Patient Educ Couns. Author manuscript; available in PMC 2013 July 29.

Published in final edited form as:
Patient Educ Couns. 2011 January ; 82(1): 69–73. doi:10.1016/j.pec.2010.02.007.

Genetic counselors' attitudes towards individuals with schizophrenia: desire for social distance and endorsement of stereotypes

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Abstract

Background—Psychiatric disorders are profoundly stigmatized conditions. Many groups of healthcare professionals harbor negative attitudes towards affected individuals, which may interfere with the healthcare relationship, but genetic counselors' attitudes towards individuals with psychiatric disorders have not been investigated. Thus, we conducted an exploratory study to assess genetic counselors' desire for social distance from individuals with schizophrenia, and the degree to which stereotypes about people with schizophrenia were endorsed.

Methods—Members of the National Society of Genetic Counselors were invited to complete an online survey, which included scales measuring: desire for social distance from individuals with schizophrenia, and endorsement of positive and negative stereotypes about these individuals.

Results—In total, 142 surveys were completed. Genetic counselors expressed greater desire for social distance from an individual with schizophrenia in more intimate proposed relationship scenarios, and felt negative stereotypes about affected individuals were more typifying than positive stereotypes. Experience with psychiatric disorders did not significantly affect desired social distance or stereotypical attitudes.

Conclusions—Genetic counselors express some negative attitudes toward individuals with schizophrenia, which may impede the counselor/client relationship. Future research in this area is suggested, and efforts should be made to promote positive attitudes, which would improve the ability of genetic counselors to provide optimal service for individuals with schizophrenia and their families.

1. Introduction

Schizophrenia is a severe mental illness that affects 1% of the population. It is a complex disorder, which arises as a result of the combined contributions of genetic and environmental vulnerability factors. When surveyed, individuals with schizophrenia and their family

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members have expressed strong interest in receiving genetic counseling [1–3], and undergoing genetic testing for the condition if and when it becomes clinically available [1]. However, we must also anticipate that even in the absence of genetic testing, as more is learned about the genetic contribution to complex disorders (like psychiatric illness), public awareness of the role of genetics will increase, and genetic counseling for these disorders may become more commonplace [4–7]. Indeed, a 2002 survey of genetic counselors showed that this group of healthcare professionals regarded referrals to discuss psychiatric illness as an area of growth [8].

However, in addition to providing services for individuals who are specifically referred to discuss psychiatric illness in the family history, genetic counselors encounter these illnesses frequently in the context of documenting family histories of clients referred for non - psychiatric indications as a result of the common nature of psychiatric illnesses.

In a 2002 pilot study, 44% of genetic counselors surveyed indicated that they felt very or somewhat unprepared to answer questions about psychiatric disorders from their clients. The majority (54%) also indicated that they did not feel comfortable providing psychosocial counseling for these disorders [8]. In another recent study, genetic counselors reported asking clients about family history of psychiatric illness only infrequently and reported personal discomfort or perceived discomfort of the client when asking about these issues [9]. A deeper understanding of the reasons underlying this discomfort would be important in developing strategies to help counselors feel better equipped to provide their services to this population.

It is possible that the feeling of discomfort reported by genetic counselors when considering asking about psychiatric illness in clinical settings may be related to stigma associated with psychiatric illnesses. Indeed, psychiatric illnesses (including schizophrenia) are amongst the most profoundly stigmatized of health conditions [1, 10–12]. Stigma is a complex and multifaceted construct. The term “public stigma” has been used to describe the reaction of the general population – in terms of their beliefs about, and attitudes and behavior towards individuals with mental illness. The beliefs people hold about individuals with mental illness, and their attitudes towards affected individuals together influence their behaviors towards these individuals. Negative beliefs about and attitudes towards individuals with mental illness can manifest in behavior as discrimination against individuals with mental illness [13]. This discrimination can have a profound impact on the quality of life of individuals with mental illness, and can directly influence opportunities for housing, employment etc [14]. Indeed, the negative impact of public stigma has been recognized as such a critical problem for individuals with mental illness, that some have argued that it outweighs the actual impairment of the illness itself [15].

In the context of healthcare, individuals with psychiatric illnesses have reported that fear of feeling stigmatized (devalued or discriminated against) can act as a barrier to accessing needed healthcare services [16], so if an individual perceives that they experience discrimination or stigmatizing attitudes in a healthcare encounter, it may make them less likely to seek help in the future. Thus, the attitudes of healthcare professionals towards individuals with mental illness can be important in illness trajectory.

Because it has been recognized as such a significant issue, several tools have been developed to measure different facets of public stigma related to mental illness in different populations. Amongst these are tools that can be used to measure the degree to which individuals endorse stereotypes about individuals with mental illness, and the extent to which individuals desire social distance from people with mental illness. Scales that assess stereotypical beliefs ask respondents to indicate the degree to which they agree with various positive and negative features being applicable to an individual with a mental illness [10]. Social distance scales assess respondents' willingness to interact with a target person in relationships of varying closeness [11], and are thought to indicate behaviors that are associated with discrimination [1]. Desire for social distance from individuals with mental illness has been described as one of the more extreme, and damaging forms of public stigma [14]. Tools like these have been used in previous studies to assess the attitudes of nurses, undergraduate students, police officers, pharmacy students, mental health professionals, and the general public towards individuals with psychiatric illnesses [10, 12, 17–22], but no similar studies have been conducted with genetic counselors.

Healthcare professionals' stigmatizing attitudes towards individuals with mental illness for whom they are providing services could significantly and adversely affect the efficacy of the service provided, particularly if those services are counseling related. Specifically, stigmatizing attitudes could negatively impact the development of a therapeutic relationship [23]. In the context of genetic counseling, good rapport and the development of a working alliance (therapeutic relationship) are critical to an effective session [24]. A counselor's negative attitudes about individuals with mental illness could interfere with the rapport building and the establishing of a working alliance with a patient who is affected, thus reducing the quality of the service for that patient. Thus, we conducted an exploratory study to assess the attitudes of genetic counselors towards individuals with schizophrenia, by measuring desire for social distance and stereotype endorsement. We chose schizophrenia as the model condition for this study because it is one of the most stigmatized of the psychiatric disorders [25]. Although this was an exploratory study, we expected to find that genetic counselors would: a) feel negative stereotypes were more typifying and positive stereotypes were less typifying of an individual with schizophrenia as compared to an individual without schizophrenia, b) desire increased social distance in more intimate proposed relationship scenarios (e.g. sharing an apartment) than in the less intimate proposed relationship scenarios (e.g. being a neighbor), and c) would desire social distance and endorse negative stereotypes less if they had experience with mental illness, (e.g. affected family member), compared to those with no experience [17, 26].

2. Methods

2.1 Recruitment

Subjects in this study were practicing genetic counselors and genetic counseling students who were members of the National Society of Genetic Counselors (NSGC). Subjects were recruited through an email sent to the NSGC list serve which invited interested genetic counselors to participate via a link to Survey Monkey, a web-site for professional and

anonymous online surveys. An electronic waiver of written informed consent was provided prior to beginning the survey.

2.2 Demographics

Demographic questions pertained to age, gender, family history of mental illness, whether or not the participant was a student, years employed as a genetic counselor, and primary areas of counseling. Additional questions that we hoped would provide context for the data of interest included how often clients were referred to them because of a personal or family history of mental illness, and whether the participant had any other experiences with individuals who have a mental illness.

2.3 Attitudes towards individuals with schizophrenia

Social distance—We used the social distance questionnaire developed by Bell *et al.*[18]. This instrument measures how likely the participant would be to engage in relationships of varying closeness with an individual who has schizophrenia (see Table 2). It includes seven questions that are answered using a 4-point Likert-scale. Individuals who answered “no opinion” to a question were not given a score for that question.

Stereotype endorsement—We used a modified version of the stereotype endorsement scale developed by Lauber, *et al.* [10]. Our modification of the scale involved changing the term “distanceless” after consultation with the author of the scale, to “unaware of social boundaries” for better interpretability. This scale allows participants to rate their perceptions of someone with schizophrenia relative to someone without mental illness/schizophrenia, on 22 negative and positive characteristics, using a 5-point Likert-scale. These items are listed in Table 3a. The negative stereotypes subscale (10 items) has acceptable reliability [12]. A value over the midpoint of 3 on this subscale indicates that more negative—and less positive—attributes are ascribed to people with mental illness than to other people.

2.4 Analysis

Respondents were placed into one of four groups based on their experience with mental illness. Group 1 had a personal or family history of schizophrenia; Group 2 had a personal or family history of other mental illness; Group 3 had other types of mental illness experience but no personal or family history; and Group 4 had no experience with mental illness. Statistical Package for the Social Sciences (SPSS) was used to determine the mean scores for social distance and stereotype endorsement questions for each group, and multiple analyses of variance (ANOVAs) were used to compare mean scores between groups. This study was approved by the Arcadia University Institutional Review Board, 07-09-70.

3. Results

3.1 Subject demographics

A total of 142 surveys were completed. Most respondents (124) indicated that they rarely (48.6%) or never (41.3%) received referrals specifically for genetic counseling relating to mental illness. Twelve (8.7%) reported that clients are sometimes referred to them and two (1.4%) reported that clients are often referred to them primarily for counseling about mental

illness. Interestingly, most counselors (n=88, 63.3%) indicated that they or someone in their family had been diagnosed with a mental illness, and twelve (13.6%) indicated that this diagnosis was schizophrenia. Additionally, 94 counselors (67.1%) reported that they had experience interacting with individuals who have a mental illness in another setting, such as a close personal friend who was affected volunteer experience for a mental health organization, or other unspecified experience. (Table 1).

3.2 Social distance

Responses for the social distance scale are summarized in Table 2. These results support our hypothesis that counselors would desire more distance in more intimate proposed relationship scenarios: counselors were least willing to have someone previously hospitalized for schizophrenia as a babysitter for their child (mean=3.28, *SD*=.645) and most willing to have that person as a neighbor (mean=1.64, SD=.554). Counselors were willing to work with that person and recommend them for a job, but unwilling to share an apartment with them. There were no significant differences in desire for social distance in pair-wise comparisons between the groups assigned according to experience with mental illness.

3.3 Stereotype endorsement

Overall, mean scores were higher for negative characteristics than positive characteristics, supporting our hypothesis that counselors would feel that negative characteristics were more typifying of a person with schizophrenia (see Table 3a). All negative stereotypes except “stupid” (2.93) were rated as more typifying of an individual with schizophrenia, whereas all positive characteristics except “creative” (3.23), “clever” (3.08), and “sympathetic” (3.05) were considered less typifying of someone with schizophrenia. The scores ranged from 3.99 for “unpredictable” to 2.10 for “self-controlled”. There were no significant differences in the degree to which stereotypes were endorsed in pair-wise comparisons between the groups assigned according to experience with mental illness. Using the negative stereotypes subscale, an average score (for all respondents) of 3.16 was generated. Average scores for the four groups previously described are listed in Table 3b.

4. Discussion and Conclusion

4.1 Discussion

In this exploratory study, when considering individuals with schizophrenia, genetic counselors desired social distance for all close relationships, but were more willing to engage in less intimate relationships, such as having a neighbor or coworker with schizophrenia. Genetic counselors also tended to endorse negative stereotypes about individuals with schizophrenia, although as a group they did not seem to hold these beliefs very strongly.

We used the social distance scale developed by Bell [18] that has been used in studies of other populations. It was interesting to note that genetic counselors’ desire for social distance was less than that of pharmacy students and graduates (as measured in other studies using the same instrument) on all measures except for sharing an apartment, for which a similar amount of social distance was desired by all groups [18]. Although comparisons

such as these should be interpreted cautiously, it is interesting to speculate about whether (if supported by future larger studies) these results might reflect differences in training between the two groups, or in the types of interactions the two groups have with individuals with mental illness. Both groups have provider-patient relationships with individuals with psychiatric illness, but genetic counselors may work closely with that individual, occasionally over an extended period of time and multiple meetings, in order to help the individual make decisions that coincide with their personal beliefs. In contrast, Bell *et al.* [18] suggested that the nature of pharmacy students' relationship with mentally ill individuals involves brief exchanges focused on providing medication, which perhaps limits understanding of these conditions. Further studies may be beneficial to directly study a wider variety of interactions with individuals that have mental illnesses and their effects on desired social distance.

Although there are difficulties with comparing scores between studies on the stereotype endorsement scale that we used, the responses from genetic counselors were similar to the attitudes expressed by mental health professionals using the same scale [10]. However, using the negative stereotypes sub-scale [12], genetic counselors attitudes towards individuals with schizophrenia were more favorable. Genetic counselors overall scored 3.16, with the group of counselors with the most negative view (those with no personal or other experience with mental illness) scoring a 3.20 (higher scores indicating more negative views), as compared to psychiatrists who scored 3.49, and psychologists who scored 3.33. These differences in attitudes may also be attributed to the differences in provider-patient relationships described by Bell *et al.* [18]. Mental health professionals have likely worked with many of their clients at a time when they were acutely ill, whereas genetic counselors may not have had this type of experience.

In regards to specific stereotypes, mental health professionals similarly rated all negative stereotypes except "stupid" as more typifying of individuals with mental illness, whereas genetic counselors tended to characterize affected individuals as more dangerous and threatening. This is potentially explained by the fact that genetic counselors may – by nature of their training -be more likely to endorse a biogenetic cause of mental illness. There is some suggestion that endorsing this type of causation model increases the likelihood of viewing affected individuals as lacking in self-control, and therefore being more unpredictable and dangerous [20]. Police officers have been shown to react to situations involving people with mental illness in a heightened state of alert that may lead to threatening body language and speech towards the individual with mental illness [22]. Similarly, counselors who perceive individuals with mental illness to be dangerous or threatening may also subconsciously portray these attitudes during a counseling session, negatively influencing the counselor client relationship.

Contrary to our expectations, and to findings of previous studies [11,18, 20, 26, 27], in the current study, experience with mental illness did not significantly influence genetic counselors' desire for social distance from or stereotype endorsement about individuals with schizophrenia. However, it has also been suggested that the amount and type of interactions with individuals with mental illness may have an influence on reducing stigma, indicating

that aspects of the relationships that were not considered may have influenced our findings [26].

4.2 Limitations

Most counselors (63%) had a family history of mental illness, and 13% of counselors reported a personal or family history of schizophrenia. At first glance, this appears to indicate ascertainment bias. However, mental illnesses are common conditions – recent studies have shown that the frequency of these conditions might have been underestimated, and that in fact as much as 50% of the population might at some point in their lives experience a diagnosable psychiatric disorder [28, 29]. If we assume that most individuals who responded to the study have several family members, and consider the likelihood that at least one of these family members has had a mental illness (when the chance for each individual in the family is ~50%), the finding that in this study 63% of respondents reported a family history of mental illness becomes less noteworthy as indicating potential bias. With regard to schizophrenia, this condition affects 1% of the population, but 13% of respondents indicated that someone in their family was affected. If we again assume that each respondent has multiple family members, and consider the likelihood that any one of those family members has had schizophrenia the 13% figure seems somewhat less dramatic, but still indicates potential ascertainment bias. Indeed, intuitively, those counselors who had a family history of schizophrenia might be more likely to participate in a study about perceptions of this illness. However, despite the fact that our sample was potentially biased towards individuals with a family history of mental illness – a group in which we would expect to find more positive attitudes towards individuals with mental illness – we still found evidence of stigmatizing attitudes. Thus, in a broader cross section of genetic counselors we would expect to find more extreme negative attitudes. This study paves the way for future, larger studies of a more representative cross section of this group of professionals.

Also, the questions used in this survey did not specify whether the individual in question was currently taking medication for schizophrenia and their illness was well controlled, or whether they were still symptomatic. Several respondents commented that this would influence their responses.

Although we used an anonymous online survey to reduce social desirability bias as much as possible, as with all self-report studies, this must be considered when interpreting the results of the study. Future, larger scale studies could investigate implicit attitudes and compare these attitudes towards their explicit attitudes and stated beliefs.

4.3 Conclusion

Despite the fact that our sample may have been enriched with those with a family history of schizophrenia: a group that we might expect to have less stigmatizing attitudes towards affected individuals, the data from this exploratory study indicate that genetic counselors seem to desire social distance from and endorse negative stereotypes about individuals with schizophrenia. These negative attitudes may: a) contribute to genetic counselors' reported lack of comfort in asking about family history of mental illness, and b) be evident to clients during counseling. If a genetic counselor holds negative attitude towards their client, the

establishment of rapport will be more challenging, and as the service relies heavily on rapport, the effectiveness of the session will be reduced Increasing awareness amongst genetic counselors about these issues may promote efforts to improve these attitudes. This exploratory study suggests that there is a need for further larger scale research in this area, and also that there may be a need for education in genetic counseling training programs regarding mental illness and the impact of stigma on counseling relationships, especially as counseling for these illnesses becomes more common.

Acknowledgments

The authors would like to thank Vivian Weinblatt, MS, CGC and Kathy Valverde, MS, CGC for their support through the project and for their assistance in reviewing this manuscript. JA was supported by CIHR, the Michael Smith Foundation for Health Research, and the Provincial Health Services Authority of British Columbia.

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Table 1

Respondent demographic information.

Characteristic	N (%)
Age	
20–30	77 (54.2)
31–40	42 (29.6)
41–50	10 (7.0)
51–60	11 (7.7)
61+	2(1.4)
Gender	
Female	138 (97.2)
Male	4 (2.8)
Student	
Yes	5 (3.5)
No	136 (96.5)
Years employed as a genetic counselor	
0–5	86 (60.6)
6–10	28 (19.7)
11–15	7 (4.9)
16–20	7 (4.9)
21+	14 (9.9)
Primary area(s) of counseling	
Prenatal	69 (49.3)
Cancer	38 (27.1)
General adult genetics	18 (12.9)
Pediatrics	42 (30.0)
Other	30 (21.4)
Have you or anyone in your family ever been diagnosed with a mental illness?	
Yes	88 (63.3)
Schizophrenia	12 (13.6)
No	48 (34.5)
I don’t know	3 (2.2)
Have you had experience interacting with individuals who have a mental illness in any other settings (e.g. have you had a close personal friend who was affected, or have you volunteered with a mental health organization, etc)?	
Yes	94 (67.1)
No	46 (32.9)

Table 2

Genetic Counselors' Attitudes towards a Person with Schizophrenia:Social Distance

For a person previously hospitalized with schizophrenia how likely would you be to:					
	All respondents (n=135) Mean (SD)	**Group 1 (n=12) Mean (SD)**	**Group 2 (n=73) Mean (SD)**	**Group 3 (n=33) Mean (SD)**	**Group 4 (n=17) Mean (SD)**
Share an apartment with that person	3.00 (0.622)	2.64 (0.505)	3.00 (0.559)	3.07 (0.740)	3.14 (0.663)
Work alongside that person	1.72 (0.528)	1.58 (0.515)	1.75 (0.465)	1.61 (0.496)	1.88 (0.781)
Have that person as a neighbor	1.64 (0.554)	1.42 (0.515)	1.64 (0.510)	1.66 (0.653)	1.76 (0.562)
Have that person as a babysitter for child	3.38 (0.645)	3.50 (0.527)	3.22 (0.591)	3.38 (0.677)	3.25 (0.856)
Have one of your children marry that person	2.58 (0.718)	2.78 (0.667)	2.49 (0.653)	2.68 (0.852)	2.67 (0.778)
Introduce that person to a friend as a relationship partner	2.44 (0.636)	2.55 (0.522)	2.38 (0.580)	2.55 (0.736)	2.38 (0.768)
Recommend that person for a job	1.97 (0.446)	2.00 (0.447)	1.94 (0.396)	2.00 (0.471)	2.07 (0.616)

*Higher scores indicate greater social distance and a more negative attitude. Items were scored on a 4-point Likert scale on which 1=definitely willing and 4=definitely unwilling. Counselors were placed into one of four groups based on experience with mental illness. Group 1 had a personal or family history of schizophrenia, Group 2 had a personal or family history of other mental illness; Group 3 had other mental illness experience but no personal or family history; and Group 4 did not have a personal or family history or other experience with mental illness.

Table 3a

Genetic Counselors' Attitudes towards a Person with Schizophrenia: Endorsement of Positive and Negative Stereotypes

	N	Mean (SD)
Negative stereotypes		
Unpredictable	128	3.99 (0.693)
Unreliable	126	3.63 (0.666)
Dangerous	127	3.55 (0.530)
Threatening	126	3.50 (0.548)
Abnormal	125	3.42 (0.542)
Weird	126	3.40 (0.594)
Delinquent	127	3.32 (0.518)
Bedraggled	119	3.32 (0.581)
Mad	124	3.28 (0.487)
Unaware of social boundaries	128	3.04 (0.778)
Stupid	127	2.93 (0.287)
Positive stereotypes		
Creative	128	3.23 (0.461)
Clever	128	3.08 (0.346)
Sympathetic	127	3.05 (0.517)
Charming	128	2.98 (0.355)
Highly skilled	127	2.94 (0.290)
Sociable	128	2.69 (0.599)
Healthy	127	2.69 (0.496)
Reasonable	127	2.54 (0.652)
Autonomous	127	2.52 (0.688)
Responsible	127	2.36 (0.586)
Self-controlled	127	2.10 (0.561)

*Counselors were asked to rate how an individual with schizophrenia differs with respect to the general population with respect to the following characteristics. Items were scored on a 5-point Likert scale on which 1=much less, 3=no difference, and 5=much more.

Table 3b

Genetic Counselors' Attitudes towards a Person with Schizophrenia: Negative Stereotypes Subscale.

Negative stereotypes subscale score	
	Mean (SD)
Group 1 (N=12)	3.16 (.72)
Group 2 (N=71)	3.14 (.55)
Group 3 (N=29)	3.17 (.62)
Group 4 (N=16)	3.20 (.56)
TOTAL (N=128)	3.16 (.58)

* Negative stereotypes subscale score was calculated by taking the average score of ten items from the negative stereotypes scale: dangerous, unpredictable, stupid, bedraggled, abnormal, unreliable, weird, reasonable, self-controlled, and healthy. Counselors were placed into one of four groups based on experience with mental illness. Group 1 had a personal or family history of schizophrenia; Group 2 had a personal or family history of other mental illness; Group 3 had other mental illness experience but no personal or family history; and Group 4 did not have a personal or family history or other experience with mental illness.