Adherence to Follow-Up in First-Episode Psychosis:
Ethnicity Factors and Case Manager Perceptions

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ABSTRACT

Objective: To determine whether visible minority patients with first-episode psychosis are at higher risk for treatment nonadherence than white patients and elicit the perceptions of case managers regarding visible minority patients.

Methods: Data for 168 patients referred to a tertiary first-episode psychosis clinic from January 2008 to January 2012 were collected via chart review. For 110 patients, a questionnaire filled out by each patient's case manager collected quantitative and qualitative data regarding the case managers' perceptions of patients' insight, cooperation, and adherence to appointments and medication. Differential treatment adherence in white and visible minority patients was tested via χ^2 analyses. Case manager ratings of adherence were compared to objective data via Cohen κ. Qualitative data were analyzed via thematic analysis.

Results: Black patients had poorer follow-up compared to other patients (adjusted $\chi^2_1 = 4.3$, $P = .04$). Concordance of case manager–reported adherence and chart data was significant for the visible minority group only ($\kappa = 0.4$, $P = .002$). In case manager perceptions, there was no significant difference between ethnic groups in adherence to appointments and medication, insight, or family involvement.

Conclusions: Although Canada is often perceived as tolerant of diversity, our data regarding poor follow-up in black patients indicate similar problems to those reported in the United Kingdom and United States. Clinicians may have low expectations for visible minority patients and thus notice more consistently when these patients adhere to treatment. This is the first study to examine ethnic differences in adherence to first-episode psychosis follow-up in a Canadian setting.

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Ethnic and racial disparities in mental health care quality and utilization have become important fields of study in recent years. The literature from the last few decades shows that visible minority patients are less likely than white patients to visit a mental health professional, use mental health services,[1–4] or regularly attend outpatient visits for mental health care.[5] Furthermore, visible minority patients are less likely to be treated in community-based settings and more likely to be hospitalized for any reason,[6–8] hospitalized involuntarily,[9,10] and hospitalized for longer durations than white patients.[11] Visible minority status is associated with longer delay to initiation of mental health care[12,13] and poorer quality of care (misdiagnosis, treatment by junior professionals, less treatment options).[12,14–19] Visible minority patients in mental health care settings may also have poorer outcomes, eg, more readmissions, coercive routes of readmission, and a higher likelihood of imprisonment.[6,9] These differences persist after controlling for sociodemographic and financial factors.[1,3,8,20]

The reasons for these disparities remain uncertain, although individual and institutional racism very likely plays a role.[20] The history of racism in mental health care is long and has taken different forms over time.[21] Despite that clinicians may unwittingly employ biased attitudes or practices,[18] many psychiatrists do not recognize the pervasiveness of unequal access to psychiatric care and may attribute racialized thinking to others but not to themselves.[22] Some studies[23] report significant perception of bias and racism among black patients and their relatives, and the relatives of black patients report receiving less assistance and opportunity to participate in treatment.[17,24] On the basis of this perception, some visible minority patients may delay or fail to seek mental health treatment,[14] deem psychiatric services to be irrelevant,[25] and expect that health care providers cannot be trusted.[5] These negative perceptions of psychiatric care may decrease service engagement, with a worsening of untreated symptoms. On the other hand, stereotyped perceptions of patients by clinicians and treatment teams may compromise appropriate care,[16] perpetuating a self-fulfilling prophecy.

Belonging to a visible minority group and living with the stigma of mental illness presents a social burden and may be why some of these patients avoid or prematurely withdraw from treatment.[26] Visible minority patients with psychosis may represent a population that is particularly vulnerable due to the severe symptoms they experience and the baseline discrimination they face in Canadian society. Further, patients with psychosis have been reported to have high rates of nonadherence to medical treatment and scheduled appointments,[27] presenting an even greater challenge to the delivery of appropriate care.

Most data on racial disparities in mental health care come from European and American studies with respect to black patients. There are very few studies on such disparities in Canada, wherein cultural and historical factors have created a different environment (eg, a less

Clinical Points

- Clinicians should be aware of how they engage visible minority patients with psychosis.
- Particular attention should be paid to engaging black patients early in the course of treatment.

well-known history of black slavery and the emphasis on multiculturalism, as opposed to an assimilation/acculturation model).[28] The few available data are contradictory. Jarvis et al[29] reported that Afro-Canadian patients with psychosis have a higher likelihood of experiencing police or ambulance referral to emergency services. Adeponle et al[30] reported misdiagnosis of psychotic disorder in 49% of a multiethnic sample, and Anderson et al[31] reported a higher likelihood of black patients being referred from inpatient services. Conversely, Archie et al[32] found no ethnic differences in duration of untreated psychosis or initiation of treatment-seeking by friends or family, police, or self. Furthermore, no Canadian data are available on ethnic disparities in adherence to appointments or on clinician bias in visible minority populations.

In this study, we aimed to determine the quality of follow-up as a function of patient ethnicity in a multicultural first-episode psychosis program. Further, we aimed to elicit the perceptions of the case managers toward ethnic patients in terms of perceived adherence to medication and scheduled appointments, perceived insight, general cooperation with the treatment team, and family involvement.

We hypothesized that visible minority patients with first-episode psychosis would be more likely to have a problematic follow-up and that they would be less likely to be perceived by their case manager as insightful, cooperative, and adherent to medication and scheduled appointments compared to white patients.

METHODS

Study Setting

The First Episode Psychosis Program (FEPP) at the Jewish General Hospital in Montreal, Quebec, was started in 2008 as a partner of the Prevention and Early Intervention Program for Psychosis (PEPP)–Montreal.[33] This specialized treatment program comprises close follow-up and specialized services for patients and their families over a 2-year period by a psychiatrist and a case manager (social worker, mental health nurse, or occupational therapist). Patients referred to the FEPP are triaged by a psychologist and admitted to the program on the basis of inclusion criteria that confirm the presence of a first episode of psychosis. The patients are then followed according to a standardized protocol detailing the number of appointments with the psychiatrist and the case manager and the schedule of laboratory and other investigations. The program involves 2 psychiatrists and 4 case managers. All FEPP clinicians are white.

Study Design and Participants

This study involved 2 participant groups: (1) patients of the FEPP at the Jewish General Hospital in Montreal (N = 168) and (2) their case managers (n = 4). We specifically chose to include patients who did not show up for their first appointments because we suspect that much of the ethnic variation in follow-up takes place early in the evaluation process. Data from the patient group examined patient adherence to scheduled appointments. Data from the case manager group evaluated perception of patient insight, adherence to appointments and medication, general cooperation, and family involvement. The accuracy of case manager perception of adherence to appointments (as opposed to objective chart data) was assessed via Cohen κ as a measure of case manager bias.

All case managers provided written informed consent. The Research Ethics Board of the Jewish General Hospital approved the study protocol and consent forms.

Chart Review

The first author (K.N.) reviewed the charts of all patients (N = 168) referred to the clinic between January 2008 (the inception of the clinic) and January 2012 (3 months prior to the start of the data collection so that case managers would have had time to form an opinion) and collected data on age, sex, ethnicity, immigration history, and adherence to scheduled appointments. Adherence to 50% or more of scheduled appointments was given the designation "good follow-up." This cutoff was chosen on the basis of clinical reasoning and the authors' knowledge of the clinic population. These data served as a standard to compare to data collected from case managers.

Case Manager Questionnaires

Patients who had been referred, triaged, and followed for at least 3 months at the clinic (n = 110) were selected for the case manager questionnaires, allowing for the case managers to have achieved a degree of familiarity. New referrals and patients who had been referred but lost before triage were excluded. These questionnaires were devised by the authors based on real-world issues that arise during the routine practice of the FEPP team. For each patient, the assigned case manager completed a questionnaire asking about the patient's age, sex, education, employment status, marital status, ethnicity, country of origin, religion, and citizenship status. Case managers were instructed to respond from memory and to avoid consulting the patients' charts. The second part of the questionnaire consisted of 2 types of alternating questions. The first was a 4-point Likert scale question assessing the case manager's perception of the patient's insight, adherence to appointments, adherence to medications, general cooperation with the team, and the family involvement. Each multiple-choice question was followed by an open-ended question assessing the case manager's explanation of the elicited response.

The case manager questionnaire (Supplementary Appendix 1) was designed to elicit their perceptions of the

clinical factors relevant to each patient's care and not to gather strictly factual information. The purpose of the study was to determine how the case managers remembered the patients and what qualities they attributed to them. The case managers knew these patients best and worked with them the most extensively, so their recollections and impressions were of primary importance.

Ethnicity Assignment Procedure

On the basis of categories from Census Canada 2006,[34] the authors developed an ethnicity assignment procedure using retrospective data, including recorded ethnicity, languages spoken, country of origin, immigrant status, religion, and family name, resulting in 5 ethnic categories (Arab, Asian, black, Latin American, and white) for this sample. Two raters applied the procedure independently for 168 patients (with $\kappa = 0.9$; 95% CI, 0.82–1.00; $P < .001$). Visible minority status was assigned using the Census Canada 2006 tables for visible minority groups. In our study, visible minority categories included Arab, Asian (East, South, and Southeast Asian), black, and Latin American patients. These categories were mutually exclusive.

Statistical Analysis

Statistical analysis was conducted using the IBM SPSS Statistics 21 software. Bivariate associations between adherence to follow-up, case manager perceptions, and ethnicity/visible minority status were assessed using χ^2 analysis. Logistic regression was used to control for age and sex. A P value < .05 was considered significant with 2-sided testing.

The first author (K.N.) conducted a power analysis using the calculator provided by the Division of Biostatistics at Columbia University Medical Center (http://biomath.info/power). Sufficient power (> 80%) was detected for the analysis of black versus white patient follow-up but not for visible minority versus white or for analyzing the differences in case manager ratings of patients of different ethnicities.

Content Analysis

The data collected in the narrative response fields from the case manager questionnaires were transcribed by the first author (K.N.). The transcribed data were then read several times to ensure data immersion. Building on these readings and ideas generated during data handling, a number of codes were created to represent features of the data considered pertinent to our questions. The codes were then further combined into themes for each visible minority category separately and for the whole sample.

RESULTS

Data were available from 168 patient charts and 89 questionnaires filled out by case managers (response rate of 81%). The 89 patients for whom we had questionnaire data were a subset of the 168 reviewed charts and of the 110 questionnaires we distributed to case managers. These patients were selected from the chart sample on the basis of the previously described inclusion criteria. The distribution of questionnaires among case managers was based on their caseload (case manager 1: n = 35, case manager 2: n = 28, case manager 3: n = 25, case manager 4: n = 22). Response rates were similar across case managers.

Table 1. Sample Characteristics By Ethnicity

Ethnicity	Sample, n (%)	Male, n (%)	Age, mean (SD), y
White	81 (50)	57 (70)	22.6 (4.3)
Visible minority	82 (50)	49 (60)	22.7 (5.5)
Black	41 (25)	23 (56)	24 (5.4)
Asian	22 (13)	15 (68)	21.2 (5.7)
Arab/Middle-Eastern	14 (9)	9 (64)	21.6 (3.9)
Latin American	5 (3)	2 (40)	22.5 (10.6)
Total	163 (100)	106 (65)	22.6 (4.9)

The sex and age characteristics of the sample are presented in Table 1. The mean age was 22.6 years (SD = 4.9 years), with the youngest patient being 12 and the oldest 35. Two-thirds of patients were male. We were able to assign ethnicity and visible minority status to 163 patients (97%), with the remaining 5 patients designated as unknown ethnicity. One-half (50%) of the patients were white, 25% were black, and another 25% were from non-black visible minority groups. Thus, 50% of our sample was assigned a visible minority status. There were no significant differences in age, sex, ethnicity, visible minority status, or objective quality of follow-up distributions between the subsample of patients for whom case manager questionnaire data were available and those for whom data were unavailable ($P > .05$ in all cases).

As summarized in Table 2, only 41% of patients attended at least 50% of appointments (ie, had good adherence). A stepwise binomial logistic regression model with ethnicity, age, sex, mother tongue, proficiency in English or French, and whether the case manager completed a questionnaire as the independent variables and good versus poor follow-up as the dependent variable was statistically significant ($\chi^2_5 = 5.0$, $P = .03$) and predicted follow-up values for 61% of cases. Only black ethnicity was a significant factor, with black patients 24% less likely to have good follow-up compared to white patients (Exp(B) = 0.22, adjusted $\chi^2_1 = 4.3$, $P = .04$).

Chart review data compared to case manager questionnaire subsample data (n = 89) showed modest but significant concordance for appointment adherence when all ethnic groups were included ($\kappa = 0.3$; 95% CI, 0.1–0.5; $P = .001$; ie, chart data and case manager reports agreed about 33% of the time, excluding chance concordance). When κ was calculated for white and visible minority patients separately, case managers displayed higher and significant concordance in estimating treatment adherence in the visible minority group only ($\kappa = 0.4$; 95% CI, 0.2–0.7; $P = .002$). For white patients, κ was the lowest (0.2) and not significant.

Specifically, case managers displayed higher accuracy in reporting good adherence in visible minority patients (91% of actual "good follow-up" from chart review) compared to

Table 2. Adherence to Follow-Up and Case Manager Perceptions

Ethnicity	Chart Data: Good Adherence, n (%)[a]	Adjusted χ^2 for Chart-Based (Actual) Adherence	Case Managers: Good Adherence, n (%)[a]	Concordance of Case Managers' Perceptions With Chart Data, Cohen κ
White	39/81 (48)	…	28/45 (62)	0.2, $P=.13$
Visible minority	28/82 (34)	Not significant (compared to white)	31/44 (70)	0.4, $P=.002$
Black	10/41 (24)	Adjusted $\chi^2_1=4.3$, $P=.04$ (compared to white)	15/22 (68)	…
Asian	11/22 (50)	…	7/11 (64)	…
Arab/Middle-Eastern	5/14 (36)	…	6/8 (75)	…
Latin American	2/5 (40)	…	3/3 (100)	…
Total	67/163 (41)	…	59/89 (66)	0.3, $P=.001$

[a]Good adherence was defined as attending ≥ 50% of scheduled appointments.

Table 3. Major Themes of Case Manager Perception Comments by Visible Minority Status

Theme	White, n (%)	Example	Visible Minority, n (%)	Example
External structure	25 (17)	"Living in a structured/supportive environment (group home) encourages attendance"	40 (20)	"Family refuses pharmaceutical treatment"
Insight	40 (28)	"Zero insight"	43 (22)	"Doesn't always recognize symptoms as such"
Intellect	12 (8)	"Extremely bright individual, understands symptoms very well"	20 (10)	"Very bright, articulate individual"
Therapeutic alliance	5 (4)	"Good therapeutic relationship with case manager"	23 (12)	"Sense of trust in treatment team"
Motivation to get well	9 (6)	"Scared, wants to get better"	10 (5)	"Committed and motivated to get better"
Illness symptoms	20 (14)	"Disorganized"	21 (11)	"Untreated paranoia"
Response to treatment	17 (12)	"He sees the difference, sees benefits, gives him common sense"'	24 (12)	"Feels better, sleeps better, doing better in school"
Pejorative comments	15 (10)	"Not the brightest bulb"	14 (7)	"Kind of needy"

correctly reporting good adherence in 72% of white patients. In all patients, case managers accurately reported objectively poor follow-up (again, from chart review) only 50% of the time.

In reported case manager perceptions, there was no significant difference between visible minority groups in adherence to appointments, adherence to medication, insight, or family involvement. In other words, whether patients were black, Asian, Arab, or Latino made little difference in these ratings.

Content Analysis of Case Manager Comments

In their reported perceptions of adherence, insight, and family involvement for each patient, case managers made relatively brief (1–3 sentences) comments for each question. There were more comments for visible minority patients than for white patients (200 and 144 comments, respectively). After thematic analysis, several themes emerged (Table 3). The frequency and percentage of comments pertaining to each theme were also calculated by visible minority status.

Themes were similar across the 2 groups, with slight variations in the frequency of comments. Main themes included explanations based on external structures (family, group home, or court order), insight, intellect, therapeutic alliance, motivation to get well, illness symptoms (including psychosis, personality disorder, or substance use), and response to treatment (including positive and negative effects). Cultural factors were seldom mentioned. Other themes included references to appointment and medication adherence, desire to please parents or clinicians, and prioritizing school and work over appointments.

DISCUSSION

The key finding in this Canadian sample was the confirmation of findings reported in UK and US studies,[1–19] namely poor follow-up in black patients with first-episode psychosis. Black patients in our sample were significantly less likely to attend appointments than white patients. In our study, this finding was not explained by negative clinician bias, as black patients were not perceived by case managers as different from others on any of the factors investigated. While the black population in our clinic may be more heterogeneous than at other sites, official language matching (French/English) was provided in the clinic, and the regression model showed no effect of official language use on adherence ($P=.31$). Possible explanations may derive from community perceptions, particularly in those of the Afro-Caribbean patients. Seeman[28] discusses the attribution of stress and perceived injustice to young Canadian Caribbean immigrants' perception of racism, which may lead to a reluctance to engage in mental health services, even when negative clinician bias is absent. Studies of black Canadian patients' perceptions of racism in clinical settings would be important to clarify with respect to these differences. The present results underscore the importance of making clinical programs more adaptable and receptive to Afro-Canadian patients with psychosis, despite a popular perception in the Canadian context of an absence of historical adversity for blacks in Canada.[35,36]

The rate of good adherence to follow-up in all visible minority patients was lower than that of white patients, although not statistically significant. It is possible that poorer

rates of adherence are present in all visible minority patients with first-episode psychosis (compared to white patients) but that this difference was not detected due to insufficient power.

Overall rates of nonadherence to scheduled appointments in our sample (almost 60%) were slightly higher than those previously reported in first-contact services for severe mental health disorders (48%).[27] This difference may be due to several factors. In our study, patients who were referred to the clinic but failed to show up to their first appointment were included in the analysis, increasing the overall rate of nonadherence. A significant proportion (25%) of the sample were black patients, whose level of nonadherence (76%) was higher than that of non-black patients, while the latter groups' adherence was closer to previously reported rates. We specifically included patients who were lost to follow-up before their first appointment because we suspect that ethnic factors are more prominent in service engagement early in the evaluation process. Our study results seem to support this notion and may indicate a need for extra effort to engage black and other visible minority patients in the early phases of referral to capture patients from racialized communities before they are lost to follow-up.

How best to accomplish these aims remains unclear. Reviews[37] in the service engagement literature generally point toward illness-related and social determinants of treatment adherence (eg, insight, symptom severity, family involvement), while a small Dutch study[38] found no direct correlation between ethnicity per se and service engagement. It may be that different or enhanced engagement strategies in a multidimensional approach could improve treatment adherence in visible minority patients: such as increased clinician awareness through diversity training programs and early assessment of barriers to engagement (including acknowledgment of patients' race and cultural beliefs), enhancing clinicians' capacities in expressing caring and nonjudgmental attitudes, and improving service accessibility and flexibility.[39]

Contrary to our initial hypothesis, we did not find negative clinician attitudes toward visible minority patients compared to white patients. While the quantitative analyses were underpowered, reported good adherence was very close in both groups (62% white vs 68% black), and content analysis of narrative comments revealed no negative attitudes. In fact, case managers more accurately reported treatment adherence and, in particular, good treatment adherence in visible minority patients than in white patients, while reporting poor adherence approximately to the same degree in all groups. This finding may be due to implicitly lower expectations of visible minority patients, leading to a positive recall bias (perhaps a sense of relief) when these patients attended appointments regularly and did generally well. It may also be that case managers were eager to display an absence of ethnicity-based bias and thus paid more attention to reporting follow-up for their visible minority patients. It is worth noting that case manager estimates of patients' poor follow-up were no better than chance, indicating a possible need to increase appointment adherence vigilance for all patients with first-episode psychosis.

Limitations

This is a retrospective cohort study and thus some measures could not be implemented, such as directly interviewing patients about their perceptions of the clinic and expectations of the clinical process. SES data were not sufficiently present to allow statistical control for socioeconomic factors. The structure of the clinic, however, inherently equalizes SES barriers to attendance of appointments: universal health care, free bus and taxi tickets for patients who need them, and extensive efforts to engage families, caregivers, and patients via free individual and group psychoeducation. The most important limitation may be the small number of case managers (N = 4) who completed questionnaires, thereby reducing the generalizability of these findings. Additionally, responses within case managers could be correlated. Due to small sample numbers, nested analysis was not performed.

CONCLUSION

These results may be clinically helpful to those working with vulnerable populations with early psychosis. First, clinicians should note that visible minority youth may be dropping out of psychiatric services very early in the treatment process, perhaps even before seeing the psychiatrist or entering the clinic doors. Second, first-episode psychosis clinical teams should focus resources on these earliest contacts with visible minority patients to help them access psychiatric services in a timely manner. Third, clinical programs should be adapted and receptive to linguistically and culturally diverse patients and their families. Finally, case managers and clinicians should be aware of their preconceived expectations of visible minority patients since clinician attitudes and beliefs may influence perception of adherence and other outcomes. Furthermore, the double subject set (patients and case managers) and mixed-method design of this study is an original and useful approach to investigating multifaceted phenomena such as bias and service engagement.

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Supplementary material: See accompanying pages.

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Supplementary material follows this article.

THE PRIMARY CARE COMPANION FOR CNS DISORDERS

Supplementary Material

Article Title: Adherence to Follow-Up in First-Episode Psychosis: Ethnicity Factors and Case Manager Perceptions

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List of Supplementary Material for the article

1. Appendix 1

Disclaimer

This Supplementary Material has been provided by the author(s) as an enhancement to the published article. It has been approved by peer review; however, it has undergone neither editing nor formatting by in-house editorial staff. The material is presented in the manner supplied by the author.

Questionnaire for Case Managers

Case Number:

1. To the best of your knowledge, what is your patient's age? _____
2. What is your patient's gender? _____
3. What is your patient's marital status? _____
4. What is your patient's employment status? _____
5. To the best of your knowledge, what level of education has your patient achieved?
   _____
6. To the best of your knowledge, what is the ethnicity of this patient?
   _____
7. Was this patient born in Canada?
   a. Yes
   b. No
8. If not, where was the patient born? _____
9. What is the patient's current status in Canada?
   a. Citizen
   b. Permanent resident
   c. Refugee or refugee claimant
   d. Student or working visa
   e. Other: please specify _____
10. To the best of your knowledge, what is the patient's religious affiliation?
    _____
11. How regularly does this patient attend appointments (including regular appointments, home visits, phone appointments, etc.)?
    a. Very regularly
    b. Somewhat regularly
    c. Poorly
    d. Very poorly

    In your opinion, what factors contribute to the patient's pattern of attendance of appointments?

12. To the best of your knowledge, how well does this patient adhere to his/her medication?
    a. Very well
    b. Somewhat
    c. Poorly
    d. Very poorly

    In your opinion, what factors contribute to the patient's pattern of medication adherence

13. Overall, would you say that this patient has been cooperative with the treatment team?

14. How much insight do you feel this patient has into his/her condition?
    a. None
    b. Poor
    c. Good
    d. Very good

Why do you think this is the case?

15. How involved is the family in this patient's treatment?
    e. Very involved
    f. Somewhat involved
    g. Not much involved
    h. Not at all involved

What are the main issues you have experienced working with this patient's family?