

Is Psychiatric Research Stigmatized? An Experimental Survey of the Public

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Although decisional incapacity can be caused by various medical conditions, incapacity due to mental illness is often singled out for scrutiny in research ethics policy debates. We assessed whether there is a general discriminatory perception of mental illness research and, if so, aimed to characterize the nature of that perception. We conducted an experimental, randomized Internet survey of the general public. We recruited 3140 adults through a web-research survey panel, with oversampling of racial and ethnic minorities and the elderly. Willingness to allow medical versus mental illness research was compared by randomly assigning the respondents to 1 of 7 web-based experimental scenarios depicting a subject being considered for research participation. Respondents were more willing to allow research with medically ill than the mentally ill subjects, even when ethically relevant factors were equal. This difference was mediated through the respondents' tendency to view mentally ill subjects as more decisionally incapable than medically ill subjects, even when they were told that the subjects portrayed were in fact competent. Discriminatory perception of mental illness research exists and is mediated by an outdated view of mental illness and decisional capacity. Policymakers and institutional review board members may need to guard against its influence in their deliberations.

Key words: ethics/stigma/mental illness/schizophrenia/
research attitudes/decision-making capacity

Introduction

Research involving persons with impaired decision-making abilities continues to be a topic of debate among bioethicists, researchers, and policymakers.¹ The study of

decisionally impaired persons is critical to developing and improving interventions to treat them; yet, decisional impairment can be an obstacle to informed consent. There is a need for clear policies about how to conduct research with such persons.

Although decisional impairment can be caused by many conditions, including a variety of medical illnesses,²⁻⁴ recent debates have often focused on the mentally ill. For example, though noting that a policy based on group membership rather than on a “common functional characteristic (ie, questionable decision-making capacity)” can “raise the specter of equating mental disorders with incapacity and thus potentially stigmatize these individuals,” the National Bioethics Advisory Commission (NBAC) still focused its attention on “persons with mental disorders” (p. 5).⁵ The NBAC report was criticized for singling out and thereby stigmatizing the mentally ill.^{6,7} Such practices have been perpetuated in some laws that treat incompetent psychiatric patients differently than incompetent persons with other medical problems.⁸ Because stigma regarding mental illness remains strong,⁹ it seems essential to understand whether and how stigma may affect research ethics policies affecting the mentally ill.

Stigma of mental illness has many dimensions. Persons with psychosis are perceived as more violent and dangerous, although they account for only a small proportion of violence in the population.¹⁰⁻¹³ Research findings consistently demonstrate that the public prefers to maintain social distance from persons with mental health problems.⁹ The public has also been shown to attribute more personal responsibility and other specific causal explanations for mental health problems such as psychosis compared to those associated with medical illness.^{14,15} Additionally, society tolerates inequities in the allocation of resources for the treatment of mental illness,¹⁶⁻¹⁸ and funding remains grossly inadequate for the persistent high levels of need for such services.^{16,19} With regard to research participation, mentally ill patients are seen as incompetent and potentially more easily coerced.²⁰ Specific research procedures, even when commonly used in other areas of medical research, are treated as riskier when used in mental illness research.⁶ How might some of these dimensions of stigma affect how people evaluate research ethics issues?

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For the present study we conceptualized stigma as discrimination based on ethically irrelevant factors that has the potential to cause adverse effects. Specifically, stigma in the context of research ethics would be ethically unjustified discrimination that precludes otherwise valuable research intended to benefit the stigmatized population. We tested the hypothesis that there is stigma against mental illness research, specifically, that research involving the mentally ill would be seen as less allowable than research involving the medically ill, even when ethically relevant factors (such as the subject's specified decision-making competency status, risk-benefit factors of the research protocol, or the subject's chronicity of illness, functional level, and level of social support) are similar. We also hypothesized that there would be an interaction between competency status of research subjects and illness type—specifically, that the incompetent mentally ill would be “more protected” than the incompetent medically ill. We also examined various dimensions of mental illness stigma by analyzing them as potential mediators and moderators of the primary stigma effect due to illness type.

Methods

Participant Recruitment

We e-mailed 34 019 adults who were randomly selected from a volunteer survey panel of over a half million members. The panel is maintained by Survey Sampling International (SSI) and is balanced on gender and age per the 2000 US Census (http://www.surveysampling.com/ssi_home.html). In this study we oversampled African Americans, Hispanics, and the elderly (those over 60 years old) to ensure sufficient numbers for analysis of their effects on responses. There is an SSI panelwide incentive in the form of lottery cash prizes for completing surveys. We recruited 3140 persons who responded to the e-mail invitations. They were randomized to 1 of 7 experimental surveys.

Materials

The 7 experimental scenarios described a person (with randomly selected gender, identified as either “John” or “Pam”) who was being considered for participation in a research study. Each scenario had the following elements: illness label, illness description, functional level, chronicity of illness, description of social support, description of the research study (in which lumbar puncture would be used to obtain cerebrospinal fluid), including its purpose, procedures, risks, and lack of direct benefit, and a specified competency status. (The text of the survey is available at <http://www.cbdsim.org/files/downloads/stigmopsychsurvey.pdf>.) The illness label, illness description, and specified competency status were experimentally manipulated; the other elements were held constant across all 7 scenarios.

Scenarios 1, 2, and 3 described a person with “mental illness” who had delusions and hallucinations. Scenarios 4, 5, 6 described a person with “medical illness” that “affects the kidneys and the brain” who had “difficulty thinking and remembering things.”

We varied the stated competency status of the subject. Scenarios 1 and 4 stated, “[John/Pam] is currently doing well. A doctor who is not connected to the research study has examined [John/Pam], and he believes [John/Pam] is able to make [his/her] own decisions about participating in this research study.” Scenarios 2 and 5 specified that the portrayed subject was deemed by an independent physician too impaired to make his or her own decision about participating and that a family surrogate would have to consent instead. In scenarios 3 and 6, the competency status was left unspecified.

Scenario 7 was identical to the mental illness scenarios except that the illness was not labeled as medical or mental, and it included a medical causal framework (“affects both the kidneys and the brain, but the main problem has been the effects on the brain”) but with symptoms identical to the mental illness scenarios. Like scenarios 3 and 6, the competency status was left unspecified.

The main dependent variable was assessed with the question, “Imagine that you are part of an ethics committee that decides whether certain studies should be allowed. Would you allow researchers to do studies like this with patients like [John/Pam]?” Participants also rated the level of risk involved with the research described in the scenarios, the importance of the research, the vulnerability of the portrayed subject to involuntary participation, and the capacity of the portrayed subject to give consent to research on his or her own. (Note that this last variable measures the respondents' opinion about capacity and is distinct from the experimentally manipulated variable of competency status.)

The respondents also completed two widely used scales to assess stigma, the Social Distance Scale (SDS),²¹ which measures willingness to interact socially with the person described in the scenario, and an adapted version of the Perceived Causes measure (originally developed for the 1996 National Opinion Research Center's General Social Survey),¹⁰ which gauges participants' opinions on possible causes of the illness presented in the scenario.

Participants' attitudes toward biomedical research were measured using the Research Attitudes Questionnaire (RAQ), a scale developed by our group. The internal consistency for this scale was adequate ($\alpha = 0.77$).

Finally, demographic information was gathered (see Table 1).

Before fielding the research study, the paper-based version of the survey was circulated among 15 individuals, including social science researchers and laypersons. Any issues concerning the wording of questions and formatting of the survey were discussed among the researchers and resolved. Quality assurance testing was also

Table 1. Demographics of Respondents in the 7 Randomly Assigned Scenario Groups

Variable ^a	Group 1: Mental, Competent	Group 2: Mental, Incompetent	Group 3: Mental, Unspecified	Group 4: Medical, Competent	Group 5: Medical, Incompetent	Group 6: Medical, Unspecified	Group 7: Unspecified, Unspecified	Total Sample
Race^b								
% White (<i>n</i>)	78.3 (282)	80.7 (296)	80.7 (263)	79.0 (264)	81.9 (298)	80.7 (284)	82.9 (295)	80.6 (1982)
% Black (<i>n</i>)	11.7 (42)	12.0 (44)	8.3 (27)	12.6 (42)	11.0 (40)	11.6 (41)	9.0 (32)	10.9 (268)
% Asian/ Pacific Islander (<i>n</i>)	1.4 (5)	1.6 (6)	2.5 (8)	1.2 (4)	2.2 (8)	1.7 (6)	1.1 (4)	1.7 (41)
% Native (<i>n</i>)	1.1 (4)	.3 (1)	.9 (3)	.6 (2)	1.1 (4)	1.1 (4)	.8 (3)	.9 (21)
% Other (<i>n</i>)	7.5 (27)	5.4 (20)	7.7 (25)	6.6 (22)	3.8 (14)	4.8 (17)	6.2 (22)	6.0 (147)
Ethnicity^c								
% Hispanic (<i>n</i>)	12.1 (44)	12.0 (45)	13.5 (44)	15.1 (50)	11.7 (43)	12.6 (44)	9.0 (32)	12.2 (302)
Gender								
% Female (<i>n</i>)	54.0 (197)	52.3 (195)	62.1 (203)	54.5 (183)	54.2 (201)	54.2 (193)	52.4 (186)	54.7 (1358)
Age (years)^e								
Mean (SD)	47.7 (14.8)	48.1 (14.8)	47.0 (14.3)	48.7 (14.5)	48.8 (15.2)	48.1 (14.4)	48.6 (14.7)	48.1 (14.7)
Education^f								
% high school or less (<i>n</i>)	16.2 (59)	19.7 (74)	19.0 (62)	21.0 (71)	13.7 (51)	19.3 (68)	16.0 (57)	17.8 (442)
% Some Coll. (<i>n</i>)	48.9 (178)	51.2 (192)	48.3 (158)	48.5 (164)	47.7 (177)	47.9 (169)	49.2 (175)	48.8 (1213)
% Coll. Grad (<i>n</i>)	20.6 (75)	17.6 (66)	21.7 (71)	19.2 (65)	23.7 (88)	18.1 (64)	21.6 (77)	20.4 (506)
% > College (<i>n</i>)	14.3 (52)	11.5 (43)	11.0 (36)	11.2 (38)	14.8 (55)	14.7 (52)	13.2 (47)	13.0 (323)
Financial Status^{g,h}								
% > Enough \$ (<i>n</i>)	59.6 (215)	55.6 (208)	57.5 (188)	54.3 (183)	55.4 (204)	59.5 (210)	55.6 (197)	56.8 (1405)
% Enough \$ (<i>n</i>)	27.1 (98)	27.8 (104)	30.6 (100)	29.7 (100)	31.8 (117)	27.2 (96)	29.9 (106)	29.1 (721)
% < Enough \$ (<i>n</i>)	13.3 (48)	16.6 (62)	11.9 (39)	16.0 (54)	12.8 (47)	13.3 (47)	14.4 (51)	14.1 (348)

^aNumber of subjects (*n*) reported varies for each variable due to missing data.

^b $\chi^2 = 18.07$, $df = 24$, $p = .80$.

^c $\chi^2 = 6.66$, $df = 6$, $p = .35$.

^d $\chi^2 = 8.99$, $df = 6$, $p = .17$.

^eAnalysis of variance, $F = .91$, $df = 6$, $p = .49$.

^f $\chi^2 = 18.45$, $df = 18$; $p = .43$. Original 9 categories collapsed into 4 for analysis.

^g $\chi^2 = 8.46$, $df = 12$, $p = .75$.

^hAssessed by the question, "How do your finances work out at the end of a typical month: some money left over (> Enough \$), just enough to make ends meet (Enough \$), or not enough to make ends meet (< Enough \$)?"

conducted with the web-based survey to ensure usability, accurate data recording, and comprehension.

This study was deemed exempt from IRB (institutional review board) review by the University of Michigan.

Statistical Analysis

Depending on the nature of the data, comparisons across the 7 scenarios were made using analysis of variance (ANOVA) or chi-square tests. Two group comparisons were made using chi-square tests or *t* tests.

The main dependent variable that measured the respondents' willingness to allow the research described in the scenarios was recoded to create a binary variable by combining the "definitely" and "probably" categories. Using this binary outcome variable, logistic regression models were used to examine the primary research questions, namely, the effects of illness (mental versus medical versus unspecified illness) and competency status (competent, not competent, competency unspecified). Specific mediation (perceived capacity, vulnerability, importance,

social distance, and causal attributions) and moderation (risk perception) effects were examined using regression models.

We explored the general predictors of willingness to allow research. Controlling for scenario effects, we examined a forward stepwise logistic regression model with willingness to allow as the dependent variable and the following predictors: age, race, ethnicity, gender, financial status, education, perceived capacity, importance of research, total Social Distance score, perceived risk, vulnerability, the 6 causal explanation variables (choice, chemical imbalance, upbringing, stress, genetics, God's will), and Research Attitudes Questionnaire total score.

Results

The 3140 persons were randomized to 1 of 7 scenarios so that each person was presented only 1 scenario. The response rates to questions ranged from 76.4% to 81.5% for demographic questions to 79.9–91.2% for the survey questions. For no item was there a significantly different

response rate among the 7 groups (χ^2 range = 3.08 to 7.41, $df = 6$, p range = .28 to .80).

Table 1 describes the characteristics of the respondents.

The responses for the main survey questions are given in Table 2. In general, there was broad support for allowing the research described in the scenarios.

However, as summarized in Table 3, comparisons of the respondents' willingness to allow research across the various scenarios showed significant differences.

Illness effect was present in the hypothesized direction, with the respondents assigned to medical illness scenarios being more willing to allow the research than those assigned to the mental illness scenarios. This illness effect was present when the competency status was specified as either competent or unspecified but not when it was specified as incompetent. Thus, there was an illness by competence interaction, but opposite the hypothesized direction.

As expected, the effect of specifying that a subject was incompetent made the respondents much less willing to allow the research, regardless of illness. Within the illness groups, scenarios that did not specify competency status elicited responses similar to those resulting from scenarios that did specify that the subject was competent.

Finally, we compared the responses to the unspecified illness scenario (scenario 7) with responses to the analogous mental illness and medical illness scenarios. The respondents to the mental illness scenario (scenario 3) were less willing to allow the research than the respondents to the unspecified illness scenario. The responses to the medical illness scenario (scenario 6) were not different from responses to the unspecified illness scenario, despite the fact that the illness symptoms were identical to the mental illness scenario.

Mediators and Moderators

Table 2 shows the responses to the variables that we had hypothesized as potential mediators or moderators. Perception of risk was examined as a potential moderator but did not prove to be a moderator. We checked for mediating effects of perceived capacity, vulnerability, importance, social distance, general research attitudes, and causal attributions on the illness effect (using the groups 1–3 versus groups 4–6 comparison on willingness to allow research). Mediation analyses controlled for all other potential mediators of interest. Only perceived capacity was a mediator of the illness effect on willingness to allow research responses. Specifically, perceived capacity was a strong predictor of willingness to allow research (odds ratio = 2.93, $p < .001$); illness was highly associated with perceived capacity (odds ratio = 1.67, $p < .001$). When both perceived capacity and illness variables were entered into the logistic regression model, illness was no longer a significant predictor (odds ratio = 1.18, $p = 0.138$) of the willingness response, although

perceived capacity remained a strong predictor (odds ratio = 2.71, $p < .001$).

Exploratory Analysis of Predictors of Willingness to Allow Research

We conducted an exploratory analysis of predictors of willingness to allow research using multiple logistic regression models (Table 4). We controlled for scenario effects in order to ascertain an overall sense of which variables are independently associated with willingness to allow the kind of nontherapeutic research portrayed in our scenarios.

Older respondents were slightly less willing to allow the research study portrayed in the scenario. Women were less willing to allow than men; blacks and Asians were less willing than whites to allow the research study. Education, ethnicity, and financial status were not significant predictors of willingness to allow research. There were no interaction effects involving scenario and any of the demographic variables.

As expected, perceived capacity was a strong predictor. The strongest predictor was the perceived risk of the research procedure portrayed in the scenarios. General attitude toward research, as measured by the Research Attitudes Questionnaire, was a significant predictor. For every 10-point increase in the total score (which is approximately equal to a 1-point change per item that has 5 response categories), the adjusted odds ratio was 2.03. Of the 6 possible causal explanations for the illnesses portrayed in the scenarios, none independently predicted willingness to allow research except "chemical imbalance in the brain," which was associated with higher willingness to allow. The social distance variable was not a predictor. Not surprisingly, vulnerability was associated with lower willingness to allow research, while importance of the research was associated with greater willingness to allow.

Discussion

There is an extensive literature on the stigma of mental illness.²² This is the first study to clearly demonstrate that research involving the mentally ill (here portrayed as people with a chronic psychotic illness) is stigmatized. For the present study stigma was understood as discrimination that serves no ethically justifiable purpose while having the potential to cause adverse effects, in this case by precluding research that would benefit the stigmatized population. Key features of this randomized, experimental survey support this interpretation. The ethically relevant parameters—those factors that ought to affect one's responses regarding whether to allow a research study—were kept constant across all of our scenarios: degree and duration of disability, level of functioning, level of social support, the nature and purpose of the research

Table 2. Responses to Survey Questions for Each Scenario Group and for Mental and Medical Scenario Groups Combined

Variable ^a	Group 1: Mental, Competent	Group 2: Mental, Incompetent	Group 3: Mental, Unspecified	Group 4: Medical, Competent	Group 5: Medical, Incompetent	Group 6: Medical, Unspecified	Group 7: Unspecified, Unspecified	Groups 1-3	Groups 4-6	Test Statistics and Significance ^j
Allow ^b % (<i>n</i>)	74.0 (310)	58.8 (253)	69.7 (265)	83.7 (319)	63.1 (262)	80.9 (318)	78.7 (311)	67.4 (828)	75.6 (899)	$\chi^2 = 106.07, df = 6, p = .000$ $\chi^2 = 20.09, df = 1, p = .000$
Importance ^c Mean (SD)	5.25 (1.34)	5.12 (1.38)	5.14 (1.44)	5.24 (1.34)	5.20 (1.38)	5.16 (1.33)	5.14 (1.34)	5.12 (1.39)	5.12 (1.35)	$F = 0.54, df = 6, p = .776$ $t = -0.55, df = 2414, p = .584$
Risk ^d Mean (SD)	2.24 (.881)	2.33 (.865)	2.29 (.841)	2.22 (.838)	2.35 (.857)	2.23 (.848)	2.26 (.872)	2.29 (.863)	2.27 (.849)	$F = 1.44, df = 6, p = .197$ $t = 0.66, df = 2411, p = .510$
Vulnerability ^e Mean (SD)	2.95 (.759)	3.01 (.842)	2.91 (.820)	2.84 (.768)	3.05 (.772)	2.87 (.781)	2.89 (.744)	2.96 (.808)	2.92 (.779)	$F = 3.91, df = 6, p = .001$ $t = 1.12, df = 2374, p = .263$
Social Distance ^f Mean (SD)	14.7 (3.17)	14.1 (3.32)	14.4 (3.39)	16.9 (3.03)	16.0 (2.94)	16.9 (2.97)	15.3 (3.28)	14.4 (3.29)	16.6 (3.01)	$F = 51.41, df = 6, p = .000$ $t = -16.68, df = 2316, p = .000$
Perceived Capacity ^g % (<i>n</i>)	68.1 (280)	24.6 (104)	42.4 (159)	82.3 (307)	31.4 (128)	70.8 (272)	50.8 (197)	44.9 (543)	60.7 (707)	$\chi^2 = 445.08, df = 6, p = .000$ $\chi^2 = 59.58, df = 1, p = .000$
Cause ^h										
Personal Choices Mean (SD)	1.85 (.810)	1.93 (.832)	1.78 (.815)	1.97 (.844)	1.91 (.865)	2.01 (.822)	1.94 (.827)	1.86 (.821)	1.96 (.844)	$F = 2.97, df = 6, p = .007$ $t = -2.99, df = 2315, p = .003$
Chemical Imbalance Mean (SD)	3.51 (.600)	3.51 (.569)	3.54 (.581)	3.17 (.679)	3.25 (.632)	3.21 (.669)	3.32 (.653)	3.52 (.583)	3.21 (.660)	$F = 24.26, df = 6, p = .000$ $t = 11.89, df = 2322, p = .000$
Upbringing Mean (SD)	1.95 (.788)	1.93 (.755)	1.87 (.807)	1.66 (.761)	1.58 (.693)	1.59 (.709)	1.67 (.728)	1.92 (.783)	1.61 (.721)	$F = 18.39, df = 6, p = .000$ $t = 9.97, df = 2323, p = .000$
Stress Mean (SD)	2.71 (.758)	2.69 (.772)	2.77 (.816)	2.47 (.808)	2.44 (.824)	2.46 (.805)	2.48 (.810)	2.72 (.781)	2.46 (.812)	$F = 11.99, df = 6, p = .000$ $t = 7.97, df = 2320, p = .000$
Genetics Mean (SD)	3.27 (.630)	3.21 (.609)	3.29 (.656)	3.20 (.637)	3.22 (.622)	3.21 (.577)	3.19 (.615)	3.25 (.631)	3.21 (.612)	$F = 1.25, df = 6, p = .279$ $t = 1.72, df = 2321, p = .086$
God's Will Mean (SD)	1.94 (1.08)	2.13 (1.10)	1.92 (1.11)	2.15 (1.14)	2.13 (1.12)	2.13 (1.16)	2.07 (1.09)	2.00 (1.10)	2.14 (1.14)	$F = 2.83, df = 6, p = .010$ $t = -2.86, df = 2305, p = .004$
Attitudes Toward Research ⁱ Mean (SD)	37.78 (5.17)	36.92 (5.43)	37.41 (5.37)	38.21 (5.33)	37.89 (5.13)	38.13 (5.53)	37.69 (5.35)	37.37 (5.33)	38.07 (5.32)	$F = 2.60, df = 6, p = .016$ $t = -3.12, df = 2205, p = .002$

^aNumber of subjects (*n*) reported varies for each variable due to missing data.

^bAllow: Reported as percentage (*n*) who would definitely or probably allow patient to participate in the research described in the scenario.

^cImportance: Rating on a scale from 1 (not at all important) to 7 (extremely important) for how important it is to do the research on the illness described in the scenario.

^dRisk: Rating on a scale from 1 (minimal or less risk) to 4 (high risk) for the level of risk involved in the research described in the scenario.

^eVulnerability: Rating on a scale from 1 (not at all likely) to 4 (very likely) of how likely it is that the patient described in the scenario could be pressured into participating in research studies.

^fSocial Distance: Total score (minimum = 1, maximum = 20) representing how willing a person would be to (1) live next door to, (2) socialize with, (3) be friends with, (4) work with, or (5) become related through marriage to the person described in the scenario. A higher value indicates being more willing to interact socially with the person described in the scenario. Adapted from the 1996 National Opinion Research Center's General Social Survey.

^gPerceived Capacity: Percentage who feel the patient in the scenario is definitely able or probably able to make his/her own decisions about being in research.

^hCause: Rating on a scale from 1 (not at all likely) to 4 (very likely) of how likely it is that the patient's illness is caused by each of the following: (1) personal choices, (2) chemical imbalance, (3) upbringing, (4) stressful circumstances, (5) genetics, and (6) God's will.

ⁱAttitudes toward Research: Total score of Research Attitudes Questionnaire (RAQ) (minimum = 1, maximum = 55), which is intended to measure an individual's attitudes toward medical research. A higher value indicates an attitude that is more supportive of conducting and/or participating in medical research.

^jTop values represent statistical significance of tests across all 7 scenarios. Bottom values are for paired comparison of Groups 1-3 to Groups 4-6.

Table 3. Summary of Scenario Effects on the Respondents' Willingness to Allow Research

Comparison ^a	Adjusted ^b Odds Ratio	p-value
Illness Effect		
Mental Illness vs. Medical Illness (Combined Scenarios 1–3 vs. Combined Scenarios 4–6)	0.652	< 0.001
Mental Illness, Competent vs. Medical Illness, Competent (Scenario 1 vs. Scenario 4)	0.579	0.005
Mental Illness, Incompetent vs. Medical Illness, Incompetent (Scenario 2 vs. Scenario 5)	0.807	NS (0.169)
Mental Illness, Unspecified Competence vs. Medical Illness, Unspecified Competence (Scenario 3 vs. Scenario 6)	0.517	0.001
Competency Effect Within Mental Illness Groups		
Mental Illness, Competent vs. Mental Illness, Incompetent (Scenario 1 vs. Scenario 2)	2.167	< 0.001
Mental Illness, Competent vs. Mental Illness, Unspecified Competence (Scenario 1 vs. Scenario 3)	1.240	NS (0.223)
Mental Illness, Incompetent vs. Mental Illness, Unspecified Competence (Scenario 2 vs. Scenario 3)	0.561	0.001
Competency Effect Within Medical Illness Groups		
Medical Illness, Competent vs. Medical Illness, Incompetent (Scenario 4 vs. Scenario 5)	3.105	< 0.001
Medical Illness, Competent vs. Medical Illness, Unspecified Competence (Scenario 4 vs. Scenario 6)	1.085	NS (0.694)
Medical Illness, Incompetent vs. Medical Illness, Unspecified Competence (Scenario 5 vs. Scenario 6)	0.370	< 0.001
Label Effect		
Mental Illness, Unspecified Competence vs. Unspecified Illness, Unspecified Competence (Scenario 3 vs. Scenario 7)	0.595	0.005
Medical Illness, Unspecified Competence vs. Unspecified Illness, Unspecified Competence (Scenario 6 vs. Scenario 7)	1.129	NS (0.542)

^aThe reference is the second scenario mentioned in each pairwise comparison.

^bAdjusted for age, race, ethnicity, education, and gender.

procedures, and the risk-benefit description of the research procedures. Each participant responded to a single scenario in order to minimize the socially desirable answers that may occur when participants are invited

to compare medical versus psychiatric scenarios. By manipulating the specified competency status within illness groups, we were able to demonstrate that the respondents were sensitive to the ethically relevant issue of decision-making competence. By using a scenario (scenario 7) that contained a generic disease label (with a medical causal framework) along with a symptom picture identical to the mentally ill scenarios, we demonstrated that it is not necessarily the symptoms of mental illness but rather the designation of an illness as “mental,” or the lack of a medical causal framework, that elicits the stigma.

We were surprised by the nature of the interaction between the competency status and illness type. We had hypothesized that the “most protected” group would be the mentally ill persons who were specified as incompetent. Instead, our respondents discriminated between the mentally ill and the medically ill not when the research subjects' competence status was specified as incompetent but rather when that status was either unspecified or specified as competent.

The results of the mediation analyses are important because they confirm that the tendency to discriminate against psychiatric research is mediated by the specific belief that persons with mental illness are less capable of making decisions, even when it is made explicit to the respondents that the mentally ill person has been deemed competent by an independent physician. Of the respondents, 32% felt that the mentally ill subject described as competent was in fact “probably or definitely not capable,” compared with 18% for the medically ill subject. It appears that laypersons are affected by an older model of diagnosis-driven definitions of competence that has now been deemed ethically unacceptable,²³ even when they are told that the persons have been independently determined to be competent.

The illness effect was not mediated by the respondents' feeling that research into mental illness is less important or that psychiatric patients are, in comparison to the medically ill, more prone to being enrolled in research against their wishes. While general attitude toward research (RAQ) significantly predicted willingness to allow research, it did not mediate the differential responses between psychiatric and medical scenarios.

We confirmed the existence of certain aspects of stigma, but they were not associated with willingness to allow research. For example, the desire to remain socially distant from persons with mental illness did not affect responses regarding willingness to allow participation in research.

Finally, perceived risk of the research procedure portrayed in the scenario was a very strong predictor of willingness to allow research; however, it did not interact with type of illness. The perception of risk of research with the mentally ill as compared to medically ill patients was about the same, despite NBAC's concerns that psychiatric research involves greater risk than medical research.⁵

Table 4. Exploratory Logistic Regression Analysis of General Predictors of Willingness to Allow Research, Controlling for Scenario Effects

Variable	B	SE	Wald	<i>p</i>	Odds Ratio	95% CI of Odds Ratio	
Age	-.012	.004	8.480	.004	.988	.981	.996
Gender ^a	-.417	.120	12.185	.000	.659	.521	.833
Race ^b							
Black	-.455	.183	6.199	.013	.635	.444	.908
Asian	-.865	.416	4.312	.038	.421	.186	.953
American Indian	.348	.571	.373	.541	1.417	.463	4.335
Other	-.213	.244	.759	.384	.808	.501	1.304
Risk ^c							
Minimal	3.349	.303	122.448	.000	28.461	15.728	51.502
Minimum increase over minimal	2.630	.260	102.198	.000	13.878	8.334	23.109
Moderate	1.673	.255	43.201	.000	5.329	3.236	8.777
Importance	.355	.046	59.909	.000	1.426	1.303	1.560
Vulnerability	-.310	.079	15.363	.000	.733	.628	.856
Chemical Imbalance Cause	.228	.097	5.550	.018	1.256	1.039	1.518
Attitude Toward Research (Research Attitude Questionnaire total)	.074	.012	38.190	.000	1.077	1.052	1.102
Perceived Capacity (yes/no)	-.946	.129	53.816	.000	.388	.302	.500

^aReference category is male.

^bReference category is white.

^cReference category is high risk.

Limitations

Analogous to the distinction between efficacy (internal validity) and effectiveness (external validity) in randomized clinical trials, our study has stronger internal validity than external validity. The survey's experimental between-subjects design with random assignment of large numbers of respondents to each cell ensures that the primary stigma effect (ie, illness effect) is real. The exploratory analysis of the predictors of willingness to allow research also supports the internal validity of the study; our respondents' perception of risk, their perception of vulnerability of the subjects, their sense of importance of research, and so on all predicted their response in the expected directions, which shows that they were answering the questions as intended.

Although the sample frame was not a probabilistic sample of the US population, this study may still provide good evidence for the external validity of the stigma effect. We were able to recruit and randomize a highly heterogeneous group of respondents in terms of race, ethnicity, age, gender, financial status, and education. None of these demographic variables moderated the stigma effect (ie, illness effect), so it is highly unlikely that the main results are due to biased sample selection. It is true, however, that the point estimates of frequency of responses need to be interpreted with caution.

Finally, it is possible that we did not control for all the ethically relevant variables across the 7 scenarios and that our respondents were discriminating between illnesses based on this unidentified, yet ethically relevant, variable. Although this seems unlikely, it is important that future

research continue to unearth potential determinants of research stigma.

Conclusions

There are 3 main findings of this study. Even when ethically relevant factors are similar between medical and mental illness research, there is a tendency to restrict mental illness research compared to medical illness research. This restrictive view of mental illness research is largely mediated through the outdated belief that having a mental illness makes a person incapable of making his or her own decisions. Finally, this discriminatory treatment of mental illness research is not so much about biased treatment of the incompetent mentally ill but rather of the competent mentally ill. Moreover, this stigma is deep enough to override the statement that an independent physician has deemed a mentally ill person competent. This last finding is particularly troubling, as it indicates that the stigmatizing attitude may be influential in spite of "official" statements to the contrary.

This study does not prove that policies singling out the decisionally impaired mentally ill are driven by stigma. However, it does show that such policies are consistent with deeply ingrained stigma regarding the mentally ill. Since there is no reason to think that policymakers and IRB members are exempt from the influence of such stigma, they must be especially careful to guard against it in their own formulation and implementation of research ethics policy regarding the decisionally impaired.

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