

Ethnicity, detention and early intervention: reducing inequalities and improving outcomes for black and minority ethnic patients: the ENRICH programme, a mixed-methods study

SP Singh,^{1,2*} Z Islam,^{1,2} LJ Brown,^{1,2} R Gajwani,³
R Jasani,⁴ F Rabiee⁵ and H Parsons⁶

¹Division of Mental Health and Wellbeing, Warwick Medical School, Warwick University, Coventry, UK

²Research and Innovation Department, Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham, UK

³School of Psychology, University of Birmingham, Birmingham, UK

⁴Humanitarian and Conflict Response Institute (HCRI), University of Manchester, Manchester, UK

⁵Centre for Health and Social Care Research, Faculty of Health, Birmingham City University, Birmingham, UK

⁶Division of Health Sciences, Warwick Medical School, Warwick University, Coventry, UK

*Corresponding author

Declared competing interests of authors: none

Published December 2013

DOI: 10.3310/pgfar01030

Scientific summary

The ENRICH programme

Programme Grants for Applied Research 2013; Vol. 1: No. 3

DOI: 10.3310/pgfar01030

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Black and minority ethnic (BME) service users have high rates of psychosis, experience adverse pathways into care, are at greater risk of detention under the Mental Health Act (MHA) and are more likely to disengage over time, be less satisfied with their care and have poorer outcomes. Ethnic differences are evident even at first-episode psychosis (FEP); therefore, contributory factors must operate before first presentation to psychiatric services and need to be understood in a wider societal context.

Very little research has been carried out on cultural determinants of illness recognition and attribution, users' and carers' service preferences and the role of community-based strategies in improving satisfaction, reducing detention rates and enhancing outcomes. The paucity of such evidence has hindered the development of service-level interventions with the potential to improve mental health care for BME communities. It is also unclear whether generic early intervention services meet the specific demands and challenges of providing care for BME patients.

The ENRICH programme aimed to develop the knowledge base essential for reducing, and if possible eliminating, ethnic differences in pathways to care for BME groups. We proposed three studies conducted over 42 months with service users referred to the Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT).

Objectives

The specific objectives of the programme, conducted as three distinct studies, were as follows:

- Study 1: to understand ethnic differences in pathways to care in FEP by exploring cultural determinants of illness recognition, attribution and help-seeking among different ethnic groups.
- Study 2: to evaluate the process of detention under the MHA and determine predictors of detention in the assessed population.
- Study 3: to determine the appropriateness, accessibility and acceptability of generic early intervention services for different ethnic groups and establish care needs and preferences of service users and other stakeholders.

The BSMHFT provides secondary mental health care for the geographical areas of Birmingham and Solihull. All participants in study 1 were recruited from the Birmingham early intervention service as the Solihull early intervention service was not established at the time of commencement.

Study 1

This study aimed to explore three questions:

1. Are there ethnic differences in how patients and their carers recognise and understand emerging signs of early psychosis?
2. Are such differences a function of cultural factors such as explanatory models of illness or are they related to socioeconomic status, deprivation and isolation?
3. Do biological as opposed to psychological or social explanatory models of illness predict early medical help-seeking and shorter duration of untreated psychosis (DUP)?

Methods

A mixed-method approach using both quantitative and qualitative data collection was utilised to assess ethnic variations in help-seeking. A prospective cohort of FEP patients who were able to give informed consent was identified over a 2-year period (2008–10). Included users and their carers were assessed using three semistructured interview schedules: the Nottingham Onset Schedule (NOS), to determine the chronological emergence of symptoms of psychosis; the Emerging Psychosis Attribution Schedule, to determine how users and carers understood emerging symptoms and attributed causality; and the ENRICH Amended Encounter Form, to explore how, when and from whom help was sought.

A subsample of carer–user NOS interview pairs, stratified by ethnicity, was selected for in-depth qualitative analysis to understand the social and cultural processes that determine help-seeking and also to determine ethnic differences in stigma, mistrust and suspicion of services.

Results

In total, 132 participants were recruited over the study period. Of these, 45 (34.1%) were categorised as white, 35 (26.5%) as black, 43 (32.6%) as Asian and nine (6.8%) as ‘other’.

There were no ethnic differences in DUP and duration of untreated illness (DUI). DUP was not related to any type of illness attribution; long DUP was instead associated with younger age (< 18 years) and living alone. Black patients had a greater risk of MHA detention, more criminal justice involvement and more A&E presentations than white and Asian groups.

Patients from all ethnic groups held multiple attributions for emerging psychosis symptoms, but a predominant attribution type could be identified. During the prodromal phase, all three ethnic groups had similar attributions, considering the prodromal symptoms to be a reaction to social adversity. All three groups were most likely to seek help from health services, especially general practitioners (GPs). With the emergence of psychotic symptoms, Asian carers and users were most likely to attribute symptoms to faith-based or supernatural explanations and seek help from faith organisations. Some black patients also changed to supernatural explanations at psychosis onset, which influenced their care pathway, but this was in a smaller proportion of cases. There were important intergenerational differences, with second-generation Asian patients less likely to have supernatural attributions.

The key drivers for help-seeking were family members and carers. Within this there were ethnic differences in terms of which family members intervened and the types of familial networks tapped into for help. Most white respondents sought help in consultation within the nuclear family, whereas in black and Asian groups help was sought in consultation with larger family networks (aunts, uncles, grandparents, cousins) and through community organisations.

Attributing symptoms of emerging psychosis to life events and social adversity hindered medical help-seeking by providing a ‘normalising’ explanation for the change in the ill person. However, even when carers had predominantly biomedical attributions for psychotic symptoms, medical help was often not sought until a crisis point was reached.

All three ethnic groups experienced difficulties in accessing medical help. This led to BME service users and carers but not white service users and carers mistrusting services despite the latter reporting similar difficulties and delays in finding the right help at the right time.

Study 2

This study aimed to explore two questions:

1. Is there evidence of 'disproportionality' of detention for BME patients undergoing MHA assessments in the BSMHFT?
2. What are the clinical, sociodemographic, ethnicity and risk-related predictors of detention as an outcome of MHA assessments?

Methods

For all MHA assessments conducted over 1 year (April 2009–March 2010), data were collected on sociodemographic and clinical details and reasons for detention. A MHA assessment was defined as a clinical encounter in which an approved social worker or an approved mental health professional had been involved or invited, or in which at least one medical recommendation had been completed, regardless of the outcome of the assessment (detention, voluntary admission or no admission).

Self-assigned ethnicity data and other clinical information were extracted from MHA monitoring forms and cross-checked against hospital records of home treatment teams. Four broad ethnic groups were identified: white (including Irish and other Europeans), black Caribbean and black African, Asian (including Indian, Pakistani, Bangladeshi and Sri Lankan) and 'other' (including Chinese and Vietnamese). Mixed-race individuals were included in the 'other' category if they were not assigned to black, white or Asian categories in the MHA or medical records.

We stratified the quantitative data set by ethnicity and randomly selected five cases from each of the ethnic groups for a qualitative exploration of carer preceptions of the MHA assessment process, its outcome and alternatives to detention.

Results

Between April 2009 and March 2010, 1115 MHA assessments were conducted in the BSMHFT on 863 individuals (some of whom were assessed more than once during the study period). The mean age of these individuals was 40.12 [standard deviation (SD) = 14.75] years and 60.3% were men. Of these 1115 assessments, 709 (63.6%) led to detentions. The ethnic profile of those assessed ($n = 863$) was 51.0% white British, 14.8% British Pakistani, 13.9% black Caribbean, 7.0% black African, 5.6% British Indian, 1.6% British Bangladeshi, 2.5% mixed ethnicity, 3.1% 'other' and 0.5% 'refused to say'. Of the individuals assessed, 443 (51.3%) had been admitted previously to hospital. The diagnostic composition of the cohort was 48.1% schizophrenia, schizotypal and delusional disorders [*International Classification of Diseases*, Tenth Edition (ICD-10) diagnostic codes F20–29], 25.3% mood (affective) disorders (F30–39) and 4.8% disorders of adult personality and behaviour (F60–69).

A greater proportion of the BME group, particularly black Caribbean and black African patients, was assessed and detained under the MHA than of the white population. This was true when the denominator was both the general population and the population currently receiving care from the BSMHFT. However, in a logistic regression model in which age, diagnosis, risk and level of social support were accounted for, ethnicity was not an independent predictor of MHA detention.

The qualitative study found differences between the MHA experiences of carers whose family members were known to services and the MHA experiences of carers whose family members were presenting for the first time. The former received relatively unproblematic access to care; the latter felt that the system did not respond to their concerns in a timely and appropriate manner. Help arrived only following a crisis and early warning signs were usually ignored by services, particularly GPs.

Carers found the MHA process very stressful, even when they understood the need for and necessity of the process and agreed with its outcomes. Carers felt that their own mental health had suffered because

of the burden of care. Police presence during MHA assessments was particularly stressful, and black carers perceived a racial bias in police involvement.

Stigma and shame appeared to be greater in black communities than in Asian communities. Asian carers found shared spiritual explanations within the community a source of comfort and support. Amongst clinicians, risk assessment and management were the paramount drivers of MHA assessment and outcome. Although all clinicians agreed on the importance of cultural and ethnic factors in assessments, social workers placed a greater emphasis on this in practice whereas medical staff perceived themselves as being 'culturally neutral'. There was no consensus on the need for ethnicity matching in the MHA assessment process.

Study 3

The aim of this study was to determine the appropriateness, accessibility and acceptability of generic early intervention services for different ethnic groups and to establish the care needs and preferences of service users and other stakeholders.

Methods

Focus groups were conducted with service users, carers, health professionals, key stakeholders from voluntary sector and community groups, commissioners and representatives of spiritual care. All focus groups were conducted using a topic guide developed around the questions: 'How appropriate and accessible are generic early intervention services for the specific ethnic and cultural needs of BME communities in Birmingham? How can these be improved?'

Results

The BME groups had multiple explanatory models of illness, which were influenced by family and friends, but these were also competing and contrasting. These explanatory models influenced help-seeking. Crisis points were often the drivers of help-seeking, regardless of biomedical attributions or understanding of the illness.

Voluntary and community-based organisations felt that BME communities had a poorer understanding of mental illness, appropriate pathways into care and the role of interventions such as psychotherapy and counselling. GP failure to address carer concerns was considered a key factor in delaying access to appropriate services.

In the absence of appropriate help through medical pathways some African Caribbean carers had resorted to exaggerating risk or sought help from police, leading to criminal justice involvement. BME groups were more likely to have supernatural or faith-based attributions for mental illness. Faith-based help-seeking provided comfort to carers and users but could also lead to a delay in accessing medical help and sometimes financial exploitation of the family.

Stigma and shame of mental illness were prominent reasons for delay in accessing care. Early intervention services were considered accessible and appropriate and were perceived to be positive and caring and to take into account the cultural and ethnic background of users and carers. No specific changes were needed or demanded from the current model of early intervention services to make it more culturally appropriate for BME groups.

Black and minority ethnic service users did not seek BME-specific measures or interventions; they wanted to be able to share their spiritual/religious and cultural beliefs with mental health service professionals in an open manner without being judged. There was no demand for ethnic or gender matching between users and clinicians. Instead, users and carers wanted competent and caring clinicians, regardless of gender or ethnicity.

Lack of appropriate interpretation services and lack of information in accessible formats were major barriers to accessing help for some BME carers and users.

Conclusions

The ENRICH programme set out to determine key factors that might explain ethnic differences in pathways to care. We found no ethnic difference in DUP or DUI, suggesting that simply measuring treatment delay may not help understand important ethnic differences in help-seeking or differential rates of coercive service contacts.

There are important ethnic and cultural differences in illness attribution, with Asian and black carers and users attributing symptoms of psychosis to supernatural or faith-based explanations, which determines help-seeking from faith organisations. Faith-based help-seeking, although offering comfort and meaning within a cultural context, risked delaying access to medical care and in some cases financial exploitation of a vulnerable group.

The BME excess in MHA detentions is not because of ethnicity per se but because of clinical differences in BME groups, possibly related to higher rates of psychosis, greater risk and a lower level of social support.

Early intervention services are perceived to be accessible, supportive, acceptable and culturally appropriate. Any concerns that users or carers had about the cultural appropriateness of services were related to mental health services in general rather than early intervention services in particular. Users and carers are clear that no specific changes are needed for early intervention services to meet BME needs.

The most important implication from the ENRICH studies is that statutory health-care organisations need to work closely with community groups to improve pathways to care for BME service users. Rather than universal public education campaigns, researchers need to develop public awareness programmes that are specifically focused on BME groups and test whether help-seeking pathways such as faith encounters can be targeted for reducing treatment delays and preventing adverse pathways. Such campaigns also need BME-specific strategies to increase knowledge and understanding of mental disorders and treatment while combating social stigma and shame.

Funding

The National Institute for Health Research Programme Grants for Applied Research programme.

Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Programme Grants for Applied Research* journal

Reports are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was set up in 2006 to produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future. The Programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director.

The programme is a national response mode funding scheme that aims to provide evidence to improve health outcomes in England through promotion of health, prevention of ill health, and optimal disease management (including safety and quality), with particular emphasis on conditions causing significant disease burden.

For more information about the PGfAR programme please visit the website: www.ccf.nihr.ac.uk/PGfAR

This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0606-1151. The contractual start date was in August 2007. The final report began editorial review in May 2012 and was accepted for publication in May 2013. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2013. This work was produced by Singh *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Programme Grants for Applied Research Editor-in-Chief

Professor Paul Little Professor of Primary Care Research, University of Southampton, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke Professor of Health Sciences, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Peter Davidson Director of NETSCC, HTA, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Professor Elaine McColl Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Honorary Professor, Business School, Winchester University and Medical School, University of Warwick, UK

Professor Jane Norman Professor of Maternal and Fetal Health, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professorial Research Associate, University College London, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk