

# A Disorder of a Vulnerable Self: Anorexia Nervosa Patients' Understanding of Disorder and Self in the Context of fMRI Brain Scanning

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In this article, we aim to explore patient perspectives regarding the etiology of anorexia nervosa (AN) in the context of participating in brain research for AN. This is a qualitative study using semistructured interviews with 12 young AN patients. Data were analyzed according to thematic analysis method. This study shows that patients' language used to express their understanding of the etiology of AN was characterized by psychological terms such as personality, self-esteem, control, and coping rather than neuroscientific terms.

Participants held a complex understanding of the causes of AN, acknowledging a brain–mind relationship. However, participants expressed the hope that brain sciences could contribute to identify an objective, physical proof for AN, that would validate their illness, increase understanding, and reduce blame. The study suggests that prevailing biological explanations promoted by brain research did not encourage simplistic perspectives on causation among patients. Instead, patients viewed biological-based theories and brain science as a means of validating their illness.

**Keywords:** anorexia nervosa; fMRI; brain-based narratives; stigma; reductionism

Anorexia nervosa (AN) is defined by the *Diagnostic and Statistic Manual of Mental Disorders (DSM)* as a psychiatric disorder characterized by an inability to maintain normal weight, intense fear of gaining weight, and an overevaluation of the importance of body and shape on self-worth (American Psychiatric Association [APA], 2000). Etiological models proposed to understand the development and maintenance of AN have undergone different trends (Schmidt, 2003). Currently, there is consensus that the disorder is complex, attributable to the interplay of biological, social, and psychological factors. Recent advances in neurotechnologies and brain sciences, however, have rapidly shifted attention to the biological aspects of the illness (Schmidt, 2003), and especially to the brain. The increased use of neurotechnologies, like brain scanning, has generated

hopes for successful brain mapping, finding markers, and possibly early identification and intervention during the presymptomatic stage of the illness (Racine, Bar-Ilan, & Illes, 2010). Especially functional magnetic resonance imaging (fMRI), which measures blood flow and level of oxygenation in certain brain regions activated by different tasks effectuated in the scanner, is increasingly being used as a principal research method. However, there are no identified valid brain markers for AN, and fMRI is not yet widely used for determining diagnosis or designing treatment, but mostly for research purposes. Nonetheless, the influence of fMRI should not be seen strictly related to diagnosis and treatment, but also at the level of how technology shapes patients' understanding of self and illness (Buchman, Borgelt, Whiteley, & Illes, 2012).

Indeed, the increased use of neurotechnologies has been critically viewed as symptomatic of an epistemological culture in which the role of neurotechnologies becomes decisive in defining mental disorders as brain disorders (McLaren, 2011). Moreover, this is seen as part of a broader trend of neurologization of the person (Singh, 2013) where personhood is reduced to "neurochemical self" (Rose, 2003). However, the assumed changes that neuroscience would bring to concepts as self and mental disorders have been shown not to be absolute or normative (Kaposy, 2010). A growing body of literature shows that theoretical concepts such as the neurochemical self have limited empirical evidence and that neurobiological explanations do not have a totalizing or reductionistic effect on the individuals' subjectivity, for example, sufferers' understanding of the illness and understanding of themselves (Pickersgill, Cunningham-Burley, & Martin, 2011; Singh, 2013).

Not only exposure to brain-based theories of causation but also patients' exposure to neurotechnologies, such as brain scans, has been hypothesized to have an effect on self- and disorder-understanding, and possibly lead to neurorealism and neuroreductionism.

*Neurorealism* refers to the persuasiveness of fMRI to detect a disorder as more "real" than when detected through other methods (Racine et al., 2010), and *neuroreductionism* refers to equating concepts such as personhood to the brain, or localizing personality traits or disorders to correlates of brain activity (Racine et al., 2010). These phenomena have been thought to be mostly epiphenomena of media misrepresentation (Racine et al., 2010) because public discourse regarding brain scans rarely recognizes that scans represent a set of physiological responses to particular tasks performed inside the scanner. Thus, fMRI technology is uniquely positioned to uphold various public misperceptions, including the following: (a) that brain scans can determine the absence or presence of cognitive and behavioral traits and psychiatric disorders, (b) that psychiatric conditions are determined by preexisting brain abnormalities, and (c) that effective psychiatric treatments must target the brain because that is where the root cause of psychiatric disorders lies.

The validity of these theoretical concepts of neurorealism or neuroreductionism is a matter of debate, and they have been thought to be present among the general public but not among experts (Weisberg, Keil, Goodstein, Rawson, & Gray, 2007). More recent studies show that these phenomena may be present, in different degrees, among individuals suffering from a psychiatric condition. Buchman et al. (2012) showed that adults with a diagnosis of bipolar disorder or depression viewed technology as a promising means of providing a better diagnosis and effective treatment compared to the traditional methods, an inclination that the authors viewed as strengthening the ethos of neurorealism, in which the technology "reveals" the illness as more real (Buchman et al., 2012).

Although the emerging body of literature on the field offers more empirical ground for the theoretical concepts, there are few studies that explore these issues, especially among the younger population with a psychiatric condition. In this population, brain-based explanations may interact with issues of identity. Yet, there is little empirical evidence on how children and adolescents fare in their interaction with neurotechnologies. Are neurorealism and neuroreductionism at all present among young individuals? If so, are they harmful? Will neurotechnologies and brain-based explanations strengthen a biological understanding of illness or will young people growing up in a technological age simply demystify the powerful influence of neurotechnologies? In addition, attitudes toward neurobiological explanations might differ across specific psychiatric conditions, yet there is little research on this field (Callard et al., 2012).

In the case of AN, the distinctive features of “anorectic thinking” such as anosognosia (denial that something is wrong) may mediate outcomes of participation in fMRI research in relation to perceptions of the relationship of self to illness. A strictly fMRI-promoted, brain-based explanation may be perceived as alienating because it reduces the experience of the disorder to a brain dysfunction, whereas sufferers of AN may experience some aspects of the disorder as meaningful (Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006). On the other hand, a brain-based explanation can be welcomed among sufferers of AN because of intense societal stigma surrounding the condition (Crisafulli, Von Holle, & Bulik, 2008; Easter, 2012; Holliday, Wall, Treasure, & Weinman, 2005; Stewart, Schiavo, Herzog, & Franko, 2008). Brain-based theories, which provide an explanation for behavior, can help one externalize the disorder and stimulate recovery. Meanwhile, the sufferer can individualize the meaning of biological-based explanations and use them instrumentally to validate their experience. Too often, social science has positioned the individual, especially children and adolescents, as passive receivers of information (Singh, 2013). Yet, recent studies of children with attention deficit hyperactivity disorder (ADHD; Singh, 2012) and adults with different neurological conditions show that brain-based explanations do not dominate patients’ subjectivity or become the epicenter of self-understanding (Pickersgill et al., 2011).

This article aims to explore how female adolescent patients diagnosed with AN experience brain imaging, and which status brain explanations occupy in their understanding of their illness’ causation, in the context of participating in an fMRI research study. Based on prior research, we hypothesized that participation in an fMRI study and exposure to brain explanations will not necessarily strengthen a biological understanding of the disorder among patients, and further, that patients might use a brain-related perspective to explain and validate their disorder.

## METHOD

### Recruitment and Participants

Participants in this study were young women (14–21 years old) diagnosed with AN admitted to inpatient treatment for AN. They were recruited while being treated at a specialized treatment unit where they also participated in an fMRI research study on AN. After participating in the scanning study, participants were contacted and informed about our

research project. Twelve young women aged 14–21 years old consented to participate in the interview. Only one participant declined participation in the interview project after undergoing the scanning session. The period between scanning session and interview ranged from 9 to 35 days (median = 14 days). The Regional Ethics Committee approved both studies.

Inclusion criteria for the initial scanning study were a current diagnosis of AN and age 12–21 years. The scanning study aimed to test a hypothesis of dysfunction in a brain area, insula, in patients with AN. Participation in this study involved laying in the scanner for approximately 1 hr while solving different tasks such as judging whether geometrical figures were alike or not (mental rotation task), assessing body shapes or neutral objects (body image task), or exposure to different words related to food, shape, or weight (stroop task). The tasks aimed to target the executive functions of inhibiting automatic responses (stroop), general visual and spatial perception (mental rotation), and emotional reaction to body shapes (body image task).

Prior to admission, all patients had received previous treatment for AN in outpatient or inpatient settings. At the time of the interview, 11 of the participants were still hospitalized and the interviews were conducted at the treatment unit. One interview was done at the participant's home after discharge. The body mass index (BMI) of participants ranged from 14.7 to 21.8 with a median of 18.8. Although the BMI of 7 participants out of the 12 was not severely low (BMI < 18.5), inpatient treatment was still warranted.

## **Interview**

The interview was semistructured and included open-ended questions to assess motivation to participate in research, attitudes toward and experiences in the scanner, and personal understanding of the causes of AN. One master's-level researcher (AC) performed all of the interviews individually with the exception of one interview, for which a psychiatrist was also present (FS). We took a broad approach toward understanding the relationship between the brain and illness, generally, and we did not focus on specific eating disorder symptoms such as restriction, excessive exercise, or body image. In order not to create an order bias or impose a specific theoretical model regarding causation, we first asked generally how participants viewed their illness. We then asked more specifically about scanning and whether participation in brain research influenced their understanding of brain and their disorder.

Questions about stigma were not a specific aim of this study, yet these issues became relevant when discussing the value of brain research. The interviews lasted from 35 to 60 min and they were transcribed verbatim. Some patients reported prior fMRI scanning experiences, but these were not related to a research project. Most patients reported that undergoing a brain scan was one of few exposures to neurotechnology during the time of treatment. General practitioners, the media, or Internet might have been other external sources of information about brain science and AN.

## **Data Analysis**

As questions about the brain didn't elicit long narratives, we performed a thematic analysis of the data. The benefit of thematic analysis is that it is a flexible method, not bound to a specific theoretical or analytical approach. It is an experiential method compatible

both with an essentialist paradigm, which explores the nature of phenomena by how it is experienced, and a constructionist paradigm in psychology, which explores how people construct meaning (Braun & Clarke 2006). Thus, this method informed our analysis directed toward both experience and understanding of scanning, and of theories about the causation of the disorder.

The thematic analysis was carried in the following steps: First, interviews were read, notes were made, and categories of meaning were identified. Then we looked across the interviews to identify convergence, to see which categories fit together, and where regularities occurred across data. Second, the relationships between the categories were analyzed and coded, in higher-order themes. Although an inductive analysis was used, it was nevertheless informed by our research question. Computer analysis program was not used. One of the authors (AC) did the analysis and two other researchers (FS, BH) validated the categories identified.

## RESULTS

Patients reported that they were motivated to participate in the fMRI brain scanning research because of a fascination with brain research, a desire to know more about themselves and AN, and also to contribute to research that could potentially improve treatment. The analysis resulted in two main categories, each with a few subcategories: *An embedded brain and stigma and blame*. Although AN is a disorder with biological underpinnings, biology is experienced in a context where personality interacts with environment. Our patients suffer from a complex and unique illness for which there is not yet a clear causal explanation, which distinguishes AN from several other physical or mental illnesses.

Therefore, the function of a biological explanation, brain, and fMRI, is often used to validate the disorder and reduce blame. When discussing the relationship between brain and AN, the brain was understood as involved in most physical and psychological processes. However, brain dysfunction was often seen in relation to severe neurological conditions as schizophrenia, autism, or brain damage following trauma. There was also a tendency among participants to view the brain as the organ responsible for thoughts but not feelings. In general, participants expressed that the science of how the brain works and how it relates to the eating disorder belongs to natural sciences. They reported they have rarely been exposed to a brain-based approach toward understanding AN and knew little about it.

## AN EMBEDDED BRAIN

### A Vulnerable Self

Patients reported an understanding that AN is not caused by a brain disorder solely appearing outside of an environmental context. Some spoke about making a choice, although this was not seen as completely volitional or conscious. "In a way I feel I made a choice, and yet I didn't" (Participant 5, age 17 years).

Most participants talked about a stressful situation related to school, family situation, or general dissatisfaction with oneself. Eating behaviors were perceived as a way to cope with stress, a coping strategy developed during a time of emotional stress. Yet the behaviors eventually spiralled out of control.

I think it's just that you don't have control, I think everything is about having control, because you get lots of it from AN. I remember I was thinking the day before, ok tomorrow I will eat this for breakfast, this for lunch, and I will not eat anymore after that. Next evening, if I managed to do it, I was so satisfied, I had accomplished something, and I was good. It didn't matter if I got a 3 (out of six) on an exam. This meant less and controlling what I ate meant more. So I think it's about having chaos in your life, and then you stop thinking about that and you start thinking about food, you get control and things get easier for a while, so I think it's about control. (Participant 1, age 16 years)

Although AN served a function and provided short-term reinforcement, patients perceived the negative consequences in the aftermath of the recovery process. Participants talked about AN as a way of having control over a difficult situation or emotions but they realize it was a "false" sense of control. The control they had at the onset of the illness was a pseudocontrol, a control over training and eating, but not over their real psychological or social struggles.

(. . .) and you don't even get control because there is so much compulsion in the picture. (Participant 9, age 20 years)

Participants showed an awareness that emotional stress alone could not explain the occurrence of AN. They also identified a sensitive personality, low self-esteem, and perfectionist traits as vulnerability factors that could partially explain why they developed AN.

(. . .) And I think it has to do with personality also because I am quite determined and when I set my mind on something, I do fulfill it completely, and one has in a way to be quite determined to decide not to eat and to exercise all the time and get tired. I don't think just anyone would manage that. (Participant 4, age 17 years)

I believe that someone who has confidence, who can take criticism, without getting depressed, will not so easily develop an eating disorder. (Participant 2, age 19 years)

A low sense of self or low self-esteem was identified as a factor leaving someone vulnerable to the desire to change, and in AN, the body becomes the object of change.

For many people with AN it goes deeper (than being influenced by pictures of models), because you can see someone and want to be like them, but if you want to change then that means you don't have good self-confidence or self-image. (Participant 3, age 16 years)

Some participants considered the possibility that this vulnerability to develop AN can be of a biological nature. Genes, or a brain dysfunction, were cited as plausible explanations for why some individuals are more predisposed to respond to stress with eating behaviors or intense preoccupation about body.

Because when you (the interviewer) say that there are different areas in the brain that do different things, then I understand that brain can be involved and that we (the sufferers) maybe

have something in common that is a weakness. Before I didn't think about that, because it was like how do they manage to research it, but now I understand. (Participant 1, age 16 years)

Any presupposed gene or brain dysfunction was not considered by patients to exist in a vacuum but was related to how the young women experience the self and the environment. Indeed, some participants were more determined in their position that brain (or genes) is not a sufficient explanation. A lower self-esteem, high expectations from one's self or others, or intense body preoccupation can be sufficient explanations for AN.

I think (the brain) is related to psychological illnesses but I don't think it starts with a problem in the brain (. . .). I think it has to do a lot with upbringing and environment; who you are hanging out with, friends and so, or family (. . .), or what people around you are doing and expectations you set for your self [sic] and you think others are setting for you. (Participant 5, age 18 years)

I think it's much more about the environment, because I don't think it's hereditary or something like that, but how you experience your environment, and as you get more sick you see the environment in a different way, or at least I did. I interpreted what everyone said with the worst possible meaning, so I think it's a bit strange to think about what comes first. But I think it's much more the environment around you. (Participant 4, age 17 years)

Patients particularly emphasized the role of experience and environment in shaping their behavior and selves. Three of the participants were sports athletes and they saw a connection between performance, increased attention to the body, food and weight, and the development of AN. One of the three athletes had also experienced trauma as a child and she realized during therapy that trauma had contributed to her developing AN.

I cannot put blame on anyone but myself, even if I blame the mean kids, it wasn't them who said I shouldn't eat, but if I would have lived on a deserted island, I wouldn't have decided to stop eating. (Participant 1, age 16 years)

In summary, participants saw AN as caused by a vulnerable self with low self-esteem, a sensitive personality, or as a reaction to a time of emotional stress. Although some participants considered the possibility of a brain-based explanation for such vulnerability, others were more determined that psychological factors are sufficient to trigger the disorder. However, even those that were more oriented toward a biological explanation emphasized the importance of nurture (experience and environment) for the disorder.

## Cultural Context—Media

Preoccupation with body shape and weight were not thought to appear in a vacuum, but were considered subtle influences of a cultural context. Ideals in the culture and media representations of the thin ideal were other significant influences considered important within a social context because the young women felt vulnerable to defining themselves in terms of body image.

It cannot only be the brain because we as people haven't changed much during the past 100 years. I think it has something to do with TV, we live in a world focused on appearance. (Participant 1, age 16 years)

Because the illness becomes so physically visible, and media has focused a lot on eating disorders, that it's about body, weight, and food. It is a lot about the brain too, but it's so much more complex than that, and it's very individual. The way AN is described on Internet or in the newspaper doesn't reflect these individual differences. I haven't liked reading about these types of things, and it shows up in schoolbooks, thin models, they don't eat, and throw up. (Participant 5, age 18 years)

But media can also take some of the responsibility- [sic] before I couldn't read magazines . . . you can have thinner this and thinner that, if I only followed the dieting advice. (Participant 1, age 16 years)

However, media's influence was not seen as exclusively determining the illness.

Yes, I think one is influenced by it (media), but I don't think that's why you get sick. But at least for me, I was influenced by all the thin models that were pictured everywhere. Although it is not why I got sick, it's a factor that contributed and definitely didn't make it better. (Participant 1, age 16 years)

To a certain degree, I think media contributes but not like the insane media focus that we blame in all circumstances, but yes, of course, the thinness ideal is influential. (Participant 5, age 18 years)

Patients expressed that during the course of treatment and through a process of maturation over time, they learned about themselves and acquired "media literacy," in decoding media messages about bodies. They had learned to become resistant to the barrage of media images promoting an ideal that they previously equated with success.

Participants also endorsed a socially oriented understanding of mental health and referred to the concept of "normality" as relative and as a social construct. They reported that they previously viewed normality as defined by body shape and weight, a criterion that had changed as the young women recovered. Normality was viewed, in the aftermath of recovery, as not avoiding problems but finding effective ways to cope with them. Still, normality was not understood as something absolute, and some patients still struggled with thoughts about food or body.

P.: Because I don't like to hear that I am healthy or normal, it makes me sad, it sounds weird but I like it better to be sick.

I.: Better to be sick than to be like others?

P.: Yes, so I don't like to be normal and when others say I am normal, I get annoyed.

I.: What is normal for you?

P.: For me it is to be thin, eat, exercise, stuff like that. In a way, I don't like to be sick, but in another way I want to be like that. So it's a bit strange. (Participant 4, age 17 years)

From the patients' perspective, neither nature (e.g., genes or brain) nor nurture (e.g., environment and culture) could wholly explain why they developed AN. Patients identified the interaction between nature versus environment as the main contributing factor which rendered them vulnerable to AN. In this interaction, the role of culture and exposure to beauty ideals in the media exerted a considerable influence on them.

## **The Undernourished Brain**

When talking about the status of the brain in explaining AN, there was a general agreement among participants that being underweight and the behavior of restriction, adversely

influenced brain functioning. Brain dysfunction was not seen as a cause of AN but mainly as an effect of being underweight.

While in the scanner, participants experienced a sense of anxiety related to their level of performance on the different tasks. They thought that the brain scan could give evidence for the effect of underweight status or malnourishment on their cognitive performance. In this way, patients felt brain scanning could reveal differences in brain activity compared to “normal” youth. However, these differences were not viewed as a sign that their brain deviated fundamentally from a normal brain of other people. Instead, any differences were related to being underweight, not to an inborn predisposition.

One doesn't have a different brain than others, even if one is sick. (Participant 4, age 17).

Participants reflected that their performance was weaker than normal because of their poor nutritional status. However, this insight regarding weak cognitive performance did not elicit such an emotionally strong reaction as being exposed to pictures of bodies in the scanner. When discussing their experiences during the scanning session and their views on the ability of the scanner to detect pathology, the most salient response was their reaction to body images. The body image task was one of the two tasks (together with exposure for words for food and weight) in which participants were exposed to disorder-specific stimuli, that is, images of various body shapes/sizes. Exposure to this task constituted the only situation in which participants explained their reaction in terms of brain activity. This may not be surprising because most tasks in the scanner had a visual and cognitive character rather than an emotional and AN-specific one.

When I saw those pictures of the bodies (in the scanner), I thought “wow”; I knew there was something going on . . . my brain went “wow.” When I saw a thin body, I thought what is happening in my brain now? (Participant 1, age 16 years)

In a similar way, weight and food-related words such as “fat,” “French fries,” and so forth, elicited reactions that patients suspected the brain scanner would detect.

I.: Did you have any special thoughts or feelings while you were lying in the scanner?

P.: Not especially, it's only that task, where you had to say the colour of words that surprised me.

I got a bit flustered because some of those words such as cake, fat. I don't like those words, so that was a bit weird (Participant 4, age 17).

P.: I had to think a bit when those words appeared on the screen: fat, fries, and also when those pictures of houses and bodies were shown.

I.: What was it about those words?

P.: Yeah, these words are actually unpleasant, but they are just words. (Participant 2, age 19 years)

But participants also referred to potential brain differences attributable not only to underweight but also to concerns (and values) about body shape and weight, food, and self-evaluation. Having different thoughts, values, and feelings about the meaning of food and the body were viewed as potentially eliciting a different brain activity than normal individuals. However, they did not believe that brain scanning would be able to identify the eating disorder as a diagnostic entity.

(. . .) because anorexia has a function, it helps to deal with problems, and this kind of problem I don't think you can see on a scanner. (Participant 7, age 22 years)

(. . .) because I don't think I am so sick. (Participant 5, age 18 years)

## STIGMA AND BLAME

AN was not understood as being caused by a brain dysfunction. Rather, patients felt that behaviors and thoughts could influence brain functioning. Particularly, participants used a brain-based explanation to explain the strong emotional reactions elicited by images of body sizes and food. In addition to these tendencies, a brain-based explanation was adopted by patients to correct myths and misunderstandings about the disorder, especially that AN is simply a "desire to be thin." The young women were reluctant to admit a diagnosis in a society where media shapes public opinion about AN because they feared they might be misunderstood. They felt stigmatized by societal views that AN is exclusively about the body and being thin.

For me, before (getting ill), the misconceptions about AN focused on weight and body shape, negative stereotypes, like why can't they just be happy with themselves?! Now it's difficult when I see that this attitude is still out there. I think that's the typical understanding of eating disorders. I don't really like to say what my diagnosis is. (Participant 6, age 16 years)

Yet patients indicated that misunderstandings about AN were not only present in the media but also among health professionals. Participants experienced a different type of misunderstanding from health professionals, who failed to view patients with AN as unique individuals, but simply as a label or category. Such a view/attitude overlooks individuality and reduces the disorder to the physical aspects.

It would help if doctors would be more open that we are all different, that there is no standard answer for why we get an eating disorder. Many do share symptoms, that is why we get the same diagnosis, but symptoms are not the same as causes. (Participant 5, age 18 years)

In the context of countering stereotypes and being blamed for the disorder, participants expressed the hope that the brain scan could serve the purpose of an "objective proof" of AN as a serious condition of a vulnerable self and could counter the myth that AN is a self-provoked disorder of the body. In this way, it will validate the disorder and reduce blame and shame.

For me, an eating disorder has been psychological in cause, it was tough not to be able to defend that I cannot eat, it hurts, it's so hard to grasp; it was for me and those around me, it didn't make sense. I hated my self when I was eating something I thought was good. It didn't make sense and then I wish I could show to something physical but I think it's dangerous if the focus changes towards the physical because for me it was psychological. (Participant 5, age 18 years)

Participants expressed their hope that brain research might contribute to increased knowledge about the causes of disorder and improve treatment, considering recovery is

difficult and requires time. However, even if participants talked about the importance of efforts to detect symptoms earlier and intervene, a brain-based predictor or marker was seen as problematic. This was founded on patient concern that a focus on physical criteria might be perceived as deterministic, “I am born like that,” and fatalistic, “I cannot change it.”

(. . .) if you find out that there is something that makes you sick, that the brain is sick, then you can quit working preventively because it will happen anyhow. (Participant 5, age 18 years)

Moreover, knowledge about such biological markers would play an unwanted and possibly dominant role in a young person’s development and identity formation.

If there would be a marker, that would limit so much the way I live and the things I do. (Participant 6, age 16 years)

## DISCUSSION

Exposure to fMRI technology and brain-based explanations of AN did not seem to drastically affect participants’ understanding of themselves or the disorder. Collectively, vulnerability to AN was not explained in terms of neuroscience, but in terms of psychological concepts such as emotional stress, sensitive personality, low self-esteem, need for control, and preoccupation with body shape and weight. It seemed difficult for patients to “disembody” the brain explanation from the experience of the self, or the environmental context. The experience of the self was strongly related to the experience of the body embedded in a microcontext of school, family, and friends, and a macrocontext of a society with certain ideals and values regarding body shape and size. Although the young women realized the importance of the brain for the “mind,” they seemed to place greater emphasis on the relevance of the mind and of psychological causes for AN, rather than the brain. Thus, the objective language of neuroscience (Parens, 2007) did not replace the language of subjectivity among participants and brain did not occupy a dominant position in patients’ understanding of the causes or development of AN. The struggles around one’s own body tend to occupy a more dominant role in self-understanding and can therefore be more salient than the role of the brain in the disorder.

The predominance of a psychological understanding of AN in our study can potentially be explained by the fact that the current biological understanding model for AN is incomplete, and has not entered the clinics, or that sufferers resist a biologization of their illness. Some patients may still experience a strong illness identity and they may refute AN being labelled as a brain disorder. The idea of how “authentic” AN is for some patients has been discussed elsewhere (Hope, Tan, Stewart, & Fitzpatrick, 2011). Moreover, the clinic and mental health services, which are largely characterized by psychological assessment and treatment, may exert a strong influence on the individuals. This may represent a point of resistance that helps counteract the neurorealist tendency that brain scanning might promote.

Patients expressed a nuanced, individualized, and complex understanding of AN, and a brain explanation played an instrumental role in validating the disorder and reduc-

ing stigma and blame. The fact that others typically misunderstand the nature of AN, as reported by our patients, resonates with societal views that AN is an obsession with thinness and within the control of the sufferer (Crisafulli et al., 2008; Holliday et al., 2005; Stewart et al., 2008).

It could be argued that patient hopes for the discovery of biological, “objective” proof of AN, which brain imaging and neuroscience are positioned to provide, is in fact, strengthening the ethos of neurorealism, in which scanning uncovers the disorder as a “real thing” and as a better way to access truth than the subjective experience of the patient (Racine, 2010). However, our patients did not seem to believe that their illness as a whole was visible on a scan. They viewed AN as a personal experience that was not reducible to the brain and not possible to see with a scanner. We maintain that the need for an “objective proof” is not indicative of neurorealism, but rather indicates patients’ need and desire to counter myths, stereotypes, and misunderstandings to which they are often subjected.

Several limitations are present in this study. First, gathering data from interviews is bound to participants’ phase of recovery, and furthermore, responses might be influenced by social desirability biases induced by the research setting. Responses may also be influenced by sociodemographic and other clinical characteristics, such as chronicity or age; most participants in this study are adolescents. It is possible that the need for a biological explanation is different for adult patients with a longer duration of illness, or outpatients in a nonspecialist setting. In addition, developmental aspects of identity formation and “biological integrity” (Diller, 2010) may be more relevant for adolescents than for the older group, and could have influenced the impact of biological explanations. Further studies should explore the topics of biologization and reductionism in an older population that had a longer duration of illness. Our group of participants is a selected group and includes patients with severe AN in need of specialized hospital treatment. This implies that they have been exposed to biological, brain-based explanations for their disorder by participation in a research project where information about brain might have been disseminated more than would be the case for the nonhospitalized patients. This implies also that our results cannot be generalized to the whole population of individuals suffering from AN, which is a heterogeneous group.

However, this study adds to the growing body of literature that supports a position of agency and resilience among young individuals exposed to neurotechnologies. Although neuroscience does not appear to have a dominant or reductionist effect on individuals’ subjectivity or to encourage neurorealism, attention should still be directed toward ethical aspects related to the use of brain explanations and technology. One can say that exposure to fMRI brain scanning stimulated important insight among participants regarding the effects of underweight on cognitive functioning. Being in an fMRI brain scan can be perceived as a “test” situation that reveals information about one’s performance. This could have increased participants’ awareness that their condition is more severe than they originally perceived. On the other hand, it is possible that any testing situation can “produce” insight about the level of (cognitive) performance, and brain scan does not necessarily possess the unique quality of revealing qualities or weaknesses. Indeed, the effects of underweight on brain anatomy (loss of grey and white matter), a change reversible with weight gain, has some scientific evidence (Wagner et al., 2006), and is often used in the psychoeducation part of treatment to inform the sufferer about the effects of starvation on brain functioning. However, the visual, and apparently objec-

tive, nature of an fMRI scan might appear as more persuasive for therapists or sufferers, in providing information regarding certain traits or cognitive performance than self-reports, for example.

As we mentioned in the introduction, the specific feature of a psychiatric condition can mediate interaction with neurotechnologies and brain-based explanations. The distinctive feature of anorexia, anosognosia (the denial that the disorder and malnutrition have serious effects), can motivate therapists to use the seductive objectivity of the brain scan, and its supposed ability to “produce insight,” as a tool to reduce anosognosia. This thinking is in line with a more physiological-oriented approach to (diagnosing) AN where physical, objective markers can be used as a mean to educate and convince the sufferer in self-denial about the severity of the condition (Hatch et al., 2007). However, referring patients to undertake a brain scan is not a standard procedure, and there is little knowledge about how often and what determines clinicians’ use of scanning. Attitudes among health providers vary as some object the increasing reliance on technology in psychiatry (Bracken et al., 2012; Fuchs, 2010; Hofmann, 2008; McLaren, 2011) and debate its role in therapy/treatment, whereas others may be motivated to practice a more biologically based form of psychiatry (Farah & Gillihan, 2012).

In a time where biology knowledge is developing relentlessly, clinicians are faced with various ethical challenges. They are well-positioned to correct myths about the deterministic aspect of biology and should help sufferers and their families that face challenges to incorporate this knowledge into their personal understanding of illness (Mazzeo & Bulik, 2009). These are important ethical issues that need further elaboration. A more detailed and empirical-based ethical approach would therefore benefit from further investigating the role brain narratives and neurotechnologies play for health professionals.

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