individuals with EDs is critical. **Aims:** This paper aims to collate, evaluate and synthesise the extant empirical research illuminating how people with EDs experience the stigma associated with their condition. **Method:** A systematic mixed-methods literature search was performed. Articles that met a specified set of inclusion criteria underwent a quality assessment and thematic synthesis. **Results:** 29 articles were included in the review. Studies were mostly qualitative and of reasonable methodological quality. The literature was characterised by five research themes, illuminating (i) the nature and prevalence of stigma experienced, (ii) stigma in families, (iii) stigma in healthcare contexts, (iv) self-stigmatisation and illness concealment, and (v) stigma resistance. **Conclusions:** The reviewed research showed that people with EDs have extensive experience of stigma in diverse settings. They report that stigma has negative implications for their psychological wellbeing and likelihood of help-seeking. However, research also shows that people with EDs actively seek to resist and challenge stigma. The review identifies the outstanding gaps and weaknesses in this literature. **Keywords:** eating disorders, stigma, lived experience, systematic review, mixed methods

Introduction

Eating disorders (EDs) are a leading cause of mental health morbidity in young people and have the highest mortality rates of all mental disorders (Arcelus, Mitchell, Wales, & Nielsen, 2011). The suffering involved in experiencing mental illnesses like EDs does not emanate solely from their debilitating symptoms, but also from the reception the label ‘mental

illness' encounters in the social world. Research consistently shows widespread endorsement of beliefs about mental illness that disparage and marginalise those affected (Angermeyer & Dietrich, 2006; Rüsch, Angermeyer, & Corrigan, 2005). The public stigma associated with mental illness can result in a discredited social identity, which can be internalised by the individual (self-stigma) into a devalued self-concept (Corrigan & Watson, 2002; Goffman, 1963). To understand the implications of these stigma processes, research investigating how stigma is experienced by individuals with mental illness is critical. The current paper reports a mixed-methods systematic review of the quantitative and qualitative research that has investigated the stigma experiences of people with EDs.

The processes of mental illness stigma are complex and subject to numerous parameters (Pescosolido, Martin, Lang, & Olafsdottir, 2008). One such parameter is the disorder in question: research indicates that the intensity of stigma varies across different psychiatric categories, with schizophrenia and substance addiction attracting greatest stigma (Angermeyer & Dietrich, 2006; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). EDs attract more stigma than common mental illnesses such as depression (Roehrig & McLean, 2010). Research shows that negative attitudes to EDs are pervasive among the general population, within health services, and even within the families of people affected by EDs (Puhl & Latner, 2007; Puhl & Suh, 2015). Relative to other mental and physical illnesses, people with EDs receive more blame for causing their disorder (Crisp, 2005; Currin, Waller, & Schmidt, 2009; O'Connor, McNamara, O'Hara, & McNicholas, 2016; Roehrig & McLean, 2010; Stewart, Keel, & Schiavo, 2006), are ascribed more negative personality traits (Crisafulli, Von Holle, & Bulik, 2008; O'Connor et al., 2016; Roehrig & McLean, 2010; Stewart, Schiavo, Herzog, & Franko, 2008), and are seen as less pleasant to interact with (Byrne, 2000; Crisp, 2005; McNicholas, O'Connor, O'Hara, & McNamara, 2016; Stewart et al., 2008).

There are numerous potential consequences of these attitudes. First, they can be internalised by people with EDs, which exacerbates the low self-esteem typical of these disorders (Easter, 2012; Maier et al., 2014). Second, they may lead people to distance themselves from individuals with EDs (Crisp, 2005; Stewart et al., 2008; Zwickert & Rieger, 2013). The resulting isolation of people with EDs may compound their emotional distress and restrict their opportunities for seeking social support. Third, research suggests the social stigma surrounding EDs is an important barrier to illness disclosure and help-seeking (Ali et al., 2017; Booth et al., 2004; Cooper, Corrigan, & Watson, 2003; Griffiths, Mond, Murray, & Touyz, 2015; Hackler, Vogel, & Wade, 2010). Stigma therefore may increase illness duration and severity. Finally, if people do progress to engaging with mental health services, negative attitudes held by healthcare providers may impair the experience, extent and quality of the care they receive (Crisafulli et al., 2008; Currin et al., 2009).

Understanding the full social, psychological and physical burden of EDs therefore requires consideration of the impact of ED stigma. Most extant research on this topic has investigated public stigma, i.e. the endorsement of stigmatising beliefs by the general population (Crisafulli et al., 2008; Crisp, 2005; Ebner & Latner, 2013; Roehrig & McLean, 2010; Stewart et al., 2006). This gives valuable insight into the content of stigmatising attitudes, their prevalence, and their distribution across society. However, general population studies cannot reveal the frequency with which people with EDs encounter stigma in their daily life, how they respond to stigma experiences, or the implications of that stigma for their wellbeing and recovery (i.e. self-stigma). The first-person experience of people living with EDs is often marginal in the academic ED literature, which tends to focus on EDs' 'objective' medical features rather than the subjective experience of living with EDs. Addressing this gap is an empirical and ethical imperative, in order to ensure that social policies and healthcare practice are sensitive to the lived realities of the individuals they serve.

Recent times have seen increasing recognition of the principle that discussion of and interventions into ED stigma are informed by the perspective of people with first-hand experience of the phenomenon (Dimitropoulos, Freeman, Muskat, Domingo, & McCallum, 2016). There is a growing body of research enlightening this first-hand perspective on stigma issues; however, to date no efforts have been made to synthesise this diverse, multidisciplinary evidence. The current paper aims to collate, evaluate and synthesise the extant empirical research illuminating how people with EDs experience and respond to the stigma associated with their condition.

Method

Design

A systematic literature review was carried out in accordance with PRISMA guidelines (Liberati et al., 2009). Articles that met a specified set of inclusion criteria underwent a quality assessment and thematic synthesis. To facilitate a maximally comprehensive insight into the extant research, the review adopted an inclusive mixed-methods approach that accepted research with quantitative, qualitative and mixed designs (Hawker, Payne, Kerr, Hardey, & Powell, 2002; Pawson, Greenhalgh, Harvey, & Walshe, 2005). The review protocol was not published on PROSPERO.

Search strategy

A subject-specialist librarian was consulted in developing an appropriate search strategy. Searches for relevant articles were carried out in five electronic databases: PubMed, CINAHL PLUS, MEDLINE, Psychology and Behavioral Sciences Collection and PsycINFO. This set of databases affords a comprehensive overview of the peer-reviewed literature in social and health sciences.

After initial familiarisation with the terminology typically employed in this literature and discussions with the specialist librarian, a range of keywords was selected to target three dimensions of the literature:

a) *Eating disorders*: “eating disorder* OR anorexia nervosa OR bulimia nervosa OR binge eating disorder”

AND

b) *Stigma*: “stigma OR prejudice OR discrimination”

AND

c) *Patient perspective*: “experience OR perspective OR response OR internali* OR meaning OR self OR identity OR phenomenolog*”

Electronic searches identified articles that contained this combination of keywords anywhere in the article. The search was restricted to English-language articles in peer-reviewed journals, which described empirical research with human participants. The search did not impose any restrictions in relation to publication date, research location or research methods. Final searches were carried out in June 2018 (MMcN).

Inclusion and exclusion criteria

Table 1 describes the inclusion and exclusion criteria.

Table 1

Screening

References were exported to a reference management software (Endnote). All articles were initially screened through inspection of their title and abstract (CO’C, MMcN). Articles that clearly did not meet inclusion criteria were excluded at this stage, with all other articles proceeding to full-text eligibility assessment. Decisions were documented using Microsoft Excel. Inter-reviewer reliability on screening decisions, based on a sample of 10% of references and calculated in IBM SPSS 24, was 97.4% (Cohen’s $\kappa=0.92$). Doubts about eligibility were

resolved through team discussion, guided by the aim of maximal inclusiveness (i.e. erring on the side of inclusion over exclusion).

Quality assessment

The quality of each eligible article was assessed using an adapted version of Hawker et al.'s (2002) tool for evaluating mixed-methods research. The key advantage of this tool is its mutual application to both quantitative and qualitative research. This allows for the literature to be evaluated holistically, in accordance with the premise that qualitative and quantitative approaches are complementary sources of evidence and that a complete understanding of the evidence-base requires the integration of their distinctive insights (Dixon-Woods & Fitzpatrick, 2001). The development of the instrument was informed by existing literature on quality criteria for both quantitative and qualitative research (Hawker et al., 2002), and the included criteria show high overlap with those in other quantitative- and qualitative-specific research quality checklists e.g. (e.g. Critical Appraisal Skills Programme, 2017; Higgins & Green, 2011; Lockwood, Munn, & Porritt, 2015). The Hawker et al. (2002) approach rates the quality of a paper on nine dimensions: (i) abstract and title, (ii) introduction and aims, (iii) method and data, (iv) sampling, (v) data analysis, (vi) ethics and bias, (vii) results, (viii) transferability and generalizability, (ix) implications and usefulness. According to specified criteria, articles were rated on each dimension as 1 (very poor), 2 (poor), 3 (fair) or 4 (good). An article's scores on each dimension were then summed, such that its maximum potential score was 36. Each article was rated by two independent reviewers (CO'C, NMcN, LO'H, MMcN, FMcN). Both reviewers' scores were averaged to indicate the overall methodological quality. Any article that received a total score under 19 would be deemed a low quality study and excluded from the review.

Data extraction

Articles meeting the quality assessment threshold (Total score ≥ 19) proceeded to a subsequent stage of data extraction. A standardised framework for data extraction (Table 2) was designed to extract information about each study's:

- Geographic region
- Stated hypothesis/objective
- Type(s) of ED studied and how they were defined
- Theoretical framework
- Design
- Sampling strategy
- Sample characteristics
- Analytic approach.

Two researchers (CO'C, MMcN) completed data extraction. As the data extracted was relatively transparent factual information (e.g. country, sample size) or extracted verbatim from the article text (e.g. stated objective, analysis), each article was reviewed by a single researcher and no inter-reviewer agreement was computed. To guard against error, the procedure included a final verification stage where a researcher returned to each article to confirm the data extracted was correct.

Data analysis

Descriptive statistics were generated from quality assessment scores. Meta-analysis was not feasible given the heterogeneity of methodologies and outcome variables. The key features of the identified documents were summarised and tabulated. To synthesise the data into a descriptive narrative, all findings relevant to stigma were extracted and entered into another document. This data was analysed using thematic synthesis (Thomas & Harden, 2008), an approach that draws on the techniques of thematic analysis (Braun & Clarke, 2006) to identify

the overarching themes of the literature. First, each piece of text extracted from the reviewed papers was coded with a basic descriptive code that summarised its stigma-relevant finding (CoC). Coding was performed manually using colour-coded notations. Once all data was coded, all researchers reviewed the similarities and differences between the basic codes and grouped them into higher-level analytic themes. This produced five research themes, presented below.

Results

Article selection

The PRISMA flow diagram (Figure 1) depicts the process of article selection. The initial database search produced 505 results. After removal of duplicates and initial screening of titles and abstracts, 55 articles progressed to full-text eligibility assessment. Twenty-nine of these met eligibility criteria and were included in the final sample.

Figure 1

Methodological characteristics of the studies

The data extracted from each article is available in Table 2. Of the studies included in the review, 17 were qualitative in nature and 12 quantitative. The data analysed in the qualitative studies primarily derived from in-depth interviews ($n=13$), with three papers analysing material published on internet forums and one reporting a focus group study. Of the quantitative studies, ten involved surveys or questionnaires, one an analysis of online content and one a laboratory-based experiment.

In terms of analytic approaches, the ten quantitative studies all employed varieties of parametric and non-parametric statistical tests. The qualitative studies characterised their analytic approaches using a range of terminology, including grounded theory, content analysis, and interpretative phenomenological analysis. Two qualitative studies omitted to name their analytic approach.

Just over half of studies were explicitly positioned within a specified theoretical or conceptual framework ($n=16$). Most prominent were sociological and social psychological theories of stigma, with five studies indicating a specific focus on internalised or self-stigma

Most studies ($n=15$) included samples with a range of ED diagnoses. Of those restricted to a single ED subtype, most were AN ($n=10$) or BN ($n=3$). None purposively selected participants with BED or EDNOS. Of studies that specified how diagnoses were defined, most ($n=13$) relied on participants' self-report, with seven studies independently verifying clinical diagnoses and five employing researcher-defined screening criteria.

Sample size varied greatly between studies, ranging from 5 to 756 participants. Seventeen studies exclusively involved female participants. Of the mixed-gender studies that provided gender breakdowns, the proportion of male participants ranged from 2-23%. One study of internet forum content focused specifically on male experiences, but male authorship was inferred indirectly from the content of participants' posts and profiles (Wooldridge, Mok, & Chiu, 2014). Only 11 studies specified participants' ethnicity; participants in these studies were predominantly (63-96%) White/Caucasian, except for two studies that concentrated exclusively on the experiences of Hispanic/Latina women. Studies differed in modes of reporting participant ages, but most involved young adult samples (total age range 11-64).

Participants were recruited through multiple avenues, including clinical settings ($n=11$), universities ($n=4$), public advertising ($n=4$), previous research databases ($n=3$), and ED support organisations ($n=6$). Six studies were conducted in the USA, four in Australia, four in the UK, three in Canada, and two in Norway. The remainder recruited participants in more than one country.

Table 2

Quality assessment

The average quality assessment scores afforded to each article are presented in Table 2. The majority of the articles ($n=23$) showed good overall quality (Total>27). The remainder were evaluated as having fair methodological quality (Total=19-27). No study was judged to be of poor quality meriting exclusion from the review (Total<19).

Thematic synthesis

Thematic synthesis identified five themes that characterised the reviewed studies' findings on stigma experiences. These addressed (i) the nature and prevalence of stigma experienced (15 articles), (ii) stigma in families (6 articles), (iii) stigma in healthcare contexts (6 articles), (iv) self-stigmatisation and illness concealment (17 articles), and (v) stigma resistance (11 articles).

The nature and prevalence of stigma experienced

The review revealed limited quantitative data illuminating how frequently people with EDs personally experience stigma. A survey study found people with EDs reported frequently experiencing a range of stigmatising attitudes: for instance, approximately 70% often encountered attitudes suggesting "I should be able to just pull myself together" and "I am personally responsible for my condition" (Griffiths, Mond, Murray, & Touyz, 2015). Mond et al (2010) found 60.6% of symptomatic individuals predicted that a hypothetical character with BN was likely to experience discrimination.

The qualitative literature reviewed corroborates the suggestion people affected by EDs frequently experience being targets of stigma. In interview studies, participants commonly related feeling judged by other people (Evans et al., 2011; Ison & Kent, 2010). In one study, interviewees expressed concern that their symptoms would be viewed as a '*weakness*' or '*character flaw*' or would result in an enduring negative label of mental illness (a '*black mark*') (Becker, Hadley Arrindell, Perloe, Fay, & Striegel-Moore, 2010). Participants felt that eating disorders were trivialised by the general public, who saw eating disorders as volitional patterns

of behaviour motivated by vanity (Dimitropoulos, Freeman, et al., 2016; Rance, Clarke, & Moller, 2017). Other participants divulged that their own social circle could be judgemental and dismissive of their problems (Ison & Kent, 2010). Experience of social marginalisation was also a common topic of discussion on internet forums for people with EDs (McNamara & Parsons, 2016; Wooldridge et al., 2014):

Really I'm just lonely here and everywhere else too. (Wooldridge et al., 2014, p. 106)

Qualitative studies indicated that those with EDs often attributed the stigma they experience to public ignorance about EDs. Participants in numerous studies complained of a lack of understanding of EDs among the general population (Dimitropoulos, Freeman, et al., 2016; Ison & Kent, 2010; Rance et al., 2017; Walker & Lloyd, 2011). In one study, adolescent girls in a residential treatment centre expressed feeling misunderstood by others (Rich, 2006). Particular misconceptions that perturbed people with EDs included the notion that their disorder was self-inflicted (Dimitropoulos, Freeman, et al., 2016; Griffiths, Mond, Murray, & Touyz, 2015; Ison & Kent, 2010) or reflected a desire for attention (Rich, 2006; Walker & Lloyd, 2011) or glamour (Rich, 2006). For males, ED stigma involved the particular dimension of threat to one's masculinity (Griffiths, Mond, Murray, & Touyz, 2015). While the research reviewed showed that people with EDs objected to these characterisations, these negative ascriptions could also sometimes be internalised, for example in self-accusations of vanity (Skårderud, 2007).

The qualitative research reviewed contained some indication that people with EDs believed the intensity of stigma varies across the different ED subtypes. Hepworth and Paxton found that participants who had experienced both AN and BN believed that BN was more stigmatised (Hepworth & Paxton, 2007). Similarly, participants in Ison and Kent's study implied that EDs were positioned along a hierarchy whereby AN was most socially accepted, followed by BN and finally EDNOS (Ison & Kent, 2010):

I think people who hear about people with bulimia, just think that they're, greedy pigs... I don't think there's as much compassion for bulimics as there is for anorexics (Ison & Kent, 2010, p. 479)

Corroborating quantitative evidence suggested that participants with bulimia nervosa reported more frequently being stigmatised as lacking self-control than participants with anorexia nervosa or EDNOS (Griffiths, Mond, Murray, & Touyz, 2015).

Two quantitative studies queried whether people directly affected by EDs perceive greater levels of ED stigma than those without this personal experience. A survey study found that symptomatic women were more likely than non-symptomatic women to believe that people with BN would face discrimination (Mond et al., 2010). However, a comparison of AN patients and their healthy siblings found that both groups had similar perceptions of the level of stigma directed at AN patients and their families (Dimitropoulos, Freeman, Bellai, & Olmsted, 2013). Family experience may be as effective as patient experience in sensitising people to ED stigma.

Stigma in families

The reviewed papers suggested that people with EDs could perceive stigma as emanating from immediate family-members as well as wider society. Becker et al.'s (2010) interviewees expressed concern that their illness would shame or disappoint their families:

You know my family had a big problem with my going to therapy [. . .] It was like they felt there was something wrong with them because I had to go to therapy (Becker et al., 2010, p. 637)

Evans et al. (2011) similarly found that participants feared judgement from family members. Family responses may interact with cultural background: interviews with Latina women suggested that stigma around mental illness in this community led people to keep the problem within the family unit, concealing it from the outside world (Reyes-Rodríguez,

Ramírez, Davis, Patrice, & Bulik, 2013). Family members' perceptions of EDs as stigmatising could therefore prevent people from accessing external support.

The quantitative literature reviewed suggested that stigma can impact on family relationships and wellbeing. A questionnaire study of people with AN found greater perceived stigmatisation of AN was significantly correlated with higher levels of family dysfunction (Dimitropoulos et al., 2013). Perkins et al.'s (2005) regression analysis found that when parents were perceived to have a blaming attitude towards BN, adolescents were less likely to involve their parents in treatment. Judgemental attitudes towards EDs could therefore foster tension and conflict within families (Walker & Lloyd, 2011). However, the evidence for these links remained correlational, restricting the ability to establish causal relationships.

Stigma in healthcare contexts

Several qualitative studies illuminated how ED stigma can operate within healthcare contexts. Rich's (2006) study of a residential treatment facility found patients felt staff did not appreciate the severity of their emotional distress, with emotional factors overlooked due to an exclusive focus on eating and weight gain. Other participants stated they had encountered health professionals who had limited understanding or knowledge of EDs (McNamara & Parsons, 2016; Walker & Lloyd, 2011). Numerous interviewees in Evans et al.'s (2011) study reported having previously felt judged by a health professional; however, some also praised professionals they felt had treated them in a non-judgemental manner. The research reviewed therefore indicated that experience of stigma within healthcare contexts was common but not universal. No quantitative data facilitated more precise quantification of stigma experience in healthcare contexts.

A small amount of research suggested that stereotypes of EDs held by health professionals could impede detection of the disorder. In two interview studies, participants suggested that presumptions that EDs primarily affect white, middle-class girls led health professionals to

dismiss or misinterpret the symptoms of ethnic minorities, thus enabling their ED behaviours to continue unchecked (Becker et al., 2010; Reyes-Rodríguez et al., 2013):

For years [vomiting] went on, but no one ever looked at me because, you know, white girls do that, not black girls. It was one of the easiest things I ever gotten away with in my life. (Becker et al., 2010, p. 640)

These observations demonstrated how health professionals' beliefs and attitudes regarding EDs could have tangible effects on diagnosis and treatment decisions.

Self-stigmatisation and illness concealment

The reviewed research suggested that concealing one's illness was common among people with an ED diagnosis. Qualitative studies revealed that participants frequently denied, hid, avoided or downplayed their ED (Pettersen, Rosenvinge, & Ytterhus, 2008; Rance et al., 2017; Rich, 2006; Skårderud, 2007):

I'm losing track of what lies I'm telling different people... I saw two different people yesterday and I told them both completely different stories of why I'm losing weight and, you know, why I'm tired all the time and I look like crap and, you know, and I'm just thinking 'Please don't discuss it'. (Rance et al., 2017, p. 131)

Yeshua-Katz and Martins' interviews with people who contributed to ED-themed internet forums showed most remained anonymous in their online interactions and feared their online identity being discovered in their offline life (Yeshua-Katz & Martins, 2013). There was also quantitative evidence of motivation to conceal EDs: Mond et al.'s survey indicated women who were symptomatic or at high risk of BN were more likely than low-risk women to say they would not want anyone to know they had BN (Mond et al., 2010).

The research further suggested that stigma is an important contributor to this reluctance to disclose one's ED. In several qualitative studies, people affected by EDs directly stated that stigma had prevented or delayed them from seeking help. In Hepworth and Paxton's (2007)

study, fear of stigma emerged as the most prominent theme when respondents were questioned about barriers to help-seeking. Over half of Becker et al.'s (2010) participants stated that stigma or shame had prevented them from disclosing eating problems, while Evans et al. (2011) similarly found anticipation of negative judgement had prevented participants from revealing their illness.

The stigma-secrecy link was corroborated by quantitative research. Greater levels of self-stigma correlated with more negative attitudes to help-seeking (Hackler et al., 2010). Similarly, undiagnosed Latina women with ED symptomatology showed higher levels of stigmatisation of mental health treatment than women who reported a clinical history of EDs (Higgins, Bulik, & Bardone-Cone, 2016). A survey of women in inpatient treatment for AN found that higher public and internalised stigma predicted poorer attitudes to recovery (Dimitropoulos, McCallum, Colasanto, Freeman, & Gadalla, 2016). Two studies suggested the relationship between stigma and negative attitudes to help-seeking is particularly strong in men (Griffiths, Mond, Li, et al., 2015; Hackler et al., 2010).

The research suggested that as well as delaying treatment, stigma-induced secrecy could compromise people's wellbeing in other ways. A survey study indicated that extent of stigmatisation experienced was related to lower self-esteem, stronger eating disorder symptoms, and longer duration of disorder (Griffiths, Mond, Murray, & Touyz, 2015). An experimental study by Smart and Wegner suggested that attempting to conceal one's ED was associated with more intrusive thoughts (Smart & Wegner, 1999), while Pettersen et al.'s study of the subjective experience of concealing BN found that participants' attempts to hide their disorder led to a sense of living a 'double life' (Pettersen et al., 2008). Thus, the identity management demands imposed by ED stigma could carry a heavy social and emotional burden.

Stigma resistance

Research from the perspective of people with EDs provided an important insight into how people resist or challenge stigma. Griffiths et al. (2015, p. 279) defined stigma resistance as “the capacity to counteract or remain unaffected by the stigma of mental illness”. Statistical comparison of people at various stages of ED treatment found those who had recovered showed greater psychological resistance to ED stigma (Griffiths, Mond, Murray, Thornton, & Touyz, 2015). Resistance was correlated with lower ED and depression symptoms, more positive attitudes towards help seeking and higher self-esteem, suggesting that stigma resistance may contribute to regaining psychological health.

Qualitative research suggested one key way in which people with EDs coped with a devalued ED identity was to seek validation from similar others. A study of young people in a residential treatment facility found inpatients collectively reconstructed AN as an exhibition of strength and empowerment rather than weakness (Rich, 2006):

It [anorexia] shows that you have a strength that others don't, because, let's face it, not many people have the ability to starve themselves to death (Rich, 2006, p. 298)

This functioned to perpetuate disordered eating patterns, as the group normalised unhealthy eating and shared tips for concealing ED behaviour. However, Rich (2006) proposed that these intragroup processes also served an important psychological function, allowing the adolescents to assert self-determination and challenge the devalued ED identity imposed on them by others.

Similar tensions between identity validation and the perpetuation of unhealthy eating patterns emerged in five papers exploring use of online forums by people with EDs. Websites characterised as pro-anorexia or ‘pro-Ana’ can function as a platform for symbolic and practical encouragement of weight reduction (Haas, Irr, Jennings, & Wagner, 2011; Wooldridge et al., 2014). One study suggested these websites could also intensify users’ preoccupation with stigma: quantitative analysis of word use patterns suggested that online disclosure of

stigmatising experiences often prompted negatively valenced responses from other site members, which increased the original poster's focus on stigma-related issues in their subsequent posts (Chang & Bazarova, 2016). However, other studies suggested pro-Ana sites had benefits in providing a space where people could construct a positive social identity and resist narrow, medicalised representations of EDs (Haas et al., 2011). In interviews with people who contributed to pro-Ana blogs, participants indicated their major motive was seeking social support and contact with similar others, which provided a form of validation that was unavailable in their everyday life (Yeshua-Katz & Martins, 2013). This could be especially important for addressing the social isolation of males with EDs. Wooldridge et al.'s analysis of male contributions to pro-Ana forums suggested participants used the forum to develop a sense of community, within which they could discuss their common experiences (Wooldridge et al., 2014). Those who utilised such forums characterised the social support they offered as unconditional, stronger than that available in their offline life, and lacking any judgement or attempt to 'fix' them (Yeshua-Katz & Martins, 2013). Users experienced movements to ban or censure these websites as intensifying their stigmatisation and marginalisation (Yeshua-Katz, 2015). Their online interactions were explicitly positioned as means of coping with and escaping from stigma (Yeshua-Katz & Martins, 2013).

I think it was the fact that having an ED was so socially unacceptable that it pushed me to seek others that I could tell my story to. That they would listen and tell me what I wanted to hear. (Yeshua-Katz & Martins, 2013, p. 503)

Pro-Ana sites were not the only online venue where these social benefits were encountered. An analysis of a moderated, recovery-centred web discussion group found connection with similar others was instrumental in shifting participants from a stigmatised 'illness identity' to a 'recovery identity' (McNamara & Parsons, 2016). Thus, in certain

contexts, the shared identity fostered by online communications could promote disclosure and treatment engagement as well as reduce isolation.

Very little data reported in the reviewed research showed people with EDs making suggestions regarding strategies for tackling ED stigma. However, one qualitative study spoke indirectly to this issue in exploring whether, from the perspective of people with EDs, certain beliefs about EDs might promote or reduce stigma. Easter (2012) reported 90% of interviewees believed that emphasising genetic causes of AN would help to reduce stigma. However, 34% suggested that this framing of AN could also produce novel forms of stigma, by perpetuating essentialist representations of people with AN as intrinsically disordered and detracting attention from the sociocultural factors that promote disordered eating. One quantitative study tested the effects of exposure to biological theories of EDs on levels of self-blame and found no difference relative to participants who had learned about cognitive/behavioural causal factors (Farrell, Lee, & Deacon, 2015). This research therefore did not support the proposition that promoting biological accounts of ED aetiology would reduce stigma experiences.

Discussion

This systematic review identified 29 studies that illuminated how people with EDs experience the stigma associated with their disorder. The surge in studies published post-2010 indicates this is an expanding field of research, attracting interest from scholars in different disciplines and countries. By collating this diverse body of literature, the current review serves as a useful entry-point into this field. Its synthesis of the key evidence to date will prove a valuable resource for researchers, practitioners, policy-makers and service-users interested in understanding and remediating the stigma that EDs continue to generate.

Key findings

The research reviewed in this study confirmed that people with EDs commonly relate being the target of stigma, in healthcare and familial settings as well as in society in general. This corroborates previous population-based research, which has demonstrated that stigmatising attitudes are prevalent in the general community (Crisafulli et al., 2008; Crisp, 2005; Currin et al., 2009; McNicholas et al., 2016; O'Connor et al., 2016; Roehrig & McLean, 2010; Stewart et al., 2006, 2008). The finding that people with ED-like symptoms see EDs as more stigmatised than non-symptomatic individuals (Mond et al., 2010) suggests that studies that purely involve non-affected individuals may even underestimate the prevalence of stigma that people with EDs face.

Research with those directly affected by EDs provides a particularly important insight into the consequences of ED stigma. According to this group, stigma has negative implications for both their immediate psychological wellbeing and their likelihood of disclosing or seeking help for their illness (Becker et al., 2010; Evans et al., 2011; Griffiths, Mond, Murray, & Touyz, 2015; Hackler et al., 2010; Hepworth & Paxton, 2007; Pettersen et al., 2008). Negative attitudes towards people with EDs can therefore perpetuate illness duration and severity.

In considering the corrosive effects of ED stigma, however, it is important to avoid painting people with EDs as helpless victims. The literature to which they have contributed shows that stigma is not always passively internalised: people with EDs engage in active strategies to resist and challenge it (Griffiths, Mond, Murray, Thornton, et al., 2015). Through contact with similar others, individuals actively seek to validate their experiences and construct alternative, valued identities (McNamara & Parsons, 2016; Rich, 2006). The literature further suggests that internet platforms are particularly important facilitators of these processes, although this carries some risks (Chang & Bazarova, 2016).

Gaps and weakness in the literature

The overall quality of the research evaluated was reasonably good. The primarily qualitative focus of the extant literature provides rich insight into the dynamic and multifarious ways ED stigma is perceived and managed by those it targets. Methods such as interviews and focus groups offer an important route through which the voices of individuals living with EDs can be transmitted to policy-makers, health professionals and wider society (Whitley & Crawford, 2005). However, the relative paucity of quantitative research makes it difficult to draw firm conclusions about the prevalence of ED stigma in various social contexts or its causal relationships with factors such as help-seeking. Additionally, given the small sample sizes typically involved in qualitative studies, their findings are not (and do not claim to be) fully representative of the wider population of people with EDs. Expanding the quantitative data that can complement existing qualitative insights should be a priority for future research. In particular, longitudinal research with clinical samples is necessary to understand how the experience of stigma evolves across illness and recovery trajectories.

Future data collection should particularly seek to include the perspectives of males, older people, and individuals from minority communities. The systematic review revealed an overwhelming focus on the experience of Western, white, young women. This may reflect epidemiological findings that EDs are most prevalent among young females. However, an exclusive focus on demographically typical ED profiles can reinforce ED stereotypes and further relegate the experience of atypical cases. Rates of EDs among men are increasing (Mitchison, Mond, Slewa-Younan, & Hay, 2013). Gay men are at particular risk of developing EDs due to high body dissatisfaction (Morrison, Morrison, & Sager, 2004; Russell & Keel, 2002). Transgender individuals are also at higher risk of EDs due to general body dissatisfaction and desire to affirm gender through body shape (Jones et al., 2018; Testa, Rider, Haug, & Balsam, 2017). Underlining the intersectionality of stigma processes, the persistent sexual stigma experienced by LGBT communities can amplify ED proneness (Bell, Rieger, & Hirsch,

2019). However, no studies in this review investigated how the experience of ED stigma interacted with LGBT identities. A further adjacent stigma neglected in the literature is weight stigma: since dominant cultural representations of EDs associate them with extreme thinness, overweight persons with disordered eating may encounter particular difficulties with help-seeking and interpersonal responses (Durso et al., 2012). The underrepresentation of atypical ED populations in this literature is significant since these may be the people for whom stigma is most intense: the little research that directly investigated the experience of men or ethnic minorities found their social marginalisation was compounded by their divergence from the standard ED stereotype (Griffiths, Mond, Li, et al., 2015; Reyes-Rodríguez et al., 2013; Wooldridge et al., 2014). Research must take care to avoid perpetuating the notion that disordered eating is exclusively pertinent to young white females.

Much of the literature reviewed was atheoretical. Almost half of articles specified no conceptual approach to inform the research or advance existing theory. The lack of an overarching conceptual framework to inform hypothesis formation or data interpretation clearly hampers research progress. As it stands, the literature is rather incohesive, composed of isolated small studies that do not coalesce into a unifying research programme. To ensure this research field produces knowledge of social and clinical utility, theoretical development must be prioritised. Such efforts could borrow from existing theoretical frameworks in sociology and psychology; for instance, the social identity approach to mental health (Jetten et al., 2017) has highlighted how social relations can function as both risk and protective factors in EDs (McNamara & Parsons, 2016). A further useful theoretical resource is Pescosolido et al.'s (2008) Framework Integrating Normative Influences on Stigma, a multidimensional and integrative platform for a more structured approach to stigma research and interventions.

The relatively recent nature of this literature might account for the underdeveloped nature of its conceptual framework. The vast majority (79%, $n=23$) of studies reviewed were published

after 2010, while the search detected just one study published before 2000 (Smart & Wegner, 1999). This indicates that the first-hand experience of ED stigma is a nascent topic of research, with much work yet to be undertaken. This offers grounds for optimism that this promising research field will continue to develop, and furnish insights that can help enlighten and ameliorate the social context in which EDs occur.

Limitations and strengths of this review

The review was subject to a number of limitations. First, while screening decisions showed a high degree of inter-reviewer reliability, this was computed based on just a subsample of references. Resource restrictions precluded the use of multiple reviewers to screen and extract data from each article. While this is not required by PRISMA guidelines (Liberati et al., 2009), full duplication of screening and data extraction tasks would have provided an additional safeguard against reviewer bias or error.

A further possible limitation relates to the decision to appraise studies' quality through a mixed-methods evaluation tool (Hawker et al., 2002). While informed by other established quality appraisal instruments, the criteria included in this tool are necessarily more general than those typically present in a dedicated quantitative- or qualitative-specific evaluation system. However, the evaluation strategy was suited to the study's aim of providing a comprehensive and holistic overview of the literature. The integration of diverse sources of evidence is consistent with emerging trends in health research, which emphasise the mutual benefits of both quantitative and qualitative empirical insights (Dixon-Woods & Fitzpatrick, 2001; Gough, 2015; Pearson et al., 2015). Moreover, it is particularly appropriate for considering the topic of lived experience, where qualitative research predominates but can be usefully complemented by quantitative information (e.g. in elucidating the frequency of a particular type of experience or its distribution across particular groups). The inclusive methodological techniques adopted

for the current review provided an efficient means of collating a maximally comprehensive range of evidence.

An additional limitation is that the review protocol was not pre-registered in advance of conducting the review. Furthermore, due to resource restrictions it was not possible to include material published in books and grey literature, or in languages other than English. To ensure the quality of the evidence considered, the review included only published peer-reviewed research. It is possible there are other relevant sources of evidence that did not emerge in the keyword-search of five electronic databases. This notwithstanding, as the first study to collate, evaluate and synthesise this important body of research, the review serves an important function.

Implications for policy and clinical practice

The review demonstrates the value of research conducted from the perspective of the targets of stigma, which contributes unique insight into how ED stigma unfolds in day-to-day life. For example, the research included in this review proposed that the different ED subtypes carry distinctive stigma implications (Hepworth & Paxton, 2007; Ison & Kent, 2010). While previous literature confirms that the stigma dynamics of particular ED subtypes may differ (Puhl & Suh, 2015), direct comparison of the stigma experiences of people with AN, BN and BED remains lacking. The research reviewed also suggests experience of ED stigma deviates across cultural and ethnic divides (Higgins et al., 2016; Reyes-Rodríguez et al., 2013), an additional under-researched area. These are useful lines of inquiry for future larger studies that, if validated, could prove informative for mental health policy and practice.

The first-person perspective is particularly crucial for understanding the repercussions of ED stigma for those it targets. The quantitative and qualitative research reviewed converged in suggesting that stigma can prolong the duration and severity of EDs by undermining help-seeking, treatment engagement and mental health. This bolsters the humanitarian and economic

logic of investing in strategies to tackle stigmatising attitudes to EDs. The findings regarding the nature of stigmatising attitudes experienced by people with EDs particularly highlight the need for public initiatives that counteract the prevailing stereotypes of people with EDs as vain, attention-seeking and volitional in their difficulties. A recent meta-analysis confirms Easter's (2012) suggestion that biological accounts of EDs may help to reduce public stigma, as may a combination of educational and contact-based interventions (Doley et al., 2017). However, implementation of such intervention strategies should be sensitive to the potential risks of biomedical explanations in promoting essentialist images of mental illness (Haslam & Kvaale, 2015).

The findings that people with EDs can construct valued identities through contact with similar others, particularly through online communities and platforms, should inform debate and policy regarding so-called 'pro-Ana' content, which is prohibited and periodically removed by many social networking services (Casilli, Tubaro, & Araya, 2012; Norris, Boydell, Pinhas, & Katzman, 2006). The risk that such communities normalise unhealthy eating must be taken seriously (Chang & Bazarova, 2016). However, removing a valued social lifeline from a vulnerable individual, without making available compensatory support structures, could also pose serious and immediate mental health risks (Yeshua-Katz, 2015). User-informed research is critical in attaining a full sense of the psychosocial benefits that accrue from these online communities and the extent to which these benefits can compensate for the unhealthy messages that circulate therein.

Conclusions

This review collated the existing empirical literature on how people with EDs experience the stigma associated with their condition, synthesising a diverse range of quantitative, qualitative and mixed-methods studies. The findings enlightened the extent of stigma experienced by people with EDs and the negative implications that stigma may have. The

review also highlighted the resistance to stigma that people with EDs may develop. An important implication of these findings is the need for public interventions and initiatives to address the various components of ED stigma, including labelling, stereotyping, distancing and discrimination (Link & Phelan, 2001). Incorporating specific support in managing stigma into therapeutic programmes would also likely help promote recovery. Priorities for future research include expansion of the socio-demographic profile of study samples, encouragement of longitudinal designs with clinical samples, and development of theoretical frameworks that can contextualise this burgeoning field of research.

References

- Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *International Journal of Eating Disorders*, *50*(1), 9–21. <https://doi.org/10.1002/eat.22598>
- Angermeyer, M. C., & Dietrich, S. (2006). Public beliefs about and attitudes towards people with mental illness: a review of population studies. *Acta Psychiatrica Scandinavica*, *113*(3), 163–179. <https://doi.org/10.1111/j.1600-0447.2005.00699.x>
- Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724–731. <https://doi.org/10.1001/archgenpsychiatry.2011.74>
- Becker, A. E., Hadley Arrindell, A., Perloe, A., Fay, K., & Striegel-Moore, R. H. (2010). A qualitative study of perceived social barriers to care for eating disorders: Perspectives from ethnically diverse health care consumers. *International Journal of Eating Disorders*, *43*(7), 633–647. <https://doi.org/10.1002/eat.20755>
- Bell, K., Rieger, E., & Hirsch, J. K. (2019). Eating disorder symptoms and proneness in gay men, lesbian women, and transgender and non-conforming adults: Comparative levels and a proposed mediational model. *Frontiers in Psychology*, *9*. <https://doi.org/10.3389/fpsyg.2018.02692>
- Booth, M. L., Bernard, D., Quine, S., Kang, M. S., Usherwood, T., Alperstein, G., & Bennett, D. L. (2004). Access to health care among Australian adolescents young people's perspectives and their sociodemographic distribution. *Journal of Adolescent Health*, *34*(1), 97–103. <https://doi.org/10.1016/j.jadohealth.2003.06.011>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment*, *6*(1), 65–72. <https://doi.org/10.1192/apt.6.1.65>
- Casilli, A. A., Tubaro, P., & Araya, P. (2012). Ten years of Ana: Lessons from a transdisciplinary body of literature on online pro-eating disorder websites. *Social Science Information*, *51*(1), 120–139. <https://doi.org/10.1177/0539018411425880>
- Chang, P. F., & Bazarova, N. N. (2016). Managing stigma: Disclosure-response communication patterns in pro-anorexic websites. *Health Communication*, *31*(2), 217–229. <https://doi.org/10.1080/10410236.2014.946218>
- Cooper, A. E., Corrigan, P. W., & Watson, A. C. (2003). Mental illness stigma and care seeking. *The Journal of Nervous and Mental Disease*, *191*(5), 339–341. <https://doi.org/10.1097/01.NMD.0000066157.47101.22>
- Corrigan, P., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20.
- Crisafulli, M. A., Von Holle, A., & Bulik, C. M. (2008). Attitudes towards anorexia nervosa: The impact of framing on blame and stigma. *International Journal of Eating Disorders*, *41*(4), 333–339. <https://doi.org/10.1002/eat.20507>
- Crisp, A. H. (2005). Stigmatization of and discrimination against people with eating disorders including a report of two nationwide surveys. *European Eating Disorders Review*, *13*(3), 147–152. <https://doi.org/10.1002/erv.648>
- Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2000). Stigmatisation of people with mental illnesses. *The British Journal of Psychiatry: The Journal of Mental Science*, *177*, 4–7.

- Critical Appraisal Skills Programme. (2017). Critical Appraisal Skills Programme Qualitative Checklist. Retrieved May 4, 2017, from <http://www.casp-uk.net/casp-tools-checklists>
- Currin, L., Waller, G., & Schmidt, U. (2009). Primary care physicians' knowledge of and attitudes toward the eating disorders: Do they affect clinical actions? *International Journal of Eating Disorders*, *42*(5), 453–458. <https://doi.org/10.1002/eat.20636>
- Dimitropoulos, G., Freeman, V. E., Bellai, K., & Olmsted, M. (2013). Inpatients with severe anorexia nervosa and their siblings: non-shared experiences and family functioning. *European Eating Disorders Review: The Journal of the Eating Disorders Association*, *21*(4), 284–293. <https://doi.org/10.1002/erv.2230>
- Dimitropoulos, G., Freeman, V. E., Muskat, S., Domingo, A., & McCallum, L. (2016). “You don’t have anorexia, you just want to look like a celebrity”: perceived stigma in individuals with anorexia nervosa. *Journal of Mental Health*, *25*(1), 47–54. <https://doi.org/10.3109/09638237.2015.1101422>
- Dimitropoulos, G., McCallum, L., Colasanto, M., Freeman, V. E., & Gadalla, T. (2016). The effects of stigma on recovery attitudes in people with anorexia nervosa in intensive treatment. *The Journal of Nervous and Mental Disease*, *204*(5), 370. <https://doi.org/10.1097/NMD.0000000000000480>
- Dixon-Woods, M., & Fitzpatrick, R. (2001). Qualitative research in systematic reviews. *BMJ*, *323*(7316), 765–766. <https://doi.org/10.1136/bmj.323.7316.765>
- Doley, J. R., Hart, L. M., Stukas, A. A., Petrovic, K., Bouguettaya, A., & Paxton, S. J. (2017). Interventions to reduce the stigma of eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders*, *50*(3), 210–230. <https://doi.org/10.1002/eat.22691>
- Durso, L. E., Latner, J. D., White, M. A., Masheb, R. M., Blomquist, K. K., Morgan, P. T., & Grilo, C. M. (2012). Internalized weight bias in obese patients with binge eating disorder: associations with eating disturbances and psychological functioning. *International Journal of Eating Disorders*, *45*(3), 423–427.
- Easter, M. M. (2012). “Not all my fault”: Genetics, stigma, and personal responsibility for women with eating disorders. *Social Science & Medicine*, *75*(8), 1408–1416. <https://doi.org/10.1016/j.socscimed.2012.05.042>
- Ebnetter, D. S., & Latner, J. D. (2013). Stigmatizing attitudes differ across mental health disorders: a comparison of stigma across eating disorders, obesity, and major depressive disorder. *The Journal of Nervous and Mental Disease*, *201*(4), 281–285. <https://doi.org/10.1097/NMD.0b013e318288e23f>
- Evans, E. J., Hay, P. J., Mond, J., Paxton, S. J., Quirk, F., Rodgers, B., ... Sawoniewska, M. A. (2011). Barriers to help-seeking in young women with eating disorders: a qualitative exploration in a longitudinal community survey. *Eating Disorders*, *19*(3), 270–285. <https://doi.org/10.1080/10640266.2011.566152>
- Farrell, N. R., Lee, A. A., & Deacon, B. J. (2015). Biological or psychological? Effects of eating disorder psychoeducation on self-blame and recovery expectations among symptomatic individuals. *Behaviour Research and Therapy*, *74*, 32–37. <https://doi.org/10.1016/j.brat.2015.08.011>
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. New York, NY: Prentice-Hall.
- Gough, D. (2015). Qualitative and mixed methods in systematic reviews. *Systematic Reviews*, *4*, 181. <https://doi.org/10.1186/s13643-015-0151-y>
- Griffiths, S., Mond, J. M., Li, Z., Gunatilake, S., Murray, S. B., Sheffield, J., & Touyz, S. (2015). Self-stigma of seeking treatment and being male predict an increased likelihood of having an undiagnosed eating disorder. *International Journal of Eating Disorders*, *48*(6), 775–778. <https://doi.org/10.1002/eat.22413>

- Griffiths, S., Mond, J. M., Murray, S. B., Thornton, C., & Touyz, S. (2015). Stigma resistance in eating disorders. *Social Psychiatry and Psychiatric Epidemiology*, *50*(2), 279–287. <https://doi.org/10.1007/s00127-014-0923-z>
- Griffiths, S., Mond, J. M., Murray, S. B., & Touyz, S. (2015). The prevalence and adverse associations of stigmatization in people with eating disorders. *International Journal of Eating Disorders*, *48*(6), 767–774. <https://doi.org/10.1002/eat.22353>
- Haas, S. M., Irr, M. E., Jennings, N. A., & Wagner, L. M. (2011). Communicating thin: A grounded model of Online Negative Enabling Support Groups in the pro-anorexia movement. *New Media & Society*, *13*(1), 40–57. <https://doi.org/10.1177/1461444810363910>
- Hackler, A. H., Vogel, D. L., & Wade, N. G. (2010). Attitudes toward seeking professional help for an eating disorder: The role of stigma and anticipated outcomes. *Journal of Counseling & Development*, *88*(4), 424–431. <https://doi.org/10.1002/j.1556-6678.2010.tb00042.x>
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*, *12*(9), 1284–1299.
- Hepworth, N., & Paxton, S. J. (2007). Pathways to help-seeking in bulimia nervosa and binge eating problems: A concept mapping approach. *International Journal of Eating Disorders*, *40*(6), 493–504. <https://doi.org/10.1002/eat.20402>
- Higgins, J. P. T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions, Version 5.1.0*. Retrieved from The Cochrane Collaboration website: <http://handbook.cochrane.org/>
- Higgins, M. K., Bulik, C. M., & Bardone-Cone, A. M. (2016). Factors associated with self-identification of an eating disorder history among Latinas meeting criteria for past or current eating disorders. *International Journal of Eating Disorders*, *49*(11), 1032–1035. <https://doi.org/10.1002/eat.22583>
- Ison, J., & Kent, S. (2010). Social identity in eating disorders. *European Eating Disorders Review*, *18*(6), 475–485. <https://doi.org/10.1002/erv.1001>
- Jetten, J., Haslam, S. A., Cruwys, T., Greenaway, K. H., Haslam, C., & Steffens, N. K. (2017). Advancing the social identity approach to health and well-being: Progressing the social cure research agenda. *European Journal of Social Psychology*. <https://doi.org/10.1002/ejsp.2333>
- Jones, B. A., Haycraft, E., Bouman, W. P., Brewin, N., Claes, L., & Arcelus, J. (2018). Risk factors for eating disorder psychopathology within the treatment seeking transgender population: The role of cross-sex hormone treatment. *European Eating Disorders Review*, *26*(2), 120–128. <https://doi.org/10.1002/erv.2576>
- Haslam, N., & Kvaale, E. P. (2015). Biogenetic explanations of mental disorder: The mixed-blessings model. *Current Directions in Psychological Science*, *24*(5), 399–404. <https://doi.org/10.1177/0963721415588082>
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., ... Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLOS Medicine*, *6*(7), e1000100. <https://doi.org/10.1371/journal.pmed.1000100>
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology*, *27*, 363–385. Retrieved from JSTOR.
- Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-Based Healthcare*, *13*(3), 179–187. <https://doi.org/10.1097/XEB.0000000000000062>

- Maier, A., Ernst, J.-P., Müller, S., Gross, D., Zepf, F. D., Herpertz-Dahlmann, B., & Hagenah, U. (2014). Self-perceived stigmatization in female patients with anorexia nervosa--results from an explorative retrospective pilot study of adolescents. *Psychopathology*, *47*(2), 127–132. <https://doi.org/10.1159/000350505>
- McNamara, N., & Parsons, H. (2016). ‘Everyone here wants everyone else to get better’: The role of social identity in eating disorder recovery. *British Journal of Social Psychology*, *55*(4), 662–680. <https://doi.org/10.1111/bjso.12161>
- McNicholas, F., O’Connor, C., O’Hara, L., & McNamara, N. (2016). Stigma and treatment of eating disorders in Ireland: healthcare professionals’ knowledge and attitudes. *Irish Journal of Psychological Medicine*, *33*(1), 21–31. <https://doi.org/10.1017/ipm.2015.24>
- Mitchison, D., Mond, J., Slewa-Younan, S., & Hay, P. (2013). The prevalence and impact of eating disorder behaviours in Australian men. *Journal of Eating Disorders*, *1*(Suppl 1), O23. <https://doi.org/10.1186/2050-2974-1-S1-O23>
- Mond, J. M., Hay, P. J., Paxton, S. J., Rodgers, B., Darby, A., Nilsson, J., ... Owen, C. (2010). Eating disorders “mental health literacy” in low risk, high risk and symptomatic women: implications for health promotion programs. *Eating Disorders*, *18*(4), 267–285. <https://doi.org/10.1080/10640266.2010.490115>
- Morrison, M. A., Morrison, T. G., & Sager, C.-L. (2004). Does body satisfaction differ between gay men and lesbian women and heterosexual men and women? A meta-analytic review. *Body Image*, *1*(2), 127–138. <https://doi.org/10.1016/j.bodyim.2004.01.002>
- Norris, M. L., Boydell, K. M., Pinhas, L., & Katzman, D. K. (2006). Ana and the Internet: A review of pro-anorexia websites. *International Journal of Eating Disorders*, *39*(6), 443–447. <https://doi.org/10.1002/eat.20305>
- O’Connor, C., McNamara, N., O’Hara, L., & McNicholas, F. (2016). Eating disorder literacy and stigmatising attitudes towards anorexia, bulimia and binge eating disorder among adolescents. *Advances in Eating Disorders*, *4*(2), 125–140. <https://doi.org/10.1080/21662630.2015.1129635>
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review - a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research & Policy*, *10*(1_suppl), 21–34. <https://doi.org/10.1258/1355819054308530>
- Pearson, A., White, H., Bath-Hextall, F., Salmond, S., Apostolo, J., & Kirkpatrick, P. (2015). A mixed-methods approach to systematic reviews. *International Journal of Evidence-Based Healthcare*, *13*(3), 121–131. <https://doi.org/10.1097/XEB.0000000000000052>
- Perkins, S., Schmidt, U., Eisler, I., Treasure, J., Yi, I., Winn, S., ... Berelowitz, M. (2005). Why do adolescents with bulimia nervosa choose not to involve their parents in treatment? *European Child & Adolescent Psychiatry*, *14*(7), 376–385. <https://doi.org/10.1007/s00787-005-0485-4>
- Pescosolido, B. A., Martin, J. K., Lang, A., & Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: A Framework Integrating Normative Influences on Stigma (FINIS). *Social Science & Medicine*, *67*(3), 431–440. <https://doi.org/10.1016/j.socscimed.2008.03.018>
- Pettersen, G., Rosenvinge, J. H., & Ytterhus, B. (2008). The “Double Life” of Bulimia: Patients’ Experiences in Daily Life Interactions. *Eating Disorders*, *16*(3), 204–211. <https://doi.org/10.1080/10640260802016696>
- Puhl, R. M., & Latner, J. D. (2007). Stigma, obesity, and the health of the nation’s children. *Psychological Bulletin*, *133*(4), 557–580. <https://doi.org/10.1037/0033-2909.133.4.557>
- Puhl, R. M., & Suh, Y. (2015). Stigma and Eating and Weight Disorders. *Current Psychiatry Reports*, *17*(3), 10. <https://doi.org/10.1007/s11920-015-0552-6>

- Rance, N., Clarke, V., & Moller, N. (2017). The anorexia nervosa experience: Shame, Solitude and Salvation. *Counselling and Psychotherapy Research*, 17(2), 127–136. <https://doi.org/10.1002/capr.12097>
- Reyes-Rodríguez, M. L., Ramírez, J., Davis, K., Patrice, K., & Bulik, C. M. (2013). Exploring barriers and facilitators in eating disorders treatment among Latinas in the United States. *Journal of Latina/o Psychology*, 1(2), 112–131. <https://doi.org/10.1037/a0032318>
- Rich, E. (2006). Anorexic dis(connection): managing anorexia as an illness and an identity. *Sociology of Health & Illness*, 28(3), 284–305. <https://doi.org/10.1111/j.1467-9566.2006.00493.x>
- Roehrig, J. P., & McLean, C. P. (2010). A comparison of stigma toward eating disorders versus depression. *International Journal of Eating Disorders*, 43(7), 671–674. <https://doi.org/10.1002/eat.20760>
- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry: The Journal of the Association of European Psychiatrists*, 20(8), 529–539. <https://doi.org/10.1016/j.eurpsy.2005.04.004>
- Russell, C. J., & Keel, P. K. (2002). Homosexuality as a specific risk factor for eating disorders in men. *International Journal of Eating Disorders*, 31(3), 300–306. <https://doi.org/10.1002/eat.10036>
- Skårderud, F. (2007). Shame and pride in anorexia nervosa: a qualitative descriptive study. *European Eating Disorders Review*, 15(2), 81–97. <https://doi.org/10.1002/erv.774>
- Smart, L., & Wegner, D. M. (1999). Covering up what can't be seen: Concealable stigma and mental control. *Journal of Personality and Social Psychology*, 77(3), 474–486. <https://doi.org/10.1037/0022-3514.77.3.474>
- Stewart, M.-C., Keel, P. K., & Schiavo, R. S. (2006). Stigmatization of anorexia nervosa. *International Journal of Eating Disorders*, 39(4), 320–325. <https://doi.org/10.1002/eat.20262>
- Stewart, M.-C., Schiavo, R. S., Herzog, D. B., & Franko, D. L. (2008). Stereotypes, prejudice and discrimination of women with anorexia nervosa. *European Eating Disorders Review*, 16(4), 311–318. <https://doi.org/10.1002/erv.849>
- Testa, R. J., Rider, G. N., Haug, N. A., & Balsam, K. F. (2017). Gender confirming medical interventions and eating disorder symptoms among transgender individuals. *Health Psychology*, 36(10), 927–936. <https://doi.org/10.1037/hea0000497>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45. <https://doi.org/10.1186/1471-2288-8-45>
- Walker, S., & Lloyd, C. (2011). Issues experienced by service users with an eating disorder: a qualitative investigation. *International Journal of Therapy and Rehabilitation*, 18(10), 542–549. <https://doi.org/10.12968/ijtr.2011.18.10.542>
- Whitley, R., & Crawford, M. (2005). Qualitative research in psychiatry. *The Canadian Journal of Psychiatry*, 50(2), 108–114. <https://doi.org/10.1177/070674370505000206>
- Wooldridge, T., Mok, C., & Chiu, S. (2014). Content analysis of male participation in pro-eating disorder web sites. *Eating Disorders*, 22(2), 97–110. <https://doi.org/10.1080/10640266.2013.864891>
- Yeshua-Katz, D. (2015). Online stigma resistance in the pro-ana community. *Qualitative Health Research*, 25(10), 1347–1358. <https://doi.org/10.1177/1049732315570123>
- Yeshua-Katz, D., & Martins, N. (2013). Communicating stigma: the pro-ana paradox. *Health Communication*, 28(5), 499–508. <https://doi.org/10.1080/10410236.2012.699889>

Zwickert, K., & Rieger, E. (2013). Stigmatizing attitudes towards individuals with anorexia nervosa: an investigation of attribution theory. *Journal of Eating Disorders, 1, 5*.
<https://doi.org/10.1186/2050-2974-1-5>

Tables

Table 1 Inclusion and exclusion criteria

Inclusion criteria	Reports original, peer-reviewed empirical research (either quantitative, qualitative or mixed-methods)
	Data is collected from individuals directly affected by (i.e. current or previous diagnosis, either self-reported or clinically-judged) one or more of the four ED subtypes: Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), Eating Disorder Not Otherwise Specified (EDNOS)
	Findings relate to stigma specifically associated with EDs
Exclusion criteria	Does not report primary peer-reviewed research (e.g. review, commentary or methodological papers)
	Data is collected from family/general public samples, not people with EDs
	Articles about obesity, unhealthy eating or body image that do not specifically relate to the clinical category of ED
	Articles on stigma exclusively associated with factors other than EDs (e.g. race, gender, sexuality)

Table 2 Data extracted from the reviewed articles

Authors	Quantitative or qualitative	Geographic region	Stated objective	ED subtype & how defined	Theoretical framework	Design	Sampling strategy	Sample characteristics	Analysis	Quality score
Becker et al. (2010)	Qualitative	USA	“to identify and describe health consumer perspectives on social barriers to care for eating disorders in an ethnically diverse sample.” (633)	Self-report of current/past eating/weight problems/concerns	N/A	Secondary analysis of interview transcripts; semi-structured questions about experience of treatment and ethnicity/race-related barriers to care	Subsample of previous survey respondents (<i>N</i> =289); followed up people who reported eating problems	<i>N</i> =32; 3 male; 12 non-white; college-age or older; 23 self-identified reported ED (6 untreated), 24 had treatment for eating/weight issue	Qualitative analysis with NVivo software, identified themes but no named analysis	32
Chang & Bazarova (2016)	Quantitative	International	“focus on language of themes expressed through stigma-related emotions and anorexia-related and sociorelational content and consider their expressions in self-disclosing posts that initiate a conversational	Self-reported AN	Stigma, social identity, social support	Analysis of online pro-ana website message threads	Publicly accessible messages on discussion board threads from pro-ana-nation.com collected between Jan 1 2012- Dec 31 2012	<i>N</i> =1,475 members on website; age range 11-53; female = 42.6%, male = 1.4%, no gender listed = 56.0%;	Linguistic data analysis through LIWC.	30.5

			thread (ie. Initiating disclosures), followed by the analysis of disclosure-response sequences that incorporate others' responses to disclosures" (219)					22,811 messages from 5,590 conversations.		
Dimitropoulos et al. (2013)	Quantitative	Canada	"to identify perceptions of patients with anorexia nervosa (AN) and their siblings regarding differential experiences within and external to the family including sibling interactions, parental treatment, relationships with peers and events that are unique to each sibling; (2) to compare how patients and their	Current DSM-IV-TR AN	N/A	Questionnaires	Recruited from ED treatment programme	N=26; 1 male, 1 non-white; age 17-43	Parametric between-groups comparisons of patients with AN and their siblings	30.5

			siblings perceive eating disorder symptoms, parental affection/control, social support and stigma; and (3) to test associations with family functioning for patients with AN and their siblings.” (284)							
Dimitropoulos, Freeman, et al. (2016)	Qualitative	Canada	“to explore how affected individuals with AN believe the general public perceives this illness” (48)	Diagnosis of AN (DSM-IV) by psychiatrist/psychologist and currently receiving in-patient treatment	Internalized stigma	Face-to-face semi-structured interviews	Recruited from intensive in-patient eating disorder programme	N=19; all female; 14 AN-restrictive subtype, 5 binge-purge subtype; average age 26.79; 73% caucasian	Thematic analysis	33
Dimitropoulos, McCallum et al. (2016)	Quantitative	Canada	“to test an adapted three-stage Model of Self-Stigma by examining how perceived public	DSM-IV diagnosis of AN (restrictive or binge-purge subtype) by psychiatrist/psychologist and currently receiving	Internalized stigma, self-esteem, self-efficacy	Questionnaire	Convenience sample recruited from intensive in-patient eating disorder	N=36; all female; 18 with restrictive subtype, 18 with binge-purge	Regression analysis to test predictions of model	33.5

			stigma of people with eating disorders and their families, internalized stigma, self-efficacy and self-esteem predict recovery attitudes in people with AN” (375)	intensive in-patient treatment			programme within first two weeks of their admission to the programme.	subtype; average age 27.89		
Easter (2012)	Qualitative	USA	“How do women with eating disorders conceive of the impact of genetics on stigma? Do they expect genes to exacerbate or reduce stigma, and if so, how?” (6)	Current or previous AN or BN	Genetic essentialism & volitional stigma	Semi-structured interviews about general experience and understanding of EDs, and genetic explanations specifically	Recruited through clinic and university email	N=50; all female; aged 18-64, 16% non-white; 25 recovered, 25 in treatment	Grounded theory, N6 software	32
Evans et al. (2011)	Qualitative	Australia	“a prospective exploration of barriers to help-seeking in a community sample	Community sample of people not seeking treatment; all ED types screened by EDE, participants had BN; BED and EDNOS	N/A	Semi-structured interviews about help-seeking experiences	Identified for intervention through national epidemiological survey, interviews	N=57; all women; mean age = 33	Framework analysis, NVivo software	29.5

			of women with EDs” (271)				conducted 4 years later			
Farrell et al. (2015)	Quantitative	USA	“to compare the effects of biological, malleable biological and cognitive-behavioural models of EDs on individuals with disordered eating” (33)	Researcher-identified ED based on EDE-Q global scale screening and recent bulimia episode or driven/compulsive exercising	Volitional stigma	Participants watched a short audiovisual presentation and then completed questionnaire.	US residents recruited via Mechanical Turk	N=216; 76.9% female; mean age 33.9; 74.5% Caucasian	Parametric between-groups comparisons of effects of different psychoeducational messages	31.5
Griffiths, Mond, Li et al. (2015)	Quantitative	International (predominantly Australia, USA, UK)	“to examine sex differences in the association between self-stigma of seeking psychological help and the likelihood of having an undiagnosed eating disorder” (775)	Self-reported ED or suspected ED	Self-stigma	Online survey	Recruited through ED organisations and support groups	N=360 (plus 125 without ED); 344 female; residing in US (32.8%), Australia (28.9%), UK (20.8%) and other countries (17.5%); diagnosis of AN (45.3%), EDNOS (25.6%), BN	Parametric between-groups comparisons of diagnosed and undiagnosed participants; regression analysis of factors predicting likelihood of diagnosis	28

								(19.4%), BED (4.7%)		
Griffiths, Mond, Murray, & Touyz (2015)	Quantitative	International (most participants from Australia, USA, UK)	“to address the gap in stigma related eating disorder research by examining the prevalence and correlates of stigma experienced by individuals with eating disorders” and “to examine whether and how the experience of stigma might differ between individuals with different eating disorders and between males and females” (768)	Self-report of previous diagnosis of AN, BN or EDNOS	Self-stigma	Online survey	Recruited through ED organisations and support groups	N=317; 301 females; average age 24.68; residing in US (33.4%), Australia (30.9%), UK (21.4%) and other countries (14.3%); diagnosis of AN (52.1%), EDNOS (27.1%), BN (20.8%)	Parametric between-groups comparisons of ED subtypes; regression analysis of factors predicting frequency of stigmatisation	30
Griffiths, Mond, Murray, Thornton & Touyz (2015)	Quantitative	International (most participants from USA, UK, Australia)	“investigated stigma resistance in people currently diagnosed	Self-report of previous diagnosis of AN, BN or EDNOS	Stigma internalisation vs. resistance	Online survey	Recruited through ED organisations and support groups	N=452; 15 male; mean age 24-25; 127 recovered, 325 in treatment	Parametric between-groups comparisons of currently diagnosed and recovered groups	31.5

			with eating disorders and people recovered from eating disorders” (280)							
Haas et al. (2011)	Qualitative	International	“What communication strategies and messages do pro-anas exchange on internet sites in an attempt to co-construct support in the pro-anorexia movement?” (45)	Self-identified AN	Social identity, medicalization, stigma	Analysis of online pro-anablogs and websites messages	Publicly accessible	N=1200 message units; inferred to be primarily from 13–26-year-old Caucasian women	Grounded theory	28.5
Hackler et al. (2010)	Quantitative	USA	“examined the relationship between self-stigma, anticipated risks and benefits associated with seeking counseling, and attitudes toward seeking counseling among college students with disordered eating	Cut-off score on EAT-26 – at-risk rather than diagnosed	N/A	Questionnaire	Undergraduate psychology students	N=145; 86% female; 88% European-American	Regression analysis of factors predicting attitudes to counseling	31

			attitudes and behaviors” (88)							
Hepworth & Paxton (2007)	Qualitative	Australia	“To conduct an in-depth study, using concept mapping, of three factors related to help-seeking for bulimia nervosa and binge eating: problem recognition, barriers to help-seeking, and prompts to help-seeking.” (493)	Self-identified BN	N/A	Semi-structured interviews exploring pathways into and experiences with BN and binge eating	Adverts in public places	N=63; all female; 76% had sought treatment; age range 18-62	Leximancer concept mapping program	34
Higgins et al. (2016)	Quantitative	Hispanic/Latina	“to identify factors that may be associated with Latinas’ failure to self-identify as having an ED despite meeting criteria.” (1032)	Self-reported	N/A	Online survey	Publicly accessible websites, flyers around college campus and community clinics, introductory psychology classes	N=77; all female; age range 18-25; all Hispanic/Latina ethnicity	Parametric between-groups comparisons between those who did and did not self-report an ED history	27

Ison & Kent (2010)	Qualitative	UK	“to utilise the idiographic approach of interpretative phenomenological analysis (IPA; Smith, Jarman, & Osborn, 1999) to allow an exploration of social identity with people diagnosed with an eating disorder who are accessing help from treatment services.” (476)	Diagnosed with BN, AN or EDNOS	Social identity	Semi-structured interviews	Recruited from specialist outpatient services	N=8; all female; age 21-36	Interpretative phenomenological analysis	27
McNamara & Parsons (2016)	Qualitative	International	“to explore how a sense of shared identity promotes recovery in individuals with EDs.” (673)	Self-reported BED/BN/AN	Social identity	90 minute group sessions in a secure chat room for members of an online ED support group	Online support group	N=75; 95% female; 56% >25 years	Thematic analysis	31.5

Mond et al. (2010)	Quantitative	Australia	“to compare attitudes and beliefs concerning the nature and treatment of BN between young adult women: (a) at low risk of eating disorder symptoms; (b) at high risk; and (c) already showing symptoms” (269)	BN – risk assessed via EDE-Q scores	N/A	Vignette-based questionnaire (paper and online)	Recruited from university emails and adverts	N=756 (valid sample = 509); all female; mean age 27; 80.2% born in Australia; 332 (43.9%) low-risk, 83 (11.0%) high-risk, 94 (12.4%) symptomatic	Non-parametric between-groups comparisons of those at low-risk, high-risk and symptomatic of EDs	30.5
Perkins et al. (2005)	Quantitative	UK	“determining whether there are any differences between these individuals in terms of eating disorder symptomatology, psychopathology, familial risk factors, patients’ perception	Receiving treatment for BN or EDNOS	N/A	Questionnaire	Referred to services and enrolled in trial	N=85; 2 males; aged 13-20; 17.6% non-white	Regression analysis of factors predicting parental involvement in treatment	30.5

			of parental expressed emotion (EE) and family functioning.” (376)							
Petterson et al. (2008)	Qualitative	Norway	“explored how and why they conceal bulimic symptoms and the understanding of concealing in terms of social interaction.” (204)	Self-identified BN	N/A	Semi-structured interviews about daily experience of concealing	Recruited from healthcare services and patient organisation	N=28; all female; age range 20-38	Content analysis	29.5
Rance et al. (2017)	Qualitative	UK	“to give voice to the lived experience of women with AN.” (128)	Self-reported AN/BN	N/A	Face-to-face interviews	UK charity providing help/support for people with EDs	N=12; all female; age range 18-50.	Thematic analysis	32
Reyes-Rodriguez et al. (2013)	Qualitative	USA	“to explore more fully the facilitators and barriers that may contribute to or prevent the engagement and	BN & BED diagnoses/behaviour	N/A	Semi-structured interviews about perspectives on treatment	Referred by services/ advertised in community	N=5; all Latina women; age range 26-38	Grounded theory, NVivo software	32.5

			retention of Latinos/as in EDs treatment.” (112)							
Rich (2006)	Qualitative	UK	“explores the ways in which young women ‘manage’ the complexities of the presentation of an anorexic identity, the stigma attached to it, and the relationships that are developed with fellow sufferers.” (284)	AN & BN	‘Montage’ and multiplicity of voices	Interviews informed by ethnography	Residential home for young people with ED	N=7; all female; age range 11-17	Feminist post-structuralist analysis	27.5
Skårderud (2007)	Qualitative	Norway	“To define shame and describe types and subtypes of shame and their relations to symptoms and meaning in anorexia nervosa. The study	AN (DSM criteria), some also had BN	Phenomenological approach	Semi-structured interviews about experience of AN	Recruited from author’s own psychotherapeutic practice	N=13; all female; age range 16–39	No named analysis; NVivo coding of text relevant to shame	29.5

			will also describe the possible role of pride, as a contrasting emotional and cognitive experience.” (81)							
Smart & Wegner (1999)	Quantitative	USA	“examined the effects of concealing a stigma in a social interaction relevant to the stigma” (474)	AN & BN identified by screening questionnaire	Concealable stigma, preoccupation model of secrecy	Experiment – took part in conversation while pretending to be someone with/out an ED, afterwards measured preoccupation. Social interactions rated on several dimensions.	Introductory psychology course	Study 1: N=29 with ED (32 without); all women Study 2: N=28 with ED (46 without); all women	Parametric between-groups comparisons of experimental conditions	25
Walker & Lloyd (2011)	Qualitative	Australia	“examined the perceptions of treatment by service users who had been diagnosed	Clinical history of AN & BN (not currently acute or in treatment)	N/A	One focus group – questions about treatment experience and	Recruited from database of service users	N=6; all females	Consensual Qualitative Research	24

			with an eating disorder” (542)			social responses				
Wooldridge et al. (2014)	Qualitative	International	“explore how males make use of pro-ana forums” (98)	Primarily AN, self-identified	N/A	Content analysis of pro-ana websites targeted at males	Google search, identified as male through content of posts, usernames, profiles	12 forums; 689 unique posts from males	Content analysis	27
Yeshua-Katz & Martins (2013)	Qualitative	International	“explore the motivations, benefits, and drawbacks of blogging about a stigmatized mental illness” (499)	Primarily AN, self-identified	Stigma and coping with stigma	In-depth interviews over phone, skype or email	Contacted authors of pro-ana blogs via email/forum messages	N=33; all women; aged 15-33; 33% non-Caucasian	Grounded theory	32
Yeshua-Katz (2015)	Qualitative	International	To understand the “perceived motivations for online boundary work in the pro-ana community” and to examine how “boundary work takes place in the pro-ana community” (1351)	Self-reported	Stigma, boundary work, group identity	In-depth interviews over phone, skype or email	Contacted authors of pro-ana blogs via email/forum messages	N=33; all women; aged 15-33; 33% non-Caucasian	Grounded theory	31

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Scoring criteria for mixed-methods systematic review

Adapted from: Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*, 12, 1284–1299.

1. Abstract and title: Did they provide a clear description of the study?	
Good	Structured abstract with full information and clear title
Fair	Abstract with most of the information
Poor	Inadequate abstract
Very poor	No abstract
2. Introduction and aims: Was there a good background and clear statement of the aims of the research?	
Good	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND OR objectives including OR research questions.
Fair	Some background and literature review. Research questions outlined.
Poor	Some background but no aim/objectives/questions OR Aims/objectives but inadequate background.
Very poor	No mention of aims/objectives No background or literature review.
3. Method and data: Is the method appropriate and clearly explained?	
Good	Method is appropriate and described clearly (e.g., questionnaires included).
Fair	Method appropriate, description could be better. Data described. Clear details of the data collection and recording.
Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.

Very poor	No mention of method AND/OR Method inappropriate AND/OR No details of data.
4. Sampling: Was the sampling strategy appropriate to address the aims?	
Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair	Sample size justified. Most information given, but some missing.
Poor	Sampling mentioned but few descriptive details.
Very poor	No details of sample
5. Data analysis: Was the description of the data analysis sufficiently rigorous?	
Good	Clear description of how analysis was done. Qualitative studies: Description of how themes derived AND respondent validation or triangulation OR inter-rater comparison Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
Fair	Qualitative: Descriptive discussion of analysis Quantitative.
Poor	Minimal details about analysis.
Very poor	No discussion of analysis
6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	
Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).

Poor	Brief mention of issues.
Very poor	No mention of issues.
7. Results: Is there a clear statement of the findings?	
Good	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very poor	Findings not mentioned or do not relate to aims.
8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?	
Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very poor	No description of context/setting.
9. Implications and usefulness: How important are these findings to policy and practice?	
Good	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very poor	None of the above

Red text = adaptations