



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 (Iyegbe 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

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.

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 clear-cut 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

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

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