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Anticipating the Ethical Challenges of Psychiatric Genetic Testing

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Abstract

Purpose of Review—Genetic testing for mental illness is likely to become increasingly prevalent as the science behind it is refined. This article identifies anticipated ethical challenges for patients, psychiatrists, and genetic counselors and makes recommendations for addressing them.

Recent Findings—Many of the ethical challenges of psychiatric genetic testing are likely to stem from failures to comprehend the nature and implications of test results. Recent studies have identified gaps in the knowledge base of psychiatrists and genetic counselors, which limit their abilities to provide patients with appropriate education. A small number of studies have demonstrated the value of counseling in empowering patients to deal with relevant genetic information.

Summary—Psychiatrists and other health professionals must be able to assist patients and families in making informed decisions about genetic testing and interpreting test results. Filling their knowledge gaps on these issues will be a critical step towards meeting these responsibilities.

Keywords

genetic testing; ethics; psychiatry; genetic counseling; mental illness; genetics education

Introduction

Since the first, controversial effort to market a genetic test for a psychiatric disorder nearly a decade ago [1], psychiatry has been grappling with what role, if any, such genetic testing for mental illness should occupy. Over that interval, psychiatric genetic research has evolved from linkage studies, particularly useful for locating genes of large effect [2]; to genome-wide association studies (GWAS), which could help identify “common biological pathways to disease” [3], including those involving polygenic mechanisms, and examinations of copy

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number variants (CNVs), observed more frequently in individuals with some psychiatric disorders [2]; to the current application of sequencing technologies, which promises to open up the entire genome to exploration, with the hope of identifying additional genetic influences on mental disorders [4].

Translation of research findings into clinically useful genetic tests, however, has been limited by the some of the inherent characteristics of psychiatric disorders themselves. Findings on the genetics of schizophrenia, for example, indicate that—with the exception of uncommon conditions related to CNVs, such as DiGeorge syndrome—variants in a large number of genes are implicated in its etiology [5]. Similar findings have recently appeared for major depression [6], and the difficulty identifying genes of large effect that account for substantial proportions of the variance of most mental disorders suggests that polygenic mechanisms are likely involved in their etiology as well. The task of unraveling psychiatric genetics is further complicated by the interaction of genetic and environmental variables, with the latter playing an important role in the development of most disorders [7]. In addition, although pharmacogenomic tests are being actively marketed to psychiatrists today, the database supporting their use is weak, another limitation on the use of genetic testing in the field [8, 9].

Hence, the role of genetic testing in psychiatry has been restricted to date, except for a small number of disorders such as autism and other neurodevelopmental conditions. In contrast to oncologists, cardiologists, neurologists, and other specialists who routinely order genetic testing, most psychiatrists have had little-to-no experience ordering diagnostic or predictive tests, interpreting their results, or communicating the findings to patients and families [10]. Necessarily, then, many of the ethical concerns about the use of genetic testing in psychiatry are anticipatory. However, experience in other specialties has suggested the importance of being prepared to address ethical issues before genetic tests are introduced to clinical care.

Ethical concerns about genetic testing in psychiatry have centered on presymptomatic testing [11], in large part because of the possibility that positive results would carry stigma and elicit discrimination [1]. However, there are also worries about the effects of diagnostic testing on both patients' and physicians' perception of the treatability of the condition [12,13]. Moreover, both predictive and diagnostic genetic-testing results have implications for family members, who will have to deal with their potential shared vulnerability, and for reproductive planning, which may be affected by knowledge of the potential for passing genetic risk to offspring [14–18]. Concurrently, both patients and physicians are hopeful that increased precision in psychiatric genetic testing, as well as a more finely honed method of using information gleaned from testing, will provide preventive and treatment interventions to avoid the onset or moderate the course of mental illness [11, 15, 19].

In this article, we review many of the major ethical issues that psychiatry will face with more widespread use of genetic testing, even as we recognize the difficulties that are likely to slow the introduction of both predictive and diagnostic testing [20]. From a principlist perspective, these issues reflect concerns about beneficence and non-maleficence (i.e., ensuring that testing is helpful and not harmful to patients and families), and about autonomous choice (i.e., enabling patients to make meaningful decisions about whether to

engage in testing). Since many of these ethical concerns are rooted in inadequate knowledge on the part of both clinicians and laypeople about the genetics of psychiatric disorders and the implications of testing results, we focus on the need for thorough and clear education of physicians, patients, and families about the implications, potential benefits, and limitations of psychiatric genetic testing. Critical issues related to insufficient understanding of psychiatric genetic testing and its implications reviewed below include: (1) unrealistic patient expectations, including genetic pessimism and genetic essentialism; (2) decreased empathy and reduced therapeutic engagement among clinicians; (3) genetic counselors' unfamiliarity with psychiatric genetics and psychiatrists' lack of knowledge of genetics; and (4) the importance of genetic counseling coordinated by both psychiatrists and genetic counselors throughout the genetic-testing and treatment processes. Finally, we present our suggestions for how psychiatrists, genetic counselors, and, by extension, patients and their families can enhance their own understanding of the implications of psychiatric genetic testing and when it might best be used in the diagnostic and treatment processes.

Ethical Challenges for Patients and Families

Psychiatric genetic testing is inherently challenging from an ethical perspective, in part because the results of testing can have complex implications for patients and their families. Prior to agreeing to genetic testing, patients may feel apprehension about the effect of potential results on their mental health, e.g., increases in anxiety or depression [21]. When results are available, patients and family members may misinterpret the implications, especially because results will almost always indicate the extent of risk, rather than certainty, of mental illness [21]. Physicians themselves may be generally apprehensive about what sort of information generated by genetic testing should be conveyed to patients and their families. If the clinical significance of results is unclear or is likely to evolve as sequencing technologies are refined and larger samples are gathered, physicians may find themselves unable to provide reliable interpretations to guide either prevention or treatment of psychiatric illness symptoms [22]. Unclear ethical and legal obligations on laboratories and physicians to reinterpret genetic variants as more information becomes available may result in heightened confusion about their duties and the extent to which they can rely on an initial interpretation of test results [23]. Perhaps most acutely for patients receiving direct-to-consumer genetic testing, in which they might not have a physician serving as an interpreter of the results, but also for patients with physicians acting as intermediaries between them and the testing labs but lacking in adequate training in genetics, more questions than answers may be generated [23].

Incidental, or secondary, findings generated by genetic testing are notoriously ethically problematic [24]. Indeed, as sequencing generates increasingly extensive genomic data, the ethical quandary of how to handle them becomes ever more complicated [24]. Geneticists work to categorize genetic variants as either pathogenic or non-pathogenic, with an intermediate category of variants of uncertain significance, designations that may shift as genetic science improves [24]. Most commentators have concluded that patients and research participants should decide for themselves whether they want to learn of any incidental findings [25, 26]; however, this approach has raised many questions about what

categories of results should be offered and how, exactly, patients can be assisted to make an *informed* decision [24, 25].

Without effective educative measures and counseling, being offered a set of choices can prove more burdensome than liberating for patients. It is imperative, then, for patients first to grasp that they can opt not to learn of incidental findings and that such a choice may be reasonable, given their circumstances [24]. More generally, to meet an expanding understanding of genetic variants and emerging treatments, an educational paradigm that is flexible and responsive to fast-moving developments in genomic medicine must be implemented so that patients' decisions can be informed in a meaningful way [24]. Such a paradigm would include "categories of findings being offered, a wide range of potential benefits and risks of receiving secondary findings, implications for family members, how results would be dealt with if the participant were to become incompetent or die, data security measures, and how secondary findings from subsequent studies using participants' samples or data would be addressed" [25]. If a robust yet adaptable system of patient education can be established that supports and enhances informed consent, it can, in turn, help strengthen the process of genetic counseling [24].

In the absence of supportive and therapeutic education and counseling, patients may suffer under the weight of essentialist views of genetics—i.e., that disorders with genetic bases constitute part of their immutable essence—that may lead them to pessimistic perspectives on the inevitability of onset of illness and the failure of treatment [27]. Reduced self-esteem from these negative attitudes [21, 28] may be exacerbated by discrimination at the hands of others, including treaters [29]. For example, a study of young adults at high risk for psychosis found that one concern they expressed was that doctors would focus too much on genetic test results and too little on what their patients were telling them [21]. Another fear was of pressure to seek medical treatment after a diagnosis, even if such treatment was undesired [21].

Conversely, predictive genetic testing can fuel patients' genetic optimism: hope that critical information will be unearthed that could allow preventive measures to be taken [28]. Although such hope, often inspired by media representations of the reach of genetic research [28], can provide initial buoyancy, all too often it may be proven unrealistic. Because predictive genetic tests may never be able to provide individually tailored information like age of onset or severity of a disorder [28], and preventive interventions are limited, patients expecting to gain such knowledge in the hope that they might anticipate, alleviate, or evade the disorder altogether may experience serious disappointment. One benefit, however, is the potential for symptomatic patients to feel more in control of their condition after having learned of its genetic origin [30]. Because the cause of the illness is internal—;"not an outside force" [30], but also not something for which they are responsible [28] —;patients can experience enhanced autonomy, morale, and emotional stability.

The same issues of stigma [31] and genetic essentialism [32] can have a major impact on patients' family members as well, especially those in the immediate family of origin, spouses of married patients, and partners of unmarried patients. The implications of a psychiatric diagnosis with a genetic basis—;specifically, ascribing to a patient a socially

damaging label—;can include an increase in the patient's perceived dangerousness that extends to perceptions of his or her family [31], i.e., what is sometimes called "courtesy stigma" [33]. When a genetic illness is not readily observable, family members may seek to conceal it from those outside the family [32]. Parents of children affected by a genetic illness can experience intense feelings of guilt, believing themselves responsible for transmitting the condition [30, 34].

Spouses and partners of patients can be even more greatly affected by perceived dangerousness than other family members because of their shared social networks with patients, although spouses tend to report that the benefits of diagnostic psychiatric testing, were it available, would outweigh the risks [31,35]. Perhaps of greater concern for spouses and partners is the prospect of passing a psychiatric illness to their children. Relatives may find that unwelcome genetic test results could affect their marriagability, especially in certain ethnic and religious groups in which the stigma of mental illness can be prohibitive [36], but perhaps more broadly as well [37]. Helping patients and family members take these considerations into account will be an increasingly important aspect of making decisions about whether to undergo genetic testing for a psychiatric disorder.

Addressing the Ethical Challenges

Many of the potential negative effects of genetic testing in psychiatry on patients and family members relate to a failure to understand basic genetics and the implications of test results. Psychiatrists and genetic professionals, especially genetic counselors, can play pivotal roles in reducing the likelihood of negative outcomes, but neither group is prepared to do so today.

The Role of Psychiatrists

Although psychiatrists recognize the importance of educating patients and family members about the genetics of psychiatric disorders, they generally report themselves to be ill-equipped to do so [38]. Moreover, because there is a dearth of genetic counselors and the demand for them is growing, it is "expected that psychiatrists increasingly will be called upon to provide genetic counseling and testing to patients and their family members" [39]. Psychiatrists' education in the clinical genetics of their specialty is typically limited [40], making the likely demand for them to provide genetic education and counseling a daunting one. Counseling provided by genetics professionals involves a careful combination of education tailored to the patient and illness, nondirective facilitation of decision making, and therapeutic support [40]. Without adequate genetic education and training in counseling techniques, psychiatrists will continue to be stunted in their ability either to provide genetic counseling or to make referrals to those who can offer it. Part of the task for psychiatrists and other mental health professionals will be to overcome their own reactions—including reduced empathy and heightened pessimism about the likely success of treatment—to patients whose illnesses are believed to have a strong genetic and neurobiologic component, lest patients come to be seen "as systems of interacting mechanisms rather than as human beings" [13].

The Role of Genetic Counselors

Genetic counseling before and after genetic testing can help patients and their families and spouses gain critical understanding of the implications of genetic testing generally, as well as of patients' specific findings: "In the era of personalized genomic medicine, genetic counseling has the opportunity to become even more effective and valuable if it can adapt without losing the personalized essence of what it can accomplish" [24]. Indeed, genetic counseling can help to ensure that patients acquire sufficient understanding of the likely benefits and risks to enable a meaningful informed consent for testing. It can also help patients and families manage stigma, counteract the detrimental effects of genetic essentialism, and undercut unwarranted optimism or pessimism about the genetic findings [2, 28, 41]. Optimal genetic counseling incorporates both education and encouragement, assisting patients in embracing their autonomy and understanding what sort of control they might have in managing their symptoms [28]. Indeed, a specialized psychiatric genetic counseling clinic was shown in a naturalistic study to be successful in increasing patients' sense of empowerment and self-efficacy [42]. A small randomized trial of genetic counseling for people with serious mental disorders showed equivalent gains in knowledge in patients given educational material to read, but improved accuracy of risk perception as compared with patients on a waiting list; there were no significant differences among the groups on stigma or perceived control [43].

However, the role of genetic counselors in psychiatry has been limited to date. Most psychiatrists report not having had experience referring patients to genetic counselors [39], even though patients and families often have questions about the genetics of psychiatric disorders. Part of the difficulty lies in the small number of certified genetic counselors in the U.S. today—estimated at roughly 4000 [44], with many of them concentrated in major academic medical centers. Even where they exist, genetic counselors themselves may know little about psychiatric disorders. A 2002 survey of practicing genetic counselors and genetic counseling students found that a sizeable minority of the former group, and the vast majority of the latter, felt either somewhat or very unprepared to discuss psychiatric illnesses with patients [45]. As a result, a sizeable minority of both groups reported that they seldom or never raised issues related to psychiatric illnesses when taking family histories [45]. 83% of genetic counselors in a 2009 study said that they rarely or never saw patients referred primarily for a psychiatric disorder [46]. Austin and colleagues, reviewing the experience of the provincial medical genetics center in British Columbia, found only 288 referrals for schizophrenia over a 40-year period [47].

Suggestions for Moving Forward

Clearly, there has not been sufficient education of psychiatrists in genetics and genetic counseling techniques or of genetic counselors in the genetics of psychiatric disorders. As awareness grows among patients and family members of the role of genetics in psychiatric disorders, the demand for high-quality information and counseling is likely to increase. If clinically valid and useful genetic testing becomes available for a growing number of psychiatric disorders, such demand will be heightened even further. To meet the demand, both psychiatrists and genetic counselors will need education about the roles they each can

play in advising patients and families about the genetics of patients' disorders and the likely utility of genetic testing.

Currently, the system of continuing education for both psychiatrists and genetic counselors requires that licensed individuals earn only a certain number of continuing education credits per prescribed period, but not that they earn credits in particular areas of inquiry. The American Board of Psychiatry and Neurology requires psychiatrists who were board certified in 2012 or later to complete 90 CME credits every three years [48]. Many states have similar requirements for physician licensure. Genetic counselors' continuing education requirements, if any, are determined on a state-by-state basis; for example, in Pennsylvania genetic counselors must earn 30 hours of continuing education biennially, plus two hours of continuing education in child abuse recognition—;the only stipulation of a specified training area in that state [49]. In most states, genetic counselors are not licensed, and hence have no continuing education requirements [50].

Even if national professional organizations and state licensure boards do not mandate that psychiatrists and genetic counselors engage in specified training, both groups of professionals could help ameliorate the problem by voluntarily filling their respective education gaps. Psychiatrists should seek out opportunities to receive training in genetics, while genetic counselors should receive education in psychiatric disorders and psychiatric genetics. By learning the language and implications of the other's field, each group could become equipped for constructive collaboration, as well as for educational and therapeutic guidance of patients, families, and spouses.

These efforts will grow in importance as genetic science becomes more precise: "Advances in the identification of susceptibility loci for psychiatric disorders may have significant implications for genetic counseling in clinical psychiatry" [38]. Genetic counseling will be increasingly critical to an ethical experience for patients and their families before, during, and after genetic testing as a way of "counteracting a culture of genetic over-optimism," for example by "helping young adults at clinical high-risk for psychosis understand the limitations of genetic testing" [28]. By augmenting their respective training, psychiatrists and genetic counselors can collaboratively provide the supportive therapy proven invaluable for an ethical clinical encounter, supportive of both patients and their families [2].

Conclusions

The likely increase in the use of predictive and diagnostic genetic testing in psychiatry requires attention to the resulting ethical challenges. Many of the ethical problems that can be anticipated—;including unwarranted expectations from testing, unrealistic genetic optimism or pessimism, and stigma and discrimination—;relate to an insufficient understanding of psychiatric genetics and the implications of genetic test results. Education of patients and families about these issues will be dependent on having an informed cadre of psychiatrists and genetic counselors who can convey the appropriate information and help shape accurate perspectives. Acquiring that knowledge will be a critical task for the professions over the next decade.

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