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Abstract

Background: People with mental health problems are known to be socially excluded but the contribution of pre-morbid characteristics, symptoms and needs, and the impact on quality of life is unknown.

Aims: To investigate change in social inclusion after the development of a psychotic illness and factors associated with this.

Methods: A cross-sectional community survey of people with psychosis was carried out in three areas of London. Five domains of social inclusion (social integration, consumption, access to services, productivity, political engagement) were assessed prior to the onset of illness and currently using the Social Inclusion Questionnaire User Experience. Quality of life, symptoms and needs were also assessed using standardized measures. Factors associated with change in social inclusion were investigated using multiple regression.

Results: Productivity and social integration among the 67 participants reduced after the onset of psychosis. Older age at onset and longer duration of illness were associated with greater reduction in productivity. Less reduction in social integration was associated with greater quality of life. Participants reported barriers to social inclusion that were directly related to symptoms of their illness, low confidence and poor self-esteem.

Conclusions: A greater focus on interventions that can facilitate the occupation and the social networks of people with psychosis is required. Interventions that tackle 'self-stigma' may also prove useful in mitigating the social exclusion experienced by people with psychosis.

Keywords

Psychosis, social inclusion

Introduction

Social inclusion refers to the opportunities that individuals have to participate in key areas of economic, social and cultural life. Such participation is thought to be beneficial not just for the individual, but for society as a whole and was adopted as a key aspect of the UK government's social policy in the 1990s (Burchardt, Le Grand & Piachaud, 1999).

Poor mental health may be both a cause and a consequence of social exclusion (Morgan, Burns, Fitzpatrick, Pinfold & Priebe, 2007; Payne, 2006; Social Exclusion Unit, 2004). However, most research has investigated social exclusion among people with common mental disorders such as depression and anxiety (Boardman, Currie, Killaspy & Mezey, 2010). Although there has been less focus on social exclusion associated with psychotic illness, there is good evidence that this group is more likely than those with common mental disorders to have dropped out from education, to be unemployed and to experience poverty, debt and social isolation (Marwaha et al., 2007; Meltzer et al., 2002; Mind, 2008). What is not clear is

whether these markers of social exclusion are due to the illness, to pre-existing social disadvantage or to barriers to

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social inclusion such as lack of finances and stigma (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Priebe, 2007).

Current mental health policy (Department of Health, 2011) highlights the need to reduce discrimination and social exclusion among mental health service users. Along with legislation such as the Disability Discrimination Act 2005, the aim is to improve the opportunities for people with mental health problems to engage in society on an equal basis to others, for example in relation to employment (Sayce & Boardman, 2003). Similarly, the aims of recovery-orientated practice in mental health services include promotion of social inclusion through facilitation of service users' autonomy, access to work, education and leisure activities in 'mainstream' settings, better family relationships and improved quality of life (Lieberman & Kopelowicz, 2002). However, although the majority of mental health service users report that they would like to be more socially included, it is unclear whether there is a shared understanding of what this might entail (Dunn, 1999; Sayce, 2001).

Social exclusion has been reported as particularly problematic for service users with more complex mental health problems, such as treatment-resistant schizophrenia, where negative symptoms and cognitive impairment can have a major impact on an individual's motivation and ability to participate in society, to form relationships and manage the tasks needed for independent community living (Holloway, 2005). High rates of social exclusion have also been identified among users of forensic mental health services who are doubly disadvantaged by their mental health problems and the offences that have brought them into contact with forensic services, such that opportunities for social inclusion may engender particularly high levels of public fear and hostility (Brooker & Ullman, 2008; Social Exclusion Unit, 2002).

This study therefore aimed to investigate: (1) change in social inclusion after the development of a psychotic illness; (2) factors associated with this including socio-demographic characteristics, mental health symptoms and needs; (3) the association between change in social inclusion and quality of life; and (4) participants' views on the barriers to social inclusion.

Method

Design

The study was a cross-sectional survey that collected current and retrospective data from participants to allow for comparisons of social inclusion before and after the development of their psychotic illness.

Setting

The study was carried out in the London boroughs of Wandsworth, Camden and Islington, all inner-city areas

with high levels of deprivation and psychiatric morbidity (Glover, Robin & Emami, 1998). Secondary mental health services are provided through the local National Health Service (NHS) mental health trusts and include inpatient wards (intensive care, acute and rehabilitation) and community services (community mental health teams, assertive outreach, crisis resolution and early intervention services). Forensic services are provided at a regional level by separate NHS trusts.

Participants and recruitment

In order to be eligible for the study, participants had to have a clinical diagnosis of psychosis recorded in their case file (schizophrenia or schizoaffective disorder), have been living in the community for at least the last three months, and be able to speak and understand English well enough to give informed consent and participate in a research interview. Potential participants were identified by key clinicians and if willing, they were then approached by the researchers who checked eligibility criteria and then explained the purpose and process of the study. Written informed consent was gained. Participants were assessed using the structured interview schedules described below and received £10 payment for their time.

Data collection

Socio-demographic data (age, gender, ethnicity, marital status, accommodation and education), diagnosis and previous contact with mental health services (age of onset of illness, number of past admissions, previous involuntary admission(s), length of time since last discharge, current community detention) were gathered through face-to-face interview with participants. Age of onset of illness, number of past admissions, previous involuntary admissions and time since discharge from hospital were corroborated through case note review.

With the facilitation of the researcher, participants completed the Social Inclusion Questionnaire User Experience (SInQUE) questionnaire. This tool was developed using topics identified in the Poverty and Social Exclusion Survey (Gordon et al., 2000) and incorporates items that also allow assessment using the Social Outcomes Index for mental health care (Priebe, Watzke, Hansson & Burns, 2008). The SInQUE assesses the extent of social inclusion experienced in the community, prior to the onset of illness and currently, on five domains (social integration, consumption, access to services, productivity and political engagement). It has good concurrent validity with other objective measures of social inclusion, and convergent and discriminant validity have also been established (Mezey et al., 2013). Open-ended questions collect further information from respondents about the barriers to social inclusion. For example, if a respondent does not participate in a particular activity they are asked to record the reason for this.

Current quality of life was assessed using the Manchester Assessment of Quality of Life (MANSA; Priebe, Huxley, Knight & Evans, 1999). This self-report measure assesses 17 items related to quality of life, rated from 1 (couldn't be worse) to 7 (couldn't be better).

Current symptoms were assessed by the researchers (all of whom were senior trainee psychiatrists) using the Brief Psychiatric Symptom Rating (BPRS; Overall & Gorham, 1962).

Participants' current needs were assessed using the service user, short version of the Camberwell Assessment of Need (CANSAS; Slade, Thornicroft, Loftus, Phelan & Wykes, 1999). A total 22 items are rated on a three-point scale: 0 = no serious need; 1 = no serious problem or moderate problem because of continuing intervention (met need); 2 = current serious problem (unmet need).

Data analysis and sample size

Change in the domains of social inclusion (assessed by the SInQUE) before and after development of a psychotic illness were investigated using paired sample *t*-tests and presented using mean change and 95% confidence intervals. For those domains where there was a significant change, change scores were calculated. Factors associated with change in social inclusion were then investigated using analysis of covariance (ANCOVA) models. Change scores were used as these were normally distributed for all domains.

Variables tested for their association with change in social inclusion were: age; gender; ethnicity (analysed as a binary variable – white/black or minority ethnic group); age of onset of illness; duration of illness; age at leaving school; ever expelled or suspended from school; ever institutionalized as a child; any higher education; current accommodation (supported or not); 'forensic' history (committed a violent physical or sexual assault and/or ever detained under a Ministry of Justice restriction order (section 37/41 of the Mental Health Act 1983)); time in psychiatric institutions as adult (up to 12 months, one to five years, over five years); time since last discharge (up to 12 months, one to five years, over five years); medication administration (self-administered or not); any serious, long-term physical health problem(s); MANSA total score; BPRS total score; and CANSAS scores.

Univariate analysis was conducted first on each of these variables. Continuous variables were tested using Pearson correlation coefficients, categorical variables using independent sample *t*-tests or one way analysis of variance (ANOVA). Analysis of covariance (ANCOVA) was then used to investigate the degree to which independent variables found to be significant at the 5% level in the univariate analysis contributed to change in social inclusion while controlling for pre-morbid levels of the dependent variable (social inclusion).

Using Dunlap, Xin & Myers (2004), it was calculated that with a sample size of 66 patients there would be 80% power to estimate the relationship of four factors of a medium effect size of 0.41 with change in social inclusion at a 5% significance level.

The barriers to social inclusion given by participants as free text were entered into SPSS as string variables. Since respondents gave only brief answers, it was not necessary to use specialist qualitative data software to analyse these. Responses were coded by one researcher into themes and sub-themes. Coding was corroborated by a second researcher who independently coded five sets of data. Agreement was 95%.

Results

A total of 67 participants were recruited, 12 of whom (18%) were female. The mean age was 44 (SD = 12.1, range = 23–65). Twenty-eight (42%) participants self-identified as white, 14 (21%) black Caribbean, eight (12%) black African and seven (10%) black other. Fifty (75%) were single, nine (13%) were divorced or separated, one (1%) was cohabiting and marital status was unknown for one. Twenty-nine (43%) were living in 24-hour supported accommodation, nine (13%) in less supported accommodation, 25 (37%) in unsupported, rented accommodation and four (6%) in their own home. Four participants (6%) had a diagnosis of schizoaffective disorder, the remainder schizophrenia. Mean age at onset of illness was 23.3 years (SD = 7.3) and ranged from 15 to 53. Mean duration of illness was 199.2 months (SD = 133.2) and ranged from three to 43 years. Participants had had between one and 20 psychiatric admissions, with a mean of six (SD = 5.0). Almost all (60, 91%) participants had been previously admitted to hospital involuntarily on at least one occasion. Participants had a mean age at leaving school of 17.3 years (SD = 2.1), 17 (26%) had been expelled or suspended from school, 11 (17%) had been institutionalized as a child and 32 (49%) had completed degrees, qualifications or training since leaving school. Participants had spent a mean 42.4 months (SD = 43.8) in psychiatric hospitals as adults, and the mean time since last discharge from hospital was 52.3 months (SD = 78.9). Twenty-six (39%) self-administered their medication and nine (14%) had physical health problems.

Twenty-five participants (38%) had previous criminal convictions. Five (8%) had damaged property or committed theft, 16 (24%) had a history of violent or sexual crimes and four (6%) had both property/theft and violent/sexual convictions. Seven participants (11%) were currently subject to section 37/41 of the Mental Health Act 1983 (a treatment order jointly managed by mental health services and the Ministry of Justice) and one was subject to supervised discharge (a legal equivalent to outpatient commitment used in England and Wales).

Table 1. Participants' current symptoms, quality of life and needs.

	Mean score	SD	Range
BPRS	34.6	12.0	18–84
MANSA	4.2	0.9	2.1–6.7
CANSAS met needs	4.3	2.9	0–16
CANSAS unmet needs	3.3	3.1	0–13
CANSAS total needs	7.7	3.6	1–17
CANSAS % of needs met	60	29.8	0–100

One participant failed to complete the questionnaires and their data were excluded from further analysis. Descriptive statistics of the remaining 66 participants' scores on the MANSA, BPRS and CANSAS are shown in Table 1.

With regard to participants' social inclusion as assessed by the SInQUE, a statistically significant change was seen in the social integration and productivity domains, with participants becoming less socially integrated and less productive after the development of their mental health problems (Table 2). The productivity and political engagement domains were not normally distributed. Wilcoxon signed-rank tests were therefore carried out on these two variables and concordant results were found.

As a statistically significant change was only found in the productivity and social integration domains, factors associated with change were investigated in these two domains only.

Factors associated with change in productivity

In the univariate analysis, the following variables were associated with change in productivity: current age; age at onset of illness; duration of illness; and accommodation status. Age was significantly correlated with age at onset of illness and duration of illness, but age at onset of illness and duration of illness were not correlated so both were entered into the ANCOVA model along with accommodation status. Although participants in supported accommodation experienced less change in productivity than those living independently, this association was not statistically

significant. Older age at onset of illness and longer duration of illness were associated with greater reduction in productivity. Higher pre-morbid productivity scores were strongly associated with a greater reduction in score from pre-morbid to current levels.

The main reason for the change in productivity appeared to be a large reduction in the number of respondents in work or education in the year prior to becoming unwell (50/66, 76%) compared to the last year (3/66, 5%). Around half the respondents cited their mental health problem, lack of energy or motivation as the main reasons they were currently unemployed.

Working is very stressful due to my illness.

(male participant, aged 25)

I sleep too much and am too tired to get up for a paid job.

(male participant, aged 27)

Change in social integration

In the univariate analysis the following variables were associated with change in social integration: age; CANSAS total needs; CANSAS unmet needs; CANSAS percentage of needs met; and total MANSA. The three CANSAS variables were correlated with each other: $r = 0.651$ for unmet needs and total needs; $r = -0.831$ for unmet needs and percentage of needs met; $r = -0.289$ for total needs and percentage of needs met. Therefore the variables percentage of needs met and total number of needs were entered into the ANCOVA with age and total MANSA. MANSA was the only variable statistically significantly associated with change in social integration; less change in social integration was associated with greater quality of life. Higher pre-morbid social integration scores were strongly associated with a greater reduction in score from pre-morbid to current levels.

The results of the ANCOVA are shown in Table 3.

The majority of participants (91%, 60/66) reported that they had regular contact with their family prior to becoming unwell and that this contact was adequate for them at that time (54/66, 82%). With regard to their current family

Table 2. Change in social inclusion (SINQUE scores) before first contact with mental health services (T1) and currently (T2).

	T1 M (SD)	T2 M (SD)	Change (95% CI)	p
Social integration	33.2 (7.8)	27.9 (6.4)	5.3 (3.1–7.4)	< .001***
Consumption	9.8 (3.4)	10.3 (3.4)	-0.5 (-1.4–0.5)	.306
Service access	5.9 (2.0)	6.3 (1.7)	-0.4 (-1.0–0.1)	.128
Productivity	5.4 (4.4)	2.6 (1.5)	2.7 (1.6–3.8)	< .001***
Political engagement	0.6 (0.7)	0.7 (0.7)	0.1 (-0.3–0.1)	.307

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3. Factors associated with change in social inclusion.

Variable	Regression coefficient	95% CI	p
Change in productivity (Adjusted R² = 22.2%)			
Age at onset of illness	0.2	0.1, 0.3	.009**
Duration of illness	0.2	0.1, 0.3	.001**
Supported accommodation	-1.3	-3.3, 0.8	.216
Change in social integration (Adjusted R² = 13.6%)			
MANSAS total	-3.0	-6.0, 0.0	.048*
Age	0.1	-0.1, 0.3	.188
CANSAS total needs	0.2	-0.6, 0.8	.729
CANSAS % of needs met	0.0	-0.1, 0.1	.729

*p < .05, **p < .01, ***p < .001.

contact, again most reported regular contact (58/66, 88%) but fewer felt this was adequate (44/66, 67%). Most contact was with parents or siblings. Of those who wanted more contact currently, most reported that the lack of contact was due to the distance they lived from their family. Six (9%) reported that they were estranged from their family.

I would like to have more contact but they don't seem interested.

(male participant, aged 56)

I call and keep in touch with them but they never call.

(female participant, aged 52)

Prior to becoming unwell, 14 participants (22%) reported having no close friendships and 32 (50%) reported having no partner. Currently, 23 (35%) reported having no close friendships and 51 (79%) reported having no partner. The most common reasons cited for having no partner were lack of confidence (8, 16%), having no interest in a relationship (8, 16%), not knowing how to meet the right person (6, 12%), the symptoms of the mental illness or the effects of the medication (6, 12%) and fear of stigma or rejection when revealing their mental health problem (5, 10%).

My illness makes it difficult to plan, organize and execute such things.

(female participant, aged 43)

Girls keep away when they know about my mental health problem.

(male participant, aged 28)

Why would a woman pick someone with schizophrenia?

(male participant, aged 61)

Discussion

The main findings from this study were that two domains of social inclusion (productivity and social integration)

were found to change over the time since the development of a psychotic illness, with participants becoming less productive and less socially integrated. The more productive and socially integrated a person was prior to the onset of their psychosis, the greater negative impact the illness had on their subsequent productivity and social integration. Although univariate analysis found a number of factors to be associated with this change, our ANCOVA model, which took account of the interaction between these, found that only older age and longer duration of illness were associated with a greater reduction in productivity. We found no associations between pre-morbid characteristics, current mental health symptoms and needs with change in social integration. Quality of life was associated with only one domain of social inclusion; better quality of life was associated with less reduction in social integration.

A large component of productivity is employment. The reasons that most participants gave for not working currently seemed to relate directly to their mental illness rather than external factors such as stigma and discrimination. However, people with more severe mental health problems such as those who participated in this study, may have been too unwell to enter the job market and may not have been exposed to discrimination in this regard. In addition, the responses that our participants gave could represent a pessimistic view that they were unlikely to be considered fit for work.

Similarly, the barriers to social integration that most participants cited suggested that the effect of the illness on their confidence and self-esteem was more problematic than practical reasons or stigma and discrimination due to the illness. Our findings seem to fit with the concept of 'self-stigma' and 'anticipated discrimination', cited as powerful components in the social exclusion of people with mental health problems (Thornicroft, Rose, Kassam & Sartorius, 2007). Our finding that better quality of life was associated with less reduction in social integration is perhaps unsurprising since aspects of social integration (contact with family, intimate relationships) contribute to quality of life as assessed by the MANSAS.

The National Institute for Health and Clinical Excellence (NICE, 2010) recommends that supported employment and family interventions should be available for people with a diagnosis of schizophrenia, but participants in this study did not appear to have accessed these. In addition to these, interventions to address ‘self-stigma’ may have an important role in improving social inclusion for this group, alongside public information campaigns and anti-discrimination legislation.

Limitations

This is the first study to assess quantitative change in social inclusion associated with the development of a psychotic illness. However, the results should be interpreted with some caution for a number of reasons. First, participants were not randomly sampled. Sampling and response bias could therefore have been introduced since recruitment relied on key clinicians making their clients aware of the study and those with a particular interest in social inclusion may have been more likely to participate. Second, since we were interested in change in social inclusion since developing a psychotic illness, our sample necessarily all had severe and enduring mental health problems and our results do not therefore allow any comment on change in social inclusion for people with other, or less severe mental health conditions. Third, the sample size was relatively small, although we are confident that our main findings are robust since we included few variables in our ANCOVA analyses. Nevertheless, the number of married or cohabiting participants, female participants, participants from different ethnic groups, and participants with a significant forensic history was quite small and therefore univariate analyses that examined the influence of these variables on change in social inclusion may have been under-powered.

Conclusion

The development of a psychotic illness is associated with reduction in social inclusion in the areas of productivity and social integration. The more productive and more socially integrated a person is when they develop a psychotic illness, and the older they are and the longer they have been unwell, the greater decline in social inclusion they experience. Better quality of life is associated with less deterioration in social integration. Investment in evidence-based interventions that can support people with psychosis to engage in occupation and to maintain their social supports is required. Interventions that address self-stigma may also mitigate the negative impact of psychosis on social exclusion.

Disclosures of conflicts of interest

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