The effects of a documentary film on public stigma related to mental illness among genetic counselors

Kelly Anderson, MSc.¹ and Jehannine C. Austin, PhD^{1,2}

¹Department of Medical Genetics, University of British Columbia, Vancouver, B.C., Canada

²Department of Psychiatry, University of British Columbia, Vancouver, B.C., Canada

Abstract

Many people, including genetic counselors (GCs), have been found to hold stigmatizing attitudes towards people with mental illnesses. We aimed to determine whether these attitudes could be changed by exposing GCs/GC students to a documentary film about people with mental illness. We screened the documentary at the 2010 North American conferences for GCs. Immediately before (T1), immediately after (T2), and one month after (T3) watching the documentary, participants self-rated their comfort with asking patients about mental illness, and completed scales measuring two aspects of stigma: stereotype endorsement (SE) and desire for social distance (SD). A total of 87 T1 and T2 questionnaires, and 39 T3 questionnaires were returned. At T2 and T3, 34.5% and 48.7% respectively reported feeling more comfortable to ask patients about mental illness. Scores on SD and SE scales decreased significantly from T1 to T2, but returned to initial levels at T3. The documentary increased GC/GC students' comfort with asking about mental illness and temporarily decreased stigmatizing attitudes.

Keywords

Stigma; mental illness; genetic counseling; genetic counselor; documentary; schizophrenia; bipolar disorder; social distance; stereotype endorsement

INTRODUCTION

The term “mental illness” is used to describe mood disorders such as depression and bipolar disorder, psychotic illnesses such as schizophrenia, and anxiety disorders such as panic disorder. These are common conditions, and although they rarely constitute the primary reason for referral (Hunter et al. 2010) they can often be uncovered in clinical genetics settings when documenting a family history. Mental illnesses are amongst the conditions that are most profoundly affected by disease-associated stigma – indeed, it has been suggested that for some affected individuals, the effects of mental illness-related stigma are so negative that they actually often outweigh the negative effects of the illness itself (Hinshaw and Stier 2008). Stigma is a complex social construct comprising interrelated processes that operate at

the level of institutions (institutional stigma), social groups (public stigma), and the individual (internalized or self-stigma) (Corrigan and Watson 2002; Hinshaw and Stier, 2008; Lauber and Rossler 2007; Link et al. 2004). Of the three levels at which stigma operates, public stigma (defined as the phenomenon whereby large social groups have negative attitudes towards and beliefs about, and even act against those with a disenfranchised trait - like mental illness (Corrigan and Watson 2002)) has received the greatest attention. Public stigma related to mental illness has been investigated in a broad range of groups including the general public (Corrigan and Watson 2007; Kobau et al. 2009), students (Brown 2008; Chan et al. 2009; Corrigan et al. 2001; Corrigan et al. 2003; Corrigan et al. 2007; Faigin and Stein 2008; Mann and Himelein 2008; Penn et al. 1994; Reinke et al. 2004) police (Watson et al. 2004), and mental health workers (Nordt et al. 2006; Schulze 2007). In all groups in which public stigma has been investigated, negative beliefs about, and attitudes and behaviors towards individuals with mental illness have been identified. Public stigma can have damaging effects for people with mental illness. For example, negative attitudes of mental health workers and psychiatrists towards individuals with mental illness has been associated with decreased use of needed healthcare services amongst individuals with mental illness, thus exacerbating the effects and symptoms of the illness on the individual (Lauber and Rossler 2007; Nordt et al. 2006; Rusch et al. 2005).

In the context of genetic counseling, public stigma related to mental illness on the part of the clinician could negatively affect the rapport building and development of a therapeutic alliance between genetic counselors (GCs) and their clients; these are components of the healthcare communication process that are vital to positive outcomes (Zolnieriek and DiMatteo, 2009). There is a scant body of empiric research that has explored practices in clinical genetics setting related to mental illness, but, in one study, some GCs were found to not ask about psychiatric illness when taking a family history because they felt uncomfortable to do so, or because they were concerned that their patients would be uncomfortable (Monaco et al. 2009). The authors posited that a potential explanation for this was mental illness related stigma. A subsequent recent study provided direct evidence that like other healthcare professionals, GCs have negative beliefs about and attitudes towards individuals with mental illness (Feret et al. 2010).

Individuals with mental illness and their family members have been shown to want to have their concerns regarding the etiology and recurrences risks for psychiatric conditions addressed (Monaco et al. 2010, Lyus 2007). Thus, failure to enquire about personal or family history of mental illness within a genetic counseling session not only precludes the possibility of thoroughly addressing relevant client history, it also prevents genetic counselors from fully attending to clients concerns. Thus, there is a need for studies that aim to evaluate interventions designed to reduce negative attitudes towards individuals with mental illness in this population.

Although various interventions have been used in an attempt to reduce public stigma related to mental illness, education about mental illness and social contact with affected individuals seem to be the most effective. In particular, social contact with members of a stigmatized group has been shown to be effective in reducing negative attitudes concerning the labeled out-groups (Chan et al. 2009; Corrigan et al. 2003; Corrigan and Watson 2007; Faigin and

Stein 2008; Mann and Himelein 2008; Penn et al. 1994). As logistical issues can hinder the widespread implementation of direct social contact with individuals with mental illnesses, the effects on public stigma of film interventions featuring individuals with mental illness have been tested, and show similar stigma reducing effects as direct social contact and education about these disorders (Chan et al. 2009; Corrigan et al. 2007; Faigin and Stein 2008; Penn et al. 2003; Reinke et al. 2004).

The purpose of this study was to test the hypothesis that watching a documentary film about people with mental illness training to perform stand up comedy would decrease public stigma related to mental illness in GCs/GC students.

METHODS

Study design and participants

No previous studies have either used this particular film intervention or targeted this specific population, so we adopted a pre experimental one group pre-test post-test study design, in which we administered baseline (T1) measures to participants, screened the documentary and then administered measures immediately after (T2) and one month after (T3) watching the film. Certified GCs or GC students in an accredited program, who were able to read and write in English, and 19 years of age or more were eligible to participate. We obtained IRB approval for the study from the University of British Columbia, and permission from the producer of the documentary, the Canadian Association of Genetic Counsellors (CAGC) and the National Society of Genetic Counselors (NSGC) to screen the documentary for GCs/GC students attending the 2010 Annual Education Conferences (AECs). To recruit participants, information about the documentary screening event was included in both the NSGC and CAGC conference programs and an email announcement was distributed to members of the NSGC.

The intervention

While film-based interventions have shown positive effects on mental illness related stigma, a relatively small number of films have been tested and none has been accepted as a “gold-standard”. In this study, we opted to test the effect on public stigma of a documentary called “Cracking Up” (produced for the Canadian Broadcasting Corporation), which had not been used before, but seems to provide quite a different perspective on mental illness to many of the other film-based interventions that have been used. “Cracking up” is a 45-minute film that follows a group of individuals with mental illness as they participate in a Vancouver-based program called Stand Up for Mental Health (SMH), which teaches individuals with mental illness how to perform stand-up comedy. In the film, the performers use their experiences of mental illness as material for their stand-up acts. Our personal observations and anecdotal evidence suggested that the combined effects of the film showing individuals with mental illness training to do stand-up comedy (something that many of the non-mental illness population would feel uncomfortable about), and the powerful taboo breaking associated with the use of mental illness experience as comedy material could ideally position the documentary as a powerful anti-stigma tool.

Questionnaires

The T1 questionnaire included demographic items (age, sex, and ethnicity), and two scales that measure different aspects of public stigma (described below). We asked participants: "Have you ever had any mental illness yourself?" For those that had, we asked them to specify what type of mental illness using freeform text. In addition, we asked participants "Do you have any exposure to or experience with individuals with mental illness?" We provided checkbox response options: family member(s), close friend(s), work colleague, acquaintance, volunteer or paid work with a mental health organization, and asked participants to document the types of mental illness they had experience with. We also included two other items: in one, participants were asked to self-rate their comfort with asking their patients about mental illness in clinical practice by selecting one of 5 options: "very uncomfortable", "quite uncomfortable", "neither comfortable nor uncomfortable", "quite comfortable" and "very comfortable". In the other, participants answered the question: "In your practice as a genetic counselor, do you ask about family history of mental illness?" with one of 5 options: "Always", "usually", "sometimes", "rarely", or "never". Participants were invited to provide their email address, to allow us to send an email inviting them to complete a questionnaire online, one month later.

Immediately after (T2) and one month after (T3) watching the documentary we again administered the two scales that measure different aspects of public stigma (described below), and asked: "Did watching the documentary change how comfortable you would feel asking about a family history of mental illness with your patients?" In response to this, participants could select one of 5 options, ranging from "Yes, I feel a lot *more* comfortable", through "No, I don't feel any change in comfort" to "Yes, I feel a lot *less* comfortable".

As described above, at each time point, we administered two validated scales that measure different aspect of stigma. The first, the stereotype endorsement (SE) scale measures the degree to which respondents endorse stereotypes about individuals with mental illness. The scale comprises 10 items each rated on a five point Likert scale, each asks respondents to rate how they think someone with a mental illness compares to someone without a mental illness. For example, participants were asked whether they would consider a person with a mental illness to be less, equally or more unpredictable than someone without a mental illness. Scale score is derived by summing item scores and dividing by number of items. A mean value over the midpoint of 3 indicates that more negative attributes were ascribed to people with mental illness than to those without mental illness (Nordt et al. 2006). The second instrument measures respondents' desire for social distance (SD) from individuals with a mental illness. This scale includes seven items that ask respondents to rate (using a four point Likert scale) how willing they would be to engage in different social interactions with an individual with mental illness. For example, participants were asked how willing they would be to share an apartment with an individual with a mental illness. Total scale score is derived by summing items scores, with higher scores indicating increased desire for social distance from individuals with mental illness (Penn et al. 1994).

Analyses

In the primary analyses we used paired t tests to assess the effect of the intervention as measured by comparing scale scores between T1 and T2. To allow for two outcome measures (SD and SE) we used a significance threshold (α) of $p < 0.025$. In exploratory analyses, data were stratified into two groups according to self-reported comfort at baseline to ask patients about family history of mental illness, and chi-squared tests used to explore whether this related to: a) frequency with which participants ask about family history of mental illness in clinical practice (as measured by self-report at baseline), or b) self-rated comfort to ask about mental illness after watching the documentary. Descriptive statistics were applied to demographic data and in exploratory analyses, t-tests were used to interrogate differences in scale scores between different demographic groups (e.g. students and GCs, those with and without personal experience of mental illness).

RESULTS

Demographics and self-rated comfort

A total of 87 GCs/GC students participated in the study: 27 and 60 participated at the NSGC and CAGC conferences respectively (see Table 1), which, assuming the documentary to have a medium effect size (Cohen's $d=0.6$), provides 80% power at $\alpha=0.025$.

At T2, 34.5% (N= 29) of participants reported feeling more comfortable to ask about a family history of mental illness with their patients as a result of watching the film (no participants reported feeling less comfortable). We split the cohort into two groups according to self-rated comfort at baseline (T1) with asking patients about family history of mental illness in clinical practice (comfortable, $n=53$, 63.1% and ambivalent/uncomfortable, $n=31$, 36.9%) and found those who were uncomfortable/ambivalent at T1 were significantly more likely to report rarely or never asking patients about family history of mental illness in clinical practice ($\chi^2(1)=12.5$, $p=0.001$). Those who were ambivalent/uncomfortable at T1 were also significantly more likely to report increased comfort to ask about a family history of mental illness as a result of watching the film at T2 ($\chi^2(1)=5.2$, $p=0.02$).

Stereotype endorsement (SE)

As compared to T1, at T2 there was a significant decrease in the degree to which GCs/GC students endorsed negative stereotype about individuals with mental illness: $t(85)=5.54$, $p<0.0001$. The magnitude of the observed effect size (Cohen's d) was 0.7, reflecting a medium to large effect size. Post hoc analyses using the Bonferroni inequality standard ($p < 0.05/10$ items = 0.005) indicated several significant changes from T1 to T2 in individual scale items. Specifically, after watching the film, GCs rated people with mental illness as more healthy ($t(85)=-5.65$, $p<0.0001$), and reasonable ($t(85)=-5.29$, $p<0.0001$), and less bedraggled ($t(85)=3.15$, $p=0.002$). There was no significant difference in the mean SE scale scores between people who had a personal or other type of experience with mental illness. When we split the cohort into two groups according to self-rated comfort at baseline (T1) with asking patients about family history of mental illness in clinical practice and compared SE scale scores between them, we found no differences between the groups.

Social distance (SD)

As compared to T1, at T2 there was a significant decrease in desire for SD from individuals with mental illness: $t(86)=2.77$, $p=0.007$. The magnitude of the effect size (Cohen's d) was 0.15, reflecting a small effect size. Post hoc analyses using the Bonferroni inequality standard ($p < 0.05/7$ items = 0.007) indicated two significant changes from T1 to T2 in individual items. Specifically, GCs were more likely to report that they would be willing to introduce someone with mental illness to a friend as a relationship partner ($t(82)=3.48$, $p=0.001$), and to recommend someone with mental illness for a job ($t(82)=3.19$, $p=0.002$). There was no difference in desire for SD among those who had a personal or other experience with mental illness compared to participants who did not. However, when we split the cohort into two groups according to self-rated comfort at baseline (T1) with asking patients about family history of mental illness and compared SE scale scores between them, we found that while SD scale scores significantly decreased from T1 to T2 among individuals who indicated that they were uncomfortable/ambivalent about asking a family history of mental illness, ($t(18)=3.31$, $p=0.004$) there was no significant change in SD scale score in the group who indicated feeling comfortable asking about family history of mental illness at T1 ($t(53)=0.42$, $p=0.676$). The effect size of the intervention in the group who were initially uncomfortable/ambivalent about asking a family history of mental illness (d) was larger than in the whole un-stratified group ($d=0.33$ reflecting a small-medium effect size, as compared to $d=0.15$ reflecting a small effect size).

One month follow-up questionnaire

Of the 87 individuals who completed T1/T2 questionnaires, 66% ($n=57$) provided contact information to allow us to send T3 questionnaires, 39 (68%) of who completed and returned them. Of these, 48.7% ($n=19$) reported feeling more comfortable to ask about a family history of mental illness in a counseling session as a result of watching the film (no participants reported feeling less comfortable). There were no significant differences between the participants who completed the T3 questionnaire and those who did not with regard to any demographic variables (including personal history or experiences with mental illness), or mean scale scores for SE and SD. We analyzed the longitudinal data (for all three time-points) from the group of individuals who provided T3 data separately. We found a significant decrease in SE scale scores from T1 to T2 ($t(38)=3.81$, $p<0.0001$), but from T2 to T3 there was significant increase ($t(38)=-3.06$, $p=0.004$), and no significant difference between T1 and T3 ($t(38)=0.531$, $p=0.598$). We found no significant change in SD scale scores from T1 to T2, T2 to T3, or T1 to T3 in this group.

DISCUSSION AND CONCLUSION

This was the first study to evaluate an intervention for reducing mental illness associated stigma amongst GCs/GC students. Although filmed interventions have been used to try to alleviate mental illness associated stigma in other populations (Chan et al. 2009; Corrigan et al. 2007; Faigin and Stein 2008; Penn et al. 2003; Reinke et al. 2004), the specific film in this study has not been used or studied previously for this purpose. Compared to the films used in other intervention studies (whose content has comprised: education about mental illness conditions, interviews of individuals with mental illness, documentaries following

people with mental illness and their families, theatrical performance concerning issues related to living with a mental illness, post-treatment experiences of people with mental illness, disconfirmation films that highlighted the similarities of people with and without a mental illness, dramatized portrayal of daily activities, and opinions from support people including family, friends, and colleagues) this film provides a different perspective on the lived experience of mental illness. As such, this study demonstrates proof-of-principle that this specific film could be used to increase GC/GC students' comfort with asking about family history of mental illness in clinical practice, and at least temporarily to produce decreases in public stigma. Indeed, we found that the documentary had a medium-large effect on scores on the stereotyping measure.

We found significant decreases in the extent to which GCs/GC students endorsed negative stereotypes about and desired social distance from individuals with mental illness from T1 (prior to watching the documentary) to T2 (immediately after watching the documentary). In particular, immediately after watching the film, participants rated individuals with mental illness as more healthy and reasonable, and less bedraggled, and indicated more willingness to introduce an individual with mental illness to a friend as a relationship partner, and recommend an individual with mental illness for a job: these changes are congruent with the content of the documentary. Specifically, the film follows individuals with mental illness as they: voluntarily engage in stand-up comedy training in an effort to promote their own mental health, admirably handle the associated anticipatory stress, and present themselves on stage professionally, charismatically and competently.

Contrary to some previous studies in other populations (Bell et al. 2006; Corrigan et al. 2001; Link et al. 2004), we found that a personal history or other experience with mental illness did not correlate significantly with either stereotype endorsement or desire for social distance from individuals with mental illness. Interestingly our findings support those of the only other study to have investigated stereotyping and desire for social distance related to mental illness in GCs/GC students (Feret et al. 2010) suggesting that – at least in this population - experience with individuals with mental illness does not automatically and directly reduce negative attitudes.

Our study population accurately reflected the broader community of GCs in that the majority of participants were highly educated women of European descent between the ages of 20 and 40 (Mittman and Downs 2008). Women and those with higher education have been found to be less likely to endorse negative stereotypes about people with mental illness or their families (Corrigan and Watson 2007). Further, empathic people are less likely to stigmatize members of a disenfranchised group (Batson et al. 2002). Thus, given our population of highly educated women who have been trained in the importance of empathy, it is interesting that GCs/GC students still endorsed negative stereotypes and desired social distance from people with mental illness prior to watching the documentary, which is consistent with other health care professionals such as pharmacists and pharmacy students, mental professionals, and psychiatrists (Bell et al. 2006; Lauber et al. 2006; Nordt et al. 2006).

GCs reported being more comfortable to ask about mental illness after watching the documentary and consistent with previous work in other populations (Watson et al. 2004), preliminary evidence indicates that the documentary had the greatest impact on the GCs/GC students who were initially uncomfortable or ambivalent about asking their patients about a personal or family history of mental illness. This group were significantly more likely to feel increased comfort with asking about personal or family history of mental illness after watching the documentary, and the decrease in desire for social distance from people with mental illness we found was driven largely by this subgroup. These results are potentially clinically important. Studies show that although only a very small number of all referrals for genetic counseling tend to be for a primary indication of mental illness (Hunter et al. 2010) and few individuals with mental illness and their family members have had genetic counseling, most would like to have genetic counseling about mental illness (DeLisi and Bertisch 2006; Lyus 2007). In order for affected individuals and families to have their desire for genetic counseling related to mental illness addressed, it seems that either GCs would have to ask clients about mental illness (regardless of reason for referral), or genetic counseling clients would have to raise mental illness spontaneously as a concern. However, research also shows that genetic counseling clients often do not know what to expect from their appointment (Bernhardt et al. 2000; Hallowell et al. 1997), and so may not know that it would be relevant or appropriate to mention it. Thus, in order to provide genetic counseling services to this underserved population, it would be important for GCs to ask about mental illness in the family history taking with clients referred for other indications. Even one month after watching the documentary, of participants who responded to the T3 questionnaire nearly half reported feeling more comfortable to ask their patients about personal or family history of mental illness. Further, our data suggest that GCs/GC students' self rating of comfort with asking patients about family history might reflect clinical behavior: specifically, at baseline (T1) those who were initially uncomfortable or ambivalent about asking their patients about a personal or family history of mental illness were also significantly more likely to report rarely or never asking about mental illness in clinical practice at baseline. Thus, it is possible that the increase in participants' level of comfort to ask about mental illness resulted in a behavioral change in clinical practice for some participants future studies could explore this directly.

Limitations

The film intervention did not focus on one particular mental illness, instead the subjects in the film had different types of mental illness (including schizophrenia, bipolar disorder and depression), and the subjects were in different phases of illness and recovery. Accordingly, we sought to illicit participants' reactions to the term "mental illness" as a broad construct. Although we encouraged participants to provide instinctive (or "gut") reactions, some participants commented that their answers on the questionnaires may have been different if depression and schizophrenia were considered separately, or if an individual was actively ill or in recovery.

A relatively large proportion of participants in this study reported a personal history of mental illness (32%), which could suggest ascertainment bias. Previous research suggests that those with personal history of mental illness might be expected to have less negative

attitudes towards mental illness (Bell et al. 2006; Kobau et al. 2009; Link et al. 2004), and therefore that the effect of the documentary would be attenuated in this population. Despite this however, we found significant positive changes in attitude toward mental illness in response to the documentary. Furthermore, recent studies indicate that the prevalence of common psychiatric disorders are often underestimated, and suggest that up to 50% of the population experience a diagnosable psychiatric disorder in their lifetime (Moffitt et al. 2010), with up to 40% of women experiencing depression alone (Kruijshaar et al. 2005). In this context, the proportion of study respondents with a history of mental illness seems unremarkable.

As with all studies using self-report questionnaires, social desirability bias cannot be ruled out. However, we found that those who stated that they were uncomfortable/ambivalent about asking a family history of mental illness were significantly more likely to report rarely or never asking about these issues in clinical practice, thus providing some reassurance that social desirability bias was not a significant confound in this study.

The sample size we obtained ($n=87$) provided sufficient (80%) power to detect a medium effect size ($d=0.6$). Thus, given the observed effect size for the stereotyping measure (medium-large), the study was adequately powered. Although the observed effect size for the social distance measure was small (and thus there was increased potential for a type 2 - or false negative - error), we did find a statistically significant difference from T1 to T2. However, the reduced response rate and smaller sample size at T3 resulted less than 70% power even for the larger effect size we observed for the stereotyping measure, and thus the chance for type 2 error was elevated. This limited our ability to interpret the observation that scores on SE and SD scales at T3 did not differ significantly from baseline. There are two possible explanations for this observation 1) the effect of the intervention was genuinely not sustained over time, or 2) the effect of the intervention was sustained over time, but our study was underpowered to detect this effect. Future research with larger sample sizes could explore this further, but other work suggests that single interventions have limited ability to produce sustained change (Corrigan et al. 2007, Penn et al. 2003), which suggests that repeated exposure to interventions (perhaps of varying kinds) might be the most effective for producing lasting change. Other interventions that could be employed to potentiate the stigma reducing effect of the documentary for genetic counselors could include an educational session, peer supervision focusing on promoting comfort with addressing issues surrounding mental illness in a genetic counseling session, and one-on-one contact with people with mental illness such as meeting some of the performers in the Stand up for Mental Health program after watching the documentary.

Conclusion

Mental illnesses are common, complex disorders, which are relatively highly heritable. As more is learned regarding the genetic etiology of mental illnesses, the use of genetic counseling services by affected families may increase (Austin and Honer 2005; DeLisi and Bertisch 2006; Lyus 2007). Genetic counseling can provide individuals with mental illness and their families with accurate empiric risks, and information regarding what is known about the genetics of mental illness, which may have an impact on the guilt, shame, and

stigma experienced by this population (Austin and Honer 2004). If GCs/GC students hold stigmatizing attitudes towards individuals with mental illness, this could negatively affect the development of rapport and therapeutic relationship with clients with mental illness, thus diminishing the value and quality of the services for this group. After watching the documentary GCs/GC students felt more comfortable asking about mental illness, and scores on measures of public stigma indicated a transient improvement in attitudes. Future studies could compare the effect of the documentary with other interventions and look for ways the effects of the intervention could be sustained over time. The documentary could be incorporated into genetic counseling training programs as a way to increase future GCs' comfort with asking clients about personal or family history of mental illness, and potentially promote the development of the therapeutic alliance with future patients with mental illness.

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Table 1

Participant demographic information

Characteristic	N (%)
Age	
20–30	44 (51)
31–40	33 (38)
41–50	8 (9)
51–60	2 (2)
Sex	
Female	81 (93)
Male	6 (7)
Student	
Yes	15 (17)
No	72 (83)
Ethnicity	
European	72 (84)
Asian	4 (5)
Southeast Asian	2 (2)
Hispanic	3 (3)
Black	1 (1)
Other	4 (5)
Years employed as a genetic counselor	
0–5	53 (61)
6–10	17 (20)
11–15	10 (11)
16–20	3 (3)
21+	4 (5)
Have you ever had a mental illness yourself?	
Yes	28 (32)*
No	59 (68)
Frequency in asking a family history of mental illness	
Always	8 (9)
Usually	23 (27)
Sometimes	39 (46)
Rarely	11 (13)
Never	4 (5)

* Mental illnesses that participants self-reported included: depression, anxiety, OCD, and eating disorders.