An" Empowering Encounter": The process and outcome of psychiatric genetic counseling

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ABSTRACT:

Genetic counseling (GC) for individuals with mental illness (MI) has been shown to improve patient outcomes, such as increased empowerment and self-efficacy. However, we do not understand *how* the process of GC results in these improvements or what aspects of the process are critical. In this qualitative study, we explored the process and outcome of psychiatric GC from the patient's perspective. Ten adults with a diagnosed MI were interviewed prior to, and one month following, psychiatric GC. Interview transcripts were analyzed using Grounded Theory methodology. Participants described the GC process to be an "empowering encounter" and identified specific attributes of the process and characteristics of the counselor that contributed to their empowerment. Participants gained a new perspective on the cause and management of their MI, which seemed to facilitate a deeper acceptance of their condition. Consequently, participants reported being empowered and feeling less shame, blame, and guilt; which reportedly made them more able to manage their MI and protect their mental health; and more open to talking about their condition with family and friends. This study provides a better understanding of *how* the process of GC influences patient outcomes and highlights features of the process that maximize patient benefit.

KEY WORDS: process, outcomes, empowerment, grounded theory

INTRODUCTION

Mental illness (MI) is common in the general population with schizophrenia and bipolar disorder both affecting ~1% of the population and major depression affecting 10-25% of the population at some point in their life (APA 2000; Williams et al. 2010). The etiologies of MIs are complex – there is clearly a genetic component, but multiple genes are thought to act in concert with a host of different environmental factors to precipitate illness (Rutter 2002). While susceptibility genes have been identified, genetic testing is not yet clinically available (Gatt et al. 2015).

Despite the lack of clinical genetic testing, advancements are being made to translate knowledge on the etiology and management of MI into health services, including psychiatric genetic counseling (GC). Although psychiatric GC is still in its infancy, research regarding its use is growing (Inglis et al. 2015). Emerging research has demonstrated that psychiatric GC can improve outcomes for individuals with MI, with quantitative studies showing increased empowerment and self-efficacy, and decreased internalized stigma (Costain and Bassett 2012; Hippman et al. 2016; Inglis et al. 2015).

While quantitative studies indicate that psychiatric GC results in beneficial outcomes for patients, what is not clear is *how* the process of psychiatric GC has these effects; especially since genetic test results are not provided. In fact, we understand very little about what aspects of the GC process results in positive patient outcomes given that few studies have examined features of counseling valued by patients (Biesecker 2018). Thus, the purpose of this qualitative grounded theory study was to develop a theoretical model that describes the process and outcome of psychiatric GC from the patient's perspective. More specifically, we aimed to conceptualize what participants perceive themselves to receive during the GC process; identify attributes of the process and characteristics of the genetic counselor that participants perceive to be important, and gain insights on what participants perceive to be the impact of GC on their life.

METHODOLOGY

We used grounded theory methodology to explore participants' experiences of the process and outcome of GC for MI. Grounded theory is a fitting qualitative methodology for exploring social processes and interactions, such as the process of GC, including the patient-counselor interaction (Corbin and Strauss 1990; Strauss and Corbin 1998). Grounded theory generates findings that are rooted in participants' words and underscores aspects of their experience that they find most important, which yields rich data when exploring new topics. Findings of grounded theory studies can also be used to inform GC practice (McAllister 2001). Institutional Review Board approval was received from the University of British Columbia (UBC) and Children's and Women's Hospital Research Ethics Boards (H13-01918).

Participants:

Adults with a diagnosed mental illness were recruited from two sources: the ADAPT clinic, which provides psychiatric GC in a clinical setting in Vancouver, Canada; or a quantitative research study at UBC examining the effect of psychiatric GC on psychotropic medication adherence. Informed consent was obtained from all participants included in the study.

Psychiatric genetic counseling:

Participants were provided psychiatric GC via a certified genetic counselor working at the ADAPT clinic or with the UBC research team. The GC provided in the two contexts was the same in content, focus, and ethos, and the counselors work closely together. A detailed description of the process of psychiatric GC is provided in Inglis et al. (2015). Briefly, during psychiatric GC individuals are provided up-to-date, evidence-based information and support about the cause of their MI with the goal of helping them adapt to their MI and identify ways to protect their mental health. Much of the information and support provided during psychiatric GC is facilitated by the use of an analogy of a “mental illness jar”, which helps individuals understand how various genetic and environmental factors work together to “fill up their jar” and cause an episode of MI. The MI jar analogy also helps people better understand how to protect their mental health. Protective factors, such as sleep, nutrition, exercise, and social support, are discussed as ways to make a person’s MI jar larger, increasing its capacity to accommodate environmental stressors before becoming full.

Methods:

Two interviews, ranging from 45 to 90 minutes in length, were conducted with study participants either in-person or over the telephone prior to receiving, and then approximately one month following, GC. Interviews were conducted by AS, audiotaped, and transcribed verbatim. Both pre- and post-counseling interviews utilized a semi-structured interview guide (see supplemental material), which consisted of open-ended questions exploring participants’ experience living with a MI, receiving psychiatric GC, and their perceived impact of counseling on their lives. Participant demographics and a mental health focused family history were also obtained. As the data analysis progressed, the interview guide was refined to ensure questions captured emerging and important concepts and to further develop conceptual linkages (Corbin and Strauss 1990; Strauss and Corbin 1998). Analysis continued until data saturation was reached in all categories, meaning that the collection of additional data did not yield new information or insights. A small proportion of participants were asked to take part in a member-check interview were the final theoretical model was presented to participants to confirm their experiences were reflected in the developed model.

Data analysis:

We used NVivo 4.0 to store, organize, and manage the interview data. Data analysis involved the constant comparative method in which data from each participant was continuously compared and contrasted. Throughout the analysis, written memos were used to capture decisions regarding the data and the emerging theoretical model. Analysis began with open coding, a 'line-by-line' technique, where specific ideas or events were given a conceptual label or code (Corbin and Strauss 1990; Strauss and Corbin 1998). Using the constant comparison method the codes were condensed and collapsed into major concepts. Axial coding was then used establish the properties and dimensions of the major concepts and explore relationships between concepts. In the last stage of coding, the theoretical linkages between concepts were modified and verified and a core concept was identified, which encompassed the major concepts into a cohesive theoretical model. AS performed all coding and a proportion of initial interviews were also coded by JA. Any discrepancies in coding were discussed and resolved.

RESULTS

Participants:

Fourteen individuals were recruited to the study and completed the first pre-GC interview. Four participants did not complete the second post-GC interview and therefore were excluded from the data analysis. Of the 10 participants who completed both interviews, six identified as being female, three male, and one other and had an overall mean age of 45.5 years (range 23–71 years).

Participants had a range of MI diagnoses including schizophrenia (n=1), bipolar disorder (n=5), bipolar with psychosis (n=3), and major depression (n=1). Four participants also had a comorbid diagnosis of anxiety and/or borderline personality disorders. On average participants received their MI diagnosis 21 years prior to participating in the study (range 1-48 years ago). Many participants reported a family history of MI, having either a 1st (n=3) or 2nd (n=4) degree relative with a formal diagnosis. Table I provides further demographic information.

Overview of the "*Empowering Encounter*" Theoretical Model:

A theoretical model (Figure 1) on the process and outcome of psychiatric GC emerged from 20 interviews with 10 participants. Participants described the process of psychiatric GC to be an "empowering encounter", which reportedly had an immediate and positive impact on their lives. Participants shared that they gained a new perspective on the cause and management of their MI due to the support and information they received during the counseling process. Participants identified specific attributes of the GC process (engaging, individual focused, time) and characteristics of the genetic counselor (empathetic, non-judgmental, knowledgeable) that contributed to their new way of thinking. The new outlook that participants gained from the counseling process seemed to facilitate a deeper acceptance of their MI, which in turn appeared to result in participants being empowered and reducing feelings of shame, blame, and guilt. Being empowered made participants reportedly more able to manage their MI and protect their mental health and more open to talking about their MI with family and friends.

Participants' motivations for psychiatric GC – an emotional drive:

In order to understand how the process of psychiatric GC impacts patient outcomes, we first had to understand participants' motivations for pursuing it. Most participants indicated that they had *"never heard"* of psychiatric GC until they learned about it being offered at the ADAPT clinic or through the UBC research study. Participants struggled to clearly articulate their motivations for wanting GC. When encouraged to think about their reasons for seeking GC, most participants shared that they hoped GC would provide them "*information*" about their mental illness, whereas a few hoped GC would provide them with support or *"counseling*". Irrespective of whether participants' motives for pursuing GC were clear, all participants hoped the process would somehow be beneficial to them. It seemed as if participants were willing to pursue anything that they perceived could potentially "help" them in regards to their MI.

> *"I don't know what [GC] will provide, but whatever it is I'm sure it would be helpful. I would imagine it to be very knowledgeable and very supportive."*

While most participants said they were motivated to seek GC for information; there was the sense that for some individuals it was not simply the information but the *meaning* of that information. A few participants shared that they wished to receive information that would explain "*why*" they developed a MI. It seemed like some participants had the hope that the answer to this question would absolve them of *"fault"* and thus they would feel less shame, blame, and/or guilt. One participant stated that he hoped GC would specifically address his feelings of shame and guilt because he believed that reducing these negative emotions would aid in his recovery. Thus, for at least for some participants, it appeared like they were motivated to seek GC by a desire to reduce the negative emotions they felt about themselves and their MI.

> *"[GCing] might give me a better understanding of why [I developed MI] and I think I would feel a bit of ease if I had the reason why."*

> *"Maybe I would know, this is going to sound silly, [but] I would know [my MI] wasn't my fault."*

> *"I'm hoping that the genetic counseling will help with the guilt and shame component that goes with [MI] and plays a big role [for me] and if it can help with the guilt and shame then I think it will set me on the right path, [put me] in the right frame of mine, so that the energy that I waste putting into that can be put into healing. "*

Receiving support and information:

Participants described the process of psychiatric GC to be "*psycho-educational*" and provided them both "*support*" and "*information*". For some participants, the support component appeared to play a more dominant role in the counseling process, whereas for others the information element seemed to take a leading role. Nonetheless, participants felt that both aspects were integral to the overall GC process and couldn't say that one facet was more important than the other. In fact, some participants articulated that it was the unique combination of support and information that made the process of GC so helpful.

> *"In [GC] I think the person is getting information and is [being] supported at the same time and I think that's just really important to have both, to be supported and as well as getting the information."*

> *"I definitely think that in [GC] it was about support and me gaining information"*

Receiving support:

For participants the support received during the process of psychiatric GC was largely experienced as "*being heard*" and "*feeling validated*".

Being heard:

Participants shared that during the process of psychiatric GC they felt like their experiences, thoughts, feelings, and behaviors in relation to their MI were recognized and acknowledged. Participants described how the genetic counselor listened to them and expressed a genuine interest in understanding their MI *"story".* Feeling like their thoughts, feelings, and behaviours matter to the counselor seemed to help participants develop a rapport and deep sense of trust, which in turn appeared to be foundational to their new perspective and empowerment.

> *"I think part of the charm or part of what made the session helpful was that [the genetic counselor] was very approachable, very empathetic. I felt I was being heard."*

> *"[The genetic counselor] let me talk, which is something that I think a lot of people don't do… to be able to talk about what I do [to manage my MI], to be heard and be validated was helpful."*

***Feeling validated*:**

Participants explained that throughout the psychiatric GC process their experiences, thoughts, feelings, and behaviors in relation to their MI were recognized and accepted as understandable by the genetic counselor. Participants shared that the counseling process helped them realized that their experience with MI was *"normal"* and typical of others living with the condition. For some participants feeling validated appeared to support their efforts and actions in managing their MI, whereas for other participants it appeared to minimize their feelings of guilt, blame, and shame.

> *"[GC was] just validating, like now I'm sure that what I go through is what a lot of people go through."*

> *"I liked that [GC] affirmed a lot of the things that I've been trying to do to manage my mental illness… so its good to know that, like it validates my efforts."*

> *"Some of the things that we talked about in the session were things that I was already doing without knowing why I was doing them… I've explained to people [that] I need 10 hours of sleep, otherwise I go crazy, and they're like, 'yeah, right, you need 10 hours of sleep when you are twenty [years old] not now', so that was something that was really validated for me."*

Receiving information:

Participants explained that they received two types of *"information"* during the process of psychiatric GC - factual knowledge and "tool" to help them understand that knowledge.

Knowledge:

Participants described receiving knowledge during the process of psychiatric GC that was centered on two different aspects – facts about the cause of their MI and behaviours that can they can use to manage their MI and protect their mental health. Many participants highlighted that while these topics were discussed in a broad general sense, the facts provided were primarily tailored to their own personal circumstance. Interestingly, only a small proportion of participants indicated that they learned "new" knowledge during the counselling process; instead, most participants explained that GC clarified their previous knowledge or helped them understood it in a new way.

"[GC] was more like I was coming in so that I could get information so that I could get tools and knowledge, and less about me coming in to be evaluated and judged.

"Until genetic counseling, no one ever coherently explained to me why <u>I</u> have a mental illness."

"The two things that happened during my appointment with the genetic counselor were it was explained to me why this happened to <u>me</u> and what <u>I</u> can do to make it better."

A tool for understanding:

All participants acknowledged the value and importance of the "mental illness jar" analogy used in the process of psychiatric GC, and the ease with which it helped them understand the cause and management of their MI. Participants explained that they liked how the analogy presented the facts in a simple and accessible manner and discussed how helpful it was that it could be applied to everyone yet also modified to represent their own particular situation. In essence, it appeared like this analogy acted like a *"tool"* to assist participants in their capacity to understand the facts regarding the cause and management of their MI and played a critical role in the new perspective they gained.

"I think that the simplified jar analogy was good, it was easy to understand and was presented in a really good way. I thought it was a useful tool."

"I went in with a lot of the information that I gained from my personal experience, but [GC] put it into words, in a way of explaining it that is more accessible."

"[I] had a little bit of base knowledge of how mental illness works, but it hadn't been explained to me in quite that simple of a fashion. It was definitely good. I liked the [jar] visuals they used, it was really easy to understand… it's easy to remember… it's something that I will probably recall for the rest of my life."

Attributes of psychiatric genetic counseling:

Participants highlighted specific attributes of the psychiatric GC process that appeared to contribute to their new perspective and their feelings of empowerment. Most participants were able to articulate the qualities of GC that they found unique by comparing their counseling experience to other mental health care interactions.

Engaging:

Many participants described psychiatric GC to be an "*engaging"* process. Participants shared that they felt like they were part of a process that involved mutual communication and respect. They explained that they felt like they were a *"partner"* in the discussion and made a *"connection"* with the genetic counselor. It seemed like this type of interaction helped the participant and the counselor create a shared understanding. Some participants articulated that this interaction was unlike what they normally experience in their mental health care where they often feel talked *"to"* instead of engaged *"with"*.

"It was a conversation with the genetic counselor, we both asked questions, we both gave answers. It was an open dialogue a lot of two way communication, as oppose to just one way… The last few major manic episodes that I've experienced, I didn't know really what was going on… it was never really

> *clearly explained what the diagnosis was, how that came about, what my treatment options were. I never really felt like I was part of the process."*

> *"I think the way it was approached in my genetic counseling session was that it was a discussion, it wasn't a lecture, it was a two person discussion, a person-to-person type of* conversation, not a seminar being given."

Individual-focused:

Many participants recognized that the information and support provided during the psychiatric GC process was tailored to them as an individual with their own experiences, thoughts, feelings, and behaviours. It seemed to many participants that everything about the counseling process was focused on them as unique individuals from receiving customized information based on their family history or personal experience to acknowledging their specific questions and concerns. It seems that the personalized focus of both the content and nature of the counseling process assisted participants in understanding their *own* mental illness and played a significant role in the new perspective they gained and the empowerment they achieved.

> *"[GC] wasn't a one-size fits all model either, we got into a conversation about how for me one of the major things to stave off depression is having a dog."*

> *"Just the nature of how everything was explained and how the discussion flowed, it was kind of personal versus just generic for anyone."*

> *"Any question that I might have, no matter how ridiculous, whether or not I was being sarcastic or not, were answered and I think that was important."*

Time:

Many participants noted that the length of the session was an important attribute of the psychiatric GC process. Participants indicated that the counseling process took time and consequently they did not feel *"rushed"* through the session and were provided numerous opportunities to ask questions or voice concerns. Participants also explained that having ample time for the session significantly contributed to the support they felt they received.

> *"When I'm at other [mental health care] appointments, they are just so bombarded with clients and cases… you do feel rushed from time to time. With [GC] it was more a relaxed pace, where you were able to really spend time talking so that's where a lot of the feelings of support comes from."*
>
> *"The main thing is [GC] was longer, you don't get to see a professional for hours, usually like 10 minutes only, I mean I was diagnosed in 10 minutes with a major mental illness, so that was good and talking to someone who gives you enough time to say everything you wanted to say. I didn't feel rushed. I got to say what I wanted to say."*

Characteristics of genetic counselor:

Participants highlighted several characteristics of the genetic counselor that appeared to work together to help establish rapport, build trust, and contribute to the new perspective that they gained. Participants described their counselor to be empathetic, non-judgemental, and knowledgeable.

Empathetic:

Participants described their genetic counselor as someone who demonstrated kindness and *"genuine"* care. Many participants spoke about having a *"gut feeling"* that the counselor was a *"good person"* and had both the desire and ability to understand *"where they were coming from"*. Participants described how this caring nature helped them make a *"connection"* with the counselor and build trust in the counseling process.

> *"The lady that was giving me the genetic counseling, she seemed very caring and understanding about me and my mental illness and I think that made a big difference."*
>
> *"[The genetic counselor] had a genuine way about her, she was a caring person, so that was great. She wasn't asking things in a cold clinical way, she was engaging."*

> *“I just felt that [the genetic counselor] really understood what I was going through and was really open to connecting.”*

Nonjudgmental:

Participants described that throughout the GC process the genetic counselor refrained from making any value judgments about the cause or management of their MI based on either their personal or societal values. They felt like the counselor was *“open”* to hearing their experiences and perspectives and discussed MI in a *“matter-of-fact”* manner. Some participants highlighted the importance of this accepting nature particularly in regards to discussions about psychotropic medication, where the counsellor did not pass judgment about the *“laundry list”* of medications the participant took or conversely they did not criticize the participant’s decision not to take medication as prescribed.

> *“I didn’t feel like [the genetic counselor] was judging me, I felt like she genuinely wanted to help me.”*
>
> *“I went to this doctor and he didn’t seem to believe me that I was having these problems, [he thought] I was a con-man [when] I said I needed a note to take to welfare to tell them that I can’t work and he was like ‘OK, yeah, sure’, in a very sarcastic tone, ‘how about this? [Participant’s name] can’t do anything, ever’. I mean that was supposed to be a health professional but it was purely his own personal feelings on the subject, nothing scientific about it, just the viewpoint he had. So it was so nice to be around real professionals like you [genetic counselors], who know what they are talking about, who are scientific, not prejudiced or biased, and not putting their personal opinions on things.”*

Knowledgeable:

Participants described their genetic counselor as someone who was intelligent and well informed about the scientific and clinical aspects of MI but also someone who possesses insight and understanding on the lived experience of MI. Consequently, participants seemed to develop a trust with the counselor, which seemed to give more credence to the information they provided.

"With [the genetic counselor] there was a lot more knowledge on her part and [it was] evident that she's heard stories and worked with people who have mental health issues that are the same as I have."

"[It was like] talking to someone intelligent and understanding and knowledgeable, who listened and [was] interested, you could tell she cared about the subject and helping people, helping me."

Gaining a new perspective:

Through the process of psychiatric GC, participants seemed to acquire a more complete and cohesive understanding of the cause and management of their MI leading them to gain a new perspective. Participants described that GC changed the way they thought about their MI in the following way: they realized that everyone is susceptible to MI; that they did not personally cause their MI; and that there are things that they can do to manage their MI and protect their mental health.

Prior to GC many participants knew that MI is caused by genetic and environmental factors and/or that it can generally be managed by medication and appropriate sleep, exercise, and nutrition but many participants were unable to articulate what this meant in regards to the cause and management of their *own* MI. It seemed like the GC process, specifically the tailored knowledge combined with the jar analogy that acted as a tool to assist participants in their capacity to understand, provided participants a more meaningful understanding and this seems to not only facilitated their disease acceptance but also empower them.

"Now I just have a better understanding of the whole concept of mental illness."

"[GC] helped put [MI] in perspective, like how prevalent mental illness is and somewhere, you always knew that everyone was possibly susceptible but actually hearing it and knowing it, it makes it feel less like I've made mistakes and [I've] not necessarily caused my mental illness and there are things that I can do to help [manage it]."

Facilitating acceptance of mental illness:

The new perspective participants gained from the psychiatric GC process seems to facilitate participants' acceptance of their MI. While many participants described themselves as being in a place of acceptance with their MI prior to GC, these participants also explained that the process of GC helped them "*come to terms*" with their MI on a deeper level. Some participants further explained that they wished that they had received GC shortly after they were diagnosed because they believed that it would have been beneficial to their initial acceptance and their ability to *"own"* their MI.

> *"[GC] has given me a lot more acceptance around [my MI], especially the family tree part. When I was first diagnosed, I was in denial and I was also a bit angry about it, but I think if I had this type of information back then, it would [have been] helpful to me, it would have helped me understand a little better and maybe come to a place of acceptance a little earlier."*

> *"Any human being on this planet, with the right circumstances, their jar can be full. It's not about the mistakes that you've made or even just genetics, it's a combination of all sorts things… so even if [GC] doesn't fully make them accept, "yes I have schizophrenia", "yes I have bipolar" … it still empowers them to be more aware and to think about things that they can do on a day-to-day basis to help manage it."*

Being empowered:

Many participants described the process of psychiatric GC to be an "*empowering encounter*". All participants expressed feelings of shame, blame, and guilt regarding their MI. These negative emotions appeared to largely stem from participants beliefs that their MI makes them a "*bad*" or "*weak*" person and/or that their MI is their *"fault"* or something that they should be able to "*control*". While the magnitude of these emotions varied amongst and between participants, all participants described being empowered by a reduction in feelings of shame, blame, and guilt following the counseling process and seemed to express a more positive and confident belief in themselves and their MI.

> *"[GC] gets rid of some of the shame. If you have a heart attack, you can easily identify what happened to you – oh, you had a heart attack, well it probably has something to do with the 4 cheeseburgers you eat at work every week [laughs]. There's a reason you can quickly identify*

> *[about] what went wrong… whereas with mental illness, it's so hard to know what you did wrong but really you didn't do anything wrong and [GC] just explains that to you... so you're able to look at this and think, 'OK, this isn't my fault."*

> *"There's always that thought, maybe you're just a bad person, maybe you're just lazy; you know that that's not true but in the back of your mind those things are always linger. It's good to know someone who knows a lot about the subject tell you 'no, you're normal, other people experience that too', and these are the causes or reasons for it. It lifts some of the guilt and shame. It makes you feel a little better that you're not a bad person, and this happens to others, there are scientific reasons for it."*

Participants also shared that the GC process made them feel like they had greater "*control*" over their MI and the actions that affect their mental health. The counseling process appeared to empower participants by helping them internalize the idea that they can in fact "*do something*" to manage their MI.

> *"[GC] made me feel more empowered in the things that I can do, like it made me more empowered to be able to manage what I've been given or where I'm at now. Whatever has happened, whatever I've done or not done that has caused my jar to look the way it does, whether I've added the little triangles or not, I still have the power to add rings and to ensure that I'm protecting myself."*

> *"[GC] made me more empowered to help myself… I've never, since I've been put into the mental health system, I have never had anyone make me feel like I was in control of my own destiny. I've always felt like I am at the mercy of medication, I am at the mercy of whether I can get treatment, I've never felt like there's something that I could really do for myself."*

> *"After counseling I am feeling more empowered and feeling educated, feeling more knowledgeable, feeling heard and to feel that way and not receive that in other areas of counseling or in other areas of care within mental health, it was just really, really helpful."*

Improving mental illness management:

Following psychiatric GC many participants discussed feeling empowered in their ability to manage their MI. They perceived the counseling process as having had a positive and immediate impact on their ability to manage their MI. Participants shared that understanding how their behaviour can impact their mental health has made them "*stop and give pause*", meaning that they now consciously think about how their actions could impact their MI. Some participants discussed how GC motivated them to adopt new protective strategies like good sleep, nutrition and exercise; whereas other participants described how the process reinforced the behaviors they currently use to protect their mental health.

> *"I felt in control, you know [GC] made me feel more empowered than I did when I walked in and I think for me that's a big deal… I just felt after the appointment I had more tools to control my life."*
>
> *"[GC] kind of gives you that motivation to keep going with the things that you are doing to manage your mental health, whether that be continue taking your meds, getting better sleep, getting that exercise, you know, all those various things that you can do."*
>
> *"[GC] was very empowering and reaffirming and made me feel like I was on the right track and so it helped maintain that motivation and that's what I feel sets it apart from other health care - the fact that I get to be educated and if I'm already doing what I'm supposed to be doing, they cheer me on [laughs]."*

Prior to GC most participants seemed to have come to a place of acceptance about their need for psychotropic medications and routinely took them as prescribed, despite some of the drugs side effects making them reluctant to do so. While most participants did not indicate that GC impacted the likelihood or frequency of using of medication, participants did discussed how the counseling process made them feel less shame, blame, and guilt about needing medication and consequently they *felt better about using it*.

> *" [GC] didn't have an impact on how I perceive my medication at all, I mean I know I need to take my meds, and so I take my meds… it just gave me a better understanding of what I can do to improve myself and medication is one of them."*
>
> *"I don't think I'll ever be able to not be on medication, that's the severity of my mental illness and I'm okay with that. I've come to terms with it and I'm not on very much. But when you're going through the mental health system, I think a lot of it is based on pharmaceuticals; you get a handful of pills and that handful of pills is going to control your life, and if it doesn't help you then you're S.O.L. but that's not how I felt when I left [GC]. I*

> *felt that there were other things that I could do, lots of other things that I could do in addition to medication."*

Talking about MI:

Participants described being empowered to talk about their mental illness with others following the process of psychiatric GC. Individuals indicated that the counseling process provided them both the knowledge and the tools to more easily communicate with others, particularly their support network of family and friends. The reduction in feelings of shame, blame, and guilt also seemed to empower participants to be more vocal about their MI.

> *"[GC] empowered me to be able to talk with my family and friends more and made me realize the importance of having that open dialogue for my safety and others."*

> *"There's still a lot of stigma in your mind [which impacts] the way you communicate [about your MI], whereas, after the genetic counseling you feel more empowered to talk about it."*

> *"[Before GC] I had some understanding of the psychology behind mental illness but taking that information and my experience and trying to communicate it to somebody else, [it] either came across as me trying to justify what's happened, or it didn't necessarily make sense to somebody else so I couldn't communicate it effectively but [GC] has enabled me to do that."*

DISCUSSION

The findings of this study show how participants perceive the process and outcome of psychiatric GC to be an "*Empowering Encounter*". Until recently, the outcomes of GC services have focused on provider-defined measures such as knowledge, risk perception, and decision-making (Madlensky et al. 2017; McAllister et al. 2011). But as understanding of the benefits of GC evolves and attention turns to patient-reported outcomes (Deshpande et al. 2011), empowerment (McAllister et al. 2011, McAllister and Dearing 2015) and adaptation to health threatening information (Biesecker et al. 2013) have been identified as important outcomes of the GC process. While research is continuing to provide new insights about the effects of GC on patient's lives; in actuality we know very little about what the process of counseling achieves from the patients' perspective. In the *Empowering Encounter* model of psychiatric GC, patients described outcomes they perceived receiving from the counseling process. Participants shared that they gained a new perspective on the cause and management of their MI, which facilitated a deeper acceptance of their mental illness, and provided a sense of empowerment. As a consequence of being empowered, patients explained that they experienced a reduction in their feelings of shame, blame, and guilt surrounding the cause and management of their MI; which reportedly made them more able to manage their MI and protect their mental health; and more open to talking about their condition with family and friends

Empowerment as an outcome of GC has garnered much attention in recent years and our group has quantitatively demonstrated that receiving psychiatric GC is associated with a statistically significant increase in levels of empowerment as measured by the Genetic Counseling Outcomes Scale one month following counseling (Inglis et al. 2015). The *Empowering Encounter* theoretical model corroborates the significance of empowerment as an outcome of psychiatric GC from the patient's perspective. Individuals receiving GC for non-psychiatric reasons have also described empowerment as an important outcome of the GC process (McAllister et al. 2008, 2011). The significance participants attach to empowerment as an outcome of GC makes sense given that empowerment, which is conceptualized as the counterpoint to internalized stigma (Livingston and Boyd 2010; Shih 2004), has been shown to be associated with decreased feelings of hopelessness and helplessness, improved quality of life, and increased ability to cope and engage in help seeking behaviours (Angermeyer et al. 2003; Eisenberg et al. 2009). These concepts are reflected in the *Empowering Encounter* model. Participants described the GC process as having a positive impact on their life by decreasing their feelings of guilt, shame, and blame about the cause and management of their MI, and increasing their sense of control over their ability to manage their MI by engaging in protective health behaviours. These elements of the *Empowering Encounter* model are supported by quantitative findings that report decreased measures of guilt and internalized stigma after psychiatric GC (Austin and Honer 2008; Costain et al. 2014), and by previous qualitative work in a general genetics setting (McAllister et al. 2008).

As critical as it is to understand *what* patients perceive to be the outcomes of GC, understanding *how* these outcomes are achieved is equally important in order to optimize patient benefit. To date we know very little about the features of the GC process that are valued by patients for contributing substantively to the outcomes they achieve (Biesecker 2018). The *Empowering Encounter* theory identifies aspects of the process and characteristics of the genetic counselor that individuals deem important to being empowered. Participants valued the personalized nature of the information they received and appreciated the focus of the counseling on the person as a unique individual. Together this seemed to make the process more meaningful to their experiences, thoughts, feelings, and behaviours. They also highlighted the usefulness of the mental illness jar analogy as "tool" in which to understand the knowledge they received. It seemed like this tool helped link the cause of MI with protective health behaviours and facilitated the creation of a shared understanding between the participant and the counselor by providing a common language in which they could engage and talk about the cause and management of MI, allowing individuals to gain a new perspective on these aspects of their MI.

While research has shown that genetic health information alone does not result in individuals changing their behaviour in order to mitigate health risks (Hollands et al. 2016), the *Empowering*

Encounter model shows that individuals perceive the process of psychiatric GC, which includes the provision of genetic health information, as empowering them to improve the management their MI by adopting or reinforcing protective health behaviours. Our model, which closely aligns with the *Reciprocal Engagement* model of GC, recognizes that while the communication of genetic health information is an important element of the GC process, the counseling relationship plays an integral role and individuals' emotions matter in the process (Veach et al. 2007). Participants in our study similarly indicated that in addition to the genetic health information they received, being heard and feeling validated in an engaging, empathetic, and non-judgemental manner played an important role in being empowered, which facilitated behaviour change improving their mental health (Austin 2015). This finding underscores the importance of listening and truly hearing what individuals are saying in order to understanding and attend to the emotions behind their words (Austin et al. 2014). The important link between genetic health information and addressing individuals' emotions is demonstrated by participant's apparent desire for GC to provide them information that will explain 'why' they developed MI, which often alleviates feelings of blame, shame, or guilt regarding the cause and/or management of their illness. Thus, it seems that addressing participant's implicit self-stigma enables their cognitive processing of genetic health information, which has the potential to empower behaviour change.

Limitations:

Participants in this study were a self-selected group of individuals who sought GC at the Adapt clinic or through the UBC research study and who were willing to participate in an interview research study. Therefore, it is possible that the *Empowering Encounter* model of psychiatric GC does not reflect the broader collective experience of individuals with MI. However, there was good distribution amongst participants' age, gender, MI diagnosis, and time since diagnosis, which suggests a range of experiences and perspectives were captured. Another limitation of this study is that while participants reported being empowered and thus more able to manage and talk about their MI one month following GC, it is not clear whether these outcomes persist over time. Anecdotally, it seems like the outcome of psychiatric GC is long lasting since participants who took part in a member-check interviews shared that they were still reaping benefits despite having received the counseling over two years previously. Examining the longevity of outcomes following psychiatric GC represents an interesting and important area for further study.

Practice Implications:

This study provides further evidence that GC improves outcomes for the psychiatric patient population, which supports the need to implement psychiatric GC as a standard practice offered to all individuals with a MI. The *Empowering Encounter* theoretical model contributes important insights on the process of psychiatric GC from the patient's perspective and could help inform the development of practice guidelines, which are not currently available. The development of clinical guidelines may encourage the provision of psychiatric GC as a routine clinical service by providing direction on appropriate practice, especially since few genetic counselors have received formal training in providing psychiatric GC.

Research Recommendations:

This research points to a number of avenues that warrant further study such as a detailed examination of the behavior change individuals reportedly engage in following psychiatric GC and the specific protective strategies that individuals adopt. A number of participants in the study expressed a wish for family members, particularly parents, to receive psychiatric GC. Research could also explore the impact of psychiatric GC for family members on family dynamics, support, and stigma. Lastly, many participants who had received GC years following their diagnosis commented that they wished they received GC earlier believing that it should be provided as soon after diagnosis as possible. Research examining when GC should be offered following diagnosis in order to maximize patient benefit is needed, especially if psychiatric GC becomes routine practice.

CONCLUSION

The *Empowering Encounter* theoretical model conceptualizes the process and outcome of psychiatric GC from the individual's perspective; identifies attributes of the process and characteristics of the counselor that patients perceive to be valuable; and substantiates empowerment as a positive outcome of GC services.

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Human Studies and Informed Consent:

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Conflict of Interest:

AS and JA declare no conflicts of interest.

Authorship Contributions:

Alicia Semaka: Provided substantial contributions to the conception and design of the work; the acquisition and analysis of the data; the drafting of the manuscript; and approved the final version to be published. AS agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Jehannine Austin: Provided substantial contributions to the conception and design of the work; the data analysis; the revising of the manuscript; and provided final approval of the version to be published. JA agrees to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Table I: Participant demographics

Characteristics		n (%)
Gender		
	Male	
	Female	
	Other	
Age (years)		Average: 45.5 (Range: 23 - 71)
Education		
	High school	3
	College	4
	Undergraduate	3
Employment		
	Full Time	1
	Part time	3
	Unemployed	1
	Medical Leave	2
	Disability	1
	Retired	2
Marital Status		
	Single	3
	Common law	2
	Married	3
	Divorced	2
Children		
	No	4
	Yes	6
Mental illness diagnosis		
	Schizophrenia	1
	Bipolar disorder	5
	Bipolar disorder with psychosis	3
	Major depression	1
	Co-morbid anxiety and/or borderline personality disorders	4
Time since diagnosis (years)		Average: 21 (Range: 1 - 48)
Family history mental illness diagnosis		
	None	3
	1st degree relative	3
	2nd degree relative	4

Figure 1: The *"Empowering Encounter"* theoretical model of psychiatric genetic counseling