
Original Article

Parent perspectives on brain scans and genetic tests for OCD: Talking of difficult presents, desired pasts, and imagined futures

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Abstract This paper investigates parent perspectives on potential future applications of neuroimaging and genetic research in the OCD clinical setting. Grounded in qualitative interviews with parents whose children had participated in an OCD neuroimaging and genetic research study in the United States, we situate parent discussions of imagined futures in their projections from difficult presents and into desired pasts. Parents reported apparently high receptivity to potential future neuroimaging and genetic tests. Yet when they responded, ‘yes, anything that helps’, uncertainty, caution, and resistance were expressed in implicit negotiations over what it means to ‘help’. We situate the discussion of future technologies in the wider context of how a biological approach figures in parents’ understandings of OCD. A biological perspective was prioritised when it facilitated a journey towards understanding-as-acting; the intense gathering of knowledge judged likely to lead to better outcomes. When biological knowledge did not seem likely to lead to or itself constitute action, parents were often reluctant to even discuss it. The perspectives of those who may encounter future technologies are relevant to shaping their development, but gathering and interpreting such perspectives presents methodological, conceptual, and normative difficulties. These difficulties with time-travelling talk are discussed throughout the paper.

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Introduction and Approach

This paper investigates parent perspectives on potential future applications of neuroimaging and genetic research for the diagnosis, prediction,¹ and treatment of obsessive–compulsive disorder (OCD), grounded in qualitative interviews with parents whose children had participated in an OCD neuroimaging and genetic research study in the United States. Parent perspectives on technological futures are discussed in the wider context of how a biological approach figures in parents' understandings of OCD, their child's experience, and their own capacities to help. The interviews reported here were part of a large research project that interviewed neuroscience researchers, psychiatric practitioners, persons with mental illness diagnoses, and parents of children with such diagnoses, aiming to bring these perspectives to bear on discussions about neuroscientific and genetic technologies in research and commercial settings and in future clinical scenarios (see also Buchman *et al*, 2013; Borgelt *et al*, 2010, 2012; Anderson and Illes, 2012; Anderson *et al*, 2013).

What is OCD?

In popular imagination, OCD is often viewed as comprising an obsessive fear of dirt alongside compulsive cleaning rituals, such as repeated hand-washing, that are used to manage the accompanying anxiety. On the other hand, the term OCD is often used colloquially to refer to a potentially desirable tendency towards perfectionism. The American Psychiatric Association (American Psychiatric Association, 2015) defines OCD as “an anxiety disorder in which people have recurring, unwanted thoughts, ideas or sensations (obsessions) that make them feel driven to do something repetitively (compulsions). The repetitive behaviours, such as hand-washing, checking on things, or cleaning, can significantly interfere with a person's daily activities and social interaction”. Obsessions are highly diverse and can include intrusive violent, sexual, religious, illness, and symmetry-related obsessions. OCD often emerges during childhood or young adulthood, and whilst some experience full remission, for many others it becomes a chronic condition (Stewart *et al*, 2004). Epidemiologically, OCD affects an estimated 1–3% of children and adults across the lifespan (Karno *et al*, 1988; Ruscio *et al*, 2010).

Increasing clinical visibility of OCD has been paralleled by an expansion of media depictions of those dealing with the disorder (e.g. *Phoebe in Wonderland*, 2008; *As Good As it Gets*, 1997; *Monk*, 2002–2009), often in their own voices via documentary (e.g. *Bedlam*, 2013) or reality TV shows (e.g. *Extreme OCD Camp*, 2013; *The OCD Project*, 2010), and by an array of support groups and foundations (e.g. www.ocfoundation.org; www.ocduk.org; and www.anxietybc.com). However, a dearth of OCD specialists and lack of recognition has resulted in prolonged delays to diagnosis and treatment for many families (Fireman *et al*, 2001).

OCD, as with most psychiatric diagnoses, derives from a complex and iterative entanglement of (epi)genetic, environmental, sociocultural, and experiential factors. It can

1 Much of what we refer to by ‘prediction’ would fall under the clinical notion of ‘prognosis’ – the prediction of probable course and outcome of a disease. However, we used ‘prediction’ as a term more familiar to participants, and to include prediction of the occurrence of the condition as well as its likely course.



be found in both mind and brain, genes and environment. As such, children and their parents have diverse ways of thinking about the causes, triggers, or origins of symptoms. A subset of children with OCD presents with symptoms consistent with PANS/PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections), which refers to a rapid onset of OCD triggered by an autoimmune process (Brimberg *et al*, 2012; Moretti *et al*, 2008).

There is active research into neural correlates (Brem *et al*, 2012; Anticevic *et al*, 2014; Britton *et al*, 2010) and genetic components (Stewart *et al*, 2013; Mataix-Cols *et al*, 2013; Pauls, 2010; Walitza *et al*, 2010), but this has not yet resulted in the kind of biomarkers² that would support reliable tests for diagnosis, prediction, or treatment choice (Linden and Fallgatter, 2009; NIMH, 2010; Gillihan, 2016). However, future research may lead to clinically useful tests (see Anderson *et al*, 2013; March, 2011), and people do already encounter these technologies in research studies and via commercial providers (e.g. Amen Clinics, 2016). Researchers, clinicians, and parents involved in the present study were all invested in neuroscientific and genetic research, but also recognised OCD as causally affected by the environment and as requiring the engagement of the sufferer for successful treatment outcomes. Indeed, the standard OCD treatment recommendation in the United States is to combine medication with cognitive-behavioral therapy (CBT) such as exposure-and-response-prevention, with medication often considered as a tool to remove barriers to CBT (American Psychiatric Association, 2007; OCD Foundation, 2014).

Prioritisation and the Normative Role of Sociological Analysis

Recognising that OCD can be understood neither from a purely neurobiological perspective nor from a purely psychosocial perspective leaves crucial questions about *priority* unanswered. Which definitions and forms of knowledge are prioritised in terms of research funding and technological development, within the constrained frameworks of diagnosis and treatment provision, and within the attentional limitations and normative structures of both the individual mind and the cultural sphere? What makes prioritisation so important – setting aside structural questions of professional jostling and economic investment – is of course that the allocation of these diverse forms of resource³ has the potential to change, and hopefully improve people's lives. What makes prioritisation even more difficult is adjudicating between differences of opinion about what improvement means – the definition of the problem also colours the solution towards which resources are directed.

In line with previous sociological studies of the impact of biological perspectives on the lived experience of mental illness and psychiatric care, our participants described trying many different treatment approaches and flexibly combining neurobiological understandings with other ways of thinking about OCD (e.g. Adame and Knudson, 2007; Buchman *et al*,

2 There are multiple definitions of 'biomarker', ranging from general indicators of disease to specific information about the state, site, or potential treatment of disorder. In this study, when we use the term 'biomarker', it is shorthand for neurobiological tests that could inform diagnosis, prognosis, or treatment choice for OCD.

3 We use 'resources' here to refer loosely to all kinds of objects or capacities that might be limited, from money or research time to attentional capacity or the choice of preferred explanatory frameworks – the economic resonance of the metaphor is intended to be usefully provocative.

2013; Singh 2005, 2012, 2013; Pickersgill, 2011). They were doing “anything to help” (Borgelt *et al*, 2012). However, there was a limit on their capacity to do so. Parents still had to decide which approaches to spend time researching, communicating, and investing in; which perspectives to introduce into their interactions with their child; and when they could tolerate apparent dissonance between neurobiological and other approaches. In making these decisions – and future speculations – about what would *help most*, they also wrestled with what it is to help, and what they could realistically hope for.

This study follows a growing sociological literature grounding speculative assertions about the effects of a neurobiological lens in the details of lived experience. As Singh (2013) argues, we need “agent-centered conceptual and theoretical frameworks” for understanding the impact of biological approaches to mental illness. In this study, we were particularly interested in connections between a biological perspective and parents’ feelings of guilt and blame (Callard *et al*, 2012; Singh 2005, 2011); in the conditions under which the brain and gene were seen as fixed vs. malleable in relation to disorder⁴ (Malabou, 2008; Pitts-Taylor, 2010); and in the connections between neurobiological approaches and obtaining treatment resources (Borgelt *et al*, 2012). Throughout, we attend to ways in which the cultural meanings and institutional structures surrounding the specific diagnosis of OCD infect these general questions (see also Callard *et al*, 2012; Singh 2005, 2012; Coveney, 2011; Barr and Rose, 2008).

The relationship between descriptive empirical work and normative analysis is a matter of lively debate (see, e.g. Illes and Sahakian, 2011; Borry *et al*, 2005; Draper and Ives, 2007; Hurst, 2010; Singh and Rose, 2009; Nordmann, 2007; Nordmann and Rip, 2009; Grunwald, 2010), with some scholars arguing against the very notion of a delineable is/ought divide (Chan and Coggon, 2013). As Chan and Coggon (2013) write, “engagement in normative analysis does not and should not rule out drawing on descriptive analysis; meanwhile, empirical does not imply value-free or even value-neutral” (p. 3). The present study does not claim to offer direct ethical guidance, but hopes to inform ethical, practical, and policy discussions about prioritisation. But ‘informing discussion’ is not a neutral act; our qualitative, descriptive work is of course itself normatively inflected. Most obviously, by virtue of conducting this study we implicitly advocate for involving those who are, or may be, affected by technological scenarios in discussion about their future development. Methodologically, an interview is always part of the social context that shapes what it elicits. This limits the use of our data for direct prediction and regulation, but participant responses can nonetheless be used to elucidate the “resources, norms, and values that are drawn on to evaluate the acceptability of new and emerging technologies” (Coveney, 2011, p. 212).

This work also starts from the position that effectively understanding, researching, and treating mental illness requires the combination of different perspectives, including the neurobiological. However, we do not expect an easy or harmonious rapprochement: these different perspectives are not obviously commensurable, and as such must still negotiate for

4 This coheres with a broader trend in which increasing evidence for neural plasticity has been used to argue that neurobiological explanations can be integrated into our understandings of mental life and wellbeing whilst avoiding the spectres of determinism/essentialism. However, authors such as Rose (2010) and Pitts-Taylor (2010) have argued that ideas of neural plasticity in cultural and therapeutic contexts are also associated with an individualising of responsibility for recovery, and with a focus on the possibilities of prevention via ethically contentious programmes of monitoring and early intervention.



the allocation of resources. For instance, prioritisation of neurobiological approaches can play into a neglect of (expensive) psychological therapies, and can foster a neglect of systemic, economic, and social causes for mental distress (Rose, 2010). And on the personal scale, the cultural dominance of narratives about, e.g. chemical imbalances and their embedding in clinical pathways, can make these approaches and their implications hard to resist (Rose, 2010). We do not attempt to adjudicate here on disagreements about the precise role that neuroscience and genetics should play in the complex field of mental illness (compare, e.g. Rose and Abi-Rached, 2013 to Choudhury *et al*, 2009 and Choudhury and Slaby, 2012). Rather, by focusing on the details of our participants' experiences and perspectives, we attempt to elucidate some of the substantive dilemmas within this rocky middle ground.

Time-Travelling Talk

The prioritisation of biological approaches to mental illness and its treatment can be discussed in relation to the past, present, or future. But no temporal domain can be considered in isolation – the past influences our evaluation of the present and attitude to the future; the developing present affects our remembrance of the past. Particularly relevant to this study, Adam (2004) discusses how the futures we imagined in the past shape our evaluation of futures we project from today. We asked participants to discuss possible technological applications that may develop too late to help their child, but which depict futures they may well have hoped for in the past.

These affectively guided projections must be taken into account when interpreting talk about the future, alongside the conceptual and normative difficulties with setting up the context for such talk. It is impossible to depict the future neutrally, and influential cultural tropes for future technological scenarios tend to oscillate between risk and benefit; and dystopia and utopia (Marris and Rose, 2012). The further into the future one looks, the more speculative the scenarios one describes, and the less likely it is that one can directly influence the outcome (Selin, 2008). In setting up the interviews, we attempted to describe the current state of neurobiological tests in a clear but technically accurate manner, to communicate the uncertainties surrounding their development, and to be honest about the intended outcomes of the study. Yet the very depiction of potential brain scan and genetic tests in a clinical context may have been taken to imply that such tests would be effective – or alternatively, that there was some risk we were attempting to mitigate. Describing future realities always participates in their creation, just as sociological studies of neurobiological approaches to mental illness to some extent participate in their cultural prioritisation (Pickersgill *et al*, 2011; Coveney, 2011). We take this into account in the analysis and discussion.

Methods

Recruitment and Ethics Approval

We recruited parents whose children had previously participated in a research study using brain scans and genetic tests. Full ethics approval was obtained from the hospital research

centre that had run the original study and at University of British Columbia. A total of 30 families were re-contacted, and from these 14 interviews were conducted with one parent per family. Usual informed consent procedures were followed. All participants received reimbursement for travel expenses and a \$50 gift certificate.

Questionnaire and Semi-Structured Interviews

At the start, a short text was read giving information about the topic of the interview and the purpose of the study. Parents were told that the study seeks to:

...find out about their experiences and about their opinions on using brain scanning and genetic tests. Our aim is to ensure that if brain scans and genetic tests do become routinely available in clinics, they are used and communicated in a way that is as helpful as possible for children and their families.

This short description aimed to place value on participant perspectives, resist reifying the future scenarios depicted, and avoid promising specific policy or practice outcomes. A questionnaire was then completed in the presence of the interviewer (LW), including information about demographics and family history; the child's current diagnosis, treatment, and reported severity and impact of OCD; whether families had participated in any other research studies; and if they would consider taking part in neuroimaging, genetics, treatment, therapy, or interview studies in the future. This was followed by a semi-structured interview, covering (1) parent reports of their child's diagnosis and treatment, and whether they/their child thinks about OCD in terms of brain and genetic links; (2) parent reports of their/their child's experiences of taking part in research; and (3) parent perspectives on potential use of brain scans and genetic tests for diagnosis, prediction, and treatment choice. All interviews were audio recorded, stored in a locked cabinet, and transcripts fully anonymised. The questionnaire plus interview lasted approximately 45 min.

Analysis

The analysis took a qualitative and inductive approach drawing on principles of grounded theory, including initial line-by-line coding (Glaser, 1978), openness to emerging themes, constant comparison, and memo writing (Charmaz, 2006). However, it did not follow a full grounded theory approach: we had specific questions, and were unable to pursue further recruitment. The interviews were transcribed then coded by LW and EB, first separately and then together to reach a consensus version including open analytic questions. A thematic coding guide was developed using a process of constant comparison, and LW then refined the coding to saturation using Dedoose software (www.dedoose.com). All participants and those to whom they refer to are given pseudonyms, and some identifying details have been altered to protect anonymity.

The coding guide was organised into three clusters. The first contained sections corresponding roughly to the interview guide; past and everyday experience; experiences of the neuroimaging and genetics research study; and perspectives on the future use of



biomarkers. Individual codes were ontologically diverse and could refer to, e.g. a reported experience, an attitude or belief, or emotional tone. The second cluster identified language features, including metaphors for the brain/gene/OCD and spatial metaphors for participants' journeys, and the third identified ways participants understood OCD and its relation to the brain/genes. In a final stage leading to the writing of this manuscript, we focused on excerpts expressing the most-coded themes in relation to participants' perspectives on technological applications, alongside excerpts relating to past experience and understandings of OCD that help elucidate these perspectives. An additional theme developed in the final stage was temporality, the hypothetical and often counterfactual logics at play in time-travelling talk.

Participants

This study is about the parent perspective. Caution is required in interpreting parents' talk about, and depictions of, their children. But parents are nonetheless a key group in considering the development of clinical technologies; they are often gatekeepers to a child's diagnosis and treatment. They are also an important part of the wider picture of the impact of biological approaches to mental illness; they are deeply affected by the child's diagnosis, which our participants often reported as also affecting their view of their own or family difficulties. Ideally, we would have liked to speak to the children of our participants, to bring forward their perspectives within this study, within the literature to which this study belongs, and within the wider discussions it seeks to inform. However, time constraints and consent procedures prevented us from doing so. We therefore tread with care and acknowledge the power dynamics at play, and we propose this as an important question for future sociological work in the OCD context, following the detailed insights advanced by Iliina Singh (2011, 2012, 2013) with regard to children's own perspectives on ADD/ADHD (see also Ortega, 2009 and Hart, 2014).

The parents we spoke to were a doubly self-selecting group; they had already chosen to take part in the original neuroimaging and genetics research study, and then to take part in this interview study. They were recruited in a wealthy geographical region and in connection with a highly respected research institution. By self-report, they were primarily female, married, highly educated, and white/Caucasian. Several were regular research participants and/or members of a parent support group, and five had professional experience as either a doctor, researcher, or clinical social worker. The majority reported family history of OCD or other mental illness diagnoses, often including relatives who they considered to be undiagnosed. These parents were thus relatively well resourced and well informed. Nevertheless, we propose that features of their experience can be usefully extrapolated to discussions about parent experience in general, as can some of our observations about the impact of these experiences on attitudes to potential future technologies and the structuring of future-oriented talk. Our participants were also able to speak to the questions at stake more readily and explicitly by virtue of having considered them before, and indeed were recruited in part *because* they had experienced brain scanning and genetic tests.

All the children were under 18 at the time of the original research study, but at the time of the interviews reported here, six were 18 or over. Almost all parents spoke about the distress

of waiting for diagnosis, and ongoing difficulties with disentangling OCD from concurrent mental health, neuropsychiatric, or medical problems. Four reported that the child's OCD symptoms had been triggered by infection (PANDAS), though 3 of the 4 considered that the OCD would have existed anyway. Parents spoke with emotion about the process of finding treatment – both in the face of limited specialist resources, and as a process of trial-and-error resulting in increasing numbers of prescribed medications and side effects that can become 'out of control'. Eleven parents reported that their child was currently on medication, and of those 7 reported that it somewhat or significantly helped. Six parents reported that their child was currently undergoing individual therapy or cognitive Behavioural Therapy (CBT), and of those 4 reported that it somewhat or significantly helped. Following standard treatment recommendations, many parents saw medication as facilitating CBT, but would have preferred to avoid the difficulties with finding the right medications and disentangling side effects. CBT was reportedly difficult to access, and therapies such as CBT that require the child to practise strategies outside of therapy sessions also place the parent in a complex semi-therapeutic role. Several parents described their child's resistance to them requesting the kind of access to their child's thoughts and internal battles that a therapist might be permitted.

Findings

The findings below are split into three sections. Section 1 presents the core concept of a 'journey towards understanding-as-acting' that emerged to describe participant experience and attitudes to technologies: parents reported pursuing knowledge vigorously, but only when it either led to or itself constituted action. Section 2 reports parent perspectives on (a) neural explanations and (b) genetic explanations, and Section 3 reports parent perspectives on potential future brain scan and genetic tests, first elucidating the conditional logics that lie behind apparently high receptivity to neurobiological tests; and then discussing specifically (a) diagnosis, (b) prediction, and (c) treatment choice.

Findings 1: Prioritisation Within a Journey Towards Understanding-as-acting

We propose that many of our participants' narratives, and the way technological futures were affectively inflected and positioned within them, can be described in terms of a 'journey towards understanding-as-acting'. Participants reported pursuing knowledge vigorously, but only when they judged that it could be connected to action to improve the conditions under which they experienced OCD and its symptoms. Thus, action might be anything from obtaining new treatment or referral, to a new way of talking, thinking, or advocating. Improved understanding of OCD could lead to diagnosis and thus to the right specialist and to treatment, and to gaining the appropriate educational support. In parent narratives, neurobiological understandings were potent in unlocking these practical resources. Neurobiological understandings of OCD also helped parents explain their child's behaviour to others and decide when to challenge it. Some parents also reported that neurobiological perspectives offered the child a way to share what could be a painfully isolating sense of



being ‘crazy’ – though in the analysis below we discuss some of the limits of these more rhetorical functions.

Parent prioritisation of knowledge that directly facilitates or constitutes action is perhaps unsurprising. What was striking was the powerful ways in which this shaped participants’ willingness to even discuss the scenarios we presented. Participants often seemed to find it improper and uneasy to even speak about knowledge that did not fit into a journey towards understanding-as-acting. But whether knowledge would lead to action was not always obvious. Parents often had to judge whether to allocate precious resources to *trying out* a particular form of knowledge – to working out if they were asking ‘the right kind of questions’. The analysis below draws out some of the factors that influence this process.

The concept of a ‘journey’ is also intended to evoke a spatio-temporal trajectory, an urgent quest forwards. Participants frequently described feeling ‘out of control’ prior to diagnosis, and that there had been limited time to find the right information to prevent worsening of the child’s condition. Many used dynamic spatial metaphors to describe the kind of movement that a purposeful journey towards understanding-as-acting replaced, e.g. describing a ‘rollercoaster’, ‘spiralling’, or going ‘downhill’. In contrast, participants frequently described their child’s symptoms and internal experience as being ‘stuck’, ‘hooked’, or ‘blocked’ by obsessive thoughts or rituals; as being unable to mentally and/or physically move, or described a ‘wall’ that separated them from their child’s thoughts. Chaotic, directionless motion failed to unlock a frustratingly static and opaque situation; a knowledge-driven, forward motion promised to gradually unpick it.

When we asked participants to imagine future technological scenarios, they frequently manipulated them in order to locate them within a journey towards understanding-as-acting. On the one hand, they projected future scenarios back in time to what they would have hoped for (and thus by definition did not achieve) in the past. Alternatively, they tweaked future scenarios to apply to unresolved issues for their own child, or applied them to the potential futures of siblings or family members. The latter seemed more comfortable; it located a hypothetical in the future of their current journey rather than in a regretful projection of a future they might have wanted in the past. A consequence of this malleability was that parents often gave their perspectives on *generic* diagnostic and treatment functions, rather than focusing on the *specific* brain scan and genetic tests described by the interviewer. Or in other words, to be made personally specific, future scenarios were treated as technically generic.

It was particularly hard to draw out forms of action that were primarily explanatory or persuasive; and to talk about ways of talking. For instance, when the interviewer asked parents whether they think or talk about the brain or genes in relation to OCD, it often took some conversational work to reach a shared understanding that talk could *do* something and could thus be properly discussed:

- Maggie I’m sure there’s something to it. I mean, obviously there’s something somewhere [in the brain]
- Interviewer But it’s not part of the way you generally talk and think about the symptoms?
- Maggie Do I think it’s a brain disorder?



Interviewer Or when you're say, talking about what's going on, some people talk about, oh there's something going on in your brain which is making thoughts get stuck or—

Maggie Well, no... It just is what it is. You know, you just have to deal with what – well, I do tell my children they just can't help it, you know? Because my other son has a lot of anxiety and I just said, you know ... I do say something in your brain just doesn't connect right... Actually I do say that. I see what you're saying. Um, so I make it like, I don't want them to think it's a character flaw

Maggie resists the notion of 'talking as if' until it becomes clear that this is a practical strategy for action, not a criticism of inaccurate scientific chat. As in exchanges with several other parents, Maggie also seems to resist talking about scientific details, drawing on the rhetorical implications of a neurobiological lens selectively and when needed rather than trying to mobilise an internally coherent scientific framework.

When positioned as research participants, parents revealed a more abstract curiosity, and puzzled over cause and ontology. The context of research carried the promise of future benefits, but on a timescale that participants could not themselves control, allowing them to step outside the urgent quest for actionable knowledge. Nick said that "It'd be neat to see actual pictures of the brains ... Things that pointed to, you know, 'This is different here'", and for Allison 'it would be interesting to know, you know, if, for example, Taylor's brain looks any different from other people's, because of the fact that she has OCD".

Findings 2: Neurobiological Perspectives

Our participants brought up many of the potential impacts of a neurobiological lens discussed elsewhere, balancing potentially reductive and deterministic effects against relief from blame, guilt, and stigma, and the rhetorical potency of having a distinct name and origin for symptoms. As indicated in the excerpts above, this negotiation is rarely an either/or; these effects aren't mutually exclusive, and the blurry ontological status of the brain and gene allowed for selective combination of forms of knowledge.⁵ In the spirit of the sociological studies outlined in the introduction, we below elucidate some specific details of these negotiations with regard to (a) neural and (b) genetic lenses.

(a) What kind of thing is a brain? It depends what you want to do with it

Allison describes the diagnosis as allowing her child to pull apart self and OCD, giving an amorphous situation concreteness and certainty:

Allison ... [the diagnosis] eventually helped for her to be able to sort of separate it and for her to be able to, you know, basically to label it and for her to be able to say, you know, it's not me, it's the OCD. Um, I'm not crazy and, you know, there's something going on that's making my brain do funny things

⁵ To follow Annemarie Mol (2003), the diagnosis of OCD can precipitate multiple, overlapping 'disease ontologies' with differing implications for the future: the body can be both determined and non-determined in different settings.



But Allison does not simply align the OCD with a faulty brain. Instead, ‘something’ makes the brain behave badly, and this vagueness allows Allison to sidestep the ontological dilemma of a mind/brain dichotomy (see also Pickersgill *et al*, 2011; Wilson, 2004; Singh 2005, 2012, 2013).

In the excerpt below, Nick connects the ontological implications of a brain-based perspective to a reduction in negative judgements:

Interviewer Could you tell me a little bit more about any other ways in which [thinking of OCD in terms of the brain] is useful that we haven’t discussed already?

Nick [...] it gave us, it gave us hope because we knew the, ah, amygdala would continue to develop. A couple of people had told us that, you know, that what happens happens, you know, she might grow out of it to an extent, so that was certainly something to hope for. And it’s very useful in terms of judgment, you know, not judging someone as good or bad or sick or healthy or, just there’s this mechanical thing going on. It was easy, it helped us to deal with it because it wasn’t a question of us, ah, you know, trying to coerce her to do one thing or another. And it helped her because it puts a name on it and a place, a thing, if that’s coherent

Nick finds the siting of OCD in the brain helpful to avoid judgments both of goodness/badness, and of health/sickness. A ‘mechanical brain’ doesn’t just disperse moral judgments, but also the potentially stigmatising framing of his child as ‘sick’. As with Allison’s ‘something’, understanding OCD partly as a brain disorder doesn’t force a mind/brain, holistic/reductive dichotomy⁵. As part of a combination of ways of looking, the brain appears rather as a temporary way of avoiding some irresolvable normative dilemmas – a break from the existential allowing the family to act. Interestingly, Nick and other parents were often well aware that this might not appear ‘coherent’. Perhaps it is rather the setting of the interview that is strange, in asking participants to discuss simultaneously kinds of explanation that are usually deployed separately in different contexts – and thus perhaps appearing to challenge their utility.

Another important feature of Nick’s brain-based explanation is the emphasis on developmental change, sketching out a hopeful destination for his journey towards understanding-as-acting. In this and other interviews, the flexibility of the brain and the notion that both pharmaceutical treatment and therapies, such as CBT can be understood as helping correct what is ‘wrong’ with it, seemed to be key to allowing a brain-based explanation to be hopeful rather than deterministic². Yet in two other parents’ stories, the flip side of the hopeful, malleable, blame-absorbing brain dominated. Unlike most of the parents, Laura and Janine both reported that their children were failing to get better, struggling to engage in psychological or behavioural treatment, and seeing OCD as something physical that could only be fixed physiologically.

Janine described her understanding of her son Jack’s hopes for physiological treatment:

Janine And he thinks there’s going to be a magic pill out there that’s going to solve all his problems. ... and so that’s why he’s, again, with anything to do with the brain and turning it off, and if you can find that little spot that’s something, I don’t know, can be fixed, then he’s, he’s all for it, you know

She reported that Jack's desire to have the affected part of the brain "turned off" was associated with the desire to be "totally out of it ... almost in a trance" so that he could overcome his compulsions. This powerfully expresses the barriers to movement that characterise the experiential field into which hopes surrounding neurobiological approaches and technologies enter. In the context of the journey towards understanding-as-acting, not just Janine's depiction of Jack but Janine herself is unable to move forwards. Neurobiology has not yet delivered a magic pill or anatomical switch, and Janine experiences Jack as blocking (her) pursuit of other forms of knowledge that could maintain a forward trajectory towards improvement.

Heather related the story of her son Patrick's sudden and severe onset of atypical OCD, which was repeatedly misdiagnosed as, e.g. bipolar disorder or schizophrenia, but was eventually thought to have been triggered and exacerbated by an infectious disease. Four of the participants reported that their child's OCD onset was consistent with PANDAS/PANS, and, like Heather, most considered that the OCD would likely have existed anyway. In the excerpt below, Heather describes their struggles to find an adequate way of understanding their son's illness:

Heather ...he knew, he knows OCD is a mental illness, um, but he felt like whatever they were trying to teach him about what was happening to him was not right. So, his way of describing, I think, what was happening to him that something was not wired right or something was not lining up ...

He felt like something was misfiring. He felt like something is miswired and the fact that, you know, now that we look back and it was some type of an infectious process going on, it was exacerbating the OCD. But Patrick feels since he was a little boy that there's been something miswired... The OCD I think started young but was manageable, and then when he probably developed an infectious process it just blew it out of the water

Physiological triggers interweave with existing disorder that is itself not situated in a mental/biological dichotomy. And when employing neurobiological framings, official medical knowledge is contested – a folk neurology (Vrecko, 2006) of miswiring is prioritised over 'whatever they were trying to teach him'.

(b) 'Ah, it's some weird genetics again': Embedding OCD in a familial narrative

It often took some discussion to identify what parents wanted to say about the brain and its role in their ways of talking and thinking about OCD. In contrast, a genetic narrative was easily accessed, common, and often eagerly described:

Interviewer And in terms of the genetic connection, is that something you also think or talk about?

Maggie Oh, absolutely. Oh, there's absolutely a genetic – absolutely, without a doubt. I know there is. I can't prove it, but I know there is. [laughs]

Parents spoke of family histories of OCD, related mental health issues, and difficulties with, e.g. alcoholism that were viewed as self-medication for undiagnosed anxiety disorders. In their narratives, the process of integrating the child's experience into a family and social context was often associated with parents becoming more open with others and stronger



advocates for their child. It also allowed parents to use their awareness of OCD to assist relatives struggling with related issues, or to find relief from past feelings of blame and anger.

However, there were a few participants who preferred not to think about genetic connections, either in relation to a PANDAS diagnosis, which meant they were committed to the explanation of an infectious cause, or in relation to a negative relationship with the family member deemed to be a potential source of a risk for OCD. Laura describes her reluctance to view OCD as genetically linked, and her growing recognition of familial history as an unhelpful movement towards seeing the disorder as more long-term and inevitable:

Laura His father, who I'm divorced from, is, is quite unstable mentally, so I think that I just didn't really want to think about that. But unfortunately, since Jacob's really struggling, I'm starting to think that maybe there's — well, my side of the family suffers from anxiety, so I kind of feel like he's kind of loaded on both sides a little bit

For other families, genetic knowledge fits within the journey towards understanding-as-acting; here, it seems to be a block to progress.

For parents with younger children not currently exhibiting OCD symptoms or mental health problems, there was also a more explicit focus on the potential negative effects of gene talk. Heather explained that, when speaking with her younger, unaffected child, “We talk about OCD all the time because Patrick lives it. But I have been very careful to talk to [Patrick's brother] about the genetic component of it because I'm, I guess I'm concerned that he'll worry about it, which might make him more nervous”. In all these differing scenarios, ‘gene talk’ (Keller, 2000; Callard *et al*, 2012) is avoided when it blocks the ongoing journey towards understanding-as-acting; whether this is the case depends not just on participants' beliefs about the malleability of genetic inheritance, but also on the existing structures of blame within the family.

As in Callard *et al*'s (2012) interviews with family members of persons with schizophrenia diagnoses, genetic narratives were reported to relieve blame, but did not entirely eliminate feelings of responsibility and guilt. For example, recognising a family history of OCD enabled parents to recognise early signs of the disorder in others and intervene, but this process was also often associated with feelings of failure at *not* having had this lens available to them previously. In contrast to Callard *et al*'s (2012) study, parents seemed equally comfortable discussing OCD symptoms, diagnoses, or related issues in themselves, in their spouses, and in more distant relatives. This makes sense given that OCD is not as stigmatising as schizophrenia, and was also described as a trait, as part of human nature, or as something that one can have an ‘amount of’, implying that genetic predispositions are partial and malleable.

Findings 3: Parent Perspectives on Future Use of Brain Scan and Genetic Tests

In this final section of the analysis, we discuss participants' perspectives on the potential future use of brain scans and genetic tests, commenting separately on (a) diagnosis, (b) prediction, and (c) treatment choice. But we begin by describing the cross-cutting notion of receptivity, and the methodological challenge of delineating its contours and conditions.

As described by Borgelt *et al* (2012) with respect to parents of children with ADD/ADHD diagnoses, participants generally expressed high receptivity to technologies and focused on utility rather than risk. Concerns about negative effects of brain scans or genetic tests were rarely expressed directly, even on prompting, with parents focusing discussion on whether the information provided would have clinical or pragmatic utility. In the words of three of our participants when asked if they would be interested in brain scans or genetic tests:

Stella I think that the more information, the better it is. I really believe that, you know, the more – it's just about gathering information, data, whatever, you know?

Robert I think, you know, at the time, anything that was offered to us to help – I think we would have taken it. The whole experience for us – going through it, I think we were, we were looking for any – all the answers we could get

Gina He would have been, done anything that we thought was worthwhile

It would be easy to conclude from these short statements that participants had no qualms and are thus vulnerable to situations in which technologies are translated into clinical settings without thorough consideration/communication of their potential effects. But, as we discuss below, parents were actually very selective in defining what was a useful test. Where 'understanding' implies *understanding-as-acting*, here 'useful' implies that the benefits have already been determined to be concrete enough to outweigh potential concerns. In the three statements above, the weight is thus as much on the implicit evaluations preceding and underlying the use of 'help', 'worthwhile', and 'better' as on the apparently indiscriminate use of 'anything'. In other words, anything to help – if it helps. In presenting the hypothetical technological scenarios, we made clear that they were still in the research stage and left participants to bring forward possible benefits, risks, or specific scenarios. But this openness required conversational work to ensure that participants didn't think we were suggesting that there are no concerns, thus refiguring the motif of 'anything to help, if it helps' as 'would you like something that would help?'.

These observations about the evaluative work that lies behind apparently high receptivity are not intended to neutralise concerns about parent vulnerability – portrayals of technological benefits may well be less closely interrogated by parents on a quest for anything-to-help. It is also important to note that our participants had already had a positive research experience and were interviewed in a trusted clinical setting. Others may well be more concerned about confidentiality, physical safety, and psychological effects, and perhaps less trusting of medical professionals.

(a) Diagnosis: black and white in grey

Given our participants' experiences with a long and painful wait for diagnosis, it is unsurprising that potential brain scan and genetic diagnostic tests were often associated with the possibility of speeding up this process:

Heather So if there's anything that can be done to help diagnose OCD earlier ... you know, if there's anything that can be done to help people relieve some of the suffering they have to go through early on, it's well worth it. I wish there were ... imaging tests that you could see what was going on



As in several of these exchanges, Heather makes a general statement about the desirability of earlier diagnosis, her ‘anything’ placing brain imaging as one of many possible technologies that could fulfil this function.

Despite generally high receptivity, participants also expressed scepticism that a more objective, certain diagnosis would actually be possible. For instance, they doubted brain scan or genetic tests would remove the need to look at the child’s symptoms and behaviours, with several recalling the essential role of a psychiatric evaluation in understanding what was going on. Robert spoke about having to video his daughter’s ‘outbursts’ in order for the psychiatrist to understand, and doubted whether a neurobiological test would have removed the need for this. Similarly, Alice said that a brain scan “couldn’t show me everything that was going on in her head”, Heather asked “if your brain looked like it had OCD, but you had none of the symptoms, does it really matter, you know?”, and Nick expressed the boundaries of a future brain scan’s ability to change his knowledge of his child’s condition:

Interviewer And if there was a brain scan that was able to confirm a diagnosis of OCD, is that something that you’d be interested in for your child?

Nick Ah, at this point, you know, she has OCD and she’s dealt with it incredibly well and it’s become less of a part of our life than it had been five years ago. I certainly wouldn’t object to it. I’d be surprised if the diagnosis was no, but it’d be up to her

This integration of the hypothetical question about biomarker diagnosis into a current situation in which it would not necessarily change anything was typical of the way participants negotiated temporality. As discussed above, parents seemed most comfortable with projecting hypothetical futures onto their present journey towards understanding-as-acting, rather than into past experience or an abstract future. Several expressed the hope that an additional confirmation of their child’s current diagnosis would be more black and white, resolving comorbidity and difficulties disentangling behavioural problems from symptoms that the child cannot control. Relatedly, some wondered whether brain scans would reveal change over time, but this was often situated in speculations about future research studies. Here again, considering research studies seemed to sanction parents’ curiosity, as they still promise action even if not immediately for the individual child.

As indicated above, it was difficult to communicate the uncertainty surrounding risks and benefits in a way that left meaningful space for participant evaluation. When asked whether she would weigh a brain scan differently to a verbal evaluation in diagnosis, Nancy stated “I would weigh the brain scan probably a little more heavily, if it was... if they’d already determined that brain scans can tell you what disorder you may have then yes I would weigh that heavier”. In other words, if the technology has been proven to fulfil its hypothetical promise, then of course it would be used as such. It is difficult to communicate a degree of potential benefit that leaves it open for discussion whether, and why, a new technology would trump other tools. In our study, this difficulty was also illuminating of the potency of participants’ need to make quick and decisive decisions about utility; it is not in line with the journey towards understanding-as-acting to prioritise attentional resources to as-yet unresolvable speculation about possible risks and benefits.

(b) Prediction: ‘that would be wonderful’ vs. ‘what possible good would that do?’

As for diagnosis, participants often focused on the potential for prediction to relieve a long wait for diagnosis – i.e. prediction of occurrence rather than prognosis of severity. In reaching back to a period when prediction could have facilitated action to reduce severity or even prevent development of OCD, the ‘if it helps’ of ‘anything to help, if it helps’ became more pressing. Participants brought up questions about when and who should be tested, how accurate such tests would need to be (and could in principle be), and whether such knowledge should lead to preventive interventions. Here again, the emphasis was on knowledge having to lead to action to be worth having, but with a stronger emphasis on possible negative effects. There was also a sense in which one could have *too much* information about the future, potentially threatening the notion of a plastic brain that is malleable given treatment³, and the hopeful dynamism of a journey towards understanding-as-acting.

Some participants discussed concerns that fore-knowledge would exacerbate anxiety or lead to self-fulfilling prophecies. In doing so, Allison delineates her interest and ability to handle genetic information from her concerns about how a broader public might respond:

Allison I’m always interested in that kind of stuff. But in terms of, you know, thinking about the population in general, is that information helpful?... depending on people’s level of education and how much they understand, it could almost make things worse if they were worried about something that they didn’t really understand

Interviewer So can you imagine any scenarios where that might happen?

Allison I think if you had a child and you – say there was a gene and they were positive for the gene for OCD, but weren’t exhibiting any symptoms. But the parents, you know, told everybody about it and then people treated the child differently because they were concerned about this. Didn’t really understand it. I mean, I feel like with most sort of mental illnesses, a lot of people don’t understand it, and there’s a lot of stigma around them

Allison doesn’t focus on whether the other parents she imagines understand the technical aspects of genetics, but on whether they understand the appropriate actions to take on the basis of genetic knowledge. In locating the tipping point of the balancing act between positive and negative effects, many parents stated that there must be preventative treatment available for prediction to be justified. Others doubted that prediction would be accurate enough to be useful, either given the nature of OCD or given the current state of the science. As Gina said, “I don’t think a doctor can do that”. Here, we can see both the benefits and constraints of speaking to expert participants. Their speculations are knitted into real-world complexities of knowing and acting, but this also seems to make them reluctant to entertain scenarios they judge to be unlikely. When our participants did allow more speculative talk, they often used words such as “wish”, “miracle”, or “wonderful”.

In discussing prediction, we again often had to negotiate its relevance. When prediction or prognosis didn’t make sense for the child’s current situation, the focus shifted to the less comfortable domains of alternative pasts or parallel futures. In this context, several parents discussed vigilance over siblings, and expressed a desire to reduce the inevitable period of watching and waiting.



(c) Treatment choice: Ironic hopes for miracle pills

Alongside a distressing wait for diagnosis, negative experiences with choosing, combining, and judging medications were a key theme. Many participants had suffered through great uncertainty in determining which medications would work and in adjusting dosage, worries about long-term effects, and feelings of losing control over combinations of medications whose effects and side effects were difficult to disentangle. Nancy told us that “if a brain scan could say, ‘Do not take this, this will cause tics’, it would have saved me hundreds of dollars, hundreds of hours of time”, and later laughed ruefully as she expressed the hope that targeted treatment choice could “get him off everything, I mean he takes five pills, get him off all that, that’s not working, give him one miracle pill no side effects and it would be great”.

In contrast to diagnosis and particularly to prediction, the idea of using brain scans or genetic tests to increase specificity in treatment choice evoked fewer concerns or negotiations of utility. This is perhaps in part because the notion of treatment choice assumes the child’s need for treatment is already determined – and as such it is more pragmatic and less epistemologically potent. For some parents, the need for more precise treatment choice was also still very real, and as such projected easily into the present or near future of their journey towards understanding-as-acting. On the other hand, some parents whose child’s medication was currently stabilised resisted even the hypothetical notion of being pointed in a different direction.

Robert links his receptivity to brain scans or genetic tests for treatment choice to a dissatisfaction with the ability of a symptom-based evaluation to fully explain – and thus specifically medicate – his child’s particular combination of symptoms:

Robert There was no set way with medication – the diagnose was based on sitting down, talking to her, giving her tests. ... Listening to the problems that were going on at home, the fighting and the arguing and the anger and the outbursts. ‘Okay, well, let’s try her on this’. Now, whereas if they could pinpoint something in the brain that was causing her to act that way that would be great, you know. I think I, I probably would have felt better if they said to me, ‘Yeah, we see this in her brain. This is what’s causing the anger, so this is what we’re going to do to treat that anger part’, versus trying different medications to see what’s going to work, and then keep up with them and add more

Resistance to the idea that responsibility for medication could ever be fully transferred to a brain scan or genetic test recalled participants’ musings about what would happen if a diagnostic test failed to match what they *knew* to be the case. Several explained that being pointed towards a medication would not be the end of the matter – unless, as Nick explained “it’d been used for 10 years safely and there were no side effects, you know, why not, but that doesn’t happen”. Other participants emphasised that the method used for treatment choice – whether symptom-based or biomarker based – doesn’t dictate future compliance:

Interviewer Would you have any worries about using a brain scan to choose medication?
Alice Not any more than any other way. I mean, it’s all—you never know, every day. I mean ‘cause you know within a couple weeks whether it’s going to work or not, so I—I’d be willing to try it. But I would be just as willing to say no to it

As in Heather's earlier alignment of brain imaging with a variety of technologies that might help with diagnosis, Alice here resists the specificity of the scanner. Hopes for greater certainty, concreteness, objectivity, and psychological relief were certainly associated – if not without caveats and conditions – with neurobiological or genetic knowledge. But the technological specificity of these hopes is an open question.

Conclusion

In this study, we investigated the perspectives of parents of children with OCD on potential brain scan and genetic tests for diagnosis, prognosis, or treatment choice. In doing so, we aimed to temper abstract arguments about risks and benefits with a glimpse into how biomarker technologies and the neurobiological framings they imply might be integrated into parents' complex and context-dependent combinations of perspectives on mental illness. In discussing a particular question about future technological applications, we also aimed to contribute to a general understanding of how parents might integrate ideas about the brain and genes into a continuous stream of difficult decisions about how to prioritise resources. And in studying the particular group of parents of children with OCD diagnoses, we aimed to contribute to a broader patchwork of understanding of how neurobiological perspectives on mental illness are understood, experienced, and deployed.

We developed the concept of a journey towards understanding-as-acting to reflect the central role that gathering knowledge played in parent narratives, but knowledge that concretely facilitated action. This emphasis on actionable knowledge was visible both in participants' evaluation of technological scenarios, and in their willingness to even discuss those scenarios with us – the journey towards understanding-as-acting wasn't bypassed by the interview situation. But parents sometimes had to try out an idea before deciding if it was indeed going to facilitate their forward journey. And in choosing which forms of knowledge to 'try out', they often had to reconcile projections of possible utility from their own experience with scientific and clinical knowledge, sometimes contesting the latter via the former.

In general, parents appeared highly receptive to potential future neuroimaging and genetic tests. Yet when they responded, 'yes, anything that helps', uncertainty, caution, and resistance were expressed in implicit negotiations over what it means to 'help'. This can also be seen through the lens of the journey towards understanding-as-acting, as a way of dealing with the uncertainty about whether a particular form of knowledge will *become* actionable, and whether that action will lead to improvement in the parent and child's experience and condition. Parents have a primary attitude of openness to any and all knowledge, but also have a set of sophisticated, experience-based filters of utility that immediately spring into action and are hidden behind apparently uncritical statements of receptivity.

As expected, our interviews demonstrated a fluidity in the implications of neurobiological perspectives, which oscillated between hopeful and despairing; between implying plasticity and confirming stasis; and between reducing guilt and increasing stigma. The details of our analysis suggest some factors that may affect these oscillations and which could serve as the basis of further research. For instance, if their child's condition was worsening at the time of participation, parents seemed more likely to be both receptive and scientifically sceptical,



both wishing for a miracle pill but doubtful that the framework it was associated with could really deliver. On the other hand, experiences of improvement and change – in line with the notion of a malleable, hopeful brain – seemed to be a key factor in whether parents' found brain talk useful and comforting. Similarly, most parents found a genetic narrative helped them make sense of common experiences across the family without invoking deterministic fears, but having relatives with intractable anxiety issues or siblings who the parent worried might develop OCD could trump the softening assumption that OCD is only partially and non-specifically heritable. Or in other words, whether a particular form of knowledge was admitted into the journey towards understanding-as-acting can depend on whether its positive or negative affordances were a better match to the concrete circumstances of the journey.

More speculatively, for some families, a reported interpersonal battle between a child's purely physiological and their parent's psychologically tractable perspective seemed to damage the fragile reconciliations of multiple 'ways of looking' that other parents describe. In order for potentially contradictory perspectives to be held alongside each other and drawn on when needed, some uncertainty about their potential implications was required. This was the case within an individual parent's mind, between parent and child, and also between interviewer and interviewee; and between the present experienced and the future described. In drawing such observations from parental reports of their child's experiences and perspectives, it is crucial to remember that one person spoke on behalf of another, and where the former was a position of power.

There were specific expectations surrounding brain scans as being more concrete, visible, and persuasive than genetic tests, but this was not as dominant a theme as we had expected. Participants focused more on the desirability of the functions and their feasibility given the ontology of the disorder than on the specific characteristics of a particular technology. This trend may have been exacerbated by the difficulty of discussing both brain scans and genetic tests within a single interview, and by their inevitable abstraction within the interview setting. This poses the methodological question of how interviews could more strongly evoke and consider the materialities of specific technologies.

With this study, we also hoped to elucidate participants' relationships to the past, present, and future, and implications for the methodology of interview time-travelling itself. In general, telling a well-rehearsed history seemed comfortable for both participant and interviewer. Far more difficult was discussing hypothetical future applications whose relation to the participant's temporal landscape was unclear. Were we asking if they would have wanted something that is not yet available in a remembered past? If they would still find such tools useful today, or if the past were repeated today (Adam, 2004)? Or if we were asking them imagine the future for another child? The interviews involved an implicit process of negotiating which of these settings participants were comfortable commenting on, moulding scenarios to fit into a journey towards understanding, whenever in the enfolded temporal imaginary that journey took place. In general, the temporal movement within participants' reflections knitted them tightly to the present – not exhibiting the wild disconnection or arid acquiescence that can sometimes characterise discussions of hypothetical technological futures (see, e.g. Nordmann, 2007; Nordmann and Macnaghten, 2010).



Regardless of whether the technological futures we depicted are close enough for our findings to directly shape the translational process, we would argue that our participants' reflections are a valuable source of information about how potential technological futures might be experienced (see also Grunwald, 2010). Some might object that the methodological difficulties with gathering and interpreting such perspectives outweigh their utility, but here we would pose the counterfactual: if this kind of work is not done, what kinds of future projection *will* be guiding technological developments? Is there an alternative and better mode of representing the perspectives of those who may encounter these technologies in the clinic? It is also important to acknowledge that this kind of work does not connect directly to policy or translation processes, though it could be included in policy research and may be relevant to designing communication or consent processes. We hope to have contributed to a climate where discussions about future bio-technological scenarios automatically invoke questions about lived experience. And we suggest that such questions place us in an often-uncomfortable zone between concrete near-futures and fictional speculation, and between descriptive sociology and empirical ethics work; a zone where speculations will eventually become memories of past futures.

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