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Stigma and Difficulty Accessing Medical Care in a Sample of Adults with Serious Mental Illness

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Abstract

Introduction—Wellness of people with mental illness is increasingly a public health priority. This study examined factors associated with difficulties receiving medical care in adults with mental illness.

Methods—In a sample of 1,670 adults with mental illness, we assessed difficulties in accessing medical care and stigma.

Results—A total of 465 (28%) participants reported difficulties in accessing medical care; 211 (13%) attributed difficulties in access to stigma. Lack of comprehensive medical care coverage and mental health symptoms were associated with increased odds of perceived difficulties in accessing medical care; personal empowerment was negatively associated with perceived difficulties attributed to stigma; education was positively associated.

Discussion—The findings highlight unmet need for medical care in this population and the need to recognize stigma as a barrier medical care. Interventions to empower patients and educate medical providers about wellness for people with serious mental illness could help to reduce barriers.

Keywords

Stigma; access to medical care; mental illness; health care reform

People with serious mental illness (SMI) die 25 years earlier on average than the general population from preventable chronic diseases, such as heart disease, metabolic syndromes,

and respiratory illnesses.¹ Nationally representative epidemiological studies indicate that significant associations between mental disorders and chronic medical conditions are only in part due to worse health behaviors.^{2,3} As the country moves towards integrating behavioral and physical health care, we need to recognize barriers to care to remedy these problems.

Individuals with SMI are disproportionately uninsured,⁴ a circumstance often attributed to discrimination based on pre-existing conditions.⁵ The Affordable Care Act (ACA) remedied the latter problem, yet concerns persist regarding outreach to this population.⁶ People with mental illnesses are less likely to obtain needed medical care⁵ and receive less preventive services⁷ than others. Despite differing perceptions of access, both perception and objective measures are identified as important.⁸

Implementation of the ACA will increase Medicaid coverage to single, childless adults who live under 133% of the poverty level in those states which are choosing to expand Medicaid coverage.⁹ New efforts to reform integration of behavioral and physical health care under the ACA can provide an opportunity for people with behavioral health conditions to receive mental health services and also better access to medical care, and potentially to medical care providers who are educated about coordinated care and people with mental illnesses.

The U.S. health care system relies on people's ability to navigate a complex system and evaluate treatment options.¹⁰ Government agencies define *empowerment* as a person having "authority to choose from a range of options and to participate in all decisions that will affect their lives, and are educated and supported in so doing."¹¹[p.1] People who lack empowerment have difficulty navigating the health care system and may be unable to take charge of their health care.¹¹ Some people with mental illness experience decreased self-efficacy—a component of empowerment—because of stigma.^{12,13} However, past research has rarely connected all the dots—i.e., examined the association between empowerment and stigma in accessing medical care in this population.

Our study explored perceived difficulty seeking medical care among people with SMI, as well as their attribution to stigma, and personal- and illness-related factors associated with such difficulties. We hypothesized that difficulty getting medical care would be attributed to stigma. This becomes especially important as health systems are reformed to promote greater access and prevent chronic diseases.

Methods

Sample

Data are from the Consumer-Operated Services Program Multi-site Research Initiative (COSP-MRI), funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). The COSP-MRI was a randomized controlled trial comparing traditional mental health services alone with those augmented with consumer-operated services implemented between 1998 and 2008. All research procedures were reviewed and approved by the institutional review boards (IRBs) at the individual research sites as well as by the IRB at the Coordinating Center at the University of Missouri. The study sample for this analysis includes 1,670 adults age 18 years or older who were diagnosed with a serious

mental illness. They were recruited from traditional mental health service settings by the original study team based on inclusion criteria related to diagnosis of serious mental illness and disability.¹⁴ Half of participants were diagnosed with schizophrenia or other psychotic disorders, and 44% with mood disorders (such as bipolar or major depressive disorder); 4% were diagnosed with anxiety disorders, and 2% with other diagnoses. Most participants (96%) were taking psychiatric medication, and all had been involved in traditional mental health services in the 12 months before recruitment.^{15,16}

Although the COSP-MRI had three follow-up data collection points to measure service outcomes, the data used in the analysis reported here are from the baseline measurement (conducted in 2000–2001); the analysis ignores the randomized design to avoid confounding by the study interventions. The COSP-MRI data provide an opportunity for looking at a large, homogeneous sample of adults with serious mental illness.

Measures

Outcome—Participants were asked whether they had difficulty receiving the physical health care they needed in the past four months (“In the past four months have you had trouble getting the physical health care you needed?”), and if they said they had, whether this was because of stigma (“Do you believe that you’ve had trouble because you are a mental health consumer?”).

Predictors—Predictors used in the full model included whether participants felt their medical care benefits covered all the services they needed and wanted; whether an individual had at least one of eight common chronic physical health conditions (diabetes, cardiac problems, hypertension, asthma, chronic bronchitis, frequent headaches, arthritis, and stomach ulcer); personal empowerment measured by the Personal Empowerment scale (PES),¹⁷ and the Hopkins Symptom Checklist–25 (HSCL–25),¹⁸ which is a measure of mental health symptoms; level of education; and basic demographic characteristics such as age, gender, and race (White or other). Perception of medical coverage and presence of chronic conditions were collected as categorical self-report variables. The PES is a 20-item measure of control over one’s own life, including services received, and ability to minimize unwanted occurrences, and maximize desired life domains.¹⁷ Both the Personal Empowerment scale and the HSCL–25 have been shown to have acceptable psychometric properties in past research.^{17,18} The HSCL–25 scores were standardized by dividing each person’s score by the standard deviation of the scale in the total group. Thus, the odds ratio associated with a 1 unit higher score on the standardized HSCL–25 indicates the odds ratio associated with 1 standard deviation difference in the score.

Statistical methods

Analyses were conducted in three stages. We first assessed the prevalence of perceived difficulties overall and difficulties attributed to stigma and to other reasons in accessing medical care in this population.

Next, multinomial logistic regression analyses were conducted to examine the associations between characteristics of participants and difficulty receiving physical health care. Three

outcome groups were identified for these analyses: 1) those who reported no difficulties in accessing care, 2) those who reported difficulties due to stigma and, 3) those who reported difficulties due to other reasons. It was assumed that individuals who reported difficulties but did not endorse stigma as a reason had experienced difficulties due to other reasons. An adjusted multinomial logistic regression was used to analyze factors that contributed to difficulties accessing care. Characteristics included in the model were based on theory and previous research, consistent with the Andersen model, which includes factors that predict access to care such as health status, population resources and characteristics, and consumer perceptions.¹⁹ These included adequate medical care coverage, mental health status as measured by HSCL-25, personal empowerment, and chronic physical condition. Demographic characteristics were also included. Analyses included both those who had seen a health care provider and those who had not, and regardless of presence of a chronic condition. Follow-up analyses on frequency of contact with a medical doctor were also conducted.

Less than 0.1% of the outcome data were missing, and missing data appeared to be missing at random, as individuals who had missing data were not different on any observed variable with those who did not have missing data. Model-wise deletion was used to remove missing data from the analyses, which reduced the number of observations in the final model by 7%.

Analyses were conducted in Stata version 12.²⁰

Results

The characteristics of the sample overall and categorized according to perceived difficulty in accessing medical care are presented in Table 1. A majority of participants were female and White with an average age of 42.6 years (standard deviation [SD]=10.0 years). The majority had at least graduated from high school. A majority also had at least one chronic physical health condition as well as comprehensive medical benefits.

A total of 465 (28%) of the participants reported experiencing difficulties in accessing medical care. Of these, 211 (45% of the 465) attributed such difficulties to stigma. Another 254 (55% of 465) did not attribute their difficulties to stigma and were assumed to have experienced difficulties in access due to other reasons. The majority of people in the sample (73%) had seen a health care provider.

The results of the multinomial regression analysis for are shown in Table 2. Difficulties in access due perceived stigma and due to other reasons were both associated with perceived inadequacy of medical care coverage and more mental health symptoms. However, sense of empowerment was negatively associated and at least some college education was positively associated with greater likelihood of experiencing difficulties in accessing medical care due to stigma but not due to other reasons.

Less comprehensive medical benefits and more psychological symptoms were associated with greater difficulties in accessing physical care, due to stigma and other reasons. Participants with comprehensive medical care benefits had a 50% lower odds of having difficulty accessing medical care due to stigma and 66% lower odds of having difficulty

accessing care for other reasons than those without benefits that covered what they needed and wanted. Furthermore, a 1 standard deviation increase (15.9 points) in the HSCL-25 was associated with a 59% higher odds of difficulty accessing physical health care due to stigma and a 34% higher odds of difficulty accessing care due to other reasons.

In contrast, personal empowerment and college education were specifically associated with difficulty accessing physical health care and were not significantly associated with difficulty in access due to other reasons. A 1 standard deviation increase (9.7 points) on the personal empowerment scale was associated with a 44% lower odds of having difficulty accessing physical health care due to stigma; in contrast, those with at least some college education had a 49% higher odds of perceived difficulty.

Further analyses indicated that those who had some college education were more likely to have seen a doctor ($\chi^2 = 13.69$, $df = 1$, $p < .001$); 76% of people who had at least some college education compared with 66% of those with less education had seen a doctor in the past four months.

Discussion

This analysis explored three primary predictors of poor access to medical care and stigma for people with serious mental illness: comprehensiveness of medical care benefits, severity of mental health symptoms, and personal empowerment. The results showed that these factors were important in predicting whether people had trouble receiving the medical care that they needed, but were differentially important for those who did and did not experience stigma in this process.

Stigma of mental illness

The stigma against serving people with mental illness in medical care is well-documented.²¹ There are often more complications treating those with a mental illness and a comorbid physical condition.^{22,23} This analysis showed that nearly half of those who had difficulty accessing medical care believed it was because they are a mental health consumer. (Notably, other studies have shown that people with serious mental illness feel that primary care is important to them.²⁴) Although this analysis did not show that presence of a comorbid chronic physical health condition affected difficulty accessing care, other studies of people with chronic physical conditions show that they also perceive, experience, and anticipate stigma from health care providers, and that this affects access.²⁵ Therefore, having a chronic physical condition may increase barriers to medical care for the entire population, but in people with a serious mental illness and a chronic physical health condition, barriers created by the stigma of mental illness may be more important. The data presented here show that many consumers perceive the stigma of mental illness when seeking health care, although it did not explore the attitudes of providers. Health care providers who work with people with serious mental illness are both the objects of stigma themselves within the medical profession and may exacerbate self-and public-stigma that the patients face, which can negatively affect care-seeking.^{26,27} Community-level stigma-reduction could be more effective in promoting access to care by addressing concerns of patients and providers.

Comprehensive essential health benefits

Expanding medical care coverage to those with comorbid physical and mental disorders is an important part of the implementation of the Affordable Care Act and the essential health benefits (EHB) package. This analysis showed the importance of these benefits for access to care for a sample of people with serious mental illness. Those with inadequate medical care coverage were significantly more likely to have difficulty accessing physical health care. Even with current insurance efforts, particular attention will need to be paid to previous problems with stigma and discrimination against people with mental illness in gaining and keeping insurance coverage, and how this will affect outreach and enrollment strategies. Significant educational efforts should be undertaken to clarify that people with pre-existing conditions may no longer be discriminated against. Those with high quality benefits that covered what they needed were less likely to report poor perceived access. It is not only important that people with serious mental illness have medical care coverage, but that we ensure that those benefits cover essential services that are needed and wanted by consumers, and that they know their rights in obtaining adequate coverage.

Mental health symptoms and access to medical care

This study showed that increased mental health symptoms were associated with difficulties in accessing medical care for both people who attributed this difficulty to stigma and those who did not. We found that only a small increase in mental health symptoms had a small but significant effect on access to care. This may point to the importance—identified in legislation and implementation strategies for the Affordable Care Act—of integrated care models where people can receive services and supports for mental health issues and physical health issues in either co-located or coordinated care settings. One model for this is the “health home” established as a Medicaid state plan amendment under the Affordable Care Act. Health homes do not need to provide the full array of required services themselves, but must ensure such services are available and coordinated.²⁸

Empowerment of people with mental illness

Empowering people is also an important part of improving access. We found that even a small increase in empowerment had a significant impact on access to care. This study showed that it was particularly important in those who perceive stigma from health care providers. The personal empowerment scale used in this study measured whether people felt they had a choice in their future circumstances and how much chance was associated with future circumstances. Improving perceptions of choices and stability in life events, particularly concerning health care, can be gained by providing people with more personal resources from which to draw upon when making choices and facing difficulty. Empowerment may improve a person’s ability to ask for care, but not suffice to ensure receipt of care when barriers such as lack of health insurance and stigma about treatment of people with mental illness are present. In addition, because of historical disempowerment experienced by people with mental illness and pervasive stigma and self-stigma that impacts self-efficacy, empowering this population will be more complicated than simply educating them about health and health care—it will require targeted empowerment strategies to help people overcome stigma and discrimination in health care settings.

Education

While it is surprising that those with higher education were more likely to perceive difficulty accessing physical health care, there are a number of possible explanations for this, particularly as the results show education was significantly associated with difficulties in access in those who attributed difficulty to stigma. Education is associated with more health care utilization.²⁹ People with more education seek care more—and therefore have more chances to have difficulties in access. They may perceive this trouble at the point of care, and therefore attribute the difficulty to the stigma of mental illness that they perceive from a provider. They may also be more likely to *perceive* difficulty than those who have less education and may expect less from the health care system. Furthermore, the problems in receiving care reported by people who have had some college education may be problems in *processes* of care rather than barriers to accessing a provider—which may be a problem of their counterparts who have not attended college at all.

Limitations

One limitation of this study was that we could not compare the access problems of people with serious mental illness to a control group that did not have a serious mental illness. Another limitation is that, although there are studies on objective access and quality of care,^{5,7} this study does not provide data on the relationship between perceived barriers and whether people did or did not objectively receive the health care that they needed, based on their physical health status. Another limitation is the age of the data, especially since we are now in a period in which significant changes have been made in the health care system. This is a rare dataset where the study population exclusively includes people with serious mental illness. Efforts should be made routinely to collect up-to-date data on this population. While this is not a population-based sample, we have no reason to believe (given demographic characteristics of the study sample) that it is not generalizable to others with serious mental illness receiving mental health services.

Conclusion

Although past studies have examined the impact of stigma, empowerment, health insurance status, co-morbid physical conditions, and treatment seeking behavior in accessing mental health care by this population,^{5,21,30} this is one of the first studies to include whether individuals with serious mental illness attributed difficulties in seeking medical care to stigma, and what personal and illness-related factors, including symptoms and empowerment, were associated with such difficulties. This analysis allowed us to tease out the effects of these factors when the others are also taken into account. Future studies should expand the analyses of these factors to population-based samples.

It is important to continue monitoring access to physical care in this population and the many factors related to access, quality of care, and outcomes of such care as the health care system evolve in the coming years. The significantly shorter life-span and higher rates of chronic health conditions in this population remains a major concern. Wellness promotion and illness reduction in people with serious mental illness should be of central importance to health care reform as we make efforts to integrate physical health and behavioral health. However, we must also recognize the patterns of stigma and discrimination that have

affected insurance status, provider attitudes, and attitudes toward oneself when seeking health care.

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Table 1

**DESCRIPTORS OF PERSONS WITH AND WITHOUT DIFFICULTY ACCESSING MEDICAL CARE
DUE TO STIGMA OR OTHER REASONS**

	Total Mean (SD) or % N = 1,670	Did not perceive access difficulty N= 1,205 (72%)	Difficulty accessing medical care, attributed to stigma N=211 (13%)	Difficulty accessing medical care, not attributed to stigma N = 254 (15%)
Age	42.6 (10.0)	42.6 (0.7)	42.5 (10.1)	42.5 (0.5)
White	57.5%	57.9%	54.0%	58.2%
Male	39.8%	41.2%	39.8%	34.2%
Education				
Less than high school	32.7%	33.5%	27.4%	30.7%
High school diploma/GED	25.4%	26.5%	22.7%	22.6%
Some college	27.5%	26.9%	32.2%	29.1%
College degree	14.2%	12.9%	17.5%	17.4%
Comprehensive medical benefits	59.4%	66.9%	43.6%	37.8%
PES	70.5 (9.7)	71.7 (9.2)	65.4 (11.2)	68.9 (9.3)
Chronic condition	68.1%	65.2%	77.2%	74.4%
HSCL-25	50.0 (15.9)	47.5 (15.3)	58.5 (16.6)	54.4 (14.7)

PES= Personal Empowerment Scale

HSCL-25= Hopkins Symptom Checklist-25 items.

Table 2

ADJUSTED MULTINOMIAL LOGISTIC REGRESSION OF PREDICTORS OF DIFFICULTY ACCESSING MEDICAL CARE AMONG 1,670 ADULTS WITH SERIOUS MENTAL ILLNESS (REFERENCE CATEGORY IS THOSE WHO DID NOT HAVE TROUBLE WITH ACCESS, N=1,205, 72%)

Predictor variable	Difficulty accessing medical care, attributed to stigma (N=211, 13%)			Difficulty accessing medical care, not attributed to stigma (N=254, 15%)		
	β	AOR ^a	(95% CI)	β	AOR ^a	(95% CI)
Comprehensive medical benefits	-0.69	0.50 ^b	(0.37, 0.69)	-1.08	0.34 ^b	(0.26, 0.46)
Standardized HSCL-25 score	0.46	1.59 ^b	(1.34, 1.89)	0.29	1.34 ^b	(1.14, 1.57)
Standardized PES score	-0.40	0.66 ^b	(0.56, 0.78)	-0.12	0.88	(0.76, 1.03)
Some college or more	0.40	1.49 ^a	(1.09, 2.04)	0.11	1.12	(0.88, 2.11)
Chronic condition	0.33	1.39	(0.95, 2.04)	0.25	1.29	(0.92, 1.80)
Age	-0.00	0.99	(0.98, 1.01)	-0.00	0.99	(0.98, 1.01)
Gender (male)	0.21	1.24	(0.90, 1.71)	-0.10	0.90	(0.67, 1.22)
Race (white)	-0.16	0.85	(0.62, 1.17)	-0.02	0.98	(0.74, 1.31)

^aThe PES score was standardized by the standard deviation (9.7). The HSCL-25 was standardized by the standard deviation (15.9).

^b AOR stands for odds ratio obtained from the multinomial logistic regression adjusting for chronic physical health conditions, age, gender, and race (white vs. other).

CI = Confidence Interval.

PES= Personal Empowerment Scale

HSCL-25= Hopkins Symptom Checklist-25 item version