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"Nothing is absolute in life": Understanding uncertainty in the context of psychiatric genetic counseling from the perspective of those with serious mental illness

Catriona Hippman[1,2,*], **Zoe Lohn**[2,*], **Andrea Ringrose**, **Angela Inglis**[1], **Joanna Cheek**[1], and **Jehannine C Austin**[1,3]

[1]University of British Columbia Department of Psychiatry, Vancouver, Canada

[2]Women's Health Research Institute, Vancouver, Canada

[3]University of British Columbia Department of Medical Genetics, Vancouver, Canada

Abstract

No genetic tests are currently clinically available for serious mental illnesses such as schizophrenia and bipolar disorder. Rather, the full spectrum of genetic variants that confer susceptibility remain unknown, and estimates of probability of condition recurrence typically have the form of ranges rather than single absolute numbers. Genetic counselors have been shown to feel that the information that can be provided for patients with serious mental illness could be more confusing than helpful. However, how those with serious mental illness perceive this uncertainty remains unknown. So, to investigate this, individuals with serious mental illness participated in a psychiatric genetic counseling (GC) session and responded to a single open ended question about their reactions towards the uncertainty that they encountered in their GC session immediately and one month post-counseling (from which themes were identified), and completed the Genetic Counseling Satisfaction Scale immediately post-session (descriptive statistics applied). While some of the 37 participants were disappointed with the uncertainty, twice as many were unconcerned. Overall, responses from immediately and one month after GC were very similar; participants were very satisfied with, and found value in GC despite uncertainty, and four approaches to coping with uncertainty emerged. Ultimately, these findings offer insight into providing GC for those with serious mental illness, and potentially could be applied to other areas of GC where uncertainty lies, with downstream impact on GC practice and future research.

Keywords

Mental illness; Genetic counseling; Uncertainty; Psychiatric disorders; Bipolar disorder; Schizophrenia; Schizoaffective disorder; Satisfaction

Corresponding Author: Catriona Hippman, Women's Health Research Institute, Rm B324A – 4500 Oak Street (Box 42), Vancouver, BC., V6H 3N1, Tel. 604 875 2424 x. 4909, Fax. 604 875 3895, catriona.hippman@ubc.ca.

*joint first authors

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INTRODUCTION

Serious mental illnesses such as schizophrenia and bipolar disorder cumulatively affect approximately 1% to 4% of the population worldwide (Merikangas et al. 2007; Okkels et al. 2012). These disorders arise as a result of factors that include a genetic component, and therefore fall squarely within the range of conditions to which GC can be usefully applied (Resta 2006). Indeed, guidelines from both the Canadian Psychiatric Association and the American Psychiatric Association suggest that GC might be beneficial for individuals with serious mental illness (Canadian Psychiatric Association 2005; American Psychiatric Association Practice Guidelines 2006).

As with GC in other contexts, psychiatric GC involves the interpretation of family history and the provision of an explanation for illness pathogenesis (Austin and Honer 2005; Austin and Honer 2008; Austin et al. 2008; Peay et al. 2008; Resta et al. 2006). Non-syndromic serious mental illnesses represent the vast majority of cases and are considered to have a multifactorial etiology. At present, no genetic variations have yet been unequivocally implicated in the etiology of these cases, and there are consequently no genetic tests available that aid meaningfully in prediction of risk. Rather, genetic counselors derive recurrence risks for serious mental illness from empiric risk data and specific characteristics of the family (e.g. age at illness onset, age of individual for whom risk is calculated) (Austin and Peay 2006). As such, there is considerable uncertainty (e.g. regarding serious mental illness etiology and recurrence risks) inherent to psychiatric GC (Austin and Peay 2006; Finn and Smoller 2006).

Uncertainty is common in health care, arising from imprecise, absent or complex health information (Han et al. 2011). In the context of GC, uncertainty may arise from a lack of predictability (e.g. inconclusive diagnosis, uncertain disease severity) and controllability (e.g. no therapeutic or preventative measures) (van Zuuren et al. 1999). Uncertainty has been most studied with respect to hereditary breast and ovarian cancer, and Huntington's disease (HD), and has focused specifically on uncertainty in the context of genetic test results. Health care professionals have been shown to feel uneasy about inconclusive genetic test results, and patients tend to expect "black and white" answers and so feel frustrated or shocked when they receive other types of results, and have difficulty interpreting their meaning (Hallowell et al. 2002; Kenen et al. 2011; Maheu and Thorne 2008; O'Neill et al. 2006; Semaka et al. 2012). In one previous study, parents of children with rare chromosome deletions perceived the usefulness of GC to be lower in the presence of higher levels of uncertainty (Lipinski et al. 2006).

We were able to only find one study to have investigated either the concept of uncertainty in GC that is unrelated to genetic test results, or uncertainty as it relates to psychiatric GC. Specifically, a survey of genetic counselors found that: some felt that explaining what is known about the etiology of serious mental illness to be more confusing than helpful for patients, and counselors perceived that patients find the inherent uncertainty underlying the explanation of serious mental illness frustrating (Monaco et al. 2010). However, no study to date has explored this issue among individuals with serious mental illness. Indeed, there

have been very few studies exploring the patient's perspective towards uncertainty in GC at all.

Understanding the perspectives of those with serious mental illness is imperative to providing effective GC to this population, and may be applied to other counseling contexts where inconclusive genetic results arise, or other forms of uncertainty exist. Therefore, the aim of this current study was to investigate the perceptions of individuals with serious mental illness towards the uncertainty associated with recurrence risk estimates and the current understanding of disease etiology.

METHODS

Design

We used a pretest posttest study design, involving questionnaires administered pre-GC (T1) and at two time points post-GC: immediately post (T2) and one month post (T3). The Institutional Review Boards at the University of British Columbia and BC Children's and Women's Hospital approved this study (H07-02427).

Participants

Individuals were eligible to participate if they had a diagnosis of schizophrenia, bipolar, or schizoaffective disorder, were fluent in English, and at least 19 years of age. Individuals were excluded if their diagnosis of serious mental illness was attributable to substance abuse; they were currently floridly psychotic and/or intoxicated. None of the participants had received GC prior to this study.

Questionnaire

The questionnaires comprised of the following: 1) sociodemographic items (See Supplemental Information) (T1), 2) one open-ended question: 'There are some areas where there is still uncertainty (e.g. exact chances for family members to become affected, exactly how many genes are involved in developing a mental illness, exactly what other factors are involved in developing a mental illness). How did you feel about not getting concrete answers to questions that you might have had about these issues?' (T2, T3), and 3) the Genetic Counseling Satisfaction Scale (GCSS) (See Supplemental Information) (T2). The GCSS is a 6 item self-report scale, where each item is rated on a 5 point anchored Likert scale (1 = strongly disagree, 5 = strongly agree), yielding total scores ranging from 6–30 (Tercyak et al. 2001). Higher scores reflect greater satisfaction. The scale is broadly applicable to measuring satisfaction with GC in a range of settings with strong internal consistency reliability (Cronbach's alpha = 0.80).

The GC session followed standard procedures for psychiatric GC (Austin et al. 2008; Peay et al. 2008) and was provided by one of three board-certified/board-eligible genetic counselors (JCA, CH, AI). Specifically, detailed three-generation psychiatric family histories were documented and interpreted, existing explanations for illness were elucidated, and then participants were provided with evidence-based information about the etiology of their condition. In addition, participants were asked about their perceived recurrence risk and

motivation for seeking GC. Recurrence risk information was presented as requested by participants. All participants were given written information to take home in the form of an educational booklet.

Data Collection

Participants were recruited from two sources: 1) referrals by local psychiatrists, and 2) self-referrals from those who had seen study advertisements in the local community. Consent forms were delivered to each potential participant with follow-up (by phone or in person) from the research co-ordinator (AR) to confirm interest in participation. An in-person enrollment appointment (T1) was arranged with those who were interested to review the consent documentation, confirm eligibility, and complete a demographic questionnaire. To confirm psychiatric diagnosis (and therefore eligibility), participants signed a release of information form to allow the researchers to access psychiatric history records, and participated in a Structured Clinical Interview for DSM disorders (SCID) administered by a trained individual (Spitzer et al. 1992). Any discrepancies between SCID diagnosis and diagnosis from psychiatric records were reviewed by a psychiatrist (JC) to establish best fitting diagnosis based on all available information. At T2, GC sessions lasting approximately 1 hour were provided by one of three board-certified/board-eligible genetic counselors (JCA, CH, AI) within clinical research space. Immediately after the appointment, participants completed questionnaires. One month later (T3), the questionnaires were completed again at the participants' homes and returned via mail.

Data Analysis

Descriptive statistics were applied to quantitative data. All qualitative data (participant responses from the open-ended question at T2 and T3) were reviewed independently by two researchers (CH, JCA) and: first, classified according to whether or not the participants appeared to perceive the uncertainty inherent to GC as being problematic using a deductive content analysis approach (Elo and Kyngas 2008); and second, coded in order to identify emerging themes among participants' strategies for coping with uncertainty using an inductive approach (Braun and Clarke 2006; Coffey and Atkinson 1996). The data collected from T2 and T3 were considered independently. Discrepancies were discussed and consensus reached. Participant verbatim quotes were selected to illustrate key points.

RESULTS

Response Rate

A total of 37 individuals received psychiatric GC. The response rate was 97% for the quantitative components (n=36) and 84% for the qualitative question (n=31).

Sociodemographic Items

Sociodemographic items are summarized in Table I. The average age of the participants was 40 years old (Range: 24 to 62).

Participants' Expectations and Motivations

When asked about their motivations for seeking GC, all the participants indicated that they were seeking information and some (n=6, 16%) stated that they were seeking information specifically for reproductive decision making purposes. When the participants were asked, prior to GC, about what they perceived the chance to be for other family members to develop the same condition, none indicated that they felt the outcome to be certain (no participants indicated that they felt the chance was either 100% or 0%). Percentages estimated by the 32 participants responding to this question ranged from 10 –95.5%, with the majority (n=20) indicating a percentage estimate between 26 – 75% and only four indicating a percentage estimate of more than 75%.

Participants' Perceptions of Uncertainty

The participants' responses were coded according to the following: 1) uncertainty is disappointing; 2) uncertainty is not disappointing.

1. Uncertainty is disappointing

   While no participants expressed strong negative reactions to the uncertainty inherent to GC, some participants (19%) were disappointed by the uncertainty. One participant said that the explanation was "kind of disappointing" because "you are always hoping to find a concrete explanation to help make sense of things."

2. Uncertainty is not disappointing

   Many participants (42%) did not find the uncertainty inherent to GC to be disappointing. One stated:

   > "I'm okay with not getting completely concrete answers. I understand that there are unknowns and also factors that are beyond our control."

It is important to note that some of the participants whose responses were classified as "not disappointed" conveyed a sense that the uncertainty was not a high priority to them; for example, they described it as "neither here nor there", or were "okay" or "fine" with the uncertainty. One participant stated, "I was happy to learn as much as I did from the session."

The remaining responses (39%) were ambiguous – neither expressing disappointment or lack thereof. For example, "I am glad that the areas of uncertainty are identified."

Participant Expectations of Uncertainty

In reviewing participants' comments, we noted that about half (52%) of the comments indicated that they had expected uncertainty. For example:

> "I don't think that there are any exact answers as each person's genetic makeup is unique and the body is a very complex machine."

Most who expected uncertainty attributed this uncertainty to the fact that "genetics is still a developing field" so "concrete answers" were unreasonable to expect.

Strategies for Managing Uncertainty

Most participants (57%) described strategies for coping with uncertainty, which led to the identification of four key themes: philosophical acceptance, spiritual comfort, trust in experts, and hope for the future.

First, the participants described philosophical acceptance as one way to manage uncertainty. For example, one participant stated:

> "No one is omniscient and even science is not fool-proof in my opinion, so I guess we just have to live with uncertainty and make the best decisions we can based on the knowledge we have at the moment."

At the basis of this acceptance was the notion that some factors are "beyond our control" as "nothing is absolute in life, so I was pleased with the info[rmation] I acquired."

Second, some participants expressed spiritual sources of comfort. One participant stated:

> "…the body and brain are very complex systems made by a sovereign, infinite Being (God) and the more we learn, the more we realize there is [more] to know."

One participant drew on these beliefs as a source of strength for coping with the uncertainty: "I have faith that my family, friends, and faith will carry me through despite these unanswered questions."

Third, participants expressed a trust in experts as one participant stated:

> "…science and medicine is ever-evolving, I am open to hearing about what the latest experts believe and will go with that."

Many acknowledged the complexity in serious mental illness etiology, which hinders advances in knowledge:

> "I can understand it is going to take some time to figure these things out. It's a huge problem. There aren't going to be any quick easy answers. I know the researchers are doing the best they can."

Fourth, many participants expressed a hope for concrete answers in the future. One participant was "optimistic that with more time and research more answers will arrive." The participants felt "encouraged" and "excited" by the "promise" of research studies. In addition to simply obtaining more information about the etiology of serious mental illness, several expressed a hope that additional knowledge will help individuals in the future who suffer from serious mental illness. For example, one participant stated:

> "Hopefully in time we will know more than we know today….I believe there will become a time when we will be able to get earlier diagnosis/screening and have more effective treatment or even a cure for everyone affected by mental illness."

Another participant was hopeful that in the future, more information would have a broader impact by helping to "remove the fears from society."

There were no apparent differences between qualitative responses written immediately after counseling and those responses written one month after counseling. However, one factor that

appeared to affect responses was the number of years of education as those with cumulatively more years of education were more likely to be unconcerned with the uncertainty and adopt philosophical and spiritual coping mechanisms. Participants with fewer years of education were much more likely to express hope for more information and advances in treatment in the future.

Genetic Counseling Satisfaction

Participants rated their satisfaction with the GC session through the GCSS. The GCSS scores ranged from 18 to 30. Three individuals scored the maximum possible score of 30. Both the average score and the median score was 25. There was no apparent association between satisfaction and demographic items such as age, education, relationship status, number of children or ethnicity. Of those participants who expressed disappointment with uncertainty (n=7), the average GCSS score was identical to that of the whole group (25), with a range of 22 to 29. One participant specifically expressed satisfaction with GC despite the uncertainty:

> "Not knowing 100% is a concern, however…. knowing more about how the genes work and the relationship to environmental factors goes a long way in mitigating most concerns"

DISCUSSION

This was the first study to report the perceptions of individuals with serious mental illness towards uncertainty in the context of psychiatric GC. These results shed light on what currently remains a relatively under-studied aspect of GC, that is, communicating about risk and etiology of illness when there is uncertainty and ambiguity.

Overall, the participants in the current study were very satisfied with the GC, as the average GCSS score was 25 of a possible 30. These results are similar to that of women who had received prenatal GC who showed an average GCSS score of 28 (Tercyak et al. 2001) and women who had pre-test hereditary breast and ovarian cancer GC who had an average GCSS score of 27 (DeMarco et al. 2004). Collectively, these results indicate that even though there are differences between these three types of counseling, patient satisfaction is consistently high.

Some participants in this current study were disappointed with the uncertainty underlying the current understanding of serious mental illness pathogenesis. However, the average GC satisfaction scores were 25 out of a possible 30 (with similar ranges) both for those who were disappointed and those who were not disappointed. This suggests that the relationship between disappointment with uncertainty and satisfaction with the GC overall is not direct, and that participants valued the GC process despite the uncertainty involved. This resonates with a previous study that found that parents of individuals affected with serious mental illness accepted the incomplete nature of the current state of knowledge (Austin and Honer 2008). These results and the data from this current study provide some evidence that genetic counselors' perceptions that the uncertainty related to psychiatric disorders renders some

aspects of GC more confusing than helpful for patients (Monaco et al. 2010) is largely projection, and that this perspective is often not shared by patients themselves.

Interestingly, almost half the participants in this current study did not find the uncertainty inherent to GC to be disappointing, and no participants expressed a strong negative reaction towards uncertainty, which is perhaps surprising given that in the context of hereditary cancer syndromes (van Asperen et al. 2002) and HD (Decuyenaere et al. 1993; Dufranse et al. 2011; Messien et al. 1991), a key motivator for pursuing clinical genetics services is to reduce uncertainty through the clarification of risk for illness. In the context of HD specifically, those who did not know whether they had inherited the HD allele length that confers disease and thus were in a state of uncertainty, had significantly higher rates of depression and poor well-being than both those known to be unaffected and those known to be affected (Wiggins et al. 1992). Altogether, these results suggest a preference towards clarification of disease development for those pursuing genetic services, if possible. The disparity in reactions towards uncertainty between this current study and previous studies may be explained by the fact that previous studies revolved around genetic conditions for which there is genetic testing available, while this is not the case for serious mental illness. Therefore, the difference in reactions to uncertainty may be related to patient expectations for clear genetic test results.

It may appear somewhat surprising that we found that most participants actually *expected* uncertainty given that, in the context of HD and cancer, patients have been shown to expect clinical genetics services to provide “black and white” answers (Kenen et al. 2011). On the other hand, previous studies have found that the lay public attributes bipolar disorder to interactions between genetic susceptibility and environmental factors, providing suggestive evidence that the lay public has an intuitive grasp of the complex etiology of serious mental illness and the uncertainty inherent in the causes of complex disorders (Meiser et al. 2005; Meiser et al. 2007). This interpretation of our findings would suggest that a strategy to mitigate disappointment with uncertainty in GC in other contexts (e.g. HD and cancer) would be to clarify expectations upfront, both one-on-one and through public education, that genetic testing and GC do not always provide clear-cut answers.

A novel and potentially significant finding was the various coping mechanisms for uncertainty described by the participants. These strategies complement those described in the literature. For example, recent studies of women with inconclusive test results from hereditary cancer genetic testing and parents of children with rare or undiagnosed conditions found that fostering a sense of control over their health was one means to cope with the uncertainty (Lipinski et al. 2006; Mendes et al. 2011; Madeo et al. 2012). Interestingly, increasing the perceived personal control of the patient has been proposed as a potentially important outcome of GC (Berkenstadt et al. 1999). Another study of parents of children who were recently diagnosed with cystic fibrosis found that collecting information about the condition reduced the uncertainty that the parents felt (Tluczek et al. 2010). Several reports have described hope as a source of comfort for those facing uncertainty in the genetic context. For example, parents of children diagnosed with genetic conditions that have a range of possible phenotypes have utilized uncertainty to open up the possibility of better outcomes than those projected by providers, serving as a fundamental construct in the

parents' coping (Truitt et al. 2012; Whitmarsh et al. 2007). While the participants in this current study also utilized hope as a coping mechanism, the idea underlying the hope was different than these studies. Specifically, the participants in this current study expressed altruistic hope for more knowledge in the future to help others, while previous studies described hope as an avenue for improved prognosis for family members (Truitt et al. 2012; Whitmarsh et al. 2007).

Implications for Practice

The results of this current study indicate that GC has value to those affected by serious mental illness, despite uncertainty surrounding risk estimates and etiology specifics. We hope that these data provide a foundation from which genetic counselors can develop confidence in the value of their services to patients affected by mental illness, even in the face of uncertainty. Genetic counselors may consider sending information in advance of a GC appointment to prepare patients for uncertainty, and/or directly exploring patients' perceptions of and reactions to uncertainty during the session. In addition, it is important to acknowledge the uncertainty and the fact that not all of the patients' questions may be answered, as also noted by Peay and colleagues (2008). Finally, genetic counselors may share the coping mechanisms described by the participants in this current study with patients who have difficulty accepting uncertainty and further explore additional coping mechanisms with patients. While these implications are most relevant for counseling those with serious mental illness, uncertainty underlies other areas of GC, so these concepts could potentially be applied more broadly.

Strengths and Limitations

In this study, we used a mixed methods approach, which allowed for the capture of a broad range of views and beliefs. As well, the longitudinal nature of the study described the participants' perspectives over time, which brought to the forefront the most consistently expressed and thus, strongest views. While these results add to the body of literature surrounding uncertainty and GC, these data have a number of limitations. This study was relatively small, and designed to be primarily exploratory and descriptive in nature, which limits our ability to generalize or extrapolate from this study to other populations, some viewpoints may have been missed, and associations with education level, for example, must be interpreted with caution. Similarly, the participants were limited to English-speaking and most were highly educated and Caucasian. Future research should explore the perspectives of those from different ethnicities or cultures, for example. There were three genetic counselors who provided GC in this study, which is a relatively small number, however, the counselors involved had different numbers of years of experience and backgrounds. This diversity somewhat mitigates the impact on the generalizability of the findings. It is possible that the dual role of the genetic counselors as researchers could have impacted the participants' responses. While all authors strove to approach the data objectively and impartially, it is important to note that three of the research team (CH, JA, AI) provided GC for participants. Last, theoretically, participants' pre-GC perception of chance for other family members to develop mental illness could impact their perception of the value of GC despite its inherent uncertainty. Specifically, those who believed that recurrence was inevitable may have found the uncertainty reassuring. However, none of the individuals in

this current study indicated that their perceived recurrence risk was 100% prior to counseling.

Future Study

Further exploration of the relationship between uncertainty and satisfaction with GC in different contexts and different genetic conditions would be valuable. Additionally, further research into issues such as the relationship between expectations of the genetics visit and satisfaction with GC with uncertain information, and coping strategies in the context of uncertainty in GC would be helpful. For example, one may explore how coping with uncertainty changes over time in relation to the time since diagnosis.

Conclusions

This study sheds light on the role of uncertainty in GC. While some participants were disappointed with the uncertainty inherent to the GC session, twice as many expressed not only that they were unconcerned by the uncertainty, but that they expected it. Four strategies for coping with uncertainty were identified and described. Ultimately, we propose that the presence of uncertainty should not be considered as necessarily diminishing the value of the GC process for patients.

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Table I

Sociodemographic Characteristics of Participants (*N*=37)

	***n* (%)**
Diagnosis	
Bipolar Disorder	27 (73)
Schizoaffective Disorder	4 (11)
Schizophrenia	6 (16)
Sex	
Female	21 (57)
Male	16 (43)
Ethnicity	
Caucasian	28 (75)
Asian	6 (16)
Mixed	3 (8)
Age	
19–29	7 (19)
30–39	11 (30)
40–49	11 (30)
50–59	7 (19)
60–69	1 (3)
Education	
Completed High School	35 (95)
Attended College or University	34 (92)
Marital Status	
Single	20 (54)
Partnered	17 (46)
Number of Children	
0	22 (59)
1	7 (19)
2	5 (14)
3	1 (3)
4	1 (3)
Unsure	1 (3)