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Ethical issues associated with genetic counseling in the context of adolescent psychiatry



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ABSTRACT

Genetic counseling is a well-established healthcare discipline that provides individuals and families with health information about disorders that have a genetic component in a supportive counseling encounter. It has recently been applied in the context of psychiatric disorders (like schizophrenia, bipolar disorder, schizoaffective disorder, obsessive compulsive disorder, depression and anxiety) that typically appear sometime during later childhood through to early adulthood. Psychiatric genetic counseling is emerging as an important service that fills a growing need to reframe understandings of the causes of mental health disorders. In this review, we will define psychiatric genetic counseling, and address important ethical concerns (we will particularly give attention to the principles of autonomy, beneficence, non-maleficence and justice) that must be considered in the context of its application in adolescent psychiatry, whilst integrating evidence regarding patient outcomes from the literature. We discuss the developing capacity and autonomy of adolescents as an essential and dynamic component of genetic counseling provision in this population and discuss how traditional viewpoints regarding beneficence and non-maleficence should be considered in the unique situation of adolescents with, or at risk for, psychiatric conditions. We argue that thoughtful and tailored counseling in this setting can be done in a manner that addresses the important health needs of this population while respecting the core principles of biomedical ethics, including the ethic of care.

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1. Introduction

Psychiatric genetic counseling is emerging as an important service that is associated with positive outcomes, and that fills a growing need to reframe simply of the causes of mental health disorders (Inglis et al., 2015; Costain et al., 2012b, 2012a; Austin and Honer, 2008). However, until now, studies of psychiatric genetic counseling have been restricted to adult populations. In order to determine whether genetic counseling is an intervention that should be considered in the context of adolescent psychiatry, we first review the purpose and philosophical underpinnings of genetic counseling, and then consider the ethical principles of autonomy, non-maleficence, beneficence, and justice in this unique context in order to arrive at recommendations.

2. What is psychiatric genetic counseling?

Genetic counseling is typically, but incorrectly, simply viewed as an activity concerned with the provision of information about the risk for children to have a heritable condition, and/or genetic testing (Hadjipavlou et al., 2014). In practice, it is a specialist discipline defined as "a process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease." (Resta et al., 2006). Rather than being restricted to applications related to rare genetic conditions, it can be applied in the context of all conditions with a genetic component - including psychiatric disorders¹ (the relatively high heritabilities of which have been well documented (Cannon et al., 1998; Cardno et al., 1999; Cardno and Gottesman, 2010; Kendler and Diehl, 1993; Bertelsen et al., 1977; Kendler et al., 1995). Genetic counseling is a client-centered, therapeutically oriented interaction (Austin et al., 2014) involving bidirectional and highly personalized communication about etiology of illness, and when requested, risk. In the context of psychiatric illness, genetic counseling also uses the shared understanding of etiology of illness that is developed during the session as a framework for helping clients to identify strategies that can be used to protect their mental health for the future. There is a strong emphasis on uncovering (Skirton and Eiser, 2003) and addressing any psychological issues that may be attached to pre-existing or new explanations for cause of illness (e.g. guilt, shame, stigma, fatalism) (Inglis et al., 2015; Austin, 2007), as these issues influence behavior (e.g. treatment adherence and help seeking) (Phelan et al., 2006).

It is important to note that genetic testing is not a pre-requisite for genetic counseling. Further, while for typical families, genetic testing may eventually surpass family history assessment (lyegbe et al., 2014) as the gold standard for determining chances for recurrence of many psychiatric illnesses of later childhood/adolescent/young adult onset (like schizophrenia, bipolar, depression, obsessive compulsive disorder, anxiety, eating disorders), this is not currently the case. As currently practiced, for families in which psychiatric illness appears to occur in the absence of indicators of a genetic syndrome, genetic counseling often involves no genetic testing (Inglis et al., 2015).

2.1. The philosophical underpinnings of genetic counseling

The philosophical underpinnings of genetic counseling practice are founded on care-based and feminist ethics (e.g. 'the counselor-client relationship is based on values of care', National Society of Genetic Counselors (2015a) Code of Ethics. This position recognizes not only the importance of the individual patient or client factors in providing care and counseling, but also recognizes the importance of broader-based contextual relationships and factors that influence a person's needs, decision making and approach (see Table 1).

For example, in recognition of the fact that genetic information has an impact on relatives (including both loved ones and estranged relatives alike), genetic counselors help individuals consider both the personal and familial aspects of such information, and when appropriate, encourage family members to be present during counseling appointments. In the context of genetic counseling for adolescent psychiatric illness the service may be appropriately offered (on a case by case basis) to: the adolescent alone, the parent(s)/guardian(s) alone, adolescent and parent(s)/guardian(s) together, or a session where each individual has time alone with the counselor, as well as time for the family as a group with the counselor.

3. Defining the ethical considerations associated with providing genetic counseling in the context of adolescent psychiatry

3.1. The importance of autonomy

Autonomy, which pertains to respecting an individual's right and ability to understand information and make decisions that are right for themselves, is a core concept enshrined by the National Society of Genetic Counselors' Code of Ethics which states that genetic counselors should: "enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences" (National Society of Genetic Counselors, 2015a). Autonomy, in its traditional sense, has been criticized by some for being too narrowly focused on the individual, without considering the importance of relationships and interdependence on a person's autonomy. However, because of its foundations in feminist ethics and the nature of the practice, genetic counseling takes a broader, relational approach to understanding autonomy than that traditionally encapsulated in ethical theory. A relational autonomy approach takes into consideration, explores, and values an individual's family and other relationships, while also recognizing that people are also embedded in a social and historical context (Mackenzie and Stoljar, 1999).

The concept of relational autonomy becomes somewhat less clearcut when considering genetic counseling in the context of adolescent psychiatry. On the one hand, the autonomy of an individual undergoing genetic counseling for psychiatric illness can clearly be promoted in a number of ways: 1) the service is offered, never forced, and it is a client's choice to engage or access the services at a time of their choosing, either once or over a series of visits; and 2) the genetic counseling sessions are client directed, and from the outset, the client's concerns, questions and needs are prioritized. On the other hand, however, the ability of a genetic counselor to promote a client's autonomy during such sessions is complicated, not just by the relational autonomy issues and considerations discussed above, (including the fact that by its very nature,

Table 1

¹ The individual genetic variants that have been identified as associated with psychiatric illnesses are not *causative* of those illnesses. The complex nature of these illnesses means that there is an interaction between the genetic variants and environmental factors, which together contribute to a person's risk of developing a psychiatric illness. The genetic material that is inherited can be considered as conferring a vulnerability to illness, rather than the illness itself. Further, in the context of genetic counseling, the genetic material can be framed not just as conferring vulnerability, but also as potentially increasing susceptibility to the beneficial effects of supportive environments (Belsky et al., 2007). There are also many contributing environmental factors which are explicitly discussed in psychiatric genetic counseling, and used to frame a discussion of modifiable risk factors, potential sources of new habits that can decrease the chance of developing a psychiatric illness, or of having a future relapse.

Strategies employed in genetic counseling that embody the recognition and valuing of contextual and relationship factors.

Actively exploring social and familial dynamics and hierarchies

Attention to cultural and religious factors

Understanding how relationships and socioeconomic structures influence an individual's capacity and constraints to choose and advocate for themselves Appreciating the medicalization of health

Exploring the client's perspective, viewpoint and, decision-making context

genetics has a familial basis), but also by the developing autonomy and capacity of the adolescent. The concept of developing autonomy recognizes that adolescents may not yet have the full emotional and cognitive ability to process complex medical information, risks and benefits; understand implications of choices; engage in rational deliberation regarding circumstances and options; and make decisions that are in keeping with their values and interests. However, the prefix of 'developing' recognizes that this ability matures over time, and that we must respect that adolescents may develop these abilities at different ages, stages and within different contexts. Experiences with life and health also contribute to an individual's unique capacity; this is particularly pertinent in this population as they may have parents or other family members living with mental illness (Diekema et al., 2011). Additionally, the concept of developing autonomy is of course complicated further if the adolescent client themselves has an underlying diagnosed (or undiagnosed) psychiatric illness.

This developing autonomy and potentially concurrent psychiatric illness have important implications for the informed consent process. Informed consent is traditionally defined as "the willing acceptance of a medical intervention by a patient after adequate disclosure by the [healthcare provider] of the nature of the intervention with its risks and benefits and of the alternatives with their risks and benefits" (Jonsen et al., 2006, pp. 56; Jonsen et al., 2010). While informed consent might not be a usual or necessary component of psychiatric genetic counseling in the traditional sense (specific informed consent for other interventions/treatments - such as genetic testing - if indicated, can be sought separately), the concept is useful in that it provides an insight into the appropriate approach that should be taken when providing medical services in general. For consent to be adequately informed, the commonly accepted standard is that the healthcare professional should provide information that a reasonable patient would need to make an informed decision. Clearly, in an adolescent population, where an individual's capacity and ability make informed choices may be in question due to their age and development (and potentially, in this context, psychiatric factors), a more tailored approach to informed consent (or assent in the case of minors) is appropriate. Such a tailored approach individualizes the information provided based on the specific client's needs, questions and contextual factors. This approach is clearly in keeping with the relational and care based underpinnings that define the genetic counseling practice discussed above, and indicates that genetic counseling is ideally suited to naturally accommodating needs associated with adolescent clients' developing autonomy.

3.2. Avoiding harms: non-maleficence and genetic counseling in adolescent psychiatry

Non-maleficence relates to ensuring actions or services do not harm the individual client. In this context, several potential harms may exist, each of which we consider below:

 The harm associated with the possibility that because of age (and/or psychiatric illness) an adolescent lacks the ability to make a fully informed choice regarding counseling (and potentially, genetic testing), resulting in decreased autonomy and potential emotional and psychological consequences.

As discussed above, these potential harms may be mitigated by provision of a carefully considered service model, grounded in the principles of care-based, or feminist ethics. Further, though it is of course beyond the scope of practice of genetic counselors to make psychiatric diagnoses, it is important that individuals providing this service have adequate training and expertise to recognize when a client may potentially be experiencing psychiatric symptoms (Inglis et al., 2015), so as to respond appropriately (e.g. by facilitating referrals to psychiatry as appropriate, rescheduling the session). Additionally, if genetic testing is being considered for an adolescent who has decreased capacity for providing fully informed consent, the position of the National Society of Genetic Counselors states that unless the test will directly inform medical care, it should be deferred until the client can consent (National Society of Genetic Counselors, 2015b).

2) The potential for harms related to privacy breeches about a youth's psychiatric diagnosis or risk status, which may lead to genetic discrimination or other harmful outcomes.

Though many types of relatives (e.g. aunts, uncles, grandparents) of currently unaffected children/adolescents can express interest in understanding chances for the child to develop psychiatric illness, we suggest that these probabilities should not be discussed with anyone other than the direct caregiver(s), or the adolescent themselves - and in these instances, only when this information is sought. Even when direct caregivers seek genetic counseling with the primary purpose of understanding the chances for a child to develop psychiatric illness, the counselor should first ensure that the client has a thorough understanding of the etiology of psychiatric illness, as well as strategies that can be used to protect mental health before providing probabilities. These discussions can help caregivers to understand that the chance for the child to develop psychiatric illness is not 100%, and that there are things that can be done to protect mental health, even if psychiatric illness cannot be definitively prevented. It is our clinical experience that in many cases, after this kind of discussion, caregivers will no longer be interested in discussing numeric probabilities for illness recurrence. Thus, after engaging in a discussion about etiology and protective factors, the counselor should reconfirm the client's continued interest in learning specific probabilities. If specific probabilities are ultimately provided to the caregiver, these should not be included in their medical record or consult report (given that the probabilities are personal information about someone other than the individual to whom the chart relates). Instead, a broad overview of the general nature and multifactorial inheritance pattern of psychiatric illness can be provided, together with a note to the effect that "individualized information about probability for recurrence was provided". This mitigates potential harms related to privacy and confidentiality breeches, both in terms of harms to the adolescent and to other family members.

3) The potential for foreseeable or unforeseen negative impacts in the short and long term on family dynamics and relationships, as well as other family members, including siblings.

Perhaps the greatest potential for negative impacts of this nature may arise when caregivers have information about the probability for a currently unaffected youth to develop psychiatric illness. Thus, if after the discussion described above, a caregiver is still interested in learning specific probabilities, the counselor must explore whether there may be limits to the autonomy of a parent/caregiver tasked in making decisions in the best interests of their child. Such an exploration must consider the autonomy and desires of the adolescent as well as the parental motivation for seeking such information. These factors should be fully but gently explored, and considerable care should be taken to discuss with the caregiver how they will psychologically manage this knowledge. It is also critical to help the caregiver consider both the potential impact this knowledge could have on their relationship with their child, and the potential consequences of sharing the information with the child in question. Other potential harms that are sometimes cited as potential consequences of psychiatric genetic counseling relate to increased fatalism or stigma that could be associated with attributing illness to genetics (Rusch et al., 2010; Bennett et al., 2008). However, as discussed above, true genetic counseling does not espouse a genetics only model of psychiatric illness, but rather an evidence based model is used, in which genes and environment interact to precipitate illness, and a key psychotherapeutic goal of the intervention is to alleviate any of fatalism or stigma that may be present (Peay and Austin, 2011).

3.3. The benefits of genetic counseling in adolescent psychiatry: the principle of beneficence

Genetic counseling in adolescent psychiatry can be provided in such a way as to not only avoid potential harms, but also promote positive outcomes, as described below.

3.3.1. Alleviating guilt through modifying clients' understanding of cause of illness

Carefully implemented genetic counseling services in adolescent psychiatry embody beneficence by respecting and accommodating an individual's right to accurate information. This is critical, because in the absence of being provided a coherent explanation for cause of illness, people will create their own, based on the lived experiences and information (sometimes erroneous) that they have gathered (Skirton and Eiser, 2003). There are serious potential negative consequences for adaptation associated with attributing an illness to either genetics or environment alone. For example, if an individual attributes their illness or family history of psychiatric illness to genetics alone, they may experience feelings such as guilt (e.g. parents of children with psychiatric illness can feel guilt for passing on "bad genes", see Table 2), fatalism and loss of hope (Bennett et al., 2008). Conversely, if individuals attribute their illness to environment alone they may experience selfblame (e.g. youth with psychiatric illness who have smoked cannabis can feel guilt about the role this may have played in the illness onset, parents can feel guilty that their actions may have somehow caused their child's illness (see Table 2)), or resentment/blame of family members and their upbringing (Phelan et al., 2006).

Genetic counselors are specifically trained in strategies for using a psychotherapeutic approach to communicate sensitively about the interplay between genetic and environmental risk factors, and can help parents and youth gain insight into the causes of psychiatric illness and reframe their role in a less accusatory lens. A genetic counselor can help clients to explore their sense of responsibility, normalize their feelings, and gain a more nuanced understanding of the etiology of psychiatric illnesses; while conveying a clear message that no single factor (whether it be parenting style, home environment, or cannabis use) *caused* the illness. This can not only alleviate some of the guilt and shame that may have been present, but also foster support and further involvement in caring for their affected child or family member. The goal is to help clients understand and appreciate that it is not

Table 2

Parents' explanations for cause of psychiatric illness among offspring, and quotes illustrating the consequences of that explanation on guilt.

| Explanation for cause of illness | Concept underlying guilt | Illustrative quote |
|--|---|---|
| Genetics only | Responsibility for illness due to passing on "bad genes" | "It came from my side, I've got the guilt if I hadn't had him, he wouldn't be like that. If I had known more at the time I probably wouldn't have had any children because of what I've seen happen to him. I didn't think about this being passed on when I was 23 years old. You think, this will never happen to me I would have made different decisions if I had known."(Austin and Honer, 2004) |
| Environment only | Responsibility for illness due to having been a "bad parent" | "The feeling that we somehow caused this is strong. This happens because we are judged harshly due to our child's behaviors. I was lectured by family members about our parenting skills." (Selkirk et al., 2009) |

their fault, and yet that there are things that they can do to protect their mental health for the future (Peay and Austin, 2011).

3.3.2. Reducing the impact of anxiety about risk of illness recurrence

Risk of illness recurrence is an important concern for people who have a relative with psychiatric illness. It is sufficiently compelling that it can lead some individuals, including resourceful and internet-savvy adolescents, to seek information out by themselves on the Internet. Because this information is not individually tailored to personal context, it may be inaccurate. Regardless of the accuracy of the information, it can produce anxiety without an appropriate avenue to address these emotions. Misunderstandings or unknowns regarding psychiatric genetic risk status for themselves or relatives may in fact be worse than the reality of their true risk.

In fact, research shows that people with a personal or family history of psychiatric illness often overestimate the chance for relatives to develop similar conditions (Costain et al., 2012b, 2012a; Austin et al., 2012). Overestimating the chance of offspring being affected can influence future life decisions, for example, deciding to have fewer or no children (Austin et al., 2006; Peay et al., 2009). Genetic counselors aim to help clients make more fully informed decisions about childbearing, which, in this context, stands to open the possibility of parenthood to some who previously felt it was not an option.

Overestimation of the chance for offspring to be affected can also lead some parents to adopt a hyper-vigilant stance, constantly on the look-out for possible symptoms (Corcoran et al., 2005). In this situation, genetic counseling can validate efforts to develop a stable and supportive home environment as a strategy that is likely to be helpful, and can provide the positive perspective that parents with personal or family history of mental illness are ideally placed to quickly recognize symptoms and seek appropriate help (which is important given that early intervention can improve long-term prognosis in psychiatric illness (Farooq et al., 2009). However, it is also important to recognize and validate the discomfort that parents often feel with having imperfect control (even "perfect parenting" cannot prevent the onset of psychiatric illness), and the anxiety that goes along with the difficulty of distinguishing emerging psychiatric symptoms from normal adolescent behavior.

Many individuals who perceive themselves to be "at-risk" (e.g. siblings or children of a person with a psychiatric illness) have fears about their own future mental health, and may feel fatalistic, that they are "destined for illness". Genetic counseling emphasizes that while the individual may have increased genetic vulnerability to psychiatric illness compared to the general population, this does not necessitate the onset of illness (indeed, the same genetic factors that confer vulnerability under some conditions may predispose an individual to thrive under others (Belsky et al., 2007)), and focuses on addressing affective responses to this information, including the difficulty associated with living with uncertainty.

3.3.3. Reducing internalized stigma and increasing empowerment and self-efficacy

The nature of genetic counseling (as described above) has led to a longstanding speculation that it could serve to decrease stigma associated with psychiatric illness (Austin and Honer, 2004; Phelan, 2002). Recent preliminary evidence supports this idea, by revealing that internalized stigma (a process whereby individuals devalue themselves, as a result of either having a psychiatric illness, or from having a family member with a psychiatric illness), can be reduced through genetic counseling (Costain et al., 2012b, 2012a).

Empowerment has been conceptualized as the polar opposite of internalized stigma (Livingston and Boyd, 2010) and has been demonstrated to be a core outcome of genetic counseling in non-psychiatric settings (McAllister et al., 2008), so it is clearly of interest in the psychiatric context. The discussion in genetic counseling of strategies like avoiding exposure to cannabis and methamphetamines (both of which have been associated with increased risk for psychiatric illness; Capsi et al., 2005; Degenhardt and Hall, 2006; Callaghan et al., 2012), and factors that are generally protective to mental health (e.g. healthy balanced diet, regular exercise regime, sleep hygiene, stress management strategies and good social supports) certainly lend themselves towards the potential for those receiving genetic counseling to feel empowered (see Box 1). Indeed, the first publication to report on the patient outcomes of psychiatric genetic counseling in a naturalistic clinical setting revealed that both empowerment and the related construct of self-efficacy were both significantly increased one month after genetic counseling (Inglis et al., 2015).

It could be argued that this benefit to the client results from the healthcare provider's duty to warn, in a non-traditional sense. While traditionally duty to warn has been conceived of as a person's duty to warn another individual about potential negative circumstances or outcomes, so that the individual can take necessary steps to reduce or eliminate potential harms, in this case, duty to warn relates to a healthcare provider's duty to provide information that is emotionally and psychologically beneficial so that an individual can take steps which are helpful to them.

3.4. Considering the bioethical principle of justice

In the context of genetic counseling in adolescent psychiatry, justice relates to the fair treatment of individuals in the healthcare system, so that individuals with like illnesses, risk factors or needs are treated

Box 1

Clinical case example of the effect of genetic counseling in an adolescent psychiatry context.

Having been referred by a child psychiatrist, Anna (age 13) and her parents came in together for genetic counseling to discuss Anna's recent diagnosis of depression and anxiety. After documenting a detailed three-generation psychiatric family history and exploring the family's understanding of the etiology of psychiatric illness, the counselor discovered that Anna's mother had received the same diagnoses as her daughter in early adolescence, and was feeling profoundly guilty about having passed on "bad genes". The whole family attributed the cause of illness to genetics alone. Anna's father pulled out a news article about a "gene for depression", and wondered whether the counselor could order a test for them. Anna's parents were feeling hopeless about things and afraid for the future, feeling very much that there was nothing that they could do to help their daughter. Anna was withdrawing from her friends, saying that she felt different in a fundamental and negative way. The counselor used the family history and discussion of Anna's experiences to personalize a discussion with the family about what is known from research about the causes of depression and anxiety. She addressed the issue of genetic testing, but repeatedly brought the conversation back to the fact that these conditions are not caused by genes alone, and that Anna's experiences with depression and anxiety were no-one's fault. Anna was able to see the temporal relationship between some stressful events that she had experienced and the onset of her symptoms, and was excited to hear the counselor talk about how research suggests that everyone is likely to have some genetic vulnerability to mental illness - she expressed feeling "less weird and different". The counselor was able to help Anna's mother slowly release some of her guilt, and to talk with Anna about "protective factors" - strategies she had used herself in her own recovery from active episodes of depression. The family left having made a pact to help each other to work on their protective factors, having decided that they were no longer interested in genetic testing.

alike (Beauchamp and Childress, 2001). Psychiatric genetic counseling services have been demonstrated to have beneficial effects for clients in the adult setting (Inglis et al., 2015; Costain et al., 2012b, 2012a; Austin and Honer, 2008) and, if implemented in a carefully considered manner, as discussed above, will conceivably have similar benefits in an adolescent setting.

Restricting this service to the adult population would mean purposefully withholding these benefits from families affected by psychiatric illness until their child reaches the age of majority; in effect, missing a critical window in which emotional well-being and social development could be supported and promoted. Making genetic counseling for mental illness available to adolescents (affected or at-risk) would help address misconceptions early, during a unique time when a myriad of options and life choices are available, before major life decisions (like parenthood) have been fully considered, and while self-identity is in development (Fanos, 1997). Providing this service for the family unit (parents and adolescents, affected or at risk) could help further strengthen the family support that is an important factor in recovery and relapse prevention for individuals with psychiatric illness (Bird et al., 2010). In sum, it seems unjust to exclude adolescents from receiving such services, which are of likely benefit to them. However, the ethical principles discussed above are critical to keep in mind as these services are implemented. While providing a detailed algorithm for providing psychiatric genetic counseling is not possible here (interested readers are directed to Peay and Austin (2011) for full details), Table 3 summarizes key elements of a recommended protocol for service delivery that is targeted towards overcoming the potential ethical challenges.

The principle of justice also relates to the allocation of resources within a healthcare system. Unfortunately, there are limited data regarding the cost effectiveness of genetic counseling in general, this is equally true in the psychiatric context. However, genetic counseling is considered to be a valuable and worthwhile endeavor in other areas of healthcare, which suggests that it makes sense that such services should also be considered a valuable and worthwhile endeavor in the psychiatric and adolescent setting.

4. Conclusion

Having reviewed the ethical issues related to the provision of genetic counseling services in the context of adolescent psychiatry, we believe that the potential psychological and emotional harms, and those related to adolescents' limited autonomy can be mitigated. The potential for benefits arising from the carefully considered application of this service are substantial. Further, we argue that the potential ethical harms related to not providing genetic counseling services are considerable, compelling, and on balance, support the need to provide these services to this population. From a justice perspective, restricting this service to adult mental health serves to further marginalize a population that is already in the shadows, and runs counter to the principle of justice that seeks to distribute limited societal resources in a manner that protects those who are most vulnerable and in need. All things considered, we argue that there is an ethical justification, indeed a moral imperative, to provide genetic counseling services in a skilled, professionally, appropriate environment in the adolescent psychiatry context.

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Table 3

Key elements of a psychiatric genetic counseling protocol to address ethical considerations in the context of adolescent psychiatry.

| Ethical considerations related to psychiatric genetic counseling in the context of adolescent psychiatry | Relevant components of the psychiatric genetic counseling protocol |
|--|---|
| Anxiety and stress due to perception of chance for psychiatric disorder recurrence | Provide bi-directional and highly personalized communication about etiology of illness. Focus on affective responses to information, including addressing the difficulty associated with living with uncertainty Estimates of probability of recurrence are provided in accordance with the following recommendations: |
| | First, the general principles of psychiatric genetics are reviewed and discussed The genetic counselor then confirms that the client still wishes to discuss numerical probabilities The client's pre-existing ideas of risk in their own family are elicited, before the genetic counselor provides probability estimates Probabilities are contextualized through explanation of the meaning and derivation of the estimates and through re-framing the number (including specification of the chance of a relative being unaffected) Affective response to receiving this information is actively explored |
| Feelings of powerlessness and lack of control over | Encourage the development of empowerment and self-efficacy: |
| future | Engage in a bi-directional dialog about lifestyle strategies to decrease risks for illness onset or for recurrent episodes Help clients identify protective factors that they are already practicing or have found helpful in the past Suggest sharing these strategies with other (possibly unaffected but at risk) family members |
| Fatalism, stigma, guilt and self-blame | Connect clients with appropriate mental health resources, peer and advocacy support groups, and community services Use a psychotherapeutic approach to communicate sensitively about the interplay between genetic and environmental risk factors: |
| | Actively explore these issues (using therapeutic techniques of reflecting listening, validation, and empathy); while also considering less self-recriminating alternate points of view Use shared understanding of etiology of illness to help client identify strategies that can be used to protect their mental health for the future. Provide physical resources to take home that summarize the information provided on a general level; encourage the client to use this medium to facilitate translation of their newsfound knowledge to family and friends. |
| The developing autonomy and capacity of adolescents | Use a client directed and tailored approach that individualizes the information provided based on the specific client's needs questions and contextual factors |
| Privacy and confidentiality of information | Ensure that the client has a thorough understanding of the etiology of psychiatric illness before providing probabilities for illness recurrence: |
| | Estimates of probabilities for illness should not be discussed with anyone other than the direct caregiver(s), or the adolescent themselves (based on an individualized capacity to appreciate this information) If probabilities for onset of illness are discussed with anyone other than the at risk individual themselves (e.g. a parent), do not include probabilities in the consult letter sent back to client's referring doctor, but instead add a general statement to the effect of: "individualized information about probability for recurrence was provided" |

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