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In Search of “Anything That Would Help”: Parent Perspectives on Emerging Neurotechnologies

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Abstract

Objective: This qualitative study explores parents’ perceptions about the future clinical translation of neurotechnologies—neuroimaging and genetic testing separately and together—for instrumentalization in the diagnosis and treatment of childhood ADHD.

Method: We conducted in-person, semi-structured interviews with parents of minor children diagnosed with ADHD ($N = 26$) and analyzed 11.75 hr of data using constant comparative analysis.

Results: Receptivity to technology and anticipation of potential benefits overshadowed discussion of risks or concerns. Four key areas of potential impact on parent experience are (a) insight and acceptance, (b) treatment and adherence, (c) stigma and blame, and (d) the endeavor to access resources.

Conclusion: The findings highlight high receptivity to emerging neurotechnologies for ADHD, key areas for which parents anticipate support from these technologies, and ethics challenges to clinical translation in light of parents’ salient hope and minimal consideration of risk in their pursuit of “anything that would help.”

Keywords

neuroethics; neuroimaging; ADHD; psychiatry; qualitative research

Background

ADHD is in the spotlight of public interest and concern today as the rates of diagnosis and prescription of psychopharmaceutical treatment for children climb steadily (Olfson et al., 2003; Parens & Johnston, 2011; Pastor & Reuben, 2008). Although public awareness has contributed in positive ways both to the availability of resources and opportunities for care, conflicting perspectives about the nature of ADHD continue to spur debate (Parens & Johnston, 2009; Singh 2008). Undergirding the debate are deeply entrenched social and moral concepts of volition, gender, normal behavior, childhood, and parenting. Thus, stigmatization of children with ADHD and their parents persists despite the emergence of

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biological explanations of the diagnosis, and public awareness efforts intended in part to remove the blame of what was once considered deviant behavior (Conrad & Schneider, 1992; dosReis, Barksdale, Sherman, Maloney, & Charach, 2010; Hinshaw, 2005; Law, Sinclair, & Fraser, 2007; Norvilitis, Scime, & Lee, 2002; Walker, Coleman, Lee, Squire, & Friesen, 2008). Barriers to resources for ADHD include social stigma, disagreement among care providers, and existing categorization schemas (Parens & Johnston, 2009).

Past research on family perspectives toward ADHD diagnosis suggest that, in addition to experiencing stigma from classmates and other adults, parents must reconcile divergent perspectives on ADHD and navigate a culture of parent-blame while making difficult treatment decisions (Singh, 2004, 2008). Studies of child and parent attitudes toward medication also reveal a plethora of competing interests. Despite symptomatic benefit, wariness persists about medication that may be attributed, at least partly, to side effects, unknown long-term impact, and exposure to negative information from physicians, friends or family, or the media (Berger, Dor, Nevo, & Goldzweig, 2008; Charach, Skyba, Cook, & Antle, 2006).

The emergence of an alternative therapy culture, including diet manipulation, vitamin regimens, and detoxification, suggests a profound desire of parents to pursue any therapy that promises reasonable hope for treatment or cure (Concannon & Tang, 2005; DiPietro, Whiteley, & Illes, 2011; Johnston, Seipp, Hommersen, Hoza, & Fine, 2005). It is no surprise, then, that private clinics offering neuroimaging have also surfaced for the diagnosis and treatment tailoring of ADHD, although routine clinical use of these technologies is not supported by the broader professional community (Adinoff & Devous, 2010a, 2010b; American Psychiatric Association Council on Children, Adolescents, and Their Families, 2005). Its use, along with genetic testing and the combined technology of “imaging genetics,” as the two technologies used together are known in the professional community, is only expected to increase both within the research arena where they are primarily applied today and outside it (Bush, Valera, & Seidman, 2005; Cyranoski, 2011; Durston, 2010).

Here, we present a qualitative interview study that explores how neuroimaging and genetic testing for the future prediction, diagnosis, or treatment tailoring of ADHD is understood by parents of children with this diagnosis. We focus on parents as the primary decision makers in clinical care of minor patients, recognizing that this does not reflect perspectives of the children themselves. This study builds on rich past work on the perspectives of stakeholders on current psychiatric practice in ADHD; however, unlike existing research, we sought to proactively inform the clinical, ethical, and policy discourse surrounding emerging technologies upstream of their future clinical translation.

Method

Participants were recruited from a large metropolitan area in British Columbia, Canada. Recruitment flyers were displayed in community health clinics, and electronic notifications were distributed by mass email within the local health authority system. Prospective participants visiting the collaborating ADHD clinic site were also informed of the study by author M.W. Inclusion criteria were 19 years of age or older, self-report of having a

minor child with a diagnosis of ADHD, and English fluency. As common in qualitative interview studies, a purposive sampling strategy was used to engage individuals who best speak to phenomena of interest. Data were collected until theoretical saturation was reached.

Participants first completed a baseline demographic. E.L.B. then conducted the semistructured, 25- to 45-min interviews, which opened with a brief, standardized explanation of the technology in question. Hypothetical scenarios were then presented with open-ended questions designed to elucidate understanding, perceptions, and attitudes about neuroimaging, genetic testing, or both. Participants were informed that the hypothetical scenarios did not represent available or professionally endorsed clinical practices. Interviews were audio recorded, de-identified, and transcribed verbatim. Research ethics approval was obtained from the institutions involved. All names were replaced with alpha-numeric codes are reported with pseudonyms to protect the confidentiality of participants.

Two authors (E.L.B. and D.Z.B.) independently reviewed transcripts of the first 10 interviews using constant comparative analysis to identify major themes (Boeije, 2002; Creswell, 2007; Glaser & Strauss, 1967) and to establish a preliminary consensus list of codes. Final themes and subthemes were organized into categories and then used in the coding scheme for the analysis of the remaining 16 interviews.

Results

We obtained 10 interviews each on the topics of neuroimaging and genetic testing, and 6 on both topics in tandem, yielding an overall sample of 26, which consisted of 20 female participants (mothers) and 6 male participants (fathers). In all, 4 participants had daughters with ADHD and 22 had sons with ADHD. The age of participants' children ranged from 6 to 18 years. Prior experience with mental health issues, generally, and their child's ADHD, specifically, varied among participants. A total of 10 participants reported that their child had no family history with mental illness, 10 reported a positive history, and 6 did not know. In all, 7 of the participants' children had been diagnosed less than 1 year prior to participation, 1 was diagnosed between 1 and 2 years prior, 9 were between 2 and 5 years prior, and 9 were diagnosed more than 5 years prior.

Knowledge of neuroimaging or genetic testing was also variable among participants. For example, some participants reported that their knowledge was limited to the standardized explanation provided at the beginning of the interview. In contrast, one participant described professional involvement in the management of neuroimaging facilities for other health care applications; another participant was a physician versed in genetics research.

Parent Experience

Participants' perceptions of neurotechnology and receptivity toward its potential clinical use in their child's care were situated, first and foremost, in the context of their parent experience. The findings highlight three aspects of parenting that participants struggle to navigate: (a) conflict within and external to the family, (b) worry about medical decision making, particularly regarding use of psychopharmaceuticals, and (c) tension between the appreciation of and pride in their child's uniqueness and a desire for stability at home.

Parent experience—especially these key struggles—contextualize these findings about neurotechnologies and the ways in which parents hope they will contribute to mental health care for ADHD.

Insight and Acceptance

Many participants responded to the question of “Is there any information you would hope to get from a brain scan (or, as appropriate to the interview, genetic test)?” by voicing a desire for clinical tools that would increase understanding and insight into their child’s behaviors and condition toward an improved ability to provide care. Early in her interview, one participant offered this perspective:

I work hard to understand him every day, and the more you understand, the easier it is to care for them and support them.

(Sharon)

Sharon, like many participants in this study, described feelings of frustration in moments of not being able to provide immediate, well-honed care for her child with extra needs. Although the extent of symptoms reported by participants varied greatly, many were looking for reassurance of their decisions, proof to help accept the diagnosis, and support from others.

There’s so much vagueness about this condition, and ... I have never actually felt supported at all as the mother of a child with this condition.

(Marcy)

The vagueness bothering Marcy would perhaps be clarified, some parents suggested, by applying new technologies to provide early identification, explanation, and, in turn, support:

I think [a brain scan for diagnosis] is a great idea ... it gives you information up front to help support your child and to say, “Okay, you know, however your brain works isn’t the same as everyone else’s necessarily, or the average person,” and it may provide opportunities ... we would have known sooner to be able to support him.

(Sherrie)

The notion that neuroimaging or genetic testing would provide upfront insight into their children’s thought process and behaviors was important to parents, especially given the context of their parent experience in which diagnosis often involved significant time, distress, conflict, and resources, and required reconciliation of the tensions discussed earlier. Participants’ high receptivity appears to be tied to their hope for a definitive, objective diagnostic tool.

I think [neuroimaging] would be phenomenal because it’s not invasive, it’s not really scary to the kid. If it is definitive and you can—and it’s an image so you can show, here’s this thing, and here’s that thing ... There’s a process in accepting it as an adult, too, especially with your child. I mean, they’re the most precious thing you have on Earth, so anything that can help with that I’d be in favor for.

(Mark)

I would like [genetic testing]. I would like that. Because, like I said, it's more concrete, it's more—very black and white rather than all of the just guessing.

(Joseph)

Neuroimaging and genetic testing promises objectivity that will aid participants' acceptance of their child's diagnosis by providing tangible explanation and, further, would ameliorate the doubts about subjective diagnoses and subsequent medication entwined in surrogate decision making. As Mark articulated, most parents described initial difficulty—to varying extents, over time—in accepting their children's diagnoses and internalizing a new, medicalized view of the “most precious thing you have on Earth.”

Access to Resources

In addition to facilitating insight and acceptance of ADHD diagnoses by offering apparently objective images of ADHD in the brain, participants postulated that neurotechnologies, similarly, would offer proof to third parties and thereby support their efforts to champion resources for their children. This advocacy was largely focused on the classroom, with two participants also noting the need for resources such as job and/or life skills training. Participants' hope to parlay neuroimages or genetic test results into resources for their children was situated in the context of British Columbia public education policy, which, like most of Canada and the United States, does not classify ADHD as a standalone educational disability per se, although individuals may make a case that their symptoms constitute an unspecified learning disability (Centre for ADHD/ADD Advocacy Canada, 2010; United States Department of Education, 2004).

[ADHD] is relatively new in the school system ... I don't know how trained [teachers] are to deal with it. I don't know how open and accepting they are of it. It's not actually considered a learning disability ... So I think if we have a, a map, like a brain scan, on the table. Here you are, teachers. This is proof there is something going on here.

(Cindy)

Although some provisions are made for ADHD without an educational disability classification, participants anticipated that greater accommodations and resources would be granted to their children if they could justify that ADHD should gain educational disability or equivalent status in the public schools. Without proof, participants were frustrated by the status quo in which they frequently defended their child's diagnosis and their treatment decisions. As one participant described,

I remember this teacher doing an assessment of him and saying people outgrow ADHD. And I'm thinking, okay, so I have this person here who's supposed to be, you know, working with him who doesn't understand what ADHD is, you know?

(Irene)

Instead, participants hoped for a more productive starting point for discussion of resources, one that met them at their children's particular needs:

So having something like [neuroimaging] would then allow for a special education program to be developed ... if they had concrete information about what it would take to train him to learn whatever ... he can take that with him and he can get the kind of support he needs because it's supposed to be individualized.

(Irene)

Neuroimages and genetic testing offered a seemingly black-and-white objectivity that participants saw as a compelling contribution to their case for resources. Also, test results would underscore the unique needs of a given child, highlighting the distinctiveness of that child and dictating individualized attention. The desire to preserve their children's individuality while achieving normal (or exceptional) classroom performance was a significant tension experienced by participants; neuroimaging and genetic testing offered an acknowledgment of the individual child while promising means to restore a stability of function.

Stigma and Blame

Participants also anticipated that biological proof via testing would affect their social interactions in a positive way, as it would demand acknowledgment from others in their private networks and greater society that their children's experiences and their own are real. Participants described a two-front battle in which they struggled to find common understanding, mitigating stigma and blame, within the family and out in public. Several mothers, who reported difficulties in negotiating treatment decisions with the child's other parent, expressed hope that new technologies would provide evidence of the condition to the child's other parent, so that the child or mother would be absolved of blame and so that treatment decision making would be fruitful. One mother explained that her husband believed that their son's erratic behavior was appropriate for his age and that he will outgrow it:

So I think by having another method of diagnosing and looking inside, I think would be—that would just assist in the decision [to medicate]. And I think more so in our case personally, because his dad does not believe it, still to this day. He thinks it's puberty ... But I think by having something else that's black and white, so to speak, by having a brain scan that's interpreted ... That would, in my personal case, in our case, that would I think help indirectly, to [my son], by perhaps his dad seeing something else like that.

(Jean)

Popular notions that behavior should be self-controlled also contribute to parent-blame and confusion outside of the home. Therefore, participants—this was particularly noted by mothers—seek proof that would aid their ongoing combat of public stigma and blame.

I think [a brain scan] gives more credibility to the people who roll their eyes and go, “there's no such thing as ADHD.” Or, um, “Oh, he's just being uncooperative.” Or, “Oh, it's just a mother who doesn't know how to raise her kid” ... So to have something concrete, like, “well, here's a brain scan, this isn't firing,” it's a lot easier.”

(Irene)

Treatment and Adherence

Inextricably linked with the process of accepting a diagnosis of ADHD, for all participants, was the process of treatment planning. Thus, just as participants hoped for tools that would demystify the diagnosis with objective, tangible evidence, they hoped that neuroimaging would assuage their ambivalence and guilt in making the decision to medicate their child.

I guess for me it would confirm that it's, it's an actual diagnosis and that you could actually see it. Because with my son and with lots of kids, it's not always that clear that it is ADHD. Certainly with, you know, medication ... that would be really great to confirm that that is the route and that's what should happen. Because I think the medication piece is a huge decision for parents.

(Tina)

Participants expressed myriad reasons for their hesitancy to medicate, each intensely personal. Among the most-cited reasons was, as the mother above notes, the persisting doubt that the diagnosis is real or “actual” by some objective standard. Also, parents doubted whether medication was absolutely necessary and what the long-term effects of medication would be; of particular concern was the frequent practice of off-label prescription. One participant described her husband's fears surrounding medication as products of such misgivings:

So the more of this information that I give to my husband, the more panicked he becomes because he doesn't like the idea of this child, this young person, being pickled with all these pills, all these drugs.

(Marcy)

Marcy proceeded to consider the impact that a technology such as neuroimaging would have on her husband's concerns about psychopharmaceuticals—widely shared among these parents. Namely, she predicted that a neuroimage, appearing to be a straightforward diagnostic, would provide a causal map of her child's treatment needs and convince her husband otherwise:

I think it would really help if he could see the amount of deficit and therefore the reason for the amount of whatever this drug is. I think it would help ... Because instead of just messing around—because it would be clarified that this scan indicates X; therefore, Y is a solution, right? ... He can't see any benefit to the current drug, and he doesn't like the idea of mixing all these other drugs. But if he were to see a scan, perhaps, and realize that this amount of drug relates to this deficit in the brain, maybe it would be easier for him.

(Marcy)

Nearly all participants voiced a similar desire for some amelioration of their persistent doubts about medication, as well as for efficiency that would subject their child and family to a “guinea pig” experience. Perceptions of precision and objectivity would, then, convince

participants of the merits of medication as well as ease doubts and conflict attached to the decision to medicate.

Anything That Would Help

Although the interviews focused on neuroimaging and genetic testing, participant responses were not technology specific. For example, when asked about neuroimaging, participants may have referred passingly to a brain scan but spoke to more general goals of parenting and ADHD care. We found little variation between views on neuroimaging and genetic testing, as each interview group expressed perspectives that had much less to do with the tool in question than the ultimate goal of finding something—anything—to help their children.

If I know that at the end of the day, if my goal is to have my child feel good about himself, feel that he's got different strategies or different tools to handle a situation, then I don't think it really matters what the route is to get there, as long as you get there ... I would just be grateful for the fact that I would have the choice of different routes. So I think it's almost like, [the] more that it's available, you're more likely to get to your goal.

(Bette)

Discussion

Neuroimaging, genetic testing, and the emerging combined technology of imaging genetics remain, at this time, research tools and are not used routinely in the prediction, diagnosis, and care of ADHD; thus, the interviews are anticipatory by design. We asked participants to first describe their current understanding of the given technology. Then, we asked them to consider their receptivity to the technology if it were to become available in the future. Many participants answered this hypothetically by imagining what their reactions would have been if the technology had been available to them at crucial decision points in the past. This contributes to the richness of the data, as the open nature of the questions allowed participants to provide their perspectives without constraint. However, this is also a limitation of the study because participant responses do not represent actual experience or health care decision making involving the technology in question. As the capabilities and limitations of future technologies in capturing objective measures of a disorder can only be anticipated but not known, we accepted this limitation in exchange for the flexibility and openness of our interview design to emerging participant perspectives. Indeed, the veracity of data derived from technologies such as neuroimaging and genetic testing will be consequential to translational efforts and necessary to consider along with patient stakeholder perspectives. A second limitation is the scope of the sample, which may have been subject to a self-selection bias. Respondents with an existing interest in neuroscience, technology, education, or other professional contexts closely associated with ADHD may have been more likely to be exposed to and respond to recruitment materials.

We did not observe marked differences in parental perspectives based on demographic factors such as gender of participant or child, age of child, length of time from diagnosis, or family history of mental illness. We detected some nuances in our interview data, for

example, about spousal conflicts, but these were not sufficiently prominent to allow us to draw conclusions about their influence.

The data support an imperative of the neuroethics discourse—the need to integrate stakeholder perspectives into ongoing clinical, ethical, and policy debates. Their perspectives reinforce the need to consider context—here, the larger parent experience in which interpersonal conflicts and social supports are constantly at play, in which striving for strategies for parenting is counterbalanced by self-doubt about parenting decisions (such as we see with the difficulty of considering medicating one’s child), and tensions run high between parents’ celebration of individuality and maintenance of stability at home. Context illuminates parents’ explanations of the areas of their experience that they most hope to improve with novel technologies—understanding their child; decreasing stigma, blame, and vulnerability around ADHD; optimizing treatment and adherence; and attaining access to resources.

Although these four areas emerged as distinct themes in the analysis, they do not exist in isolation. In addition to being part of a larger experiential framework, these themes are likely in constant interaction with one another. For example, parents’ increased insight into their child’s behaviors and condition may improve their ability to articulate the need for particular resources and successfully champion for them, while having access to greater educational resources undoubtedly improves a parent’s understanding of ADHD and available treatment options. Thus, the impact of a novel neurotechnology on one area would likely pervade medical decision making and also have an impact on parent relationships with family members—especially their child—and others such as teachers, and those who may stigmatize them. To ensure maximized benefit of any future clinical translation, it is thus critical that these interactions be recognized and that translation proceeds with appropriate respect and caution.

Conclusion

We gave voice to a key group of stakeholders vested in the clinical translation of neuroimaging and genetic testing to mental health care. As primary decision makers for their children’s medical care and loving guardians of their children’s best interests, parents of children with ADHD represent a unique perspective with which we might enrich the discourse surrounding ethical introduction of novel neurotechnologies. This parent experience is full of both frustration and unconditional love, which culminate in a salient hope for newer, better tools and treatments. In this context, new technologies represent more than anatomy or function—they represent beacons of objectivity, explanation, and reassurance. The modality of technology is secondary to what it might provide for their child. For many parents, the potential future application of neuroimaging or genetic testing technologies in clinical care may be one manifestation of their grail; as voiced by one mother, “Anything that would help, I think, would be great.”

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