Closing the gap in psychosocial rehabilitation for people with schizophrenia in South Africa: a multi-sectoral approach

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PRogramme for Improving MEntal health care

• Consortium of research institutions and Ministries of Health in five countries
  • Ethiopia, India, Nepal, South Africa, Uganda
  • Partners in the UK and the World Health Organization (WHO).

• Evidence for implementation and scale up in low resource contexts

• Priority mental disorders – depression, alcohol misuse, schizophrenia
The context – Dr Kenneth Kaunda District, North West Province

- High levels of poverty and unemployment
- Progress in decentralised care
- Psychotropic medications relatively widely accessible at clinics
- Disability grants (75GBP p/month)
- Insufficient resource allocation and intervention research for community based services
- Revolving door phenomenon
- Low human resources for mental health
  - 0.4 psychologists per 100 000 population
  - 0.1 social workers and occupational therapists per 100 000 population
The reality for service users

- Sometimes I don’t feel like a human being, I feel like a dead person.
- I feel isolated as if I was living in a cage....
- Sometimes when you go there on your scheduled appointment, you’ll find that there is no medication.
- People should have money and jobs because if you do not have money, you become stressed. This stress exacerbates your illness.
The reality for caregivers

- Whenever she starts to be ill, everyone in the house backs off and the responsibility is left for me and I have to make sure that I do something...

- People say, may God keep you alive until he gets better because if you die and leave him there is just going to be chaos. Nobody else will be patient with him like you; they won’t take care of him...

- It has affected me a lot because I can’t do anything for myself and I’m educated but I’m just like anyone who never went to school
Evidence on scaling-up mental health services for development
Evidence on scaling-up mental health services for development
The Need

- Community based psychosocial rehabilitation
- Limited programmes currently in the district
  - Psychoeducation – service users and caregivers
  - Empowerment towards recovery
  - Productive/Income generating activities
  - Linking with other resources
Psychosocial Rehabilitation: Whose Responsibility?

social development
Department: Social Development
REPUBLIC OF SOUTH AFRICA

health
Department: Health
REPUBLIC OF SOUTH AFRICA

S.A. Federation for Mental Health

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Psychosocial Rehabilitation in Dr KK District

• Objectives:

• 1. Mobilise and generate commitment for collaborative care and rehabilitation for people with schizophrenia amongst service providers in the district.

• 2. Elucidate factors relevant to recovery from the user and caregiver perspective to inform a socio-culturally appropriate PSR programme
1. Working towards a multisectoral delivery platform

- 3 Theory of change workshops – plan for delivery of collaborative care for schizophrenia in the district
- Advocacy - meetings with key representatives from Departments of Health and Social Development at national and provincial level
- Tangible actions from meetings - timeline for implementation and plan for allocation of human resources
- Identification of ‘champions’ for the programme
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The collaborative care model for schizophrenia

Referral to specialist facility for in-patient care

Back referral to local clinic for continued management

Referral to district hospital for 72 hr observation and initiation of psychopharmacological treatment

Psychosocial rehabilitation support group facilitated by aux social workers supervised by social worker/occupational therapist

Other mental disorders and communicable and NCDs including diseases of lifestyle which are inadequately controlled referred to PC doctor/ other referral sources

PHC nurse identifies psychotic disorders and other mental disorders as well as other communicable and non-communicable diseases. Initiates initial management of other diseases. Provides ongoing repeat medication for chronic conditions

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2. Qualitative research

- 19 in-depth interviews with schizophrenia service users and their care givers
- Data validated through participatory workshop with mental health stakeholders in district
  - Mental Health Society – Director, social workers, auxiliary social workers
  - PHC nurses
  - DOH Mental Health Coordinator for District
• Knowledge of schizophrenia diagnosis low; illness commonly attributed to witchcraft and stress

• I don’t agree with them [doctors], I’m not sick.

• I don’t know what it’s called, I just take pills and they help me feel normal and better.

• Little knowledge of medication and side effects

• They never give me the right medication, today they would give me certain pills and next time when I come they give me different ones.
Family conflict

• My family does not understand because they say I’m faking it and they also say I sleep too much.

• They make me behave like a servant looking after someone everyday.

• When they refuse to give me foods when I ask them. That makes me feel angry and that is when I become worse.

• They just like saying things like I should remember that I’m a lunatic. That hurts and that’s why I end up crying.
Traditional healers - role in explaining mental illness

• I would like to go to a traditional healer to help so that I can understand better. Modern doctors don’t understand and recognize muti that people gives you in your food (Jesewa). I think a traditional healer would help me understand the causes of this illness better.

Religion gives a sense of hope and security

• I went to church to tell the pastor that people say I’m a lunatic and he told me to pray all the time even in times when I don’t feel well.

• Even when I went to town with him, he would cross the traffic robots when cars are passing. That’s why I am telling you that I thank God because through it all He has protected him.
Work/productivity – the defining factor of recovery (despite disability grants)

• When I’m feeling better, I’m able to do things for myself such as washing dishes and clothes.
• I want to work. I want it [grant] to stop for a while because I want to work.
Developing a PSR Programme

- Comprehensive psychoeducation
- Respect for diversity of beliefs and explanatory models
- Productive activity/income generating activities/skills building
- Stigma is still a huge problem – help service users to deal with experiences of stigma and discrimination
Progress To Date

- Manualised psychosocial rehabilitation intervention developed
- 2 trained facilitators for group (aux social workers) – social worker supervision
  - Programme covers 12 sessions for service users
- Topics including:
  - Understanding Our Schizophrenia Diagnosis
  - Understanding Medication
  - Coping with Schizophrenia
  - Substance Abuse
  - Knowing Ourselves
  - Income Generating Activities
  - Managing Anger, Stress and Conflict
  - Dealing With Stigma and Discrimination
  - Contributing to the Household
  - Money Management
5 sessions for caregivers -

- Understanding Our Relative’s Illness
- Coping With Caring for A Person With Schizophrenia
- The Effect of Conflict in the Family
- Dealing with Stigma and Discrimination
- Caring for the Caregiver
Challenges

• Resources for mental health remain low – especially in the NGO sector

• Burn out of workers in caring professions in South Africa – social workers, auxiliaries, nurses
  • BUT there is an opportunity to revitalise - people are looking for new programmes to support the people they serve

• Tension between the research process and implementation of a psychosocial intervention on the ground

• Stigma against people with schizophrenia at all levels, lack of knowledge of this illness amongst service providers and managers
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Learnings

• Involve those who are passionate about working with people with psychiatric disability
• Importance of working with Mental Health Societies – commitment to serving people with mental illnesses
• Don’t be afraid to ask national level management for resources
• The right people can make things happen... sustainably
All I want is just to be loved and taken good care of. If I ask for help I should get it...
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