

Self, brain and illness
A qualitative study of illness representations in Anorexia Nervosa

Alina Wengard



**UNIVERSITETET
I OSLO**

MASTER DEGREE IN PSYCHOLOGY

Department of Psychology

UNIVERSITY OF OSLO

MAY 2010

"And this is of course the difficult job, is it not: to move the spirit from its nowhere pedestal to a somewhere place, while preserving its dignity and importance; to recognize its humble origin and vulnerability, yet still call upon its guidance. A difficult and indispensable job indeed, but one without which we will far better off leaving Descartes' error uncorrected" (Damasio, A : 252).

Acknowledgements

Firstly I would like to thank the young women who willingly participated in this study and allowed me to see more of their struggles and strengths. Your contribution to knowledge is so valuable. I want to thank my supervisor Associate Professor, Katrina Roen for her support and valuable commentaries who have always brought me a step closer to the accomplishment of this thesis. I would also like to thank my supervisors, Dr. Ilina Singh and Professor Bryan Lask for introducing me to this field, for their support and encouragement. Last but not least I am grateful to my wonderful colleagues and friends for their commentaries and support throughout the process. This study is a pilot study and a collaboration between Oslo University Hospital, Ullevål, Regional Eating Disorder Unit and the Bioethics program, London School of Economics (LSE) in London, and is supported through grant number 51977 from Health South East, Oslo.

TABLE OF CONTENTS

ABSTRACT

Defining Anorexia nervosa	5
What does the brain have to do with it?	6
Neural self, brain and neuroethics	7
Neuroscientific explanations	7
Neurobiological perspective	9
The biological self	10
A critical perspective	11
Cultural understanding of the biological self	12
Stigma	13
Illness representations and self-perception theory	15
Aims	18
Method	19
Research process and context	21
Analysis	23
Discussion	38
Implications	40
Literature references	42
Appendix	45

Abstract

Anorexia Nervosa is a serious disorder, affecting between 0,5 and 1% of girls and young women (12-23 years of age) but rarer in males. Currently, a clear understanding of the aetiology remains elusive, thus recent research has expanded the focus to include factors such as neurobiology. Such a research focus could lead to a new understanding of AN as a brain based illness, changing the focus from the socio-cultural model of understanding illness to a more biological one. However little is known about the impact of these developments upon society's attitude to eating disorders and on the sufferer's experience and understanding of their illness.

Employing qualitative interviewing and thematic analysis, the present study reports on how teenage girls with AN understand their illness, their participating in research, and their motivation for such participation. The identified themes were: searching for knowledge, understanding causes, finding a biomarker, problems within ourselves or outside ourselves and family literacy.

The main reason for participating in brain-based research was the wish to contribute to the gaining of knowledge. The main effects of undergoing scanning were giving the patients the sense that they had a better understanding of their illness and the sense that they were not to blame for their illness. There is a desire among the participants to understand more about the illness and to find a marker for it, that would function as a justification that AN is a serious illness not something provoked by the sufferer who is not to be blamed for it.

INTRODUCTION

This section will start by presenting current understandings of AN, with special attention given to the biological explanations and their implications for understanding of illness and stigma.

Defining Anorexia Nervosa

Anorexia Nervosa (AN) is a serious psychiatric disorder, affecting between 0,5 and 1% of the young females (12-23 years of age) but rarer in males. Symptoms include an intense pursuit of thinness, distorted cognitions and emotions, over-valuation of weight and shape, extreme fear of gaining weight and body image disturbance, among others (American Psychiatry Association, 2000). Studies of individuals with AN have also reported specific traits frequently observed in this population, such as a high need for control (Woodside, 1995), perfectionistic tendencies (Shafran, 2002), cognitive and behavioural inflexibility (Bulik, 2003), as well as a distorted body image (Fairburn, 1997). In addition, comorbidity is common in AN with anxiety disorders, depression and obsessive compulsive disorders (Birmingham & Beaumont, 2004).

The aetiology of AN is complex with both genetic and environmental factors contributing to the development and the maintenance of the disorder. The causes are best considered using the model of predisposing (risk), precipitating and perpetuating (maintenance) factors.

As yet, clear indicators for why individuals progress to eating disorders have not been identified, yet some views are widely held. Among factors identified to increase the risk of developing an eating disorder are: a family history of dieting, body dissatisfaction and comments from family members about eating, appearance, or weight. Other risk factors include childhood obesity, parental obesity, early menarche, and exposure to or concurrent presentation of affective disorder, substance abuse, or obsessive –compulsive disorder (Birmingham & Beaumont, 2004). Some suggests that there may be a causative genetic component (Birmingham & Beaumont, 2004) related to personality or stress reactivity. Aetiology is, in addition to risk of developing an eating disorder, also concerned with factors hindering recovery. Such factors have been found to include poorer/disrupted brain development as a consequence of nutritional stress, immaturity in emotional and complex inhibitory and reflective processing (Southgate et al, 2005). Despite

identification of the above-mentioned factors, a causative relationship is yet to be defined as many of the factors are considered correlates (Jacobi, Haward, de Zwaan, Kraemer & Agrad 2004).

Anorexia Nervosa, like several other severe psychiatric illnesses, is seldom simply “cured”. Relapses and a need for further treatment are common (Birmingham & Beaumont, 2004). The treatment has over time encompassed a wide range of approaches. Cognitive behavioural therapy has shown good results especially with severely ill patients as it aims to work at the specified cognitive patterns that underlie the disorder, instead of only working with thoughts related to food and eating. Despite a wide range of treatment options available, approximately 50% (Steinhausen, 2002) make a full and sustained recovery. As can be seen from the literature, despite much research having been devoted to risk factors and treatment, the jigsaw puzzle is far from complete. A different and additional focus appears to be necessary to clarify the aetiology of AN and thus create more effective treatments. Recent research suggests an underlying neurobiological component to AN, but what do we actually know about the brain’s involvement in the disease? This will be discussed in the section below.

What does the brain have to do with it?

In the case of AN, brain dysfunction has been postulated. Research into the role of the brain in eating disorders has been fruitful in the past few years. Although much of the dysfunction is a result of starvation, there is reason to believe that the functional abnormalities found in the majority of subjects with AN reflect traits suggesting an underlying neurodevelopmental abnormality that may prove to be a risk factor for AN (Brewerton, Frampton & Lask, 2008).

AN patients show average to high IQ scores, with strong verbal skills but a significant verbal/nonverbal discrepancy, impairments in executive functions, visual-spatial processing and central coherence. A specific neuro- cognitive profile has been hypothesised to explain these underlying traits. These traits could explain the causation or the perpetuating symptoms of AN. More specifically such behavioural and cognitive styles observed in AN are hypothesised to stem from one of two possibilities. They could arise as a consequence of dieting and restrictive eating or they could arise from the underlying neuropsychological and neurobiological abnormalities present prior to onset. Later studies have though reported that these features persist after

nutritional restoration suggesting an innate vulnerability to develop the illness. This hypothesis challenges the lay understanding of AN caused mainly by socio - cultural factors and suggest that some individuals are genetically vulnerable in developing the disease.

Neural self, brain and neuroethics

In this section of the paper I will elaborate upon the neuroscientific and neurobiological understandings of the illness.

Neuroscientific explanations

Our understanding of psychiatric conditions and concepts as mind, self, responsibility and identity are formed by the scientific discourse. Cognitive neuroscience has shaped this discourse remarkably in the recent years increasing the focus on understanding the biological self.

Neuroscientific research has expanded and although it initially focused on serious brain injuries and neurodegenerative diseases like Alzheimer, it has during recent decades focused more around complex psychological processes such as emotion, cognition, fear and morality, therefore addressing questions relating to psychological functions and its deviations.

Neuroscience has in the latest years used more developed technologies as fMRI, MT or PET which have become more attractive, their versatility offering a unique window into the workings of the mind (Sachdev, 2007). The introduction of functional neuroimaging has given important contributions to the understanding of the brain and its mechanism. Michael Posner likened the impact of functional neuroimaging to the impact of the telescope on astronomy (Goldenberg, 2009).

Especially the use of fMRI as a cognitive neuroscientific method has expanded. Illes, Kirschen & Gabrieli (2003) identified 3426 fMRI articles published across 498 different journals from 1991 to 2001. They also developed the taxonomy for classifying the articles. This included motor, primary sensory, integrative sensory, basic cognition, higher-order cognition, emotional, clinical, methods development, reviews, and non-human primate. They identified significant increases in integrated sensory studies, basic and higher order cognition and emotions while research on motor and primary sensory studies decreased. This in part because organization of these functions are well understood and because of the topographic nature of these regions (Illes

et al., 2003). There is thus an increased interest in the neurobiology of complex psychological phenomenon.

In spite of the contribution neuroimaging has brought to the understanding of psychological phenomena, this knowledge cannot fully explain the complexity of these phenomena. This is due to the fact that neuroimaging methods don't always measure direct neural activity, but are proxy measures or markers for blood flow or cerebral metabolism, although strong evidence exists that these markers reflect the levels of neural activity. One limitation is our ability to identify the sources of activation, relating different aspects of this activation to specific mental operations (Goldenberg: 2009). Another limitation is that although the cognitive neuroscience of individual differences has come far, it is still not deeply understood (Goldenberg, 2009). Human brains are as variable in their individual features as any other part of the body. Weight, relative sizes of different lobes, the articulations of gyri and sulci – all are highly variable.

Even if our understanding of the brain processes underlying these complex processes is increasing, our understanding of how the brain goes on to “make” the mind is still uncertain. Even if thoughts are reducible to the physical substrate of the brain (monism or reductionism), a given thought, whether crooked or straight, is not reducible to a single cause. There is therefore not a simple one-to-one relation between psychological states and brain states (Goldenberg, 2009).

The modern brain imaging methods have thus contributed much to the understanding of different psychological and psychiatric conditions such as e.g. AN. Images of brain resulting from the use of these methods provide a correlation of brain blood changes in different brain regions with mental states, yet they do not establish the salience of any particular change (Sachdev, S., *Acta Neuropsychiatrica*). Still these images have a tendency to be seen as indexes of psychological constructs. An index is a sign that has a cause-effect relationship to what is pointing at (Gripsrud, 2006), but the brain imaging images do not have a causal relationship to activity of the mind. These findings are constructing a map of the mind activity, and this construction has been criticized to be a reductionistic perspective because it ignores the social and cultural context of psychological phenomena. The fact that our understanding of how the brain goes on "to make" the mind is still lacking, is not because of failure from the science, but because of the high rate at which new neuroscientific facts appear. This then may engulf our

ability to think clearly (Goldenberg, 2009).

Shortcomings in cognitive neuroscience raise therefore broader issues of science in modern society. Goldenberg (2009) has criticized the commoditization of science, which means that research is being driven sometimes by the desire to come up with catchy, media -worthy bites, "sexy" science (Goldenberg, 2009) although there is much ongoing research that is "principled" driven. As we understand more about the neurobiological nature of complex psychological processes as well as deviations from these processes, we still need to pose questions on the validity of the neuroscientific knowledge. This implies questions about the nature of the neural signals measured by fMRI, as well as the statistical sensitivity to false positive or which functions are well or poor understood by fMRI data (Illes et al., 2003). In this context of increase in this type of studies, there have not been many following studies on the social impact of this kind of knowledge. There is therefore a need for reconstructing the findings in neuroscience and see their relevance in the social and cultural context. It is also relevant to complement this knowledge by seeing beyond the biological explanations and explore how the neuroscientific findings affect the process of giving meaning to concepts as self, normality and illness.

Neurobiological perspective

The focus on the neurobiology of different psychiatric conditions has contributed to increased knowledge of psychiatric conditions in general. At the same time the increased interest and use of modern neuroscience methods in the understanding of these psychiatric conditions has been seen as a symptom of the biologisation of the psychiatric conditions and especially of child and adolescent problems. Such a neurobiological perspective proposes a way of understanding illness and normality as brain/biological determined. On the one hand such a perspective can facilitate increased understanding of the psychiatric conditions by acknowledging the organic basis of psychological disorders. This would again imply less blame and responsibility of the person as the illness is not considered self-inflicted.

But such "biologisation" has also been criticized for purely focusing on the individual, - and the illness, and thus discounting the importance of the socio- cultural context. At the same time, attributing illness to the organic factors can discourage responsibility and actually create stigma by creating a perception of the others as distinct persons (Metha & Farina, 1997).

Another consequence of this perspective is that new understandings of the relations between body and self are established. In this way it takes place a change in the idea of personhood because the self is being (re) presented more often as the biological individual. “When an illness or a pathology is thought of as genetic, it is no longer an individual matter” (Novas & Rose, 2000), the person’s sense of responsibility and control may be affected. But how do patients perceive their self in relation to this understanding?

The biological self

Critics talk about the emergence of a biological narrative and warn about the tendency to reduce the individual to the biological dimension. A biological narrative could be hypothesized to change our notions of selfhood, responsibility and identity when one is confronted with a mental illness. In fact, Damasio (1994) whose theories have had a significant impact in the field of neuroscience, states that our self is biologically determined, and that mind comes from the brain. Still his position is not a biological deterministic one as he is considering the reason why neurons behave in such a thoughtful matter (Damasio, 1994). He seems to reconstruct and put the pieces together for us to understand the role of the brain, mind and the self. He is deconstructing Descartes statement that feelings and thoughts, mind and body are separated, a separation that has prevailed in the modern sciences (Damasio, 1994).

Although the body is more important for the mind than previously thought, Damasio proposes that the mind arises from activity in neural circuits that were formed during our adaptation to the environment. He acknowledges the embodiment of the self in the social and cultural context, but he still argues that the self is a repeatedly reconstructed biological state. “The self that endows our experience with subjectivity, is not a central knower and inspector of everything that happens in our minds” (Damasio, 1994). Still the biological self is nevertheless embedded with value.

We are actually more aware of the overall state of the body than we usually admit. However, it appears that the awareness of the body remained in the background as vision, hearing, and touch evolved. This is what creates representations of the self, our cognitions and emotions about the body, in interaction with the environment. Body and mind are not as separated as Descartes claimed (Damasio, 1994). There is evidence for a biological self, but this doesn’t have to exclude the human value in the biological self.

As science proposes a narrative for the biological self, which seems to characterise the ethos of the time, it is relevant to explore how the sufferer perceives their selves. How does a sufferer integrate the experts' discourse and how is her understanding influenced by this discourse? Is science trying to create a universal language with the means of explaining pathology as biological? Although symptoms and illness are biological, the cultural frames of a society influence the way they are coped with and understood. The present study aims to explore how participants might experience this biological explanation for their illness.

A critical perspective

The research on the neurobiological basis of mental health thus raises profound questions, challenging us to think of the nature of some psychiatric illnesses, and at implications it has for the concepts of self, responsibility and identity that individuals with a mental illness might experience.

Neuroethics is the discipline that asks general questions about the social, cultural and policy impact of neurobiological knowledge, as well as its predictive validity for real-world behaviours, especially those culturally determined and value-laden (Illes et. al, 2003), and the way the self is understood in the light of this knowledge.

Giordano (2005) writes about the field of neuroethics as giving a new worldview and as an answer to an epistemic "crisis", "a time of change based upon a mass-effect of new knowledge" (Goldenberg, 2009). The field of neuroethics sustains therefore a critical look at the neuroscientific findings and its implications. Neuroethics is a subcategory of the bioethics field and is a relatively new field whose boundaries are between philosophy and neuroscience. Neuroethics can be defined as 1) investigating the neural basis of moral thought, intention and behaviour and as 2) investigating the moral, ethical and policy-related issues arising in and from the neuroscientific research and its clinical applications (Giordano, 2005). The current study will utilise the latter definition. The term is used by neuroscientist but is less used and understood by public in general, which makes it more susceptible to less criticism from general public. Neuroethics brings in a critical perspective on the amount of new information based on appealing methods and its implications for our understanding of concepts as self, normality or illness.

Cultural understandings of the biological self

Culture and science are shaping our understandings of concepts as illness and normality, and in this case of AN. The cerebral self has become a frame of understanding in the cultural landscape where we create meaning. "The brain has a privileged place in the depiction of individuality and subjectivity in corporeal terms" (Novas & Rose, 2000). Our ideas about the mind, self, normality as well as mental illness are formed through the public discourse created by the way media presents scientific information. Science is also influenced by the ethos of the times, and scientific advances are often translated into popular beliefs and cultural stories without a critical look at the scientific process. These beliefs and stories shape society's understandings.

The use of modern neuro-technology in understanding psychiatric conditions has added to the attractiveness and popularity of these ideas of mind, self, responsibility and control. In her article, "The seductive allure of Neuroscience", Weisberg (2008) showed that there is a tendency to buy bad scientific explanations of phenomenon if they contain some neuroscience reference. According to Weisberg (2008), we are biased towards neuroscientific knowledge as we attribute it more power. The new findings from the neuroimaging field may appear to the lay people as pictures of the brain, and they may create the illusion of understanding where often little or none is gained, because of their high-tech glitter (Goldenberg, 2009). Psychological qualities and experiences become materialized and therefore measurable. Some findings in neuroscience raise in this context questions about the nature and implications of such knowledge, and how professionals translate it either in their clinical work or elsewhere for the general public.

The media often communicates an understanding of the brain as deterministic. Furthermore, knowledge about brain is often presented as purely factual statements where no attention is given to the process of research from which these facts are derived. For instance, the media can present findings literally such as "one area of the brain was "illuminated" when presented with a specific task. These reports fail to note however activation in other parts of the brain. While professionals may be able to appreciate the difference, the general public may find themselves with a simple understanding (e.g. completing task A involves varying levels of activation in structure B) of complex dynamics and structure (e.g. completing task A involves different activation levels of activation of structure B, C, D, and interactive processes between the

three). Patients might as well take their information from newspaper or health workers and construct their own explanations. This study aims to explore these ways of understanding the self in the context of biological narratives.

Stigma

In spite of the abundance of the neurobiological research and the expanding discourse of the biological self, anorexia nervosa, is still considered by some a “slimming disease” which implies that people with this disorder have the ability to choose, and thus potentially leading to the stigmatization of the sufferer. Our society accepts that many illnesses are partially self-inflicted as e.g. heart disease, but in anorexia nervosa the risk taking behaviour persists throughout the illness: the common understanding is that if only the patient would give up that eating distorted behaviour, then they would recover. This is what makes the illness so challenging, that there is something resistant in this illness that needs to be understood (Birmingham & Beaumont, 2004).

Research has shown that individuals with AN experience more attributions of responsibility, fragility, motivations for attention seeking, and admiration for their behaviours than patients with Bulimia Nervosa (BN) or depression (Roehrig & McLean, 2009). Attribution by the general population, sufferers, researchers and clinicians is influenced by understanding of the illness and by the availability of different discourses.

Attribution refers to the way people explain the behaviour of others, how they “attribute” causes to events and how this cognitive perception affects their motivation. People attribute causes to events into two types: external or situational attribution assign causality to an outside factor; internal or dispositional attribution assigns causality within the person (MacArthur, 1972).

The characteristics of the illness seem to be perceived by general population as strength to control food intake, body shape and weight, attitudes that may be unique to ED (Roehrig & McLean, 2009). This implies that the severity of the illness is not understood; instead the illness is seen as a controllable behaviour with the purpose of seeking attention (Roehrig & McLean, 2009).

Research has also shown that individuals with severe mental illness report the experience of stigmatisation as responsible for feelings of discouragement, hurt and anger (Stewart et al,

2008). The development of such feelings depends on the degree to which individuals perceive the negative cognitive, affective and behavioural reactions to be legitimate and due to internal variables such as personality characteristics and self-worth. In comparison, attributing negative reactions to external factors can serve as protective factors against the internalisation of stigma.

A recent study showed that two groups who were given different information on AN, social-cultural versus biological determinants of AN, differed in how much they blamed the ill persons (Crisafulli, Holle & Bulik, 2008). Those given information about the biological factors of AN were less likely to blame the persons with AN. Implications from this kind of research would be wide and accurate dissemination of such knowledge. Such findings could contribute to the education of the public in order to diminish the stigma these people may face.

“There is a lot of false information about AN disseminated in the popular culture. Even a nugget of accurate biological information can influence how health professionals perceive the illness.” This supports the need for accurate information to help reduce the stigma attached to AN” (Crisafulli et al, 2008).

But is it always so that information about the biological basis, the biological narrative, diminishes stigma? Or does it just give us a seemingly intellectual understanding, but in fact our actual behaviour is not compassionate and tolerant? What meanings do people ascribe to the concept of brain and biological explanations? If this implies that brain can account for the part of the illness that is uncontrollable, is then the biological explanations eliminating the stigma a sufferer can feel or does this narrative stigmatise the sufferer? Research showed that seeing mental disorders as biological makes us perceive the others as physically distinct from the “normal” persons (Mehta & Farina, 1997).

Illness representations and self-perception theory

So far I have presented how general understanding of psychiatric conditions as AN might be influenced by the cultural and scientific discourses available in the society. This section intends to highlight how a person with AN might perceive this information, and how this information shapes their understanding of illness and self-perception.

Self – perception theory

According to self-perception theory (Bem, 1972), we come to know our attitudes, emotions and other internal states from observing our own behaviour and behaviours in others. Self-perception theory has been formulated to address the "philosophy of the mind" and it has been covered mostly by philosophy and has been less grounded in empirical evidence. However, Skinner was the first to address this phenomenon from an empirically based, psychological framework. He stated that a child needs someone who can point at the events and objects in the world in order to understand them (Bem, 1972). The problems appear when stimuli are private events and one has to find words to describe them. Skinner argued that we use external cues to point to internal states when the internal signals are weak.

For the present study, it is suggested that an individual with an eating disorder, their family, and society in general, find themselves in a position where they have to understand some irrational behaviour. The general understanding of AN derives from the cultural discourses mediated by media. We make attributions regarding our own and others behaviour based on available information. The common understanding of AN appears to be that it is in the power of the sufferer to control behaviour, and that this behaviour is used to seek attention (Roehrig & McLean, 2009).

Research has shown that there are still stereotypes, prejudice and discrimination of women with AN (Steward, Schaivo, Herzog & Franko, 2008). Presenting AN as a socio – cultural determined illness creates an understanding that the sufferer is a victim of the culture unable to control behaviour. If AN patients' social networks endorses such attitudes, the sufferer may feel blamed, internalise it, and engage in self-stigmatization. Previous research has shown that blame and self-stigmatising can hinder help - seeking and that stigma can have adverse

consequences on self-esteem (Steward, et al., 2008). In the next section I will further elaborate upon how different factors/explanation models contribute to the understanding of one's own illness.

Illness representations

According to the common sense model (CSM) individuals create internal implicit models about their illness that helps them make sense of their experiences and guides coping efforts (Cooper, Stockford & Turner, 2007).

Illness representations addresses the way patients understand the nature of the illness and their attitudes, their cognitive and emotional response towards mental health and their specifically illness (Hager & Orbell, 2003). The model hypothesises that individuals create mental representations of illness based on five dimensions: identity, timeline, consequences, causes and controllability/curability (Holiday, Wall, Treasure & Weinman, 2005). These five dimensions are interrelated and can predict behaviour and outcome.

The concept of Illness Representations has typically been measured using Illness Perception Questionnaire (IPQ) to assess attitudes towards others and own mental illness. However, such self-report questionnaires may not always capture the complexity of the representations and its dimensions.

The way both patients and the general population perceive illness has received increasing interest in the field of qualitative health research. However, to the author's knowledge there appears to be a paucity of studies in the field of eating disorders and illness representations. Currently, such studies have explored perception of *causal attributions*, *sense of control* and *readiness to change*, and how these perception shape cognitive and emotional representations and behaviours.

Causal attributions. Previous studies have shown that the most common causal attributions were included in the “psychological factor”, as the emotional state and the mental attitude, and in the “specified ED factor” such as “the need to be perfect”(Marcos, Cantero, Escobar & Acosta, 2007). At the same time Rutter (Marcos et al., 2007) concluded that assuming responsibility for one's actions is a direct cause for distress. Blaming the disorder on the

“psychological factor” was correlated with anxiety level, worries and indignation (emotional representation).

Readiness to change. Stockford, Turner & Cooper (2005) examined in their study the relationship between illness representations and readiness to change. They found that understanding consequences and having an alternative illness model (e.g. that eating disorders may not be the ideal or most helpful solution to a problem) promoted change. Stockford et al. (2005) also showed that different stages of an illness are correlated with 1. different illness models, and 2. different levels of emotional distress. Changing illness representation model might also effect change in illness understanding (Stockford et al., 2005) although this has not been systematically applied. This study explores if understanding of illness as a brain- based illness influences patients cause attribution and consequently self- perception.

Control. The interaction between participant and neuro-technologies, direct or through knowledge produced by these technologies, can be seen as relevant for the understanding of the illness and the self (identity) or the attribution of causes and responsibility (Hagger & Orbell, 2003). Previous studies on patient’s perceptions show that this group of patients often has a sense of low control both in terms of their illness, and more generally, for events in the world (Holiday et al., 37). In contrast, Marcos et al (2007) found that patients, who believed they could control their illness through their behaviour, would assume control over it. Furthermore, these patients were less depressed and less anxious, as well as showing better school/vocational functioning, family relationships and global adjustment. The findings of this study advocate therefore for altering illness perception and promoting beliefs in a cure. An explanation could be the fact that the patients received treatment, something that may have educated the patients about the risks and impact of behaviour on their health. In addition one of the aims of the treatment was to increase belief in one’s ability to control behaviour and change.

Normally the model of illness representation is seen as a logical model with the elements being separate but interrelated. In the study of Stockford and colleagues, 2005, although different elements of the model correlated with changes, causality could not be inferred, implying that there is not enough knowledge about how much introducing change in illness perception would result in stage of change. Anyhow these studies seem to suggest that emotional distress, sense of

control and readiness to change, are influenced by the way the sufferer understands her illness. Can understanding of AN as biological caused influences these illness dimensions by increasing belief in a cure and reducing blame, or does this diminish the sense of control a sufferer may experience? The present study aims to explore how biological explanations can influence illness understanding and will be presented bellow.

Aims

This study aims to explore how the biological narrative can affect understanding of illness, behaviour, and the sense of control. If participating in neurobiological research can be seen as an intervention, I wanted to see if this could influence understanding of illness. Illness representations are therefore a useful concept when exploring the conceptualization patients have around the illness and its causes.

The present study focuses on the experience of girls who have been diagnosed with Anorexia Nervosa (AN) and are involved in neurobiological clinical research where they undergo a brain scan. The interest is in how this might influence the participants' perception of self, the sense of identity, sense of responsibility and attribution of illness causation. Consequently, the present study approached the task of exploring illness representations from a qualitative framework, as such an approach has been found to cover the complexity of representations. The interest is in how neurobiological explanations for mental illness, might influence a person's perception and attitude towards themselves and their illness.

It seems reasonable to assume that the participants might draw their understanding about the brain from similar sources as media or health professionals. Considering that there is currently an increased use of brain research methods, and interest in the brain generally in popular culture, and academia, I wanted to see how this may shape understandings of, for example, responsibility, what is "normal", sickness and the self. To illustrate how this can influence understanding, we are using the concept of illness representation. The study can also be seen as a debriefing for patients and controls that undergo a scanning session and the meanings they tell are our tools to access the knowledge.

The research questions of this study are:

- 1 How do participants perceive their own illness and causation?
- 2 How do young women that have AN, and who undergo neurobiological testing, understand ED in relation to biological and psycho-social explanations?

Method

Most of the reasoning in the field of neuroethics is based on philosophical arguments and there is little empirical material about this theme; therefore the interest in this study was to have a purposive sampling to explore issues of self-understanding in the light of neuro-technologies use in clinical and research context.

This study utilized therefore, semi-structured qualitative interview to explore illness representations, more specifically how patients understand and attribute causes of illness as biological versus cultural/societal determined. The study is based on this assumption that the neuro-technology changes perceptions and can influence understanding of illness and self. Since we cannot control other factors that would contribute to this influence, this study is limited to the understanding and exploration of experience in a short period of time.

The concept of Illness representations is assessed with the Illness Perception Questionnaire (IPQ), which traditionally has been used in relation to physical illnesses, and less to psychological disorders (Holiday et al., 2005). Questionnaires can be limited in the degree to which they cover the complexity of illness perceptions. Previous studies show that the IPQ for AN did not include attribution to biological factors although more research has been done on the neurobiological or genetically basis of the illness. The authors (Holiday et al, 2005) also commented on the reliability of the lay scales and concluded that the reliability may increase if the number of additional items can increase.

The data corpus for this study contains of eight interviews with young women aged 14 – 20. All of them have been in contact with the Regional Unit for Eating Disorders but only a few were still hospitalised at the moment of the study being undertaken. The interviews lasted from thirty to fifty five minutes and were done in Norwegian with a Norwegian population and two English participants. They were audio recorded and fully transcribed.

The data set was analysed according to thematic analysis. This method of analysis is an appropriate method for this study as we are mainly interested in the patient's conceptualizations. There is little knowledge of illness representations in AN, and thematic analysis is a more flexible method in regard to data analysis. Holloway and Todres (2003) identify "thematizing meanings" as one of the few-shared generic skills across qualitative analysis (Braun & Clark, 2006).

The interest of this present study was the categories of meaning and the kind of knowledge we obtain can tell us something of the conceptualization and representations participants have of the causes of their illness. Data was analysed by identifying categories of meanings and the way they "clustered" in typologies to describe dimensions of the phenomena of brain scanning and attribution of causes (Ritchie & Lewis, 2003). By identifying categories of meaning I could both compare which categories every participant refers to but also how these categories relate to each other between participants. A theme was judged not only by amount of data, but also the importance and relevance for the study.

Thematic analysis involves identifying themes and patterns among these that emerge from the data and is not wedded to any specific theory. The method can be considered an essentialist or realist method, reporting on both experiences and meanings, and the reality of a phenomena or the way meanings are constructed as part of a society trend (Braun & Clark, 2006). According to thematic analysis, data has been analysed in five steps: familiarising with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Brown & Clark, 2006). In the first place I looked at the descriptions each participant gave, then I ordered the concepts and then constructed the "story" which means in practice the construction of a schema that integrates aspects of concepts through statements of relationships (Strauss & Corbin, 25).

The structure of the topic guide is as follows:

- 1 Experience of scanning session
- 2 Understanding of scanning session
- 3 Understanding of illness and attribution of causes

4 General understanding of control and responsibility for mental illness

The interview guide was changed after I had done three of the interviews and I included more questions about the way they saw culture, as explaining factor for the illness, and not only looking for brain explanations.

Research process and context

This project is developed as an extension to an already ongoing project where the author was responsible for recruitment and assisting participants through their fMRI scanning sessions.

The scanning process: Total time of screening was two hours during which participants completed six neuropsychological tasks. The total time of screening is two hours. Participants don't receive the results immediately after the scanning, nor may they know about how such a machine functions, the kind of information and the implications a brain scanning brings with it.

The present study is a pilot study in collaboration with the Bioethics program, London School of Economics (LSE) in London. The focus of the study was to explore the meanings formed during the interaction participant – machine before the participant received any results on the scanning and got an understanding of the relevance of the findings for their lives. Participants were recruited via their contact person, doctor or psychologist, who made the evaluation of the participant's capacity to participate in the study. Further the participants met the contact person for the research study who informed about the procedure and waited for the participant's consent. The Regional Ethics Committee has approved the study. Anonymity was ensured through alteration of participant's name. I gave the participants pseudo names in order to make them anonymous.

Another issue with this group of participants, and also generally with participation in research, is the sensitivity of the topics chosen because participants are asked to speak about their illness. The stage the participant is in the illness together with the trust and relationship the researcher has managed to establish may also impact on the quality of the data collected. Chronic ill patients are excluded from this sample, which makes the findings representative only for a subtype of patients.

Interview ethics

Throughout the interviews I had to be aware of the ethics of involvement and detachment as well as the illusion of objectivity and borders of subjectivity (Ciurzo & Keitel, 2003). The focus of the interview guide was how participants conceptualised different concepts, and I had “to draw the line” by keeping the focus of the interview to the interview guide. It was important in the interview situation that I did not challenge too much openness and sudden self - understanding from the participants who should have a good experience of participating.

The dialog is both emotional and intellectual and the researcher has to reflect on the impact he/she has on the participant. The interviewer has also to reflect on the dramaturgical aspects of the situation, on the role and the directions interviewer should take (Thagaard, 2003). Consideration of the role I had in the situation, as a researcher and not a therapist, was an important issue I had to be aware of , as the interview did not have a therapeutical character. Often it is the case that the patient experiences the in-depth interviewing as having a therapeutical character (Ciurzo & Keitel, 2003).

Limitations of the study

There are some limitations to this study. It can be challenging to assess the impact of a scanning session, as one may need a follow-up study for longer effects. That is why the study explored the experience and understanding “here and now”. We do not know how much knowledge about the brain and scanning machine the participants have when coming to the session, which can make it difficult to understand how participants’ engagement with neurotechnologies might have influenced their understanding of their illness.

The study cannot therefore cover how this influences sense of self, eventually how this is translated into behaviour and how they influence the person. Longitudinal studies where participants are assessed at different time points might give an insight into the effects of the interaction neuro - technology and self - understanding. The interest of this study was to identify categories of meaning that can inform the effect use of neurotechnologies could have on understanding of illness and self-perception.

Analysis

The themes that emerged from the data were: searching for knowledge, understanding of causes, searching for a biomarker, problems within or outside ourselves, and family literacy.

Each patient had their own story but common to the patients was that they reflected on the complexity of the relationship between brain explanation for illness and their eating disorder. This reflection is included in the participants' discourse, and is an integrated part of their understanding of illness. When thinking about the brain's influence, the participants referred to the aspect of uncontrollability or anomaly. Considering the obsession element of the illness, some participants experienced a loss of control and this is often explained as possibly caused by the brain.

When it comes to the motivation to participate in clinical research on the brain, participants were motivated by their desire to understand themselves and help to acquire knowledge about themselves and the illness. This knowledge, according to the participants, would benefit family, society and themselves in order for the sufferer to be better understood, not be judged, and avoid self-stigma and blame. Stigma and blame seem to be the overarching theme that binds together the themes. Seeing problems as inside or outside us implies also different definitions of what patients see as outside and inside and how this can be controlled. Some participants see brain and personality as outside one's own control. Their thoughts about this relationship seemed also to develop throughout the process of participating in the project.

Participants expressed the need and motivation to understand the illness, themselves and to contribute to gaining of knowledge about an illness that seems to still be not fully understood. The illness causes self-blame or blame of society, eventually family. This led to the desire to find a physical proof for something unseen in order to prove that the illness is not self-inflicted. There is a tension between attributing illness to one's own personality and psyche and the brain as well as society, media, family or difficult life situations. There is a tension between perceiving that it is oneself's fault, and that one can hold some control and at the same time being controlled by an illness. When brain and biology is named, the notion of guilt seems to be challenged/alleviated.

For other participants, brain explanation does not exclude that one should work with family or individual therapy. So brain explanations are not seen as deterministic because participants are aware of the illness' and a person's complexity. But what brain narrative seems to point to is the desire and hope to find a physical proof, even a cure for the illness that would function as an objective sign. Brain narratives can alleviate guilt because the subjective experience of a feeling, thought or in this case illness becomes an objective sign that others cannot question. A physical proof would therefore allow identifying, helping and preventing the illness. More understanding would also prevent family and society from blaming the sufferer.

Themes

Following themes were identified: searching for knowledge, understanding of causes, searching for a biomarker, problems within or outside ourselves, and family literacy.

Searching for knowledge

A common recurring theme was the desire to know more about oneself and the illness, and wanting to contribute to the treatment. "Because I think that the more one knows about the illness, better is it and if it can help others I think it's nice".

I think it's very exciting in a way to be able to join and make an effort to help, it is firstly to help others, and if one can find something that helps it is useful. And I also think it's fun if I find something about my self. This is actually my motivation.

Participants stated that they were interested in what kind of information this research would bring forth either about them or the illness, indicating that they are still in the process of constructing a narrative of the illness.

I thought not so much about risks but more as advantages that one does such research for these illnesses, especially for eating disorders which is very alike in many ways for many people, but also very unlike, one gets influenced very differently, but to find some similarities is interesting.

Ella's answer to the question on motivation to participate was:

I thought that if one finds something that could somehow help some or find out why it is like it is, or little more because one doesn't know why it is like this or why some get ill, or if it influences the brain.

There is a common understanding that people participate in the search for "a cure" or a treatment for an illness that is still poorly understood. Even if the understanding and the cure would not give immediate benefits, participants were positive about "investing" in the future. Anna said that even if in the beginning she was reluctant she felt pleased to participate in the research: "No, I feel quite chuffed of the development and new knowledge, that I'm involved in that".

The benefits would be both for them and their families. "Anything, there is no fine cure, treatment, I think that anything that could be developed could be helpful".

The fact that findings from cognitive neuroscience have been presented more in the media, seems to have raised interest for the brain and behaviour both among professionals, the general public but also the participants of this study. They were receptive to this kind of knowledge as they were motivated to understand their illness. This is what Maria, one of the participants said when she was asked if she perceived the connection brain and eating disorder peculiar.

I think I considered it and thought that there is nothing strange that they ask me or I didn't think it was strange that they did research on the brain or parts of the brain that may work more than others when one has an ED. I have read some stuff, I think it's interesting to read in the newspapers about the different things they have found, that this and this part of the brain are centres for this and that, so I'm thinking that different parts of the brain have different tasks and that the different parts (...) so I think that most probable it's possible.

Being exposed to this kind of narratives is supposed to influence the frames of understanding concepts as responsibility, normality, illness, and their causes. "I feel I joined the study to get better treatment in the future, but I thought afterwards that maybe the brain is a more important organ that what we think of".

This group of patients is thought of as compliant, still it is relevant to know about their motivations and experience of participating in research and of their understanding of illness. Although this may not be different from the other populations of research volunteering it can also suggest involving participants in the treatment, and increasing their knowledge about illness. As people become more exposed to this kind of neuroscientific knowledge, our understanding of these concepts of selfhood, responsibility, and normality can subtly be shaped.

Understanding of causes

Filipa was not surprised about the relationship brain – illness, and she saw dysfunction in the brain as a cause of the illness. “I understand that it’s connected, I was not surprised, but it’s maybe a little scary, brain research sounds so scary, but it’s quite logical, the way one thinks is connected with the way the body reacts on things”.

Her perception of the brain is not as something totally controlling the person, it influences our behaviour but the sense of personhood does not disappear. She sees that in her case it was no traumatic experience that triggered the illness, and seeing brain dysfunction as a cause was not affecting her sense of personhood. “I was not that unsure that I was quite normal, so I know that I am quite common”. Although nervous about the scanning session, she saw the situation of scanning as a school exam and managed not to worry that she would be stigmatized by findings.

Melanie understood the causes of AN as to be psychological but, at the same time, she thinks it is difficult to point to a specific cause. “There are many factors, small and big...”. She saw the causes of her AN in her earlier psychological struggles that turned into overeating and from that into self-harming and then AN. The restrictive eating led to the shrinking of the brain so she does not see the AN as a brain caused illness. Therefore she thinks that causes are different for different individuals and that the biological explanations can stigmatize by putting individuals in categories: “even if there are the same concepts, we are different”.

Melanie demands that health professionals should see each patient in the context of their own life story.

I have thought about my own (AN), but I understand that many have it of different reasons, it’s not something specific, that anorexia is caused by this, there are some similarities but for me I think it has many differences too, that it is an individual problem, that there is not only one situation leading to it, (...), there are different things that influences, friends, family, society, media, but in addition the personal problems one has.

It was challenging for Catherine to point to a specific cause: “Thoughts in the subconscious mind being suppressed, past experiences, childhood experiences, it could be anything, if I knew then I would get better straight away but I don’t know so I can’t give you a sound answer”.

Understanding causes for illness is a part of creating illness representations and it has

been shown to influence emotional illness representations and coping strategies.

The experience of the scanner. The experience of the scanner environment and scanning itself gave rise to psychological or physical feeling of discomfort, participants feeling vulnerable to the physical environment of the scanner: “it was a challenge that it lasted for so long especially when you’re in such a state like we are with our bodies. My legs were hurting”. Participants seemed to see in brain imaging a photograph of their illness or other conditions that could be discovered. Brain imaging pictures can be seen by the general public as photographs of the brain, but the interpretation of them is much more complex with tests of significance and other methodological and theoretical decision to be made.

Participants seem also to experience anxiety when thinking they are being evaluated.

Hannah : “I was thinking you would see the eating disorder and then look at me/evaluate me differently afterwards”.

Ella : “I was a little bit anxious that they would see that I was silly or something”. “I was thinking about (if they would find something not regarding the ED) and especially in the break when I hardly looked at the screen, and it was a little unpleasant although I didn’t know what, but just like if I was silly, or if something was wrong (...)

Alexandra thought that others seeing her brain was something personal which she didn’t feel comfortable in the beginning but then she realized that this helps to more understanding of the condition of AN.

In this context where participants felt they were evaluated, the theme of shame or low-self esteem judgements and unpleasantness of disclosing information about oneself appeared as a natural consequence.

Discomfort or the feeling of being stigmatized by the findings or the researcher – “maybe the risk was if they would have discovered something that I would have felt uncomfortable with, I don’t know” - can also be experienced when participants often don’t know the meanings of the findings. As Hannah said: “It’s ok to get a feed-back that everything is fine when you first have to be in there and listen to that noise”.

Searching for a biomarker

Participants had an understanding of the research on brain as trying to find the differences and traits those patients with AN might present in comparison to other people, to the "normal" standard. "That one can show that the brain gets a different look than it would have had in a normal development".

More than that, the participants expressed the desire to prove with something physical what Melanie called "an unseen scar". The lay understanding of Anorexia Nervosa is still that the illness is self-inflicted and even for the patients there is a need to make sense of this and prove that it is an illness with serious consequences.

I'm thinking it gives a better picture of people that have had an eating disorder, one can see that they had it, while those that didn't they have a normal development, I have stopped in my development, that things started to go slower, you get paralysed, and everything got influenced. It is interesting to prove that through research, that this is what is happening, that it's not only something I do, that this is an exposed group.

Knowledge about the physical reality of this illness would make people realise the severity of this conditions and its sequels that the sufferer has to deal with. It demands working at "yourself", and many participants referred to losing years: "Even if I learned a lot, I don't think I want anyone to experience this", although they have learned from having a psychological illness. "Because this illness, it can last for years, for some maybe the whole life".

For those participants that saw the cause of the illness in a psychological problem, they also emphasized the "virtue" of learning from it and from working with the "self". For Melanie, this experience even led to her choosing a different profession, and for her developing an understanding and willingness to help other people, which she says she did not have before the illness. The experience of the illness made her into "a better person" although she still feels she isn't fully recovered. For Maria, it made her realise that one doesn't necessarily have to be stigmatised for having had this disorder because one can recover. She could distance herself from the disorder.

On the other side, some participants saw the possibility of a dysfunction in the brain as a cause. "I have always thought that it is in the thoughts, a mental process". Anna thinks that if brain is shown to explain illness, then a cure, or treatment would make life easier both for her and

her family. "I think in a way it would be easier to.... if there is an actual physical cause that you can see, than just thoughts, and everybody is different with their thoughts so like it would take a longer process if it's not something physically". If a physical treatment would be easier, there is the desire to use it because "it would make life easier, my life as well as my family's life".

It would then be easier to prevent: "Yes, cause if they know what is going to happen they can start treatment earlier, or advert them from something that might trigger them, (...) about the challenges that they have to face if they go with the illness". If family, friends and society would know enough about the illness then individuals could be warned: "if someone warns you from before and might tell you that you might have this illness then it could be a reality check to some".

Patients perceived their illness as making them different from the other people, and wanted an explanation for it. Melanie talked about the shrinking of the brain as a result of restrictive eating. This is how brain is affected by the illness because one is restricting food, not because there is a biological and genetically vulnerability. She means that it's the thoughts or feelings, the psychological and emotional dimensions that is influencing the brain, not the other way around. Therefore it is the person that can work with the problem, with help from the health professionals, and the close people. This is also what makes her feel different from the others, having to work with the psychological problems daily; there is "a longing to feel normal, not to struggle".

Maria also states that:

 Hmm, family therapy or family hospital stay because I think it would be wrong to only do a simple solution and fix the brain and so you're recovered...because I believe it's wrong, you're skipping so many steps, but to work with family and those you live with around, to work yourself out of it, together with others....

It is still unclear even for the professional health workers why some people get AN. Even more, it can be harder for patients who have an insider perspective and are affected by it, to see clearly what initiated the illness. Girls talked about the influence of the genes, environment, personality and brain, showing the awareness that there is an interaction between these.

Genes were more often identified as a cause for differences or illnesses than the brain. Brain is more often seen in relation to the effects starvation has on the brain rather than the brain as a determining factor. "I didn't give it much thought, the physical is connected with the

psychological so it's the psychological that is driving it, that it's an illness that's clear for me, but I don't know if it's a fault in the brain".

According to the professionals and critics in the field, the genetic self is more "popular" than the cerebral self and it might be the cerebral subject's strongest competitor". In spite of this, "if one compares "genome-based" and "brain based" explanations of self and behaviour, it turns out that the neural aspects of the human nature are more directly relevant, and in spite of the increasing convergence of genetics and the neuroscience, issues of self and personhood remain primarily related to brain structure and functioning (Ortega, Vidal, 2007)".

Being underweight and experiencing the effects underweight had on their mind, influenced the girls' will to seek treatment. At the same time, they realized that this was affecting their brain and their state of mind.

It was also something I have seen in the period when I didn't eat very much before I was in the hospital for the first time, I was very tired and I didn't manage to think, my brain didn't work, I hardly managed to speak, so the doctors said that the body had started to eat from the brain, so it says itself, I have heard that all the way. In this way it was highly a motivation because I could be more with it, I was more together, I managed to move again, I got more energy, was more awake.

There seems to be among the participants a desire to find a blueprint, something physical, a sign that would distinguish between patients and "normal" people and would explain unseen struggles. So the brain is both seen as a direct cause of illness, the brain may provide a marker for the illness, but also as a mediator between genes and environment.

If one can see the anorexia? I don't know, maybe this is what you're searching for, if you scan many healthy people and many with eating disorders (ED), I don't know if there is something similar for those with an ED, the same if one takes chemotherapy and you loose hair, then you know that they take that therapy, I don't know if there is something like that.

Hannah is pointing here intuitively to the issue of brain markers for psychological disorders, and maybe for the desire to find an identifiable sign, marker for some unseen or not understood struggle. "I don't know what one can do because one doesn't know why it becomes so, but one gets an understanding that there is something that is different, that there is something wrong compared with a usual sickness". While physical illness may be easier to understand, mental illness is still less understood.

At the same time Melanie refers to seeing the differences between each individual “even if there are the same concepts, we are different”. Even if many individuals have the same diagnosis, she mentions the need from doctors, health workers and researchers to differentiate and see the individual. The diagnosis can also create a stigma and even if shrinking of brain is a common factor for those with the disorder, the experience is different for each individual, as Melanie explains it. Seeing beyond the physicality of the illness is just as important.

When it comes to research, to not put all in the same boat, in the same way as people are different so are our diagnosis different, even if there are the same concepts, research is putting everyone in a boat but after all it would be positive if one manages to see the differences, that eating disorders are anorexia, bulimia, and that one makes the difference, and make the differences again within anorexia that I had, that there are different "tunnels" and make the differences between them, even if one is a doctor or researcher maybe one thinks this way but one behaves differently.

There is a sense of hope that knowledge would identify causes, prevent illness or help treatment. " What I like about this research is that is trying to change a perspective in hope that they don't actually judge those with eating disorders, that everyone feels it that way, and try to think individual even if it's difficult".

Problems within or outside ourselves

“(...) I believe it can happen to anyone (...).”

There is a dynamic in the understanding of the causes, a movement between seeing the cause within oneself and the environment, family, culture, media. The brain is seen as a mediator, but also can give rise to contradiction, as it is conceived as “it decides everything”. But the self as something separate is responsible to deal with the psychological dimensions of feelings, thoughts and struggles either related to identity, adolescent crisis or other problems.

It varied how much thinking about the brain was involved in explaining illness; as for some participants it was new while for others it was not surprising. Media and the health professionals had provided some with the input to think about this kind of explanations. It varied though if brain's influence was seen as deterministic or in other complex ways. “I think the brain shapes you as a person, your mind resides in the head and the brain is in the head, or the brain is the head.”

Participants had different connotations to the brain or the biology of the illness. Hannah

thought of it as explaining the uncontrollable behaviour. In this way the more problematic a situation is experienced, the more probable that the person does not feel in control and therefore something “outside” one’s own control, as the brain can explain.

There is variation in how much participants thought their self is determined by brain or how much self-determination they can maintain. “It’s all in the head, and the head is the brain and the brain is me”(Hannah). Illness identity and the stage one is in the illness, can here explain why some can justify their experience of symptoms and illness as uncontrollable. On the other side more recovered participants seem to have a balanced understanding of the brain’s implications. “As long as I have an all right life, I don’t mind how my brain looks even if it has some irregularities”.

“I think it’s interesting to read that they found centres for this and that in the brain”.

Although brain is seen as determinant, participants still referred that treatment should aim at working with their past or their relationship with food and body.

I think that if there is something one can do with the brain, I don’t think one should do it and go further, but it would have been very helpful to use the findings. But at the same time work further with different treatment as therapy because you have anyway the past that you have even if you can change what is driving you.

But interventions on the brain is sometimes seen as short-term, simple solutions, that would only help the present while the scars from the past must be worked on with therapy.

There are many factors, family, friends, but there is one self that is standing in the midst of all. If it would have been someone who could take away what I am struggling with, I would have taken it away but I think people themselves must work with it, I don’t think it can be deleted by other methods, medication or other things, it can soften but it lays there until you work with it yourself.

There is responsibility that lies within oneself to influence thoughts and feelings. “I think it’s the thoughts and feelings that determine instead of the brain’s function in itself”.

Mass media’s influence does not seem to be the first cause participants name as often as it would be expected since this is the popular understanding of the disorder. But when asked specific about media’s influence participants think it accounts for much of the precursors of an eating disorder. The blame is then taken further to one self who is not strong enough to face the challenge of this experienced pressure.

Fashion... when one makes a new product it's less fat and less sugar, at least when you are young and shall try to find out what is best for you, and try to stand on your own feet a little bit, I think it's unbearable that there are so many thin models, that people...that these are the ideals, that they are prettiest, half of them have an eating disorder, that they should be ideals is terrible.

Very, a big influence, they can't be small cause if they were small they would not affect ...

Well, they can either agree or disagree with the influences, go along or not, but they have to be big enough not to go, be confident enough not to.

The struggle to find one's identity in the years of adolescence has not often been named as a cause but more as a mediator for the illness. Childhood, family and environment seem to be common factors that participants named.

(...) one has lots of possibilities, and one tries to find out the best one and not everyone manages to find out what is best for me, and one gets it wrong and it goes badly, and one can develop an ED, take the wrong choices and get a very rigid eating habit. Yes, and also what you have experienced in your childhood has a lot to say for what you become as a person and how you relate to things later in life, maybe many have problems to find out where they are standing as youth.

It is hard to name one single cause of the illness: "it can be anything, something someone is saying to you, childhood (...)"

Some participants thought that personality was a factor that explained illness. "The way one is" seemed to be the alternative to brain explanations. The experiences one has, as a child and also anxiety are factors Hannah referred to: "I think anxiety has a lot to say for what you experience (...)". Even if media, family, society, childhood events can trigger, it's the way one tackles the influences that determines who is developing an ED. "One has to be strong, to say yes or no to those influences", as Catherine says.

Although participants acknowledged the influence of media or group pressure, they reflect also on the ability to face this influence, another type of literacy as something they are or not. "I'm thinking that not everyone who is hearing from media or friends internalises it".

When family can not see, someone else one can bond with could prevent from falling in the wrong pattern, by helping one fight against those obsessive thoughts: "but if you have someone from the side, that goes again the stream and can help you not listen to that, that you

become strong, can prevent you from falling in the pattern”.

I tried for a long time to find the cause of it, but they found nothing they could write down, this is the cause, and so we decided not to focus so much on that,(...) so I think it’s everything around you, (...) it can be anything but in the end is the way your brain tackles things, stress and pressure of expectations.

Often personality can be thought of as “outside” the brain. Goldberg refers to the public blind spot who makes a distinction between physical illness and mental illness which results in that the former one does not give as much compassion and health care as the other one. Impairments of the hearing, sight or memory seem to be better understood than the executive functions (Goldenberg, 2008) that are also hypothesized in the case of eating disorders.

Some participants referred to the mental illnesses in terms of analogy to physical illness, proposing in this way an experience and understanding of mental illness as equally devastating as a physical illness, and one that needs to be seen. To see beyond the appearances is demanded by the sufferer. One can also think in terms of a cure when illness is thought of as a physical or biological.

But there can also be a risk of knowing that the uncontrollable is determined by brain, because it can be stigmatizing. Therefore the knowledge should be presented in a nuanced way:

(...) but it can be dangerous to think that it can be something wrong with the brain, that they are in a way crazy, that it’s easier to think so, I think more that there is a part of the brain that it’s overworked, that this part of the brain works more than it should, or not the way it should, or because it happened because of things one has experienced different things in life or that there are some genes that explain that.

“Maybe this would have been the risk, if they would find something....”

Filipa thought it was something alienating that it is not one’s own will or fault that generated the illness or its symptoms because there is no one to be held accountant. This is part of making sense of the illness and one self was the first one to blame. Seeing a brain dysfunction as a cause was associated with having little control and this in turn gave feelings of blame and the experience of hurting those around.

It was at the time when I was in hospital, because then my family was very keen on telling me that it was not my fault, that there was not much I could do

for it, and then it was like if someone could have just come at me and tell me that it was my fault, I was so sure that people just wanted to calm me down, can just one person be honest with me, so I could get over with it, so I don't go around and fool my self, but it was just because I was so upset and didn't manage to control any of my thoughts.

For other participant when thinking of AN as a brain based illness was not equivalent with loss of responsibility, although agreed in the case of schizophrenia, - where there is also more general consensus of the biological basis and uncontrollability of symptoms, than it is for eating disorders. This is also consistent with the field's acknowledgement that lay women, men and health system in some countries do still not acknowledge ED as a mental disease (Holiday et al., 2005). Therefore as a consequence, treatment would not only involve the "treatment" of brain, but also working with thoughts and feelings from the past, the environment or the family, according to the patient.

Melanie knows that one doesn't have a lot of control especially when one realizes that there is an illness and not only one's own will that is generating the illness. But she thinks that responsibility is an unfair concept, as society through mediatization is not talking about how to help and how to be there for the ill. "To pick up the warnings", to be seen and understood in their seemingly irrational behaviour was a topic many participants named.

Family literacy

Both culture and biology were mentioned as factors that can influence the illness, and participants expressed that they are more "literate" in seeing the symptoms of the illness in others. They would now see the signs of illness in others. This literacy seems to be underlined by the participants who demand this from the relevant ones around them. Still many patients acknowledge the support they received from their family or health workers, and are aware of the difficult situation the family has been through.

Many participants expressed the need to have someone close to talk to all along the "way", and named family or friends that they wished they could have understood the symptoms of the illness earlier. This understanding as Hannah said would result in family not asking "*obvious things*" when one is sick and struggling.

I talked with another girl who has an ED and her brother had asked if she wants to join for a dinner out just like that, and it gets difficult for her because she maybe wants to and she knows that she can't manage. It gets so that the family says stupid things that makes it difficult and maybe it's so that they should learn to keep their mouth --- so that they don't ask obviously things that of course are difficult when one is in an illness.

Melanie demands this literacy also from health workers who see recovery as something physical. She has had some unpleasant experience with health workers that did not see her AN or thought that she just wanted to be thin. But both family, friends and health workers should see behind AN as wanting to be thin, they should see the struggle and the motivation behind using food as a mean to deal with difficulties.

Research in the area of stigma has suggested that target-specific stigma change model are developed with the aim of decreasing stigma among key individuals who are important in the lives of individuals with AN (Corrigan, 2004).

Catherine refers to the understanding some people just don't have because of their way of thinking. Anne refers to the training that families should get early in the illness, in order for them to understand, handle situations and avoid blame.

Not necessarily to have family therapy, that one talks more at home, that family gets help to understand that this is a serious illness, and that maybe they can get a little bit of training for how to best handle this, that they can know that this is something irrational, that if X. reacts strange on different things it's because she doesn't think rational about things, and they can know what the illness is about, so that they can help the family members the best way possible.

Information in itself is not enough to make an impact on the understanding of the irrationality of the illness and the skills to tackle it.

There is a lot of knowledge around but I think it's important that families can talk with someone who knows a lot about it in the beginning of the treatment, when they find out that it is a serious illness and that they get information about what is about and why one doesn't think normally about things.

Melanie says that family is an important source of support but also of struggle when you are not understood:

I had in a way some many around but no one, and I was receiving much response for losing weight, and then all of a sudden it went wrong, so the same people that encouraged me first, were critical now, I mean where were they, they could see that there was a pattern.

Research has shown that carers of people with eating disorders have high level of distress.

Their negative experience of caring was related to the dependency of the individuals with ED and the stigma associated with the illness. The belief that the illness was attributable to the sufferer's personality was related to fewer positive appraisals. Therefore interventions that help reduce dependency and reduce stigma may help decrease carer's distress (Whitney, Haigh, Weinman & Treasure, 2007).

Throughout the interviews participants expressed that they were motivated to participate in the research study in order to find out more about them selves, the illness and to contribute to more understanding of this condition. Mental illness seems to still puzzle both the sufferer and the significant others, as well as society. While physical illness is more accepted and understood, mental illness seems to be more subject to prejudice and blaming. Therefore more information about the complexity of the mental illness is needed in order to prevent self-blame and stigma both for the sufferer and her significant others.

Discussion

Cultural and psychological contexts

In the beginning of the study I mentioned that the concept of illness representations supports the understanding of the data. The kind of representations, cognitive or emotional, that people form of their illness has been shown to predict the understanding of illness and the way the sufferer is coping with the illness (Hager & Orbel, 2003). The present study looked at how use of neurotechnology may play a role in the understanding of illness. Particular attention has been given to how participants perceive concepts as control, responsibility and selfhood.

The research sought to investigate whether, for example, the young women saw their illness as weakness within themselves, or whether they consider their illness to be located in the brain, and the implication of this thinking. A brain – based attribution could be linked with understanding of the brain as offering objective evidence of illness, and this could be understood in a way that alleviates guilt from the person experiencing the illness. The answers participants gave varied from short sentences to more detailed narratives. There is opposition in seeing the AN as a brain caused illness, at the same time as participants saw the potential of understanding the biology of illness. This perspective could affect treatment and even prevention or cure of illness. Asking participants what they understood to be causes of illness also led to discussion about prevention and a notion of “literacy”. Some participants wished that close family, friends, and society in general could be more literate in understanding their illness. This literacy was understood to influence prevention, early intervention and outcome.

These representations of the illness that we are creating, I argue, have to be understood in the context of the society and culture we live in. The culture is the frame where we create and are subjects to different understandings. Lately these frames of understanding have become more influenced by a genetic and brain form of thought and practice. These are re –shaping the space that Descartes draw between mind and body. These are not seen as two separate entities, but are intertwined, and the findings of modern neurotechnology that confirm a material basis of psychological processes seem to support and build this understanding. The psyche is no longer a depth structure but it becomes flattened on the corporeality of the brain (Novas & Rose, 2000). Rose refers to the increased tendency to define our states of mind and emotions in terms of

medical categories and the ratios of serotonin to dopamine transmitters in our brains (Rose, 2005).

The critic of reductionism is based on the idea that the genetic code/biological basis is a deep inner truth that modern science is expressing it on the surface of corporeality. Although the characteristic way of thinking of modern times is depth-surface thinking, the contemporary genetics is operating in a “flattened” world, a world of surfaces rather than depths.

The way genetics and brain knowledge shape the concept of personhood is not necessarily in depths but in surfaces and associations (Novas & Rose, 2000), as the participants in this study expressed. The knowledge about the genetic and brain does not change the essence of us being humans, but it gives us more associations and references when describing and understanding our selves. Seeing a genetic, neurobiological factor may not necessary provoke resignation and passivity, as exemplified by our participants. Biological narratives are not deterministic and reductionist, and the participants did not necessarily isolate themselves as individuals from the cultural and social context or saw their illness as purely genetic or brain -based. It did vary how much they saw themselves as the somatic individual and they did not only relate to oneself as to the expression of an underlying genetic identity alone (Novas & Rose, 2000). Their identity was not fully represented through their biological self. They were not passive observers, but were motivated to participate in, for example, understanding them selves and their eating disorder. Still there was a tension between seeing one self as autonomous and self-determined person, and the sense that the biology and the brain are controlling one.

General worry in the neuroethics community relates therefore more to an increase in bodily discourse, not necessarily a new paradigm, because the hereditary thought has a long history (Novas & Rose, 2000). Although neuroethics is a new preoccupation within the neurosciences, this is not necessary equal with the birth of neuro essentialism, that is critical of a way of seeing individuals as reduced to the neural activity. Instead this new perspective links with modern ways of thinking personhood (Novas & Rose, 2000) and not only effaces with it. Genes, as well as brain discourse, have become the “ethical substance”(Ortega & Vidal, 2007), which add to the work of constituting personhood not necessarily in simplistic ways but in more complex ways. Yet the data of this study is heterogenous and can only identify patterns of

meaning. Therefore in order to investigate the longer - term effect neurotechnologies and biological narrative can have on understanding of illness and self-perception, longitudinal studies should be conducted. These studies could aim at exploring the way interaction with neurotechnologies and exposure to biological narratives can influence the different dimensions of the concept of illness representations such as understanding of identity, cure, control, consequences and eventually their effect on coping strategies.

Implications

Research shows that AN is more exposed to attributions of attention seeking and blame. The stereotypes people hold about AN indicate that AN is still understood as a socio-cultural determined disease (O'Hara & Smith, 2007). The emerging themes of finding a blueprint or a marker for the illness, illustrates the blame the sufferer can feel either from society or family, or simply the struggle to understand and come to terms with a complex, devastating disorder.

Although it is true that exposure to media images can promote poor body image and dieting, as precursor for eating disorder, it may be detrimental not to present the biological and genetical underpinnings of the disorder (Crisafulli et al, 2008). Participants named media as a predominant cause, but they also expressed self-blame for not withstanding this influence. If AN is presented as a socio-cultural determined disease then girls can also internalise this reasoning, leading therefore to self blaming their short-comings in resisting this influence. Research shows that even if specialist increasingly see AN as complex mental illnesses with both genetic and social roots, the public still perceives these as a manifestation of personal or social problems among women (O'Hara & Smith, 2007). This may in part be influenced by the way information is presented in media. A research study showed that information about these disorders ran mostly in art and entertainment sections, and only 8% of patient profiles discussed treatment and recovery in a medical context (O'Hara & Smith, 2007). This study's findings illustrate the importance of presenting relevant and complex information about the disorder in order to affect general knowledge about the illness.

Therefore, campaigns that inform about the biological element of the illness can be a relevant intervention. At the same time, information about the biology of the illness can provoke

unwanted effects of stigmatizing. Therefore informing about the complexity of the illness, with biological, societal and cultural factors contributing to the development of the illness, should be the target.

Understanding more of the neurobiology and neuropsychological basis of the AN can have implications for the psycho-education of the family, as well as for how clinicians explain results findings and discuss issues related to how the brain is involved in the illness and recovery. One patient stated that understanding consequences of dieting on the brain was a motivator for change. This seems to be in accord with the finding that motivation to change is influenced by understanding consequences of illness (Stockford et al, 2007), but also with intervention where family in the treatment get information not so much about the aetiology of illness, but more on the consequences of restrictive food intake or bingeing on the brain function (Holiday et al, 2009). Furthermore, participation in research can be thought of involving patients in the process of understanding themselves and illness by being exposed to different models of understanding the illness.

Patients expressed interest in understanding themselves and the illness, which can point to the need of education in decoding both cultural and biological information about the body, self, brain and culture. The material of this study includes different stories about what caused the illness. Some participants were open to the idea of AN as a brain based disorder. Some have not been exposed to this narrative, and participating in brain -based research was an exposure to this narrative. Others saw it as an effect of starvation mediator of the illness. Those that saw the brain only as mediator saw the causes of the disorder in them selves such as personality or the psychological dimension of depression, low-self esteem, eventually difficult situations such as group pressure and pressure from media. The connotation to the brain was that brain accounts for the uncontrollable. Although the diagnosis is the common denominator, participants had different life stories, and therefore understandings of the AN 's causes.

Literature:

- Birmingham, L.C.& Beaumont, P. (2004). *Medical Management of Eating Disorders*, Cambridge University Press
- Braun, V., Clark, V. (2006). Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3, 77-101
- Brewerton, T.D., Frampton, I., Lask, B. (2008) *The neurobiology of Anorexia Nervosa*
- Corbin, J.M. & Strauss, A.L. (1998). *Basics of qualitative methods - Techniques and procedures for developing grounded theory*, London: Sage
- Cooper et al (2007). Stages of anorexic and bulimic disorders: The importance of illness representations, *Elsevier, Eating behaviours* 8, 474 - 484
- Crisafulli, M.A., Holle, A.V. & Bulik, C. M. (2008). Attitudes towards Anorexia Nervosa: The impact of Framing on Blame and Stigma, *International Journal Of Eating Disorders*, 41: 333-339)
- Damasio, A. (1994). *Descartes' error*, New York, MacMillan General Books
- Diagnostic and Statistical Manual of Mental Disorders (2000). Fourth Edition
- Giordano, J. (2005). *Neuroethics*, Retrieved 6 July, 2009, from: <http://www.neurobioethics.org/>
- Goldenberg, E. (2009). *The New Executive Brain, Frontal Lobes in a Complex World*, Oxford: Oxford University Press
- Gripsrud, J. (2006) *Mediekultur, mediesamfunn*, Oslo, Universitetsforlaget. 2 ed.
- Hagger, M.S.& Orbell, S. (2003). A Meta-Analytic Review of the Common Sense Model of Illness Representations. *Psychology and Health*, Vol. 18, No.2, 141-184
- Holiday, J., Wall, E., Treasure, J., Weinman, J.(2005). Perception s of Illness in Individuals with Anorexia Nervosa: A comparison with Lay Men and Women, *International Journal of Eating Disorders*, 37: 50-56.
- Illes, J., Kirschen, P. & Gabrieli, J. D.E., (2003). From neuroimaging to neuroethics, *Nature Neuroscience* 6, 205
- Jacobi, C., Zwaan, deM., Hayward, C., Kraemer, H.C., Hayward, C.(2004) – Coming to terms with Risk factors for Eating Disorders: Application of Risk Terminology and Suggestions for a General Taxonomy, *Psychological Bulletin*, vol. 130, No.1, 19-65
- Lask, B., Bryant-Waught, R. (2003). *Eating Disorders in Childhood and Adolescence*,

Routledge

- Marcos Q.Y., Cantero, T.C., Escobar, R.C., Acosta, P.G.(2007) – Illness perception in Eating Disorders and Psychological Adaptation, *European Eating Disorders Review*, 15, 373-384
- MacArthur, L.,A. (1972). The how and what of why: Some determinants and consequences of causal attributions, *Journal of Personality and Social Psychology*, Vol. 22, No. 2, 171 – 193.
- Mehta, S., Farina, A.(1997). Effect of the disease view of mental disorder on stigma, *Journal of Social and Clinical Psychology*, Vol. 16 (4), Win 1997, 405-419.
- Nancy C. Andreasen (2001). *Brave New Brain: Conquering Mental Illness in the Age of Genome*, Oxford: Oxford University Press
- Neurophilosophy at scienceblogs.com. (2006) Ethics and the emerging neurotechnologies, Retrieved at 27.06.2009 from <http://www.neurophilosophy.wordpress.com>
- Novas, C., Rose, N. (2000). Genetic risk and the birth of the somatic individual, *Economy and Society*, Volume 29, Number 4, Nov. 485-513
- O'Hara SK, Smith KC (2007). Presentation of eating disorders in the news media: What are the implications for patient diagnosis and treatment? *Patient Education Counselling*, Sept. 68(1): 43-51. Epub 2007, May 22.
- Ortega, F., Vidal, F. (2007). Mapping the cerebral subject in contemporary culture *E Journal of Communication Information & Innovation in Health*, Rio de Janeiro, 255.259, Jul-Dec.
- Ritchie & Lewis (2003). *Qualitative Research Practice - A Guide for Social Science Students and Researchers*. London: Sage
- Roehrig, J. P., McLean, C., P. (2009). A comparison of Stigma Toward Eating Disorders Versus Depression, *International Journal of Eating Disorders*
- Rose, Steven (2005). *The 21st-Century Brain, Explaining, Mending and manipulating the mind*, London: Jonathan Cape.
- Sachdev, S. (2007). Neuropsychiatry and Neurophilosophy, *Acta Neuropsychiatrica*, 19, 136-138
- Singh, I. (2002). Bad boys, good mothers and the “Miracle” of Ritalin, *Science in context* (15), 577 - 603, Cambridge University Press
- Singh, I. (2007). Clinical implications of Ethical Concepts: Moral self-understanding in children taking Methylphenidate for ADHD, *Clinical child and psychology and Psychiatry*, Vol.12 (2), 167-182

- Singh (2006). Neuro-Forum: An introduction, *BioSocieties*, 1, 97-102
- Science daily (2009, June 26). People with Anorexia Nervosa less likely to be blamed when biology, genetics explained. Retrieved from: [http://www. Sciencedaily.com](http://www.Sciencedaily.com)
- Skårderud, F. (2003). *European Journal of Eating Disorders Rev.* 11, 155–169
- Steinhausen, H. C. (2002). The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry*, 159, 1284-1293
- Steward, M.C., Schaivo, S.R., Herzog, D. B., Franko. D.L. (2008). Stereotypes, Prejudice and Discrimination of Women with Anorexia Nervosa, *European Eating Disorders Review*, 16, 311-318.
- Stockford, K., Turner, H. & Cooper, M. (2007). Illness perception and its relationship to readiness to change in the eating disorders: A preliminary investigation, *British Journal of Clinical Psychology*, 46, 139-154
- Thagaard, T. (2003). Systematikk og innlevelse, Fagbokforlaget, Bergen
- Weisberg, D.S., Keil, F.C., Goodstein, J. Rawson, E. & Gray, J. (2008). The seductive allure of neuroscience explanations, *Journal of Cognitive Neuroscience*, 20 (3), 470-477.
- Whitney, J., Haigh, R., Weinman, J. & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative care giving appraisal in carers of people with eating disorders, *British Journal of Clinical Psychology*, volume 46 (4), November 2007, 413-428 (16)

APPENDIX

Intervju Guide (skrevet av Dr. Ilina Singh)

1. Jeg er interessert i hvorfor du har valgt å delta i det forskningsprosjektet. Kan du fortelle litt om det?
 - motivasjon
 - hva trodde deltaker forskning handlet om
 - meninger om fordeler og risiko med forskningen
 - fordeler og risiko vurderinger med hjerneforskning generelt.

2. Hvordan opplevdes det for deg å være i en skanner?
 - beskrivelse av skanner miljøet, og sammenligninger med forventninger følelser, tanker mens i skanneren – noen spesielle ekstreme emosjoner.
3. Som du (kanskje) vet, så er prosjektet du deltok i om spiseforstyrrelser og hjernen. Gir det mening for deg at forskerne vil avbilde hjernen din for å forstå mer om spiseforstyrrelser?
- 3a. Tror du at SF, (eller generelt mental sykdom) kan ha årsak i et problem i hjernen?
 - Hvor lenge har du tenkt slikt, og hvordan kom du til å tenke på det?
 - Hvordan har den ene opplevelsen av å ha et hjerneavbildning har påvirket denne meningen?
 - Flere årsak eller en årsak forståelse? Ex: Er hjernen den eneste som kan være årsaken til SF? Hvem har fortalt deg det? Hvilke andre ”ting” tror du kan være årsaken til SF? Har du forandret meningen i all den perioden du har vært syk, fra å tenke at det er X til å tenke at det er Y?
- 3b. Hva tror du forskerne letter etter i hjernen?

Hvordan problemet er visuelt og metaforisk konseptualisert? For eksempel:
Tror du at det er mulig å SE problemet en som har en SF har på et hjerneavbildning? Hva tror du man ser? Hva tror du er annerledes hos de som har en SF? Hvordan tror du den delen blir påvirket?
- 3c. Vet du noe om hvordan hjerneskaning fungerer?

4. La oss tenke at en dag tar vi et hjerneavbildning, ser hva som årsaker en SF, og da kan vi

gå og rette opp akkurat den delen av hjernen uten å forårsake smerte eller skade i det hele tatt. Ville du hatt denne behandling?

4a. Hvis du hadde hatt denne behandlingen, tror du at det hadde forandret deg som person, eller hadde den bare rettet bare et problem i hjernen?

(forholdet mellom hjerne og selvet. Er hjernen det samme som ”personen” eller er det en oppfatning om ”sinnet”?)

4b. Hvis du hadde hatt den behandlingen og blitt frisk fra SF, tror du at du ville savne noe om hvordan du var før behandlingen når du hadde sykdommen? For eksempel, noen personer med depresjon vil ikke bli behandlet med medisiner fordi de ville ha følt at det ville forandre hvem de er ved å forandre hjernen deres.

- forholdet sykdom og personlig identitet
- Hvis jeg sier en person er normal hva betyr det for deg?
- Hva blir da det motsatte av normal?
- Er det å være normal en god ting?
- Hvordan kjenner du igjen en slik person?
- Tror du det er mulig at noen har en unormal hjerne? Hvem? Hva tror du det skyldes?
- Kan en person med en unormal hjerne være en normal person?

5. Vi har snakket mye om hjernen. Er det andre ting som du tenker kan forårsake en SF? Hvilke? Kan du tegne en sirkel og fortelle meg hvor mye av disse tingene på lista påvirker deg?

6. Etter å ha deltatt i denne studien, hva slags behandling tror du er tilpasset for en person med SF?

- a. familierapi
- b. individuell terapi
- c. intervensjon som direkte påvirker hjernen, slik som medisiner eller operasjon.
- d. Forandre personenes miljø
- e. andre

7. Du sa at xyz behandlingen er det som passer for en person med sf. Tenkte du annerledes før du deltok i denne studien

8. Du sa at en SF kan ha årsak i xxx og kunne best behandles med xxx. Hvor mye kontroll, tror du, en person har over en SF?

-(få personen til å konstruere en narrativ for sykdommen, som knytter en årsaksteori til å begrunne en behandling). Her vil vi bruke ideen om kontroll for å se om narrativen er sammenhengende. Hvis ikke prøv å få deltaker til å forklare seg selv.

9. Hva eller hvem tror du er ansvarlig for at en person har en SF?

-Igjen prøv å forbinde sammen forrige teorier deltakeren har uttrykt, og derfra prøv å få deltaker til å snakke der hvor narrativen ikke er koherent.

10. Vi har snakket en del om ”kontroll” og ”ansvarlighet” for SF. Finnes det, tror du, psykiatriske sykdommer som en ikke har noe kontroll over? Eller hvor en ikke bør holdes ansvarlig?

11. Tror du en person bør ha rett til å ikke bli behandlet for SF?

12. Hvis du hadde vist at du kunne bli født med en risiko for å ha en sf, tror du at du kunne unngå at den risikoen ble virkelighet?

13. Ville du likt å vite om nivået av en slik risiko?

14. Hvis under en hjerneavbildning, forskerne hadde funnet en tilstand som kunne være en risiko for deg, men hadde ingenting med en spiseforstyrrelse, ville du ha likt å vite om det

