



## “Not all my fault”: Genetics, stigma, and personal responsibility for women with eating disorders

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### ABSTRACT

Medical researchers and clinicians increasingly understand and present eating disorders (anorexia and bulimia nervosa) as biologically-based psychiatric disorders, with genetic risk factors established by high heritability estimates in twin studies. But there has been no research on interpretation of genetic involvement by people with eating disorders, who may hold other views. Their interpretations are particularly important given the frequent presumption that biogenetic framing will reduce stigma, and recent findings that it exacerbates stigma for other mental illnesses. To identify implications of genetic framing in eating disorders, I conducted semi-structured interviews with 50 US women with a history of eating disorders (half recovered, half in treatment; interviewed 2008–9 in the USA). Interviews introduced the topic of genetics, but not stigma per se. Analysis followed the general principles of grounded theory to identify perceived implications of genetic involvement; those relevant to stigma are reported here. Most anticipated that genetic reframing would help reduce stigma from personal responsibility (i.e., blame and guilt for eating disorder as ongoing choice). A third articulated ways it could add stigma, including novel forms of stigma related to genetic-essentialist effacing of social factors. Despite welcoming reductions in blame and guilt, half also worried genetic framing could hamper recovery, by encouraging fatalistic self-fulfilling prophecies and genetic excuses. This study is the first to elicit perceptions of genetic involvement by those with eating disorders, and contributes to an emerging literature on perceptions of psychiatric genetics by people with mental illness.

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### Introduction

Medical researchers and clinicians increasingly understand and present eating disorders as biologically-based psychiatric disorders, frequently with the presumption that biological explanations will help reduce stigma (e.g., Herpertz-Dahlmann, Seitz, & Konrad, 2011). Genetic risk factors are part of this multifactorial biological model, and supported by the high heritability of eating disorders as estimated in twin studies (48–76% for anorexia nervosa (AN); 50–83% for bulimia nervosa (BN); Striegel-Moore & Bulik, 2007). As with many other psychiatric disorders, the heritability identified by twin studies is still largely “missing” because no candidate genes have been correlated with eating disorder phenotypes (Pinheiro et al., 2010; also see Manolio et al., 2009). Nevertheless, biogenetic models of AN/BN have been disseminated via major media (e.g., Tyre, 2005), medical websites (e.g., Mayo Clinic Staff, 2012), advocacy groups (e.g., EDC, 2008), and other sources. Against this backdrop, I consider in this paper how genetic reframing is interpreted by people with AN/BN.

There is evidence that genetic framing is helpful for countering stigma in eating disorders, despite findings to the contrary for other mental illnesses, such as schizophrenia. Recent studies show mental illness stigma is usually exacerbated by biogenetic framing (see reviews by Angermeyer, Holzinger, Carta, & Schomerus, 2011; Read, Haslam, Sayce, & Davies, 2006). Yet studies of AN/BN suggest stigma-alleviation with genetic etiology (Crisafulli, Thompson-Brenner, Franko, Eddy, & Herzog, 2010; Crisafulli, Von Holle, & Bulik, 2008; Wingfield, Kelly, Serdar, Shivy, & Mazzeo, 2011), likely because eating disorder stigma centers on personal responsibility, rather than dangerousness or unpredictability (which genetic framing appears to exacerbate; Angermeyer et al., 2011).

In this article, I consider the impact of genetics on stigma according to people with a history of AN/BN. Stigma studies more often assess public attitudes than those of mental health consumers or recovered people (Schulze & Angermeyer, 2003). However, the labeled person's perceptions are important in the stigma process (e.g., Link, Struening, Dohrenwend, Cullen, & Shrout, 1989). I examine whether people with AN/BN expect genetic causal attribution to exacerbate or alleviate stigma and self-stigma, and how it may do so. This study is the first to examine implications of genetics

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for stigma from the perspective of people with AN/BN, and contributes to an emerging literature on implications of genetics for people with mental illness generally (Laegsgaard, Stamp, Hall, & Mors, 2010; Meiser, Mitchell, McGirr, Van Herten, & Schofield, 2005; Rusch, Todd, Bodenhausen, & Corrigan, 2010). It also calls attention to unique features of eating disorders and how they shape interpretation of genetics.

### Genetics and stigma for different psychiatric diagnoses

Genetic causal attribution tends to exacerbate stigma of mental illness (e.g., Angermeyer et al., 2011; Read et al., 2006). The optimistic predictions of attribution theory – in which the presence of a genetic causal factor increases compassion for individuals (Phelan, 2005; Weiner, 1986) – are not usually borne out. Indeed, a recent review contends that “biogenetic causal beliefs and diagnostic labeling by the public are positively related to prejudice, fear and desire for distance,” for schizophrenia and other serious mental illnesses (Read et al., 2006: p. 303). Genetic causal attribution also makes mental illness seem more serious and persistent (e.g., Bennett, Thirlaway, & Murray, 2008; Dietrich, Matschinger, & Angermeyer, 2006; Phelan, 2005), and therefore more like an essential, defining aspect of the person (“genetic essentialism,” Lippman, 1992; Nelkin & Lindee, 1995; Phelan, 2005).

However, the impact of genetics on stigma ought to vary by diagnosis, not least because stigma is different across mental illnesses. Schnittker (2008) found genetic attributions to correlate with perceived dangerousness in schizophrenia, but enhance social acceptance in depression (also see Cook & Wang, 2011; Dietrich et al., 2006; Goldstein & Rosselli, 2003). People with depression or eating disorders are similarly stereotyped as more “competent” (and “warm”) than those with schizophrenia (Sadler, Meagor, & Kaye, 2012), suggesting greater responsibility. As with depression, describing AN in terms of genetics elicited less blame or responsibility (Crisafulli et al., 2008, 2010; Wingfield et al., 2011), as well as less perceived triviality, weakness, and selfishness (Crisafulli et al., 2010), and self-destructiveness (Wingfield et al., 2011).

In general, interpretations of genetics in one disease context ought not be presumed to transfer to another (Sankar, Cho, Wolpe, & Schairer, 2006; Shostak, Zarhin, & Ottman, 2011; also see Timmermans & Haas, 2008). Eating disorders have specific features that may affect interpretations of genetics and stigma; in addition to the perception of those with eating disorders as competent, intentional actors, there is also a striking gender disparity (9:1 women to men; APA, 2000). Gender stereotypes may encourage interpretation of AN/BN behaviors and their stigmatization as vain, trivial, and voluntary. Despite their high mortality rate, eating disorders have been likened to “contested illnesses” (Giles, 2006: p. 466), which disproportionately involve women (see Barker, 2010). While emphasizing biological factors may help validate the existence of a condition (Barker, 2011; Fausto-Sterling, 1992; Zavestoski et al., 2004) and help women get their needs met, it can also serve an ideological function against women, by making social disparity appear natural and immutable (e.g., Fausto-Sterling, 1992; Nelkin & Lindee, 1995). The feminist cultural model of eating disorders (e.g., Bordo, 1993; Malson & Burns, 2009; Orbach, 1986) is thus critical of medical models for locating the problem in the individual body, rather than cultural contexts that direct many women toward destructive bodily practices. Cultural actors may be aware of gender stereotypes, gendered causal factors, and/or feminist perspectives as they interpret genetics in the specific context of eating disorders.

Although there are no genetic tests for treatment or diagnosis, some people with eating disorders and their families are likely to have encountered information about genetic risk factors and genetic research through the media, patient-oriented literature,

and advocacy groups. For example, genetic research and theories on eating disorders have been disseminated by major media (e.g., a *Newsweek* cover story sub-titled with the phrase, “anorexia is probably hard-wired”; Tyre, 2005: p. 50) and popular medical websites (e.g., “There may be genes that make certain people more vulnerable to developing eating disorders”; Mayo Clinic Staff, 2012). Biomedically-oriented advocates have also strategically publicized genetic research to “fight stigma with science,” (EDC, 2008) and to argue for better insurance coverage (Bernstein, 2007). Some individuals with family history of AN/BN may have developed their own theories about genetic transmission, like people with other disorders (Walter, Emery, Braithwaite, & Marteau, 2004). Even those without family history may interpret clinicians’ questions about it to indicate genetic etiology, particularly given widespread public endorsement of other psychiatric conditions as “genetic or inherited problems” (Pescosolido et al., 2010). In summary, people with AN/BN may have heard of or thought about the idea that genes play a role, and are likely to interpret its potential meaning and consequences specifically for eating disorders.

### Two kinds of stigma in eating disorders

AN and BN are characterized by bingeing, purging, and/or food restriction, with serious health consequences and high mortality rates compared to other psychiatric disorders (Arcelus, Mitchell, Wales, & Nielsen, 2011; Sullivan, 1995). Their classification as psychiatric disorders (APA, 2000) confers the stigma of mental illness. Yet they are also trivialized as behavioral choices, which is theorized as stigma in studies of AN (e.g. Crisafulli et al., 2010). The interpretation of eating disorders as voluntary, chosen behavior is hereafter referred to as “volitional stigma.” “Volitional” stigma provides an interesting contrast to stigma as usually studied. Rather than stigma from being mentally ill and set apart from “normals,” volitional stigma involves being judged by normal behavioral standards. Stigma in eating disorders can thus be very broadly divided into two types: (1) stigma from being perceived to have a mental illness; and (2) stigma from AN/BN being interpreted as an ongoing voluntary behavioral choice rather than as a mental illness. After describing each broad type of stigma, I examine how genetic framing might affect each.

In the first type of stigma, the label of mental illness “marks” a person as different and “spoils” her identity (Goffman, 1963) by linking her to negative stereotypes, resulting in status loss and discrimination. Perception of the mental illness as severe would exacerbate such stigma by emphasizing difference from “normal” people (Phelan, 2005). For eating disorders, being perceived to exhibit psychopathology is indeed stigmatizing (Rich, 2006). This broad type of stigma resembles that of other mental illnesses, in which individuals are perceived to be unstable, dangerous, and fundamentally different from others.

By contrast, the second kind of stigma involves the “trivialization” of eating disorders as behavioral choices rather than serious mental illnesses. People with eating disorders are often perceived as *choosing* to behave as they do, because they are morally bad (vain, conformist, greedy for attention), and/or because eating disorders must not be so bad (Crisafulli et al., 2008; Crisp, 2005; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Holliday, Wall, Treasure, & Weinman, 2005; Mond, Robertson-Smith, & Vetere, 2006; Roehrig & McLean, 2010; Stewart, Keel, & Schiavo, 2006). This “volitional” stigma is measured by endorsement of survey items describing people with AN/BN as “acting this way for attention,” or “able to pull themselves together if they wanted to,” etc. (Crisp, 2005; Roehrig & McLean, 2010; Stewart et al., 2006: p. 322). While personal responsibility is a component of stigma in other

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