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Strengthening the call to involve mental health care service users and their families in psychosocial rehabilitation programmes.

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Introduction

This paper explores the benefits and value of involving mental health care service users in psychosocial rehabilitation but also encourages greater discussion on the reasons and the way in which to successfully do so via a holistic model of care and service delivery in global mental health. The approach can take the form of multidisciplinary teams, including psychiatrists, psychologists, and non-mental health professionals such people with lived experience, peers, and families. Existing global acknowledgement of this type of intervention aims to inspire healthcare services to be more focused on a holistic, person-centred approach to recovery, empowerment, and overall well-being. "The demand for greater partnership with users reflects a shift from decisions based on professional values to user values" (Petersen, Hounsgaard, & Nielsen, 2008). Mental health as a field is a broad and complex rhetoric and it is worthwhile exploring the term, mental health, to facilitate the discussion on psychosocial rehabilitation. According to the World Health Organisation (WHO), mental health is not the absence of an illness (WHO, n.d.). Having mental health does not mean or identify it as being a negative concept. In fact it reflects a healthy state of well-being. As stated in the WHO report on transforming mental health for all (WHO, 2022), mental health is a fundamental part of our general health and overall well-being and having good mental health means that individuals are better able to connect, function and optimally thrive.

In Weiten and Hassim (2016) the authors describe, for individuals to be optimally functioning in the settings of life, work, and within relationships, the different domains of wellness, key components of positive psychology, must be carefully worked on by every individual to ensure harmony and successful integration in community. The biological domain of wellness reflects an individual's physical well-being, genetics, and physiology while the psychological domain includes our memories, belief systems, perceptions, self-esteem, emotions, thoughts, coping skills, and strategies. The social domain of wellness refers to an individual's relationships, both social and personal, and further encompasses the individual's environment and their family context. Importantly, these dimensions do not exist in silos, affecting, either positively or negatively, the general state of well-being and mental health of individuals. (Weiten, & Hassim, 2016)

Psychosocial Rehabilitation

Psychosocial rehabilitation is an intervention tool based on principles that are used to support the individual to recover and regain their independence, and improve their quality of life (Cnaan, et al., 1988). This approach is not solely clinical or focused on symptom reduction, but encourages empowerment and support towards recovery.

Psychosocial rehabilitation programmes are characteristically provided by a multidisciplinary team of mental health professionals, including psychiatrists, psychologists, social workers, occupational therapists, peers, and people with lived experience of a mental health condition facilitating the individual's move towards optimal functioning. A key principle of psychosocial rehabilitation is that everyone's role and responsibilities ought to be made clear from the inception of care to ensure proper care is provided to individuals. The nature of psychosocial rehabilitation programmes promotes individuals' reintegration into

society and this can be delivered in various settings (Cnaan, et al., 1988). Settings include, but are not limited to, community mental health centres, residential facilities, vocational rehabilitation centres, schools, universities, and even correctional facilities.

Key components of comprehensive psychosocial rehabilitation

While the nature and objectives of psychosocial rehabilitation are agreed upon, it is necessary to also briefly mention the components that psychosocial rehabilitation programmes comprise of.

Capacity building and training are essential in psychosocial rehabilitation programmes because they involve teaching individuals how to identify and use specific skills that can help them manage their mental health symptoms and conditions and function more effectively in their daily lives. This can include social skills training, problem-solving skills, and coping strategies.

Relatedly, individuals learn how to **manage their medication**; when to take medication, why they taking it and how to take it, which may be crucial to their plan towards wellbeing. Managing medication cannot take place without capacity building and training.

Supportive counselling is crucial to psychosocial rehabilitation as it helps individuals learn to identify and manage their emotions and learn available coping strategies in a safe space, free of judgment and stigma.

These strategies can be applied at any given time outside the counselling space.

Peer support is an invaluable resource in any mental health setting. Having someone who can understand and recognise challenges is a powerful tool. Peers would have had similar experiences or would have been in similar situations as the service user and has the insight to provide hope and inspiration to the service user in an honest and compassionate manner. Importantly, there is no hierarchy in peer-to-peer relationships. Strategies for peer support-based service delivery is encouraged in psychosocial rehabilitation, because having the support of a peer who has been exposed to similar experiences allows for meaningful conversation in a safe environment (Sunkel, & Sartor, 2022).

The inclusion of **family support** in psychosocial rehabilitation, provides family members and caregivers the opportunity to play a significant role in the individual's recovery journey. However, they can only do so effectively with the guidance and education by the care team. Teaching family members and caregivers about mental health conditions, its symptoms, what to look out for and how to respond to and support the individual is crucial in their ability to support their loved ones along their recovery journey.

Another key component of psychosocial rehabilitation is **reintegration into the community** as it facilitates the process of individuals obtaining the necessary skills and tools to become independent and self-sufficient in the community. Psychosocial rehabilitation should involve **planning** that is led by the individual, whose choices about their reintegration are respected in the process.

The journey to **recovery** is not linear, nor is it a one size fits all approach and therefore should always involve the development of a cohesive and personalised plan. Goals that align with the individuals needs and aspirations must be set and there should be clear steps in place to achieve their respective goals. Family member and service user support can be a great path to enhancing this process of recovery and to help identify challenges and opportunities for recovery. Individuals must agree with the personalised plan, otherwise it may be a fruitless pursuit.

Critical reflections

It is established and globally recognised that involving mental health care service users in the design, delivery, and evaluation of mental health services is a crucial aspect of promoting patient-centred care and improving the overall quality of care and services. However, it is important to recognise that there remains global concern, which is related to power dynamics, inauthentic participation, tokenistic relationships and care, stigma, and bio-medical preference in care. It is necessary to move away from tokenistic approaches and approaches contributing to power imbalances and move towards creating approaches that ensures diversity among participants (Sunkel, & Sartor, 2022).

The medical field remains the primary rhetoric of health and it is relied upon greatly for recovery, at times ignoring other types of interventions that exist that are holistic and concerned with social as well as cultural aspects of health. This results in perspectives where society visualises "recovery as an add-on to conventional services, rather than a that all of us can find a way to participate in" (Ragins, & Sunkel, 2023, p. 2) .

The paper calls for this narrative to change, for mindsets to transition into a more recovery-oriented focus, focusing on individuals needs and goals in addition to medication. There is no doubt that medication may be necessary, however, people with lived experience and specific service users' involvement in psychosocial rehabilitation programmes would be the preferred method for improving the current state of mental health services.

There has been great emphasis placed on efforts made through mental health advocacy-led organisations and leaders, to improve mental health matters in the global mental health space. While these contributions do not go unnoticed, many countries, not only those in the lower-income regions of the world, continue to have limited or even no access to mental health care and treatment. The reasons for this limited or lack of access to mental health care and treatment may vary from restricted usage to only bio-medical treatment and perhaps the lack of awareness and access to psychosocial rehabilitation programmes. This may further be a result of understaffing or a lack of financial support to sustain such programmes. While the goal may be to move towards a more community-based approach to care, these challenges continue to exist.

Why psychosocial rehabilitation programmes work

Psychosocial rehabilitation programmes are a model of empowerment that benefits service users, creating safe spaces that allow for meaningful interactions and shared activities in the programme, promoting space for outcomes of gaining improved functioning including social functioning and improved quality of life. These programmes further create an inclusive and welcoming environment that values the perspectives of clients or patients, people with lived experience and their families. Alongside professionals and family members, people with lived experience bring unique and diversified experiential value to the psychosocial rehabilitation programmes.

Voice of Lived Experience

In this next section, country mental health advocacy leaders from the Global Mental Health Peer Network share their perspectives on psychosocial rehabilitation, based on personal experiences of involvement in such programmes. All statements in this article appear with the permission of those named.

Elizabeth Berk (South Africa)

When I was in a clinic myself and I was struggling with an eating disorder and substances I found being able to share my journey with a counsellor or support counsellor that had been where I had been refreshing. It allowed me to feel hopeful and realise as to why I was there. In the last couple of years in South Africa it has become evident that the system however has been abused in many ways. In some cases, not all, the counsellors are underpaid and treated as if the clinics are doing them a favour by employing them because they are in recovery and have the stigma of being a "drug addict or recovery person' attached to them. They might be a lay counsellor with 12 (twelve) years sober, yet are still identified and labelled as the addict. While rehabilitation centres often say that the lack of contact is more for the family than the individual in treatment as the family needs space, this is not communicated to the individual on admission. There is a lack of individualised treatment and there is very much a one size fits all and if you do not fit you are labelled as high risk for relapse.

Group counselling sessions can be a great benefit for rehabilitation centres if it is used as a peer support network instead of powerlessness and damage sessions. Group sessions need to be based on sharing

experiences that can build one another up, allow for flourishing and build resilience instead of a space where individuals are broken down.

Zivile Valuckiene (Lithuania)

What works in these programmes: support groups; education; psychotherapy; and active inclusion into activities, and society. What currently does not work in these programmes: institutionalization; medical treatment; and labelling (diagnoses).

Anto-Agus Sugianto (Indonesia)

The application of a human rights approach is equally critical. A programme rooted in respect for the fundamental rights of individuals ensures their dignity is upheld throughout the rehabilitation process. Human rights principles promote non-discrimination, equality, and the right to self-determination. A lack of understanding and appropriate policies from governments can lead to a breakdown in this essential dimension, jeopardizing the quality of psychosocial rehabilitation.

Laura Van Tosh (United States of America)

I am a member of a psychiatric rehabilitation programme called Seattle Clubhouse. Originally, I started my involvement in the 1980's at Fellowship House, a clubhouse programme in Miami, Florida (US). Both clubhouses are modelled after Fountain House, based in New York city. Clubhouse provided me with psychiatric rehabilitation and housing services. I also had social interaction which helped me to navigate support services. Lived experience opportunities were few and far between then, yet current clubhouse opportunities have developed over the years.

Keshnie Mathi (South Africa)

I believe that there must be a focus on full family wellness within the recovery journey. Currently it is done as an afterthought or a suggested intervention but recovery takes a community and often someone in recovery that returns to an unchanged environment does not cope well. Restrictions such as not having a cell phone and isolation from families also needs to be better explained. Even in expensive facilities, those in recovery are treated like prisoners with an emphasis on breaking down rather than digging into the why. Whilst this is needed, peer support is recommended to ensure that this is done ethically.

Recommendation

To address the critical issues discussed earlier, this paper calls for the herein listed recommendations to be considered to achieve inclusion of mental health service user involvement and family in psychosocial rehabilitation that is truly reflecting commitment and adaptability to the changes that need to be made. For this to be achieved there must be acknowledgement and changes made as far as increasing financial aid support for programmes and their continuity, increased human resources within the workforce space, and continued evaluation by beneficiaries of these interventions to monitor impact and outcomes.

Conclusion

In summary, the involvement of mental health service users is a significant step toward patient-centred care. However, to make service user and family involvement effective and efficient, it must be meaningful, authentic, empowering and transformative with a genuine commitment to challenging the status quo of mental health services. Therefore, a strong call for action is necessary to remove the existing power imbalances and tokenistic approaches and to cater for safe spaces. A call is made for the involvement of people with lived experience of mental health conditions as well as families and carers in the development, implementa-

tion, and facilitation of psychosocial rehabilitation programmes. Mental health advocacy efforts should take place not only at community level but at policy drafting and implementation levels too. These efforts, when supported by relevant stakeholders, promotes hope and complementary decision-making for individuals dealing with mental health conditions in advocating for systemic change.

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