REVIEW

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Reducing psychosocial disability for persons with severe mental illness in South Africa

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Some of the challenges of psychosocial disability include lack of epidemiological data, the complexity of assessing impairment, the economic impact, stigma, and recovery.

Severe mental illness, which includes disorders such as schizophrenia, bipolar disorder and major depressive disorder, is associated with significant impairment, but the severity of the impairment and the associated psychosocial disability varies significantly within each disorder. While South African legislation and policies support interventions aimed at reducing psychosocial disability and promoting recovery, implementation remains a challenge.

This chapter argues that the assessment of psychosocial disability should be individualised. Some of the key challenges of psychosocial disability are examined, and recommendations are made to improve access to health care for persons with severe mental illness and to reduce psychosocial disability.

Some of the challenges of psychosocial disability include lack of epidemiological data, the complexity of assessing impairment, the economic impact, stigma, and recovery.

The recommendations to reduce psychosocial disability include equitable access to health care, management of mental illness in the workplace, establishment of recovery-oriented mental health services, prioritisation of South African research on mental health, and legislative and policy recommendations.

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Introduction

Mental disorders vary in the frequency and severity of their occurrence, from common mental disorders (CMDs) such as anxiety and trauma-related disorders, to severe mental illness (SMI).[1-3] SMI broadly includes disorders such as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, and neurocognitive disorders.[2-4] The impact of mental illness on populations worldwide remains high, with depression being the leading cause of disability and affecting about 300 million people.[5] Excluding persons with psychotic disorders, the South African Stress and Health Survey found a lifetime prevalence of 30.3% for any mental health disorder in South Africa.[6] In sub-Saharan Africa, the epidemiology of the burden of disease is evolving, from decades dominated by communicable diseases to an era of disease burden largely due to non-communicable diseases (NCDs), including mental illness.[7,8] Over the past three decades there has been a 113.9% increase in disability-adjusted life-years (DALYs) due to mental disorders in sub-Saharan Africa, while in the same period there has been a decline in communicable diseases, despite the contribution of HIV to disease burden.[8] Epidemiological data on the burden of mental illness and disability remain, at best, extremely limited in South Africa.[9]

There is an inverse relationship between SMI and socioeconomic status of persons with mental illness, which can be explained by the social causation and social selection hypotheses. The social causation hypothesis suggests that poor social and economic circumstances result in increased risk of mental illness, while the social selection hypothesis (also called the social drift hypothesis) proposes that persons with mental illness drift into poverty as a consequence of the disability associated with mental illness.[10,11] There is a concurrent interplay between social causation and social selection in SMI, and without appropriate intervention, this results in psychosocial disability in persons with mental illness.[11]

The impairment due to mental illness may be difficult to observe directly and quantify compared with impairments from physical illnesses, yet the impact on the affected persons and society is significant. In a study by the World Mental Health Survey Initiative in Portugal, persons with mental illness were almost three times more likely to report disability than those without mental illness, and they had higher levels of unemployment.[12] Despite the negative psychosocial and economic consequences of psychosocial disability on persons with mental illness, their families and the community, prioritisation of mental illness through healthcare budgets remains lacking globally.[13,14] In the 2016/17 financial year, only 5% of the total healthcare budget in South Africa was spent on mental health care, and most of the expenditure was on inpatient care.[13] The underfunding of mental health care, stigmatisation of mental illness, and neglect of persons with disabilities, irrespective of the cause of the disability, further retards attempts to reduce psychosocial disability despite global efforts, such as by the United Nations' Sustainable Development Goals (SDGs), which make mental health a global priority.[15] The consensus report of the South African National Lancet Commission found that mental health care is neglected in South Africa, despite good policies and the negative economic consequences on affected persons.[16] South Africa must focus on mental health care and efforts to reduce psychosocial disability as an important health outcome in the effort to attain the SDGs in this country.[17]

This chapter describes the association between psychosocial disability and SMI. Some of the key challenges of mental health and disability, such as lack of epidemiological data, the complexity of assessing impairment, the economic impact, stigma, and recovery are discussed, and the argument is made for the assessment of psychosocial disability to be individualised. Recommendations include equitable access to health care, management of mental illness in the workplace, establishment of recovery-oriented mental health services, prioritisation of South African research on mental health, and legislative and policy recommendations.

Psychosocial disability in SMI

Psychosocial disability in persons with SMI refers to difficulties that extend beyond symptom severity. Psychosocial difficulties experienced by persons with mental illness include occupational difficulties, challenges with interpersonal relationships, and decline in social functioning.[18-20] Psychosocial disability, therefore, occurs when the environment of persons with mental illness is not adaptive to their symptoms and hinders the ability of persons with mental illness to participate fully in society.[18-20] In addition to psychosocial disability, mental illness is associated with a higher mortality rate than in the general population, as well as reduced life expectancy.[21,22] SDGs provide a shift from the past global focus on the reduction of mortality, to goals that aim at reduction of non-fatal health loss associated with NCDs, injuries, and substance-use disorders.[15,23]

Impairment is the "alteration of normal functional capacity due to a disease" and its extent is evaluated after a diagnosis has been made and there has been adequate management of the mental illness.[24] Disability, which "is the alteration of capability to meet personal, social or occupational demands", is due to the impairment associated with mental illness combined with an environment that is not adaptive to the degree of impairment sustained from the mental illness.[24,25] The severity and prognosis of impairment varies across and within diagnoses, and the consequent psychosocial disability is a continuum ranging from some persons with mental illness having no disability, to severely disabled persons who are not capable of independent living.[17] However, some symptom domains of mental illness, such as psychosis and cognitive

decline, are independent risk factors for psychosocial disability.[26] While a major feature of neurocognitive disorders, cognitive decline is also found in other disorders such as bipolar disorder, depressive disorders, and schizophrenia.[27] Psychotic episodes are associated with poor outcomes on disability assessment and are often associated with poor cognitive function.[28] Persistent psychosis and psychosis that is refractory to treatment, especially in schizophrenia, almost always lead to severe psychosocial disability.[29]

Recovery in SMI

Strategies to reduce psychosocial disability must include the reduction of impairment, promotion of resilience and recovery, and addressing of environmental barriers and facilitators to recovery. It is only relatively recently that recovery from SMI has been studied systematically. There has been a concerted effort from persons with SMI to inform the world that personal recovery is indeed possible. This has culminated, among other outcomes, in a more robust definition of recovery that utilises the CHIME framework (CHIME: Connectedness, Hope and optimism about the future, Identity, Meaning in life and Empowerment).[30] A recently published South African study built on this framework to define recovery in the local context.[31] The authors found that recovery is an ongoing, gradual process that involves processes such as relating to self, others, and the world, moving positively forward, (re-) gaining strengths, awareness of difficulties, and clinical understanding to support personal recovery. Clinicians need to understand that personal recovery has very little to do with symptoms of mental illness (persons in recovery may or may not have ongoing symptoms); it is about connectedness and feeling valued by others, which is influenced by environmental barriers and facilitators. Although not linear, and although heavily influenced by context, recovery is possible and studies that have painted a pessimistic picture by implying that there is significantly low recovery in mental illness have been criticised for having methodological problems.[32,33]

The vast majority of psychosocial rehabilitation programmes that support persons with SMI are not recovery oriented, yet the South African National Mental Health Policy Framework and Strategic Plan (NMHPF & SP) included recovery as a value and an objective.[34] Recovery-oriented services refer to the extent that clinicians and the service attempt to facilitate or promote personal recovery. The service needs to include ingredients such as shared decision making (or person-centred care), and learning 'what works' from the persons in recovery. Peer support is also an important ingredient in the service. Non-psychiatric services that include exercise, spiritual activities, pet ownership, acquisition of identity documents (a project from Lentegeur Hospital and the Spring Foundation) have also been found to be important in allowing persons with SMI to build a life beyond the illness.[35] Strategies that focus on resilience have also been shown to decrease psychosocial disability in persons with schizophrenia.[36] All psychiatric services should, therefore, be changed to recovery-oriented services that start with the treating team and the person with SMI, at the time the diagnosis is made, and that plan for reduction of psychosocial disability and attainment of recovery.

Assessment of disability in SMI

Disability assessment is done for various reasons, including to determine occupational disability, disability claims, disability assessment for government grant claims, and assessment of independence in persons with SMI. The initial assessment is to determine level of impairment. In mental health, this is done by a psychiatrist and a multidisciplinary team that includes a clinical psychologist and an occupational therapist. The psychiatrist and clinical psychologist use various psychometric tests to determine impairment of persons with mental illness. The occupational therapist uses a variety of standardised and non-standardised measures to assess impairment and disability for persons with mental illness. The multidisciplinary team facilitates an objective and broad assessment that is helpful in the determination of occupational disability, disability claims, disability assessment for government grant claims, and to assist with proper placement and adaptations for independence of persons with SMI.

Guidelines by the South African Society of Psychiatrists (SASOP) on "the management of impairment claims on psychiatric grounds" suggest that ideally, the psychiatrist involved in the determination of impairment should not be the treating psychiatrist.[24] Mokoka, Rataemane and dos Santos[37] express concern that the role of the treating psychiatrist and the role of the disability assessor are ethically different and incompatible in some respects.[37]

In assessing impairment and disability, occupational therapists perform a functional capacity evaluation (FCE), which assists in determining the level at which a person with mental illness is capable of functioning in a particular context and environment.[38] When performing a FCE, the occupational therapist takes a patient history and uses objective assessment tools.[39] The FCE is guided by the International Classification of Functioning, Disability and Health (ICF) in order to determine the disability of persons with mental illness.[40] The ICF is the relevant framework and classification to use as it focuses on impairment, activity limitations and participation restriction, and the environmental factors that interact with the components.[40,41] The presence of an impairment does not automatically mean that there is a disability as other factors such as the type of job, and environmental and social circumstances have to be taken into consideration.[41]

South African legislation and policies attempt to protect and promote the rights of persons with disability in the

workplace, including the rights of persons with mental illness.[42,43] The Employment Equity Act (No. 55 of 1998) (EEA)[44] stipulates that if a person with mental illness had been ill and is unable to perform his or her essential job functions, then the employer may request that the person be assessed for functional disability.[44] Appropriate tests should be used to determine if the person can safely perform the job, and if not, to recommend the appropriate reasonable accommodations required for the person to perform the work.[39,44] Gibson and Strong[45] and Ramano and Buys[39] advise that occupational therapists may also assist the employer in fulfilling the provisions of the EEA by conducting FCEs.[39,45]

Psychosocial disability: key challenges

Attempts to reduce psychosocial disability involve a number of key challenges. Psychosocial disability shares some of the challenges experienced in the broad area of disability. In addition, there are challenges related to the neglect and stigmatisation of mental illness. Some of the key challenges are discussed below.

Lack of epidemiological data

Epidemiological data on SMI and psychosocial disability remain inadequate in South Africa. Data collection on national mental health indicators is one of the areas of action of the NMHPF & SP that was supposed to have been implemented from 2013.[34] Without accurate data on the prevalence of SMI and psychosocial disability, it is difficult to plan and implement interventions to reduce psychosocial disability. Delay in implementation of the NMHPF and the recommendations of the report of the South African Human Rights Commission (SAHRC) on the national investigative hearing into the status of mental health care in South Africa,[46] are contributing to the delay in mobilisation of resources for monitoring and evaluation of psychosocial disability.[46]

Complexity of assessing impairment and disability

Assessing impairment in mental illness is difficult due to the complexity of psychiatric diagnoses, potential loss of objectivity on the part of treating psychiatrists, and stigma.[47] There is also a lack of resources to prepare persons with mental illness for return to work, leading to premature declaration of disability.[48] Ramano, Buys and de Beer[49] found that psychosocial disability assessment is challenging for occupational therapists as they have to assess numerous factors, such as the employee's biographical profile, the employee's motivation for working, the employer's willingness to accommodate the disability, and the FCE results.[49] Occupational therapists in South Africa view FCEs as intensive since the process requires numerous assessments, ranging from psychometric to worksite evaluations.[39]

Economic impact of psychosocial disability

Psychosocial disability has an economic impact on persons with mental illness, governments, employers, and society. There are limited data on the economic impact of psychosocial disability on persons with SMI, but there are some compelling data on the economic consequences of depression and CMDs. The economic consequences of psychosocial disability for persons with mental illness is dire. Schofield et al.[14] reported that the income of persons with mental illness aged 45-64 years, who took early retirement from work due to depression, was 73% lower than that of their healthy counterparts who remained in full-time employment. Under-investment in mental health by countries, including South Africa, is well recognised, and by 2030 the world could potentially lose almost 400 billion US dollars due to lost productivity associated with depression and anxiety disorders.[13,50,51] In their study, Schofield et al.[14] further illustrated that the national loss of income due to depression alone in Australia was 1 billion Australian dollars per year, with a further 1.5 billion Australian dollars in income lost due to other mental disorders.[14] In addition, there is still the cost of treating these mental disorders and the cost of caring for persons with psychosocial disabilities, as well as the lifetime cost of social and economic marginalisation of persons with mental illness.[14]

Stigma

Stigma and discrimination against persons with mental illness have substantial impact on their psychosocial functioning. The Convention on the Rights of Persons with Disabilities (CRPD), to which South Africa is a signatory, prohibits unfair discrimination against persons with disabilities, including psychosocial disability.[18] State parties to the CRPD are mandated to "take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life".[18] Despite the CRPD and other enabling legislation, including the Mental Health Care Act (No. 17 of 2002) (MHCA)[52] and the Constitution of the Republic of South Africa (Act No. 108 of 1996),[53] persons with psychosocial disability continue to be stigmatised and discriminated against in the workplace.[18,52,53] As a result of stigma, persons with mental illness may delay in presenting for assessment and treatment. One study[54] reported that 47% of the general public would not be willing to work closely with persons diagnosed with depression, and 30% would be unwilling to socialise with them.[54]

Lack of psychosocial rehabilitation

Psychosocial rehabilitation is known to reduce disability, with some scholars[55] believing that it "embodies the humanistic heart of mental health".[55] Despite the known benefits of rehabilitation, psychosocial disability remains marginalised in terms of holistic funding and treatment of mental illness.[55-57] Embedded in the goals of the NMHPF & SP is the improvement of services for rehabilitation in mental health care in South Africa, but there is still a delay in implementation of this policy framework.[34,46] In the private

sector, the Medical Schemes Act (No. 131 of 1998) (MSA)[56] and its regulations on prescribed minimum benefits (PMBs) do not obligate medical schemes to fund psychosocial rehabilitation.[56] Key to the rehabilitation of persons with mental illness is rehabilitation teams, which should include occupational therapists. However, occupational therapists are not adequately funded and very few persons with mental illness have access to occupational therapy.[55,56,58]

Conclusion

Psychosocial disability highlights the need for investment in mental health care in South Africa. There are a number of key challenges. However, there are progressive policies, such as the NMHPF, and reports such as the one published by the South African Human Rights Commission.[46] If these are implemented, there will be improvements in the care of persons with mental illness and a reduction in psychosocial disability. An improved funding model is required to reduce psychosocial disability; the model must be fully integrated into both the public and private sectors, and consistent with the principles of universal health coverage.

Recommendations

Equitable access to health care for persons with mental illness

It is increasingly evident that differential access to care, economic inequality, and imbalanced risk factor profiles can and do challenge the ability of health systems to achieve equitable health outcomes in the face of complex and resource-draining diseases and injuries. The World Health Organization (WHO) has recommended that South Africa should be spending approximately 10% of its health budget on mental health care.[50] Most provinces in South Africa are far below this important goal post.[13] One potential solution that has gained some traction over the last few years, is to have a specific ring-fenced mental health budget, which should be used to implement integrated mental health services as envisaged in the NMHPF & SP. With a ring-fenced mental health budget, the mental health programme mechanism would be very similar to South Africa's HIV, TB, or Maternal and Child Health programmes, which were significant in making inroads in the fight against HIV and TB over the past two decades.

Establish early intervention recovery-oriented services

South Africa should be moving the majority of psychiatric services and associated budgets to be more outpatient-based.[34] There is no doubt that a recovery-oriented service involving persons with mental illness and their families early on in care planning would reduce psychosocial disability.

There is also a growing body of evidence from around the world that early intervention services with multidisciplinary teams improve long-term psychosocial functioning of many persons with mental illness. Early intervention services focus on reducing the delay to treatment, and on providing intensive treatment during the critical phase of the illness.[59,60]

Mental illness in the workplace

South Africa needs to build workplace environments that are much more willing to accommodate persons with mental illness. Implementation of workplace anti-stigma interventions may be one example of a programme that will create a more supportive work environment. This may lead to reduced negative attitudes, improved knowledge and awareness of mental illness, and improvement of persons with mental illness via increased and potentially earlier help-seeking.[60]

Earlier return to work, while still in the process of recovery, may benefit persons with mental illness. Employment is seen as therapy to most persons and persons with mental illness, as it improves self-esteem, decreases psychiatric symptoms, and reduces social disability. Overall, employed persons with mental illness have better quality of life (as subjectively rated), as employment creates social identity and places them within social networks.[14] Therefore, returning to work may aid persons with mental illness in their recovery, as connection is central to the recovery process. In the case of persons with mental illness who are in steady employment, it was found that their mental health costs declined over time.[61] Indeed, long-term unemployment itself is associated with mental illness.[14] Lastly, for persons with mental illness, employment is important in maintaining a connection with the community, and potentially also in maintaining personal mental health.

Prioritisation of South African research on mental health

Psychosocial disability should be one of the priority areas of the South African research agenda on mental health, with particular focus on epidemiology as well as affordable interventions that can reduce psychosocial disability. South African data should be organised so that it features prominently in the Global Burden of Disease studies. Research will assist in measuring the non-fatal health outcomes of mental disorders, as well as informing public health measures to reduce psychosocial disability.[17]

Legislative and policy recommendations

With the exception of the MSA, there is adequate legislation and policies in South Africa to protect the rights of persons with mental illness and accelerate mental health provision, but implementation remains a challenge. MSA regulations on PMBs need to be revised in order to ensure adequate funding of mental health care in the private sector, a process that has already been initiated by the Council for Medical Schemes. Implementation of the SAHRC report (and timelines) on the national investigative hearing into the status of mental health care in South Africa will mitigate the delays that have already been sustained in mental health care.[46]

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