PRIME Policy Brief 9
March 2015

Psychiatric stigma and discrimination in South Africa: perspectives from key stakeholders

Catherine O Egbe, Carrie Brooke-Sumner, Tasneem Kathree, One Selohilwe, Graham Thornicroft and Inge Petersen

INTRODUCTION

Stigma and discrimination remain barriers to help seeking and full recovery for people in need of mental health services, yet there is scarce research investigating the experiences of psychiatric stigma on mental health service users in low- and middle-income countries (LMICs).

The aim of this study is to explore the experiences of psychiatric stigma of service users in order to inform interventions to reduce such stigma and discrimination in one LMIC, namely South Africa.

This study reports on baseline data collected as part of the formative stage of the Programme for Improving Mental health care (PRIME) in South Africa to inform the development of a mental health care plan and accompanying interventions.

The study found that psychiatric stigma was perpetuated by family members, friends, employers, community members and health care providers. Causes of psychiatric stigma identified included misconceptions about mental illness often leading to delays in help-seeking. Experiencing psychiatric stigma was reported to worsen the health of service users and impede their capacity to recover and lead normal lives.

PRIME's goals are to:

(1) Develop evidence on the implementation and scaling-up of mental health treatment in primary & maternal health care, in low resource settings

(2) Enhance the uptake of its research evidence amongst key policy partners and relevant stakeholders

PRIME programme for improving mental health care
Evidence on scaling-up mental health services for development

SETTING

Dr Kenneth Kaunda District, North West province, South Africa

The Dr Kenneth Kaunda District has a population of about 632,790 people and is a predominantly urban location with approximately 10% rural population. There are four sub-districts and the formative study was conducted in the Matlosana and Tlokwe sub-districts, both urban locations with mixed housing, public transport and public health facilities including regional hospitals, primary health care facilities and a specialist in-patient mental health facility. Kenneth Kaunda District was chosen as the study site with the approval of the South African Department of Health as it is a pilot site for the South African re-engineered primary health care system.

METHODS

Study design

This study applied a qualitative research design using qualitative individual interviews and focus group discussions.

Participants

Participants comprised a total of 77 adults aged above 18 years, made up of service providers including professional nurses, lay counsellors, auxiliary social workers and service users.

Procedure

Service users (other than those with severe mental illness) were recruited from the waiting rooms of three large primary health care facilities in the study area. Service users with severe mental disorder were recruited in two ways using a convenience sampling approach: (i) through clinic registers held in two primary care clinics, and (ii) through the North West Mental Health Society. Convenience sampling was used for the benefit of finding participants who fall within the scope of the PRIME research project and because of the integration of all categories of patients in primary health care in South Africa. All service users with severe mental illness were stable patients receiving chronic medication for schizophrenia/bi-polar disorder. Criteria for inclusion of these service users were: a confirmed diagnosis of schizophrenia/bi-polar disorder, being capable of participating in the interview and being over the age of 18. Other service users were recruited on the basis of meeting the diagnostic criteria for the priority conditions of depression and maternal depression.

Data collection

Four focus group discussions were held with a total of nineteen lay counsellors with each group comprising of between two to seven participants. The other fifty-eight participants were individually interviewed. All interviews lasted between 45 minutes to one hour each. Interviews were recorded using a voice recorder and were then transcribed and translated.

Data analysis

Two rounds of data analysis aided by the software NVivo 10.1 were carried out after the transcription and translation of the interviews. Interviews conducted in Setswana were transcribed and translated to English language. Back translation was done for these data to ensure their validity. An initial thematic analysis of various segments of the data was conducted by all authors using an 'a priori' coding framework based on the interview schedule and themes emerging through an initial familiarisation process. The data on stigma and discrimination obtained from this first round of analysis was again subjected to thematic analysis by the first author to identify more specific themes and subthemes pertinent to the objectives of this study. Both deductive and inductive approaches were therefore employed in the analysis.

RESULTS

Service users' experiences of stigma and discrimination, causes of psychiatric stigma, impact of stigma and discrimination on service users and suggestions to combat stigma

TYPES AND FORMS OF STIGMA AND DISCRIMINATION

Internalised stigma
Externalised stigma

EXPERIENCES OF EXTERNALISED STIGMA

1. From health professionals and in health facilities:
• General ill-treatment from clinic staff and avoidance of people with mental illnesses and other ill treatment from nurses
2. From family members:
• Being denied of food, made fun of, neglected, beaten, tied to a tree
3. From community members (neighbours, employers and friends):
• Being labelled, made fun of, pushed around, denied entrance to shopping outlets, forced to do unhygienic tasks, denied wages for jobs done, treated with lack of support and empathy

CAUSES OF PSYCHIATRIC STIGMA

Stigmatising misconceptions about mental illness
• Mental illness is a deliberate act
• People with mental illness are aggressive
• Mental illness is a result of the individual's weakness
Traditional explanatory models of mental illness which may lead to delay in seeking help
• Mental illness is caused by witchcraft
• Mental illness being a sign indicating a call to be a 'Sangoma'

IMPACT OF STIGMA ON SERVICE USERS

• Being unable to lead productive or socially inclusive lives
• Worsened state of health

INTERVENTIONS TO CURB PSYCHIATRIC STIGMA

1. Education
i. Education/awareness raising for:
• Family members, Community members, Service users, Service providers
ii. Education methods:
• Health education, Media (pamphlets, TV, radio), Town hall/ community meetings, Health talks at clinics
iii. Psycho-education and psychosocial rehabilitation for family members and service users
2. Acceptance and support by family and community members
3. Supervision of health care service providers
4. Integration of mental health care at health facilities
5. Sanctions/legal action against agents of discrimination

POLICY RECOMMENDATIONS

This study highlights that stigma and discrimination in its broad forms of internalised (self-stigma) and externalised stigma are rife in the lives of service users interviewed. It negatively affects their health status and chances of recovery and can result in delayed help-seeking and non-adherence due to reluctance to attend public health care facilities for ongoing care.

- There is a need for interventions at all levels to promote more supportive home and community environments
- Group-based psychosocial rehabilitation programmes for service users with severe mental illness need to be made available within the community
- Advocacy interventions on the part of people with mental illnesses is important to assist in showing how they are not a threat to society and can make a significant contribution to the development of policy and services
- Counselling of families, caregivers and service users should include how to deal with experienced and internalised stigma
- Media campaigns and interventions to reduce stigma should be designed to address specific stigmatising behaviours among specific segments of the population namely, primary health care staff and family members. This should involve service users in order to initiate a change in negative stereotypical attitudes towards people with mental illnesses

REFERENCE

Policy brief based on research by: Catherine O Egbe, Carrie Brooke-Sumner, Tasneem Kathree, One Selohilwe, Graham Thornicroft and Inge Petersen
Title: Psychiatric stigma and discrimination in South Africa: perspectives from key stakeholders
Journal: BMC Psychiatry 2014, 14:191
Available (Open Access): http://www.biomedcentral.com/1471-244X/14/191

About PRIME

PRIME is a Research Programme Consortium (RPC) led by the Centre for Public Mental Health at the University of Cape Town (South Africa), and funded by the UK government's Department for International Development (UKAID). The programme aims to develop world-class research evidence on the implementation, and scaling-up of treatment programmes for priority mental disorders in primary and maternal health care contexts, in low resource settings.

Partners and collaborators include the World Health Organization (WHO), the Centre for Global Mental Health (incorporating London School of Hygiene & Tropical Medicine and King's Health Partners, UK), Ministries of Health and research institutions in Ethiopia (Addis Ababa University), India (Public Health Foundation of India), Nepal (TPO Nepal), South Africa (University of Kwazulu-Natal & Human Sciences Research Council) and Uganda (Makerere University & Butabika Hospital); and international NGOs such as BasicNeeds, Healthnet TPO and Sangath.

PRogramme for Improving Mental health carE (PRIME)
Alan J Flisher Centre for Public Mental Health
Department of Psychiatry & Mental Health
University of Cape Town
46 Sawkins Road, Rondebosch, South Africa 7700
Web: www.prime.uct.ac.za

Alan J. Flisher Centre for Public Mental Health

Policy brief design and layout: Charl Linde

This document is an output from a project funded by UK Aid from the Department for International Development (DFID) for the benefit of developing countries. However, the views expressed and information contained in it are not necessarily those of or endorsed by DFID, which can accept no responsibility for such views or information or for any reliance placed on them.

UKaid from the British people