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ORIGINAL PAPER

Perceived racism, medication adherence, and hospital admission in African-Caribbean patients with psychosis in the United Kingdom

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Abstract
Background Differences in outcome between African-Caribbean and white British patients with psychosis may be due to perceived racism and a difficulty in trusting services seen as discriminatory.
Method In 100 participants, racism was measured at baseline using the Perceived Racism Scale; with adherence, using the Drug Attitudes Inventory and Kemp Scale, and hospital admission data determined after 12 months.
Results We found associations between total perceived racism for the previous year ($b = -0.0074$, $P = 0.013$), lifetime racism ($b = -0.0068$, $P = 0.038$), and everyday racism for the previous year ($b = -0.051$, $P = 0.0046$), with subsequent medication adherence. Shame felt about health system racism was associated with increased adherence ($b = 0.20$, $P = 0.015$), and powerlessness about it was associated with fewer subsequent hospital bed days ($b = -14.49$, $P = 0.025$). Finally, health system racism was associated with both the number of subsequent hospital bed days ($b = 5.54$, $P = 0.010$), and admission length ($b = 4.92$, $P = 0.021$). In addition, stratified analyses showed that both baseline adherence and 6-month estimated adherence appeared to mediate these effects.
Conclusions In this cohort of African-Caribbean patients with psychosis, perceived racism is a determinant of adherence over 12 months. We propose a model whereby perceived racism contributes to an individual rejecting mental health services (manifested by the mediating effect of poor adherence) which leads to a poorer outcome, evidenced by a longer hospital stay. Secondly, powerlessness about perceived health-service racism may represent a sense of resignation about the "system", leading paradoxically to greater adherence and better outcome.

Keywords Perceived racism · Psychosis · African-Caribbeans

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Introduction

The relationship between racism and psychosis is a complex one and, as yet, remains relatively under-examined [1–3]. A cross-sectional survey from a nationally representative UK community sample (EMPIRIC) found that perceived societal and interpersonal racism both exerted independent effects on the risk of both psychosis and common mental disorder in minority ethnic groups [4]. A population-based incidence and case–control study of first-episode psychosis (AESOP) similarly found that perceived disadvantage at least partly associates with the excess of psychosis among Black people living in the UK [5]. Elsewhere, a Netherlands group carried out a series of studies, the first of which found a dose–response relationship between discrimination and age- and gender-adjusted incidence rate ratios of psychosis in ethnic minority groups [6]. However, their second study failed to elicit perceived

discrimination as a risk factor at the individual level for schizophrenia [7]. Earlier UK work reported raised incidences of schizophrenia in all minority ethnic groups presenting to psychiatric services within a deprived, inner city setting [8]. Although black and minority ethnic patients with psychotic illnesses report no more life events than their white British counterparts, they are more likely to attribute them to racism, potentially disinclining the minority patients from using services they perceive to be racist [9].

The examination of racism and psychosis has run alongside a discourse upon the inequity of pathways to UK mental health care in different minority ethnic groups. An extensive systematic review found that Black patients had more complex pathways to specialist services, that the police were more likely to be involved in admissions or readmissions of Black people, and there was consistently greater use of inpatient services by Black people [10]. However, the picture was not straightforward: in one area of London they found that minority ethnic patients were less likely to maintain contact, but this was not the case in a neighbouring area, suggesting that variation in local service configuration and practice were influential and that ethnicity alone does not account for variations in patient contact. The AESOP group found that African-Caribbean and Black African patients were more likely to be compulsorily admitted with a first-episode psychosis, even after adjustment [11]; and that compared with White British patients, general practitioner referral was less frequent for both African-Caribbean and Black African patients and referral by a criminal justice agency was more common [12].

These findings have fuelled an argument that mental health services are institutionally racist, which has been vigorously debated [13, 14]. The fairly consistent findings of mental health care in relation to the Black British population seem to be that of increased coercion, more aversive pathways to care, leading to greater mistrust, sooner disengagement from services with poorer service-related outcome and greater rates of readmission. These themes have prompted the charge of either a prejudicial or discriminatory mental health system when it comes to care provision for minority ethnic groups and the need for a suitable solution if this is indeed the case [15].

If indeed there is a relationship between racism and outcome from psychosis, this would need to be unequivocally demonstrated with good longitudinal evidence; unfortunately, this is lacking. There is some evidence that discrimination may longitudinally predict psychosis in people with no history of psychosis, from the Netherlands [16]. It was found during a 3-year prospective study that perceived discrimination at baseline was associated, in a dose–response fashion, with delusional ideation at follow-up, irrespective of ethnicity and after adjusting for confounders. Additionally, there exists evidence that poor treatment adherence leads to poorer outcome from psychosis: Over a 3-year follow-up of those with psychosis, subjects with poor medication adherence presented more frequently with an episodic course of illness and were more frequently readmitted, especially with regard to involuntary readmission [17]. In other work, improved medication compliance predicted better functional outcome in first-episode schizophrenic patients [18], as well as aspects of community functioning [19], and has been strongly associated with subjective well-being in those with an established diagnosis of schizophrenia [20].

A model may be proffered where the greater levels of police involvement, involuntary admission, and complex pathways seen in Black people with psychosis in the UK is at least in part driven by the individual perceiving the system as racist and therefore avoiding it. This avoidance might be signified by poor medication adherence, leading to a poorer service-related outcome with repeated admissions, thus fuelling distrust in services.

We hypothesise that (1) there is a prospective link between perceived racism and poorer medication compliance in UK Caribbeans with psychosis, and (2) any link between perceived racism and poorer service-related outcome is mediated by medication adherence.

Methods

We undertook a 1-year prospective cohort study of participants aged 18–65 years; with a self-assigned ethnicity of Caribbean origin with either parents or grandparents born in the Caribbean; having a Research Diagnostic Criteria-defined psychotic symptoms [21] and in receipt of psychiatric services (including psychiatric inpatients, day patients and outpatients) in north London, UK. Participants with a primary diagnosis of either an organic disorder or substance misuse disorder were excluded from the study.

Community Mental Health Team (CMHT) managers and Consultant psychiatrists for all of the CMHTs in Haringey and north Camden, London were asked to identify appropriate participants: a sample of 150 participants initially approached for the study, 110 were interviewed at baseline of which 100 were successfully contacted for follow-up. The initial sample, the baseline sample, and the follow-up sample did not differ significantly in diagnostic or socio-demographic characteristics.

Measures of perceived racism

At baseline, we measured perceived racism using a modified version of the Perceived Racism Scale [22]. The PRS is a validated, self-completed instrument that measures the

frequency of exposure to perceived racism, emotions, coping behaviours, and cognitive appraisals related to racist encounters in three separate domains: at work, in academic settings, in the public domain, and responses to racist statements.

We modified and piloted the PRS to reflect that most of the participants were unemployed by substituting the work domain statements for a domain of racism from mental health services [23]. A number of sources informed the questions in the new domain. The first source was a qualitative study by the authors, which examined perceived racial discrimination described by African-Caribbean origin patients with psychosis in north London. The second source was a focus group of staff members working in an early intervention service for African-Caribbean patients with psychosis aged 16–65 years. The final source was the experience of the authors in the field of trans-cultural psychiatry. Although the subject matter of the domain was revised, the wording and style of each statement was preserved in order to retain the integrity of the original PRS as much as possible.

Measures of medication adherence

At 1-year follow-up, we measured medication adherence using two instruments that produce continuous scores: a self-report questionnaire [the drugs attitudes inventory (DAI)] [24]; and a scale which offers the view of service providers, the Kemp Adherence Scale [25].

Other measures

Other measures were used to further describe the sample and allow for adjustment for confounding: socio-demographic information; the World Health Organisation (WHO) life chart [26]; the Positive and Negative Syndrome Scale [27]; and the Operational Criteria Checklist for Psychotic and Affective Illness (OPCRIT) [28].

Outcomes and data analysis

All analyses were performed taking account of clustering in the data using outpatient/inpatient/day patients status as strata and geographic community mental health team as the primary sampling unit. The primary exposure at baseline was racism in mental health settings, school settings and in the public domain and the response to it as measured by the PRS. The primary outcome was adherence with treatment at 1-year follow-up (DAI and Kemp et al. scores). Secondary outcomes were determined by the life chart: number of days in hospital for psychiatric problems; number of hospital admissions; and length of stay of the longest psychiatric admission.

After categorising any non-normal continuous data, linear regression was used to examine the association between perceived racism score at baseline and adherence with treatment at follow-up. Variables significantly correlated with the primary exposure or outcome, were then adjusted for in each regression analysis. DAI and Kemp et al. score, gender, and baseline PANSS paranoia score were forced into the models since these are known associations with the outcome [29–31]. We took a similar approach to the secondary analyses. We undertook further analyses of hospital admissions in the data, stratified by adherence scores categorised into tertiles at baseline or averaged over baseline and follow-up, with adherence mediating the effect of perceived racism upon hospital admissions.

For the regression analyses, the missing data (i.e. from those ten participants that were lost to follow-up) were multiply imputed using STATA's "ICE" programme [32].

Power calculation

This was based upon the work of Kemp and colleagues [25]. They found that insight was associated with adherence, Pearson's correlation coefficient being 0.95 ($P = 0.001$ using a two-tailed test). We hypothesized that perceived racism should be regarded as an ethnically specific factor with a similar effect to insight, but one that varies inversely with adherence. Therefore, using a sample size calculator and a study sample size of 100, with 90% power and a significance level of 0.05, this study would be able to detect a correlation in the primary analysis of -0.33.

Results

Socio-demographic and clinical baseline sample data are shown in Table 1. The ten patients lost to follow-up did not differ significantly from the remainder successfully followed up (Table 2).

Table 3 shows the significant models generated by multiple linear regressions. The point estimates for the complete dataset are similar to the imputed dataset ($n = 110$) and retain statistical significance.

Model 1 shows that total perceived racism for the previous year negatively predicted medication adherence as measured by the Kemp et al. scale, after adjustment ($b = -0.0074$, $P = 0.013$). This translates to a 135-point increase in the total perceived racism for the previous year score being associated with a one-point reduction in Kemp et al. adherence score. Model 2 found that adjusted perceived racism over a lifetime negatively predicted adherence: a 147-point increase in the total perceived racism

Table 1 Socio-demographic and clinical information of sample

Variable	Frequency	Percentage
Gender		
Male	61	55.0
Female	49	45.0
Maternal birth country		
UK	15	13.6
Caribbean	83	75.5
Africa	7	6.4
Other	5	4.5
Paternal birth country		
UK	5	4.6
Caribbean	95	86.4
Africa	4	3.6
Other	6	5.5
Relationship status		
In relationship	22	20.0
Single	88	80.0
Employment status		
Employed	3	2.7
Unemployed	107	97.3
Presence of a close confidant/support network?		
Yes	52	47.3
No	58	52.7
Registered with a general practitioner?		
Yes	101	91.8
No	9	8.2
Patient status		
Outpatient attender	45	40.9
Inpatient	54	49.1
Day hospital attender	10	9.1
Regional secure unit patient	1	0.9
OPCRIT diagnosis		
Schizophrenia	80	72.7
Schizo-affective disorder	30	27.3
Usual symptom severity		
Severe	32	29.1
Moderate	57	51.8
Mild	21	19.1
Recovered	0	0.0
Medicated by depot injection		
Yes	45	40.9
No	55	59.1

over a lifetime score was associated with a one-point reduction in Kemp adherence score. Model 3 found that shame about racism perceived in mental health services positively predicted adherence: a five-point increase in the shame about mental health service racism score was associated with a one-point increase in Kemp adherence score. And model 4 found everyday racism negatively predicted follow-up adherence on the DAI: a 20-point increase in the perceived everyday racism for the previous year score was associated with a one-point reduction in the DAI score.

Of the secondary outcomes, those models with significant exposure variables are shown in Table 4. Model 5 shows that perceived racism from mental health services over the previous year positively predicted the number of psychiatric hospital bed days ($b = 5.54$, $P = 0.010$) (Table 4). This translates to a one-point increase in the perceived mental health service racism score associated with approximately five extra psychiatric hospital bed days. Model 6 shows that powerlessness about mental health service racism strongly predicted fewer psychiatric hospital bed days for the following year. Model 7 reveals that perceived health-service racism over the previous year predicted a longer psychiatric hospital admission in the subsequent year.

Additionally, Table 4 presents the re-analysis of the significant secondary exposure variables, after the sample was divided by mean DAI adherence score (average of baseline and follow-up values), into either "high DAI" or "low DAI" scorers. In model 5, the coefficient was slightly less in the high-DAI group and greater in the low-DAI group. Again, in model 6, the effect of powerlessness was increased in the high-DAI group. Finally, in model 7, the effect of perceived health-service racism over the previous year upon length of psychiatric hospital admission was lessened in the high-DAI group and increased in the low-DAI group.

The second raft of stratified analyses grouped the dataset into tertiles according to obtained baseline DAI score (rather than estimated mean DAI scores, as earlier). With number of hospital bed days at follow-up regressed onto baseline 1-year mental health service perceived racism score, there was a clear trend in results when grouped according to baseline adherence measured by the DAI. A greater PRS score was associated with a greater number of hospital bed days at follow-up, and within that, poorer adherers ($b = 56.40$) had more bed days than moderate adherers ($b = 54.21$) who had more days, in turn, than good adherers ($b = 51.11$); represented in Fig. 1a. There was no evidence that the slope of the three regression lines was different ($P = 0.65$); therefore assuming the three slopes were parallel but with different y-intercepts, this model tended to significance ($P = 0.058$).

Finally, with powerlessness about mental health service racism as a predictor and hospital bed days at follow-up as dependent variable, there was a negative regression coefficient (i.e. powerlessness predicted a shorted admission) and, within that, better baseline DAI adherence ($b = 179.69$) predicted less hospital time than for moderate adherers

Table 2 Distribution of baseline, follow-up and missing data

Variable	Sample seen at baseline and follow-up ($n = 100$)	Sample lost to follow-up ($n = 10$)	P value
Age years, mean (SD)	43 (14.5)	45.3 (15.3)	0.73
Male, *n* (%)	61 (55.5)	4 (40)	0.50
Employed (%)	3 (2.7)	0 (0)	0.58
Single, no partner (%)	68 (61.8)	4 (40)	0.13
Mother			
Caribbean (%)	83 (75.5)	6 (60)	0.24
White British (%)	15 (13.6)	2 (20)	0.92
Lives alone (%)	40 (36.4)	4 (40)	0.68
Status (%)			
Outpatient	45 (42.1)	3 (30)	
Inpatient	54 (50.5)	6 (60)	
Day hospital	7 (6.5)	1 (10)	
Forensic I/P	1 (0.9)	0 (0)	
Depot (%)	45 (40.9)	6 (60)	0.17
OPCRIT			
Schizophrenia (%)	80 (72.7)	7 (70)	0.20
Schizoaffective disorder (%)	30 (27.3)	3 (30)	
PANSS score (SD)			
Positive	19.3 (4.9)	20.5 (5.7)	0.25
Negative	22.8 (6.5)	21.2 (6.9)	0.59
Baseline paranoia	7.8 (2.4)	8.5 (3.7)	0.60
Baseline DAI score (SD)	4.9 (2.7)	3.3 (2.8)	0.07
Baseline Kemp et al. score (SD)	4.3 (1.1)	3.8 (1.0)	0.06
Total 1-year PRS score (SE)	54.4 (1.8)	56.2 (4.3)	0.81
Total lifetime PRS score (SE)	71.1 (2.0)	74.0 (7.0)	0.81
Racism from mental health services, past year (SE)	16.5 (0.7)	18.3 (1.7)	0.34
Racism from mental health services, lifetime (SE)	16.8 (0.6)	18.7 (1.7)	0.32
Racism at school/college, past year (SE)	2.8 (0.6)	0.1 (0.1)	0.10
Racism at school/college, lifetime (SE)	14.2 (0.7)	12.5 (2.7)	0.67
Everyday racism, past year (SE)	23.3 (0.8)	25.7 (2.2)	0.44
Everyday racism, lifetime (SE)	27.6 (0.9)	30.2 (2.9)	0.57
Racist statements, past year (SE)	11.9 (0.4)	12.1 (1.1)	0.83
Racist statements, lifetime (SE)	12.7 (0.4)	12.6 (1.2)	0.99

($b = 190.12$) and poor adherers ($b = 224.02$); see Fig. 1b. There was no statistical evidence for non-parallel slopes, but the overall model was not significant ($P = 0.18$).

Discussion

To our knowledge, this is the first study to report associations between perceived racism and medication adherence and health service outcomes in African-Caribbean patients with psychosis, and a mechanism may be proposed.

Racism perceived within mental health services acts as a significant predictor for hospital stay at 1-year follow-up in Caribbean patients with psychosis. This may reflect mistrust in services and represent a rejection of them, leading to poorer outcome, the poorer adherers having a worse outcome than their better adhering counterparts supports this. The mediating effect of adherence may be more powerful when the adherence acts more proximally to the exposure: perceived racism (i.e. adherence measured at baseline exerting more influence on outcome, than when estimated for the mid-point of the study). Secondly, powerlessness about perceived mental health service racism may represent a resignation to the mental health system and, therefore, is strongly associated with fewer subsequent inpatient hospital days. The effect again is offset by poor adherence, which could be perceived as not submitting to the mental health system paradigm. Again, where

Table 3 Significant models from the multiple regression analysis of the primary outcome measures (Kemp score and DAI score at follow-up)

Primary outcome	Coefficient	SE	t	$P > \|t\|$	95% CI
Follow-up Kemp et al. score					
Exposure variables					
Total racism, past year, unadjusted	**−0.017 (−0.016)**	0.0070	−2.37	0.020	−0.030, −0.0027
Model 1					
Total racism, past year	**−0.0074 (−0.0067)**	0.0026	−2.79	0.013	−0.013, −0.0018
Baseline Kemp et al. score	0.37	0.13	2.72	0.015	0.082, 0.65
Follow-up PANSS paranoia score	−0.16	0.044	−3.54	0.003	−0.25, −0.063
Constant	4.17	0.75	5.54	0.00	2.58, 5.75
Total racism, lifetime, unadjusted	**−0.019 (−0.016)**	0.0060	−3.23	0.002	−0.031, −0.0075
Model 2					
Total racism, lifetime	**−0.0068 (−0.0070)**	0.0030	−2.24	0.038	−0.013, −0.00041
Baseline Kemp et al. score	0.37	0.13	2.86	0.011	0.097, 0.65
Follow-up PANSS paranoia score	−0.15	0.043	−3.59	0.002	−0.24, −0.064
Constant	4.21	0.70	6.00	0.00	2.74, 5.70
Model 3					
Ashamed at mental health service racism	**0.20 (0.17)**	0.075	2.71	0.015	0.045, 0.36
Constant	3.60	0.22	16.27	0.00	3.13, 4.06
Follow-up DAI score					
Everyday racism, past year, unadjusted	**−0.080 (−0.069)**	0.033	−2.44	0.017	−0.15, −0.015
Model 4					
Everyday racism, past year	**−0.051 (−0.045)**	0.024	−2.16	0.046	−0.10, −0.0011
Baseline Kemp et al. score	0.70	0.11	6.27	0.00	0.47, 0.94
Months' antidepressant medication between baseline and follow-up	0.062	0.063	0.99	0.34	−0.071, 0.20
Constant	12.96	0.73	17.69	0.00	11.42, 14.51

Each model adjusted for baseline adherence (DAI or Kemp et al. score), gender, and baseline PANSS paranoia score

Bracketed point estimates are for non-imputed dataset ($n = 100$)

Significant primary exposure variables in bold

adherence was greater, this could be a magnification of level of submission, resulting in even less time in hospital.

That perceived racism was more strongly associated with hospital-related outcomes such as the length of psychiatric inpatient admission, than upon patient completed medication adherence, may support this model. If adherence is an interim variable along the causal pathway between perceived racism and hospital admissions, racism may be expected to exert a smaller effect upon it than the final outcome. An alternative is that this reflects a difficulty in measuring adherence, whereas hospital bed days may allow for a more profound effect to emerge, when the precision of the analysable data are limited.

Study limitations

The study had limitations. There may be residual confounding given the design of the study. It is unclear whether the group that participated differed systematically to those who did not. Both the DAI and the Kemp et al. scores are indirect measures of adherence, rather than pill counts or serum drug assays. The stratified results sometimes failed to reach statistical significance. This could be because perceived racism as an exposure may be highly significant, but it only exerts a small effect amongst a number of other putative exposures. Or it could be that the sample size was insufficiently large, the event rates for outcomes too low or that follow-up time was inadequate.

In our study, follow-up paranoia did not completely confound baseline perceived racism; therefore, paranoia is not a proxy measure for perceived racism. There remains a small but significant effect of total perceived racism, independent of clinical paranoia, upon adherence with medication. The lack of influence of socio-economic factors in our findings is striking. It may be that the population group had insufficient variability in socio-economic

Table 4 Significant models from the multiple regression analysis of the secondary outcome measures (hospital admission data for the year between baseline and follow-up assessments) for the whole dataset, then dichotomised according to mean DAI score

Outcome	Coefficient			SE			*t*			$P > \|t\|$			95% CI		
	Whole	High DAI	Low DAI	Whole	High DAI	Low DAI	Whole	High DAI	Low DAI	Whole	High DAI	Low DAI	Whole	High DAI	Low DAI
Psychiatric hospital bed days															
Exposures															
Model 5															
Racism from mental health services, past year	**5.54 (5.14)**	5.31	**6.34**	1.91	3.61	2.57	2.90	1.47	2.47	0.010	0.15	0.017	1.50, 9.58	−1.95, 12.6	1.20, 11.5
Constant	52.25			29.30			1.78			0.092			−9.57, 114.08		
Model 6															
Powerless at mental health service racism	**−14.49 (−14.55)**	−15.3	−12.7	5.90	12.6	10.2	−2.46	−1.21	−1.25	0.025	0.23	0.22	−26.94, −2.05	−40.6, 10.1	−33.2, 7.72
Constant	189.87			27.74			6.84			0.000			131.34, 248.40		
Longest psychiatric admission in days															
Exposure															
Model 7															
Racism from mental health services, past year	**4.92 (5.40)**	4.89	**6.50**	1.93	3.65	2.45	2.55	1.34	2.66	0.021	0.187	0.010	0.85, 9.00	−2.47, 12.2	1.60, 11.4
Constant	44.14			26.33			1.68			0.112			−11.41, 99.70		

Each model adjusted for baseline adherence (DAI or Kemp et al. score), gender, and baseline PANSS paranoia score

Bracketed point estimates are for non-imputed dataset ($n = 100$)

Significant primary exposure variables in bold

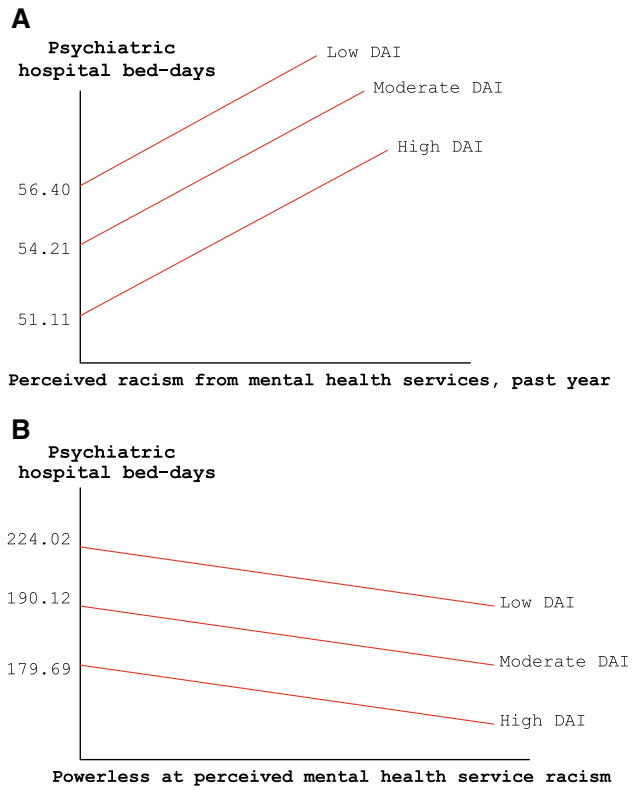

Fig. 1 Regression of psychiatric hospital bed days onto perceived racism from mental health services, by tertiles of baseline DAI score

deprivation: the "double whammy" of psychosis and racism may be too much for most to overcome to escape economic deprivation. Until these results are corroborated or strengthened by their repetition in other studies, they should be regarded as valid findings that warrant further study or replication.

Implications for practice

Our study suggests that perceived racism in the wider community and in psychiatric services is an important determinant of outcome. This begs the question of what we should do about it. Action could be taken at a number of levels. Government bodies have given guidance on improving institutional cultural competence, bringing communities closer to services and giving them more say in service configuration [33, 34]. At another level in the clinical encounter, social or psychological factors that are linked to outcome need to be assessed, understood and if possible remedial action included in the treatment plan.

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