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Neurobiological narratives: experiences of mood disorder through the lens of neuroimaging

Daniel Buchman^{1,3}, Emily Borgelt¹, Louise Whiteley^{1,4}, and Judy Illes²

Judy Illes: jilles@mail.ubc.ca

¹National Core for Neuroethics, University of British Columbia, Vancouver BC, Canada

²Department of Medicine, Division of Neurology, University of British Columbia, Vancouver BC, Canada

³Interdisciplinary Studies Graduate Program, University of British Columbia, Vancouver, BC, Canada

⁴Medical Museion and Novo Nordisk Center for Basic Metabolic Research, University of Copenhagen. 18 Fredericiagade, 1310 København K, Denmark

Abstract

Many scientists, healthcare providers, policy makers, and patients highly anticipate the application of biomedical technologies such as functional neuroimaging to the prediction, diagnosis, and treatment of mental disorders. The potential efficacy of such applications is controversial, and functional neuroimaging is not yet routinely used in psychiatric clinics. However, commercial ventures and enthusiastic reporting indicate a pressing need to engage with the social and ethical issues raised by clinical translation. There has been little investigation of how individuals living with mental illness view functional neuroimaging, or of the potential psychological impacts of its clinical use. We conducted 12 semi-structured interviews with adults diagnosed with major depression or bipolar disorder, probing their experiences with mental healthcare and perspectives on the prospect of receiving neuroimaging for prediction, diagnosis, and treatment planning. Participants discussed the potential role of neuroimages in 1) mitigating stigma; 2) supporting morally-loaded explanations of mental illness due to an imbalance of brain chemistry; 3) legitimizing psychiatric symptoms through objective representations of disorder; and 4) reifying disorder categories and links to identity. We discuss these anticipated outcomes in the context of participant lived experience and attitudes to biologisation of mental illness, and argue for bringing these voices into upstream ethics discussion.

Keywords

neuroethics; psychiatry; neuroimaging; qualitative research; clinical translation

Introduction

Ideas, concepts, and images from the brain sciences circulate widely in the popular culture and day-to-day life of industrialized societies (Cross 2004, Frazzetto and Anker 2009), and

Address for correspondence: Judy Illes, PhD, Canada Research Chair in Neuroethics, Professor of Neurology, National Core for Neuroethics, University of British Columbia Hospital, 2211 Wesbrook Mall, Koerner Pavilion, Room S124, Vancouver, BC V6T 2B5, Canada jilles@mail.ubc.ca.

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many scholars have argued that this both reflects and contributes to a shift towards thinking of persons in terms of their brains; as ‘*cerebral subjects*’ (Ortega 2009, Vidal 2009) or ‘*neurochemical selves*’ (Rose 2003). The extent to which this phenomenon is driven by and focused on contemporary neuroscience rather than belonging to a broader historical movement that conceptualizes personhood in biological terms is a matter of debate (Vidal 2009). However, it seems clear that the increasing biologization of mental illness has shifted the psychiatric gaze towards the understanding of humans as neurological or neurochemical beings (Abi-Rached and Rose 2010, Dumit 2003, Ortega 2009, Rose 2003, Vidal 2009). This way of thinking is also reflected in public perceptions. In 2006, for example, 67% of Americans surveyed attributed mental disorder to neurobiology as compared to 54% in 1996 (Pescosolido et al. 2010). The development of a biologically-oriented psychiatry is thus situated in a broader discourse that concerns the relationship between personhood and the brain, shapes notions of causality, blame, and agency, and defines how mental illness is treated and perceived.

Neuroimaging technologies such as functional magnetic resonance imaging (fMRI), positron emission tomography (PET), and single photon emission tomography (SPECT) are used to investigate the functional anatomy and neurochemistry underlying psychological processes. Many mental health providers and neuroscientists hope that research with these technologies will lead to more accurate diagnosis and prediction of different psychiatric illnesses, and will allow them to better target and tailor treatment (Agarwal et al. 2010, Demirci et al. 2008). However, recent research suggests that attitudes among practicing neuroscientists (Pickersgill 2009, 2011) and mental health providers (Borgelt et al., 2011) are not straightforward, as many express ambivalence toward such therapeutic promise. Other scholarly work originating in the social sciences has questioned the ethics of outcome-oriented translational research (Maienschein et al 2008). Still, the steadfast goal of translational neuroscience as expressed by leaders in North American research funding organizations is to ‘*reconceptualize disorders of the mind as disorders of the brain and thereby transform the practice of psychiatry*’ (Insel and Wang 2010, p. 1970, Insel et al. 2010). Indeed, a brain disease model of mental illness is reflected in the Research Domain Criteria (RDoC) of the US-based National Institutes of Mental Health, which aim to ‘*[foster] research that translates findings from basic science into new treatments addressing fundamental mechanisms that cut across current diagnostic categories*’ (NIMH 2010).

The impact of biological reconfiguration of mental illness should not be considered merely in the context of diagnostic accuracy or treatment specificity. As Deacon and Baird (2009), Rose (2003), Boyce (2009) and others have emphasized, a neurochemical explanation affects how mental illness is understood by patients, practitioners, publics, and the institutions that determine access to care. Further, categorization is never a matter of carving nature at the joints, even at an apparently objective, biological level. Instead, psychiatric categorization proceeds via interactive ‘*looping effects*’ (Hacking 1999) that traverse practices and policies, popular and scientific descriptions, and local forms of knowledge to produce certain kinds of people and ways of relating to oneself and others. For many clinicians, scientists and advocates are motivated not just by a commitment to a neurobiological level of explanation, but also by the desire to reduce stigmatizing attitudes, and to legitimize mental disorder as a *bona fide* medical condition (Illes et al. 2009).

An emphasis on neurobiology can also divert attention from the complexities of living with mental illness. As Choudhury et al. (2009) commented, ‘*the reduction of psychiatry to neurobiology tends to neglect phenomenological insights, biographical accounts of the person and the meaning—that is, the social, cultural, moral or spiritual significances — of mental illness or interventions*’ (p.71). This affects not only treatment choices, but also practical advice about how people living with mental illness should approach their lives. For

instance, clinicians might explain the risks of consuming alcohol while on antidepressants in terms of the way in which synaptic reuptake of the medication is affected. Individuals seeking mental health care are thus increasingly expected to manage their mental health through the knowledge they acquire about their brains (Rose 1998). In this context, while functional neuroimaging is not yet routinely used in the psychiatric clinic (Linden and Fallgatter 2010), it is important to note that the commercialization of SPECT scans in a small number of private clinics (e.g., Amen 2012, Mind Matters Clinic of Texas 2012) is already associated with arguments about the efficacy of neuroimages in advocating for treatment adherence (Johnson 2008).

We believe that discussion about the ethics of potential clinical translation, particularly for technologies whose efficacy, conceptual grounding, and psychological impact remains controversial, must be informed by the attitudes and experiences of those who are implicated in the epistemological and ontological shifts these technologies imply. Here, we interviewed adults with diagnoses of major depression or bipolar disorder, probing their experiences with mental health care, and their perspectives on the potential use of functional neuroimaging for diagnosis, prediction, and treatment decision-making. These mood disorders are the target of much neuroimaging research and are at the forefront of developments in clinical translation (Agarwal et al. 2010). They represent a significant burden of disease (American Psychiatric Association 2000, Health Canada 2002), are a source stigma and discrimination, and are widely discussed in popular culture.

This work is situated within the developing field of empirical bioethics (Borry et al. 2005) which argues that empirical sociological research can both inform the content of ethics analysis, and act to shift the focus of ethical reflection toward the specific, lived moral experience within which costs and benefits take on their individual meaning (Kleinman 1999). Our approach thus invokes Draper and Ives' (2007) concept of social science *in* rather than *for* bioethics, while acknowledging that this semantic play does not eliminate the need for normative work in negotiating the *is/ought* distinction. The work of Widdershoven et al. (2008) in the psychiatric domain demonstrates the value of a qualitative approach as an important empirical complement to conceptual ethics analysis and to commercial claims about the impact of emerging neurotechnologies on assumptions about mental disorder.

In this interview-based qualitative research, we probed participants' views on the future application of neuroimaging technologies in psychiatry. Our questions were thus necessarily prospective, but discussion and analysis was grounded in participants' present experience of having a mental illness. In particular, we attended to the ways in which participants negotiate brain-based concepts of disorder, and how this negotiation contributes to self-shaping, social attitudes, and healthcare practices. This allowed us to contextualize expressed attitudes to hypothetical clinical scenarios with a rich understanding of the meanings these scenarios might have for participants whose experiences with diagnosis and treatment are far from hypothetical.

Methods

The interviews discussed here are part of a larger study investigating the perspectives of stakeholders on the potential use of brain mapping methods for prediction and diagnosis of mental disorder, and for targeting and monitoring of pharmaceutical treatment. The University of British Columbia (UBC) granted research ethics approval, and the Vancouver Coastal Health Research Institute granted institutional approval.

Recruitment

Participants were recruited from the community of a large metropolitan area in British Columbia, Canada. Notice of the opportunity to participate was distributed by mass email within the local health authority system, and poster advertisements were displayed in community mental health centres and on the website of the Mood Disorders Association of British Columbia. Respondents were screened by telephone or email to determine eligibility, and they had to be age 19 or older, self-report a primary diagnosis of either unipolar depression or bipolar disorder (I, II, or NOS), and be fluent in English. Recruitment and analysis ceased once theoretical saturation was reached in the categories described below (Lincoln and Guba 1985).

Sample Characteristics

The sample of 12 divided evenly between men and women, and the average age was 44.6. Five participants reported a primary diagnosis of depression, and seven of bipolar disorder. Seven participants held a university degree, two completed some college or university courses, and two completed high school. One participant was employed part-time, two full-time, two were students, and two were working as volunteers. Five were not employed at the time of the study.

Interview Design and Data Collection

The interview guide was developed from results of a survey study by Illes et al. (2009) in which a comparable population emphasized potential benefits of neuroimaging over potential burdens. After administering a brief demographic questionnaire, interviewers in the current study provided general information to establish baseline knowledge about neuroimaging technologies and their role in mental health research. All participants were informed that brain scans can give information about the structure and function of the brain, that researchers hope to be able to use them in future clinical applications, and that having a brain scan or a genetic test to diagnose mental health issues is currently not an option. We faced a similar challenge that Barr and Rose (2008) described in their prospective analysis of pharmacogenomics testing for depression in that we had '*to simultaneously introduce the topic to respondents whilst asking their views on it*' (p.947). We reflect on these concerns in the DISCUSSION below.

The face-to-face semi-structured interviews lasted 30–50 minutes. Participants were first asked to speak about their experiences with diagnosis and mental health care. The interview continued with questions intended to explore their attitudes, beliefs and perceptions about neuroimaging, its potential use in the clinical setting and other concerns as they arose.

Interviews were conducted separately by two of the authors (DZB & ELB) in a private room in the Institute of Mental Health at UBC between February and September 2009. Written informed consent was obtained at the time of the interview, and participants were compensated for their time with a gift certificate and reimbursed for transportation costs. The interviews were recorded digitally, de-identified, and transcribed verbatim. For one interview, technical difficulties prevented audio recording; the interviewer's notes were included in the analysis in lieu of a transcript.

Data Analysis

We conducted a qualitative analysis of the interview transcripts, drawing on discourse analytic approaches (Wetherell et al. 2007, Wood and Kroger 2000). For the purposes of this study, we define discourse as a way of thinking or speaking in a particular context, such as the psychiatric clinic, that encourages people to relate to themselves and one another in particular ways (Foucault 1972). Our analysis focused on conceptual themes rather than on

fine-grained linguistic or conversational details. We specifically examined the ways in which participants conceptualized mental illness and the brain, and invoked these concepts in their discussion of neuroimaging technologies. Further, we attended to how these concepts are contextualized in the individual's experiences, their decisions about treatment and plans for the future, and their personal, social, and clinical relationships. We thus hope to ground our interpretation of participants' expressed attitudes, and broader discussion about the ethics of translation, in the complex situations in which these technologies may or may not affect ways of thinking, communicating, or acting.

In order to describe key themes and concepts arising in participants' narratives, the same authors who carried out the interviews engaged in a constant comparison analytic process (Glaser and Strauss 1967, Lincoln and Guba 1985). Analysis was informed by our existing understandings of the ethical issues surrounding translation, neuroimaging in mental health from the literature and the Illes et al. (2009) survey data. After several independent reviews of the interview transcripts, ELB and DZB began with open coding to create a list of broad categories and concepts arising from the data. Selective coding was then used to identify and expand on pertinent dimensions, category properties, and connections amongst the codes. The resulting codes were applied, checked for consistency, alternative interpretations or disagreements debated, and the coding scheme modified, continuing until a final coding framework was developed. This framework helped us to establish four key themes that relate specifically to the study participants' perspectives on potential roles for neuroimaging in predicting, diagnosing, and treating mental illness. In a final iterative stage, two authors (DZB and LW) revisited the narratives and further interrogated them for narrative fragments to structure discussion of the central themes. HyperRESEARCH™ (<http://www.researchware.com/>) was used for data management and to provide a visual tool for organizing the emerging themes. All participant names are pseudonyms.

Findings

1) Mitigating the effects of public stigma and social distance

Concerns about stigma were often associated with participants' desire to use brain scans to destigmatize their experience in the eyes of other people. Many also expressed the belief that brain scans would provide a more medical, concrete argument for their disorder than a symptom-based DSM-IV diagnosis. SOPHIE told us that:

SOPHIE: *The problem I have with self-reported symptoms being interpreted first by me then interpreted by a psychiatrist and then matched up against some DSM criteria is just... witch doctor-y. Anything that makes it a medical test would make me feel more comfortable identifying [depression] as a medical issue, instead of, as many Canadians believe it to be, an excuse for bad behaviour.*

A judgment that someone is 'badly behaved' implies both that the person could have acted otherwise, is deserving of blame, and that the behaviour has a negative consequence for others. MAI explains:

MAI: *People will look at someone who is not well mentally, and they'll just be afraid of them. But if they could see what type of behaviour, with the picture of a brain, the general public wouldn't be as afraid and they could see, 'oh, yeah, poor thing.' Right? It would be like having a brain tumour.*

In invoking a reduction in blame that might arise from a biological explanation for behaviour – one that might arise from having a brain tumour, for example – MAI invokes a reduction in social distance and fear of others. MAI is speculating that a picture of the brain

would reduce social distance from those unfamiliar with and fearful about mental disorders. She implies not just that a picture of the brain would increase sympathy, but that it would reconfigure public ideas about the type of fearful behavior associated with mental disorders. As Angermeyer and Matschinger (2005) suggest, many of the behaviors associated with mental illness may not be undesirable or frightening per se, rather they become so because of the way they are interpreted. Marie and Miles (2008) have also found that the more familiar people are with a particular mental disorder such as schizophrenia, the less likely they are to express negative reactions towards, or desire greater distance from a person with that disorder (see also Angermeyer et al. 2004).

It has frequently been argued by healthcare professionals, patient advocates, and government institutions that if the public could be persuaded that mental illnesses are brain diseases and thus beyond the individual's control, then the stigma, blame, and moral failing attributed to individuals living with mental illnesses would decrease (Corrigan et al. 2002). Many of the participants reflected and expanded on this argument, but it is unclear whether public attitudes will follow suit. Indeed, a growing body of research suggests that varying degrees of public stigma and social distance are actually increased when mental illness is attributed to genetic or biological underpinnings (Bennett et al. 2008, Pescosolido et al. 2010, Phelan 2005, Schnittker 2008). SOPHIE and MAI'S narratives draw our attention to the fact that people who are the intended beneficiaries of stigma reduction campaigns are also members of the audience, and may internalize a stigma-reduction message while the society around them fails to do so.

2) Supporting morally loaded explanations of mental illness as due to an imbalance of brain chemistry

Link et al. (1999) found that many Americans perceive an imbalance in neurochemistry to be among the primary causes of mental illness. Indeed, healthcare providers often use the explanatory paradigm of a neurochemical imbalance to communicate with their clients, who often adopt this language as well (Fekete 2004, Fullagar 2009, Schreiber and Hartick 2002). As with attempts to use disease models to reduce stigma, the use of such '*intellectual techniques*' (Rose 1998) by practitioners may be motivated by a desire to reduce the extent to which clients blame themselves. However, the use of neurochemical explanations also reflects and implicitly endorses particular classification systems and theories of disorder, with important implications for treatment decision-making and adherence. In the context of depression, neurochemical imbalance explanations are intertwined with the '*pharmaceuticalisation*' of health problems (Williams et al. 2011), the controversial serotonin hypothesis of depression (Lacasse and Leo 2005), and with the associated development and marketing of Selective Serotonin Reuptake Inhibitor drugs (SSRIs). For example, the website for pharmaceutical giant Pfizer Inc's Effexor XR®, a drug that targets both serotonin and norepinephrine, states that, '*[i]t is believed that correcting an imbalance of these two chemicals may help relieve symptoms*' (Pfizer Inc 2010, emphasis ours).

The notion of imbalance is also tightly tied to the prescription of lithium as a mood stabilizer to achieve a balance between the cycling of mania and depressive episodes characteristic of bipolar disorder. While SSRIs and lithium are beneficial to many individuals, they also have serious side effects, and recent studies have challenged the efficacy of SSRIs in mild to moderate depression (Fournier et al. 2010, Turner et al. 2008, Kirsch et al. 2008). The emphasis on neurochemistry, with the corollary that the imbalance ought to be corrected with medication, is thus far from innocuous. The problem of pharmacological specificity in psychiatry was reflected in many participants' hopes that, in addition to suggesting a diagnosis, a brain scan would point to imbalances that implicitly require correction by a particular pharmaceutical. This desire was often reported in the context of negative

experiences with trying many different medications to find an acceptable combination of benefit and side effects; a process BRYAN described as *'trial and error'* and *'more art than science'*.

In discussing a recent clinical encounter, BRYAN reports:

BRYAN: *The doctor that I've been seeing was the first doctor to actually say, 'Listen, you're never going to feel normal...you have a brain imbalance...you're going to go up and down for the rest of your life unless you correct it with medication.'*

The certainty with which the neurochemical imbalance explanation is expressed by BRYAN's doctor may discourage individuals like him from exploring other psychosocial or environmental factors that contribute to their mood *'going up and down'*. Indeed, Deacon and Baird (2009) found that chemical imbalance explanations, unlike biopsychosocial explanations that do not exclusively privilege biological, psychological or social explanatory models, led to decreased personal and moral responsibility for depression, a worsened prognosis, and the belief that psychosocial interventions were ineffective. The reported speech elides brain imbalance, unstable mood, and contentious concepts of a normal state, which may imply to BRYAN that having an imbalanced brain somehow makes *him* out of balance and therefore abnormal. It is also important to note that BRYAN describes a *'brain imbalance'* rather than referring to neurochemistry, but there is still a direct association between imbalance and pharmaceutical treatment strategies: the brain is implicitly to be understood on the neurochemical level.

MIKE describes, in folk neuroscience terms, how his serotonergic neurotransmitters might relate to his sense of *'well-being'*:

MIKE: *The chemicals in your brain control your sense of well-being. And I guess my serotonin doesn't sit in the right part of the synapse that it's supposed to.*

Here, neurobiological images and psychological explanations are again intertwined (*cf.* Hatfield 2000, Pitts-Taylor 2010). In locating his disorder in his synapses, MIKE makes his depression an individual problem. This view is potentially isolating in that it seems to imply that the source of his problem is with him (Dumit 2003). Unlike BRYAN, MIKE does not report what his doctor said to him, but his use of *'I guess'* and simplified technical language suggests that the neurochemical story he tells is a received view whose premises are not fully understood, nor straightforwardly accepted. This highlights a potential point of resistance – if an overly simple neurochemical explanation is presented to clients, or if the depth of knowledge required to make the story work is not present, they might challenge its legitimacy. Indeed, the acceptance of a neurochemical explanation did not necessarily imply acceptance of a pharmaceutical approach. Returning to BRYAN:

BRYAN: *My brain chemistry is probably more fluctuating than most people but I don't know if I disagree — I don't know if I agree that I need to be medicated for the rest of my life.*

When talking with participants about the potential use of brain scans in the clinic, implicit acceptance of neurochemical imbalance explanations was also combined with skepticism about how this might be confirmed:

ANJALI: *You know – some people suffer from a chemical imbalance. But does that show up in your brain? I don't even know what kind of testing [a psychiatrist] would do to see if you have a chemical imbalance in your brain.*

BRYAN: *I've been on Zoloft for almost 20 years, and I don't know whether that might be, you know, changing the shape of my brain. I know that it has an impact on neurotransmitter behaviour, but is it doing something physical? I don't know.*

Such questions suggest that neurochemical imbalance explanations are not obviously congruent with what these participants perceive as a physical image of the brain. It is an interesting question whether future research will lead to shifts in understanding that allow brain scans to be more directly interpreted as illustrative of imbalance, potentially allying the authoritative framing device of chemical imbalance with the desired objectivity of a physical image (see also SECTION 3 below).

Our findings suggest that while participants may employ the language of neurochemical imbalance, integrate its reductive corollaries into the way they relate to themselves, and face institutional emphasis on corresponding pharmaceutical approaches to treatment, local points of resistance are available. As BRYAN demonstrates, this may involve accepting a neurochemical explanation while resisting pharmaceutical treatment. It may also involve the selective application of biological frameworks to only some areas of the individual's life, or a skeptical attitude to the testability of such explanations, as expressed above by ANJALI. Healy (2003) describes the way in which the rising popularity of Freudian ideas in the mid 20th century led to the use of terms such as '*complexes*,' '*defense mechanisms*,' and '*repression*' in ordinary language, but in ways that bore little resemblance to their original theoretical constructs. Likewise, our participants' use of neurochemical imbalance language was not scientifically accurate, and was often used to describe their mood or experience rather than to communicate scientific knowledge. These findings also reflect the complex and sometimes seemingly contradictory ways in which people integrate notions of a disordered brain into a concept of a self that at once *has* and *is* a brain (e.g., Martin 2007, Pickersgill et al. 2011).

3) Legitimizing experience through objective, authoritative representations of disorder

As aesthetically pleasing and immediately recognizable images, brain scans are an important conduit for the passage of functional neuroimaging research into the public imagination, and are often a locus of belief and hype (Beaulieu 2000, McCabe and Castel 2008, Racine et al. 2005, Roskies 2007). This hype is partly grounded in the assumption that neuroimages represent snapshots of brain activity, imbued with the presumed integrity and validity of photography as a mode of capturing reality. However, neuroimages are not photographs: they are highly mediated representations of indirect measurements of neuronal activity that undergo many stages of processing and interpretation (Roskies 2008). Neuroimages also share in the epistemic appeal of medical images that reveal the interior of the body, an apparently superior way of knowing oneself (Lefevre et al. 2003, Joyce 2005, Roskies 2007, 2008). As ANJALI stated: *'It's my brain. It would be fun to see something that I can't actually see.'*

In the context of their apparently objective, medical status, participants often saw brain scan images as a more morally neutral vehicle for communicating about mental illness. Recalling the narrative fragments from SOPHIE and MAI, PAUL speaks to the idea that a neuroimage might reconfigure the meaning of his experience:

PAUL: *I was really looking forward to [having] a brain scan...[the image is] kind of an acknowledgement of what I'm going through and what I'm experiencing is actually happening because of brain loss and function, and not because I'm just crazy.*

PAUL'S description of having a CT scan suggests that the image of his brain serves to mark the distinction between a real PAUL who is experiencing '*brain loss and function*' from a

'crazy' PAUL. This distinction may serve a therapeutic function (Cohn 2010, Fekete 2004, Martin 2007), as the neuroimage helps PAUL to find '*acknowledgement*' of his experience, grounded in a powerful representation that bears the marks of transparency, trustworthiness, and authority.

While PAUL describes the neuroimage as having an acknowledging or legitimizing effect, other participants ascribed explanatory power to the neuroimage, as in MAI'S discussion:

MAI: *[The brain scan] would help me know what areas of my brain are [working], and how they're doing.*

Participants like MAI do not necessarily see themselves in the neuroimage, rather the neuroimage is a window onto a biological level of explanation that may have previously felt more nebulous. The importance of the certainty attached to a physical image of mental disorder was also evident in the way that participants contrasted the presumed objectivity of the scan with conventional symptom-based classification tools such as the DSM:

ANJALI: *Well, so much of it is subjective, and that's why I'm actually interested in the brain scanning because I want to see how many of these things that are subjectively diagnosed have an objective, physical reality.*

Like ANJALI, many participants used words such as '*objective*' and '*concrete*' to convey what a neuroimage of mental disorder offered them, or expressed the implications of physicality through medical or mechanical metaphors:

BRYAN: *You can't argue with the x-ray that shows a broken bone...if you end up with brain scan data that gives you the equivalent picture of a broken brain...that's a good thing.*

As with neurochemical imbalance explanations, the brain scan not only represents objective evidence but can also be a powerfully persuasive tool in arguing for biological understandings and treatments for mental disorder. As well as expressing fascination with the prospect of having a brain scan, many participants speculated that this form of visualization would change how they make sense of and manage their diagnosis:

MIKE: *[If] I had a brain scan and I could be shown concretely that this is legitimate, then I would have believed it more and actually followed up on it.*

MIKE'S narrative echoes earlier suggestions that legitimization of biologically-based disorders might introduce new thresholds for seeking treatment for mental health problems, and support an emphasis on particular treatment approaches and on client responsibility for adherence.

4) Reifying disorder categories and their links to identity

This fourth major theme in our findings reflected concerns that brain scans of particular disorder types will reify contentious categories of disorder (Dumit 2003, Joyce 2005). The role of functional neuroimaging in the endeavor to move away from the symptom-based criteria of the DSM toward a biologically-based nosology is controversial (e.g., Demirci et al. 2008). However, many participants expressed a desire to know if their disorder could be seen in the brain. For example, BRYAN was enthusiastic about the possibility that brain scans might demonstrate what particular disorders look like:

BRYAN: *In my case, if studies can demonstrate [a] common physical construction of the brains of people who have bipolar disorder...that would have made a tremendous difference to my life [...] If you have some sort of situation where you show ten people an MRI picture*

and they [all] say, 'This is what schizophrenia looks like,' that to me feels like you've got a pretty solid diagnostic tool.

A possible corollary of such statements is that imaging can locate true bipolar or schizophrenic disorder in the brain, and obscures the fact that the diagnostic constructs that guide functional imaging studies are themselves culturally and historically specific. Here, as with controversial claims about the positive impact of neurobiological explanations on public stigma, participants' attitudes generally echoed the promotional messages surrounding biologically oriented psychiatric research rather than the more skeptical discourses that accompany it.

SOPHIE also reported a desire to use neuroimaging to find out what kind of brain she had and, specifically, if it was different:

SOPHIE: *I'm morbidly curious about getting a brain scan, just because I want to know, like, is my brain different? Is there something there?*

ANJALI invoked a notion of brain-difference through metaphorical language, describing what a healthy versus mood-disordered brain might look like:

ANJALI: *I like to think that we have little wires running through our brain, and, you know, there's a healthy person – someone who's mentally stable and balanced – and also...people that suffer from depression, bipolar, and they all have similar, little broken wires in their brain.*

Dumit (2003) argues that when people see scans of different kinds of brain – in the media, in scientific articles, or in physician's offices – they are invited to ask which of those categories they belong to, 'Or more starkly: am I normal?' (Dumit 2003, p.36). This use of the neuroimage to arbitrate categories of normality implies an objective self that Dumit defines in terms of 'our taken-for-granted notions, theories, and tendencies regarding human bodies, brains, and kinds considered as objective, referential, extrinsic and objects of science and medicine' (Dumit 2003, p.39). ANJALI could be seen as engaging in her own process of objective self-fashioning by describing metaphorically the kind of brain she and others with depression or bipolar disorder have, and linking a diagnostic category tightly to her identity by placing it in the register of the medicalized body. A key component of the location of mental illness in the biological realm is the use of physical metaphors such as ANJALI's 'broken wires', or BRYAN's earlier description of the disordered brain as 'broken bone'.

How the potential introduction of functional neuroimaging into the psychiatric clinic will affect the concept of mental illness, shape categories of normality, and affect the values associated with one diagnostic category or the other remains an open question. In our findings, it is not clear that fashioning an objective self through the metaphor of broken wires actually drives ANJALI's understanding of her experience. Likewise, SOPHIE, above, wants to know if the neuroimage will signify a difference, but does not imply that the lack of such a difference would call the very existence of her disorder into doubt. However, even if brain scans do not produce a dramatic shift in self-identity, their cultural and institutional uptake has direct implications for the kind of clinical and social treatment that people receive.

BRYAN invoked the 'tremendous difference' that knowing he had a bipolar brain would have made to his life, both legitimizing his disorder and allowing him to obtain treatment at an earlier stage. We recall also MIKE's suggestion that an early diagnosis would have affected the way he managed his illness. In the context of an increasingly dominant

biological psychiatry, how neuroimaging confirmation of disorder would affect the management of illness, and whether it would deliver the benefits he anticipates is unclear. What does seem clear is that discussion about the overarching ethic and scientific validity of a biologically-based diagnosis, and the use of neuroimaging in this context, must recognize the complex implications for individuals whose illness journeys have often been colored by the struggle to obtain a satisfying and instrumentally useful explanation of what has ailed them.

Discussion

Our findings are consistent with the three rhetorical moves of imaging technologies articulated by Joyce (2005): the neuroimage is akin to '*the real thing*', like the '*neuorealism*' described by Racine et al. (2005: 160); it represents '*a better, more objective, neutral technique*' (Joyce 2005, p.441) to access truth than individual's subjective reports; and it becomes '*a core participant in the production of knowledge*' (Joyce 2005, p. 443). Participants in this study describe the desire to use a neuroimage to objectify otherwise subjective experience, rendering their mental disorder biological, external, less blameworthy, and less frightening to others. Participant discussion thus reflected many elements of scientific and public discourse surrounding the anticipated benefits of an increasingly biologically-based psychiatry, raising important questions about the epistemology and ontology of mental disorders in relation to new biotechnologies, and about how expectations of clinical benefit should be handled in communication about what neuroimages might show. Evidence that an underlying neurobiological component is only one part of the complex dysfunction that characterizes mental disorder brings into question the degree to which it will ever be sufficient to focus on a single biological approach – or any other epistemological framework (Gillett 2009, Patil and Giordano 2010). In this context, it is of concern that concepts of mental disorder as brain disease can provide powerful justification for brain-based interventions that might not otherwise provide a favorable balance of risks and benefits. The high level of hope and expectation participants expressed about psychiatric neuroimaging suggests that they are persuaded by the idea of what neuroimaging might be able to do for them.

The upstream integration of participant's perspectives regarding the complexities of living with a psychiatric diagnosis into ethics discussion also enables us to advance new questions about the relationship between the epistemological hopes associated with neuroimages, the ontological assumptions about mental disorder associated with these hopes, and the ways in which they may or may not effect changes in self-concepts, behaviour, and social attitudes.

Our findings also point toward normative concerns. For example, our analysis suggests that without a broader shift in attitudes, a neuroimage may fail to disentangle mental illness from the moral judgments often attached to a diagnosis. Participant discussion also suggested that the entanglement of concepts of mental illness with associated moral judgments might be less easy to challenge when viewed through the lens of an objective, medicalized image of disorder; the apparent objectivity of a brain scan allows people to disclose their disorder/self in a vocabulary imbued with independence and authority. However, we also found points of resistance to metaphorical neurochemical stories, the ability of brain scans to promote treatment adherence, and to the possibility that neurochemical explanations could be revealed in a brain scan.

The neurochemical explanation for mental illness was a particularly striking theme, consistent with the increasing diffusion of neuroscientific claims in industrialized societies. Concepts such as '*chemical imbalance*' have come to be associated with health and well-being, and provide a morally-laden basis on which individuals reflect and assign meaning

and value to life. Our findings illustrate that the judgments and imperatives derived from explanatory models such as the neurochemical imbalance explanation may be both complex and hard to predict.

As a qualitative study that aims to inform future discussion about clinical translation with the voices of a targeted population, there are several limitations that merit commentary. The analysis presented in this paper is our interpretation of what participants reported about their perspectives on neuroscience and neurotechnologies, and we do not make claims about generalizability. We attempt only to offer a glimpse into the complexities of individual narratives surrounding mental disorder as negotiated by their understanding of neuroscientific technologies, explanations, and concepts. As with any anticipatory enquiry or upstream stakeholder engagement process, it is important not to assume that participants' prospective attitudes will map directly onto how they would feel should these scenarios come to pass. By analyzing prospective attitudes in the context of participant experiences of the diagnostic and therapeutic functions translation is intended to serve, our goal is to bring a concrete and rich understanding of what these attitudes might mean for the individuals involved and to orient ethics discussion in this direction.

It is also important to be mindful of how the researchers' values and interests might influence both participant responses and the interpretation of participant narratives. In the study descriptions and during the interviews we tried to avoid appearing to advocate for or against the applications we discussed. However, given the framing of the study and our host site, we may have encouraged attention to both the hopes and concerns surrounding these technologies. In addition, many of the participants in the study are currently involved with the mental health system, and often reported lengthy and sometimes difficult searches for a satisfactory diagnosis and treatment regimen. Our participants were perhaps more likely, therefore, to favour research that might extend the ability of health care providers to their needs, and to discount risks.

Technologies such as functional neuroimaging, and the cultural and scientific discourses surrounding their clinical translation, are advancing faster than understandings of how these technologies shape moral experience, and how society collectively sees, judges, governs and acts upon normality and abnormality. Anticipatory ethics using empirical sociological and anthropological techniques is one way to approach this problem. Researchers can explore what really matters for individuals and communities, and how values that are considered important in everyday encounters might be threatened, promoted, or even left unchanged by the integration of emerging clinical biotechnologies. In such work, it is important to remember that perspectives of research participants are but one node in a complex network of concepts and practices that delineate experience, and that scientific research and its moral valuation proceed interactively and iteratively. Indeed, we argue that it is incumbent on all parties implicated in the process of translation to reflect critically on the historical and cultural drivers of research, on the risks and benefits of different approaches in terms of the possible integration of emerging neurotechnologies should they become available for routine use in the psychiatric clinic, and on the effects of their sociocultural representation upstream of clinical translation.

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References

- Abi-Rached JM, Rose N. The birth of the neuromolecular gaze. *History of the Human Sciences*. 2010; 23(1):11–36. [PubMed: 20518151]
- Agarwal N, Port JD, Bazzocchi M, Renshaw PF. Update on the use of MR for assessment and diagnosis of psychiatric disease. *Radiology*. 2010; 255(1):23–41. [PubMed: 20308442]
- Amen Clinics. [last accessed 17 March 2012] Success Stories. 2012. available from <http://www.amenclinics.net/clinics/success-stories/>
- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (4th Edition, Text Revision ed.)*. Washington, DC: American Psychiatric Association; 2000.
- Angermeyer MC, Matschinger H, Corrigan PW. Familiarity with mental illness and social distance from people with schizophrenia and major depression: Testing a model using data from a representative population survey. *Schizophrenia Research*. 2004; 69(2–3):175–182. [PubMed: 15469191]
- Angermeyer MC, Matschinger H. Labeling – stereotype – discrimination: An investigation of the stigma process. *Social Psychiatry and Psychiatry Epidemiology*. 2005; 40:391–395.
- Barr M, Rose D. The great ambivalence: Factors likely to affect service user and public acceptability of the pharmacogenomics of antidepressant medication. *Sociology of Health & Illness*. 2008; 30:944–958. [PubMed: 18761513]
- Beaulieu, AE. The brain at the end of the rainbow: The promises of brain scans in the research field and in the media. In: Marchessault, J.; Sawchuk, K., editors. *Wild Science: Reading Feminism, Medicine and the Media*. London: Routledge; 2000.
- Bennett L, Thirlaway K, Murray AJ. The stigmatising implications of presenting schizophrenia as a genetic disease. *Journal of Genetic Counseling*. 2008; 17:550–559. [PubMed: 18773286]
- Borgelt EL, Buchman DZ, Illes J. This is why you've been suffering: Reflections providers on the use of neuroimaging in mental health care. *Journal of Bioethical Inquiry*. 2011; 8(1):15–25. [PubMed: 21572566]
- Borry P, Schotsmans P, Dierickx K. The birth of the empirical turn in bioethics. *Bioethics*. 2005; 19(1):49–71. [PubMed: 15812972]
- Boyce AC. Neuroimaging in psychiatry: Evaluating the ethical consequences for patient care. *Bioethics*. 2009; 23:349–359. [PubMed: 19527263]
- Choudhury S, Nagel SK, Slaby J. Critical neuroscience: Linking neuroscience and society through critical practice. *BioSocieties*. 2009; 4(1):61–77.
- Clements Clinic. [last accessed 17 March 2012] Mind Matters Clinic of Texas. 2012. available from: <http://http://www.mindmatterstexas.com/>
- Cohn, S. Picturing the brain inside, revealing the illness outside: A comparison of the different meanings attributed to brain scans by scientists and patients. In: Edwards, J.; Harvey, P.; Wade, P., editors. *Technologized images, technologized bodies*. New York: Berghahn Books; 2010. p. 65–84.
- Corrigan PW, Rowan D, Green A, Lundin R, River P, Uphoff-Wasowski K, White K, Kubiak MA. Challenging two mental illness stigmas: Personal responsibility and dangerousness. *Schizophrenia Bulletin*. 2002; 28(2):293–309. [PubMed: 12693435]
- Cross S. Visualizing madness: Mental illness and public representation. *Television & New Media*. 2004; 5(3):197–216.
- Deacon BJ, Baird GL. The chemical imbalance explanation of depression: Reducing blame at what cost? *Journal of Social and Clinical Psychology*. 2009; 28(4):415–435.
- Demirci O, Clark VP, Magnotta VA, Andreasen NC, Lauriello J, Kiehl KA, Pearlson GD, Calhoun VD. A review of challenges in the use of fMRI for disease classification/ characterization and a projection pursuit application from a multi-site fMRI schizophrenia study. *Brain Imaging and Behavior*. 2008; 2:207–226.

- Draper H, Ives J. An empirical approach to bioethics: Social science 'of', 'for' and 'in' bioethics research. *Cognition, Brain, & Behaviour*. 2007; XI(2):319–330.
- Dumit J. Is it me or my brain? Depression and neuroscientific facts. *Journal of Medical Humanities*. 2003; 24(1–2):35–46.
- Fekete DJ. How I quit being a 'Mental Patient' and became a whole person with a neuro-chemical imbalance: Conceptual and functional recovery from a psychotic episode. *Psychiatric Rehabilitation Journal*. 2004; 28(2):189–194. [PubMed: 15605757]
- Foucault, M. *The Archaeology of Knowledge*. London: Tavistock; 1972.
- Fournier JC, Derubeis RJ, Hollon SD, Dimidjian S, Amsterdam JD, Shelton RC, Fawcett J. Antidepressant drug effects and depression severity. *Journal of the American Medical Association*. 2010; 303(1):47–53. [PubMed: 20051569]
- Frazzetto G, Anker S. Neuroculture. *Nature Reviews Neuroscience*. 2009; 10:815–821.
- Fullagar S. Negotiating the neurochemical self: Anti-depressant consumption in women's recovery from depression. *Health*. 2009; 13(4):389–406. [PubMed: 19491233]
- Gillett, G. *The mind and its discontents*. 2nd ed. New York: Oxford University Press; 2009.
- Glaser, BG.; Strauss, AZ. *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine-Atherton; 1967.
- Hacking, I. *The Social Construction of What?*. Cambridge: Harvard University Press; 1999.
- Hatfield G. The brain's 'new' science: Psychology, neurophysiology, and constraint. *Philosophy of Science*. 2000; 67:S388–S403.
- Health Canada. *Health Canada*. Ottawa: Health Canada Editorial Board; 2002. *A Report on Mental Illnesses in Canada*.
- Healy, D. *Let them Eat Prozac*. Toronto, ON: Lorimer; 2003.
- Illes J, Lomber S, Rosenberg J, Arnow B. In the mind's eye: Provider and patient attitudes on functional brain imaging. *Journal of Psychiatric Research*. 2009; 43(2):107–114. [PubMed: 18423669]
- Insel TR, Wang PS. Rethinking mental illness. *Journal of the American Medical Association*. 2010; 303(19):1970–1971. [PubMed: 20483974]
- Insel T, Cuthbert B, Garvey M, Heinssen R, Pine DS, Quinn K, et al. Research domain criteria (RDoc): Toward a new classification framework for research on mental disorders. *American Journal of Psychiatry*. 2010; 167(7):748–751. [PubMed: 20595427]
- Johnson D. 'How do you know unless you look?': Brain imaging, biopower and practical neuroscience. *Journal of Medical Humanities*. 2008; 29(3):147–161. [PubMed: 18604582]
- Joyce K. Appealing images: Magnetic resonance imaging and the production of authoritative knowledge. *Social Studies of Science*. 2005; 35:437–462.
- Joyce, K. The body as image: An examination of the economic and political dynamics of magnetic resonance imaging and the construction of difference. In: Clarke, A.; Fosket, J.; Mamo, L.; Fishman, J.; Shim, J., editors. *Biomedicalization: Technoscience, Health and Illness in the United States*. Durham: Duke University Press; 2010. p. 197–217.
- Kirsch I, Deacon BJ, Huedo-Medina TB, Scoboria A, Moore TJ, Johnson BT. Initial severity and antidepressant benefits: A meta-analysis of data submitted to the food and drug administration. *PLoS Medicine*. 2008; 5(2):e45. [PubMed: 18303940]
- Kleinman A. Moral experience and ethical reflection: Can ethnography reconcile them? A quandary for 'the new bioethics.'. *Daedalus*. 1999; 128(4):69–97. [PubMed: 11645882]
- Lacasse JR, Leo J. Serotonin and depression: A disconnect between the advertisements and the scientific literature. *PLoS Medicine*. 2005; 2(12):1211–1216.
- Lefevre, W.; Renn, J.; Schoepflin, U. Introduction. In: Lefevre, W.; Renn, J.; Schoepflin, U., editors. *The power of images in early modern science*. Berlin, Germany: Birkhauser Verlag; 2003. p. VII–IX.
- Lincoln, Y.; Guba, EG. *Naturalistic inquiry*. Newbury Park: Sage Publications; 1985.
- Linden DE, Fallgatter A. Neuroimaging in psychiatry: From bench to bedside. *Frontiers in Human Neuroscience*. 2009; 3(49)

- Link BG, Phelan JC, Bresnahan M, Stueve A, Pescosolido BA. Public conceptions of mental illness: Labels, causes, dangerousness, and social distance. *American Journal of Public Health*. 1999; 89(9):1328–1333. [PubMed: 10474548]
- Maienschein J, Sunderland M, Ankeny R, Robert JS. The Ethos and ethics of translational research. *American Journal of Bioethics*. 2008; 8(3):43–51. [PubMed: 18570103]
- Marie D, Miles B. Social distance and perceived dangerousness across four diagnostic categories of mental disorder. *Australian and New Zealand Journal of Psychiatry*. 2008; 42:126–133. [PubMed: 18197507]
- Martin, E. *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton: Princeton University Press; 2007.
- McCabe DP, Castel AD. Seeing is believing: The effect of brain images on judgments of scientific reasoning. *Cognition*. 2008; 107(1):343–352. [PubMed: 17803985]
- NIMH. NIMH Research Domain Criteria (RDoC). 2010. Retrieved January 30, 2011, from <http://www.nimh.nih.gov/research-funding/nimh-research-domain-criteria-rdoc.shtml>
- Ortega F. The cerebral subject and the challenge of neurodiversity. *BioSocieties*. 2009; 4:425–445.
- Patil T, Giordano J. On the ontological assumptions of the medical model of psychiatry: Philosophical considerations and pragmatic tasks. *Philosophy, Ethics, and Humanities in Medicine*. 2010; 5(3)
- Pescosolido B, Martin JK, Long JS, Medina TR, Phelan JC, Link BJ. ‘A disease like any other’? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *American Journal of Psychiatry*. 2010; 167(11):1321–1330. [PubMed: 20843872]
- Pfizer Inc. About EFFEXOR XR: Depression and anxiety disorders. 2010 May. Retrieved October 13, 2010 from Depression and anxiety disorders: <http://www.effexorxr.com/effexor-xr-treatment.aspx>
- Phelan J. Geneticization of deviant behavior and consequences for stigma: The case of mental illness. *Journal of Health and Social Behavior*. 2005; 46(4):307–322. [PubMed: 16433278]
- Pickersgill M. Between soma and society: Neuroscience and the ontology of psychopathology. *BioSocieties*. 2009; 4(1):45–60.
- Pickersgill M. ‘Promising’ therapies: Neuroscience, clinical practice, and the treatment of psychopathy. *Sociology of Health & Illness*. 2011; 33(3):448–464. [PubMed: 21281313]
- Pickersgill M, Cunningham-Burley S, Martin Paul. Constituting neurologic subjects: Neuroscience, subjectivity and the mundane significance of the brain. *Subjectivity*. 2011; 4:346–365.
- Pitts-Taylor V. The plastic brain: Neoliberalism and the neuronal self. *Health*. 2010; 14(6):635–652. [PubMed: 20974696]
- Racine E, Bar-Ilan O, Illes J. fMRI in the public eye. *Nature Reviews Neuroscience*. 2005; 6(2):159–164.
- Rose N. *Neurochemical selves*. *Society* (November/December). 2003:46–59.
- Rose, N. *Inventing Our Selves: Psychology, Power, and Personhood*. Cambridge: Cambridge University Press; 1998.
- Roskies AL. Are neuroimages like photographs of the brain? *Philosophy of Science*. 2007; 74:860–872.
- Roskies AL. Neuroimaging and inferential distance. *Neuroethics*. 2008; 1(1):19–30.
- Schnittker J. An uncertain revolution: Why the rise of a genetic model of mental illness has not increased tolerance. *Social Science & Medicine*. 2008; 67(9):1370–1381. [PubMed: 18703264]
- Schreiber R, Hartick G. Keeping it together: How women use the biomedical explanatory model to manage the stigma of depression. *Issues in Mental Health Nursing*. 2002; 23(2):91–105. [PubMed: 11901663]
- Turner EH, Matthews AM, Linardotos, Tell RA, Rosenthal R. Selective publication of antidepressant trials and its influence on apparent efficacy. *New England Journal of Medicine*. 2008; 358(3):252–260. [PubMed: 18199864]
- Vidal F. Brainhood, anthropological figure of modernity. *History of the Human Sciences*. 2009; 22(1): 5–36. [PubMed: 19860032]
- Wetherell, M.; Taylor, S.; Yates, SJ. *Discourse Theory and Practice: A Reader*. London: SAGE Publications; 2007.

- Wood, LA.; Kroger, RO. *Doing Discourse Analysis: Methods for Studying Action in Talk and Text*. Thousand Oaks: SAGE Publications; 2000.
- Widdershoven, G.; McMillan, J.; Hope, T.; van der Scheer, L., editors. *Empirical Ethics in Psychiatry*. Oxford: Oxford University Press; 2008.
- William SJ, Martin P, Gabe J. The pharmaceuticalisation of society? A framework for analysis. *Sociology of Health and Illness*. 2011; 33(5):710–725. [PubMed: 21371048]