Lived Experience in Mental Health

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Persons with lived experience of mental health conditions play an undeniably important role in the realisation of the rights of all persons affected by mental health conditions or psychosocial disability, through active involvement in advocacy and self-advocacy. Essentially, persons with lived experience can further offer a distinct function in ensuring compliance with national and international human rights instruments, reducing coercion, involvement in research, reducing stigma and related discrimination, providing peer support, in consultative roles and participation in the development, design, review, implementation, monitoring and evaluation of mental health care and services.

Lived experience is generated beyond the aspect of knowledge and skills, where persons with lived experience has an in-depth experience of the social and human rights impact of living with a mental health condition through the hardships of being ostracised, marginalised, segregated and discriminated against, whilst struggling to navigate the mental health system to seek services or support programs that would be beneficial to the person as an unique individual and that would be a departure point towards a recovery and overall wellbeing destination. The mental health system is not the only societal system that poses obstacles to navigate through – for a person with lived experience, accessing other life opportunities such as education, employment and housing are equally difficult. Lived experience's unique and in-depth perspectives can be the catalyst for change and transformation of all societal systems to become stigma and discrimination free, promote inclusion, promote life in the community, improve quality of life, respect for and protection of human rights, and empowerment of all persons with lived experience – ultimately improve mental health and overall health outcomes.

One of the challenges identified globally in providing quality mental health care has been a lack of skilled human resources, especially to provide community-based mental health care and services. The WHO Mental Health Atlas 2017 noted that (from responding countries) the global average of mental health workers is 9 per 100 000 population and as low as 1 per 100 000 population in low-income countries. There are 11.9 psychiatrists per 100 000 population in high-income countries and less than 0.1 per 100 000 population in low-income countries, and 23.5 mental health nurses per 100 000 population in high-income countries and 0.3 to 100 000 population in low-income countries.[1]

Considering this human resource gap in mental health service delivery, it is essential that experts by experience providing peer support or peer support experts be acknowledged as a fundamental discipline in providing mental health care and services. This role should not only be contained within established mental health facilities like hospitals and clinics, but should further extend to interventions in the response to humanitarian emergency situations and incorporated into ongoing mental health psychosocial support programs. In global mental health we do know that a non-clinical workforce is more than capable in providing community-based and support services through "task-sharing".[2,3]. Unfortunately, in many low-and-middle income countries, lived experience in peer roles are not widely acknowledged by the wider health workforce.[4,5] Persons with lived experience are perceived as incapable of adding value to the mental health system through supporting their peers and providing that unique perspective and understanding, and having the ability to relate to others who are on a recovery journey. In my own experience in my native country South Africa, I had encountered some degree of resistance in the concept of peer support being a fundamental

component that could aid in the recovery of persons with mental health conditions and contribute to a task-shifting approach to address the human resource gap in mental health.

Recovery on the other hand is another concept not fully understood by mental health practitioners, communities at large and even some persons with lived experience themselves, which I experienced in my own country and especially learned from persons with lived experience in other low-and-middle income countries. The lack of understanding around the concept of recovery may very well be a result of stigma and perceptions that mental health conditions are lifelong and chronic mental health conditions and disorders that deems such a person incompetent. Even though in many cases, mental disorders are lifelong and many may require ongoing treatment and support services, the term 'recovery' is often directly translated and understood as being 'healed'. Recovery in the context of mental health essentially refers to persons with mental health conditions deciding for themselves what kind of treatment and support programs or initiatives they require to achieve their highest possible level of potential and independence, despite their diagnosis. The recovery approach is giving power to the individual and instils hope, whilst respecting and protecting the basic human rights of the individual and acknowledgement of the individual's abilities and not their disability. An integrated and holistic response to mental health care and services that incorporates and considers the medical, social and human rights models, and acknowledges that mental health conditions and disorders are not merely a medical problem, is an approach supported by the recovery model.

Services provided within hospital and community settings such as clinics can be more effective and contribute to the recovery and quality of life of service users if persons with lived experience are actively involved and where they are adequately engaged with, and where their contributions are incorporated in the evaluation and improvement of service delivery. A simple example, yet an important one, is the built environment in which services are delivered, which in my own experience is often unconducive for recovery or are not dignified – hospital wards and even clinics can be very depressing environments when it appears prison-like and located in dilapidated buildings with bare walls and bars covering the windows. In my own perspective, a little painting, calming pictures on the walls and plants, could make the world of difference at very little cost. Furthermore, it is widely acknowledged and historically recorded that institutional care and asylum settings have exposed individuals with mental health conditions to severe human rights violations from the beginning of time, being segregated from society and denied inherit dignity, whilst their views and opinions had been silenced within these contexts. Experiencing acute symptoms of a mental disorder can be very unsettling and frightening, and especially overwhelming when you are removed from your own familiar surroundings to an environment that is unconducive or when it feels unsafe and threatening – this does have an effect or impact on a person's recovery, and the treatment will indeed be compromised and poor mental health outcomes can be expected. In essence, persons with lived experience can provide much guidance to service providers in developing conducive environments as they know what they need to enhance their recovery and what makes them feel comfortable, feeling safe and supported in such an environment. In fact, the NSW Ministry of Health noted that patients indicated that a "well-maintained, well-designed inpatient unit with a comforting feel" can contribute to personal recovery. [6] Other studies concluded the same. In my own personal experience, I had been involuntarily admitted to a psychiatric hospital on a few occasions, and the main reason why I refused hospital treatment was because I knew that the environment in the psychiatric hospital would cause me more distress – which it did. It is no surprise that persons in mental distress are often resisting hospitalisation – resulting in practices that often denies the person the right to informed consent or legal capacity. Through improving the built and attitudinal environments where mental health services are delivered, coercion will no doubt be reduced and the rights of persons with lived experience will be upheld.

The United Nations Human Rights Council calls upon States to "abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis" with others and to "provide mental health services for persons with mental health conditions or psychosocial disabilities on the same basis as to those without disabilities, including on the basis of free and informed consent".[7] As we have moved into an era that acknowledges that everyone has equal human rights and where the United Convention on the Rights of Persons with Disabilities[8] (inclusive of psychosocial disability) has guided much discussion around coercion in mental health, lived experience involvement in the process of reducing coercion is of utmost importance – where lived experience perspectives could be driving the transformation of mental health care and services that strives to reduce, prevent or completely eliminate coercion through alternative approaches that could realise this goal. Lived experience involvement in influencing policy and legislation in terms of coercion would be the ultimate achievement. At the same time, lived experience involvement in research that explores effective alternative approaches to coercion is another role that persons with lived experience could play in this process.

The World Dignity Project, a UK-registered charity, with its mission "to stand up and fight for mental health and well-being for all, with equality of treatment and dignity in patient experience, as a basic human right" conducted a qualitative research study in 2018[9] with persons with lived experience to add perspective to the understanding of dignity in the mental health patient experience and to develop specific conclusions for ensuring dignity in patient experience and equality of treatment. This study produced some powerful responses from persons with lived experience on what makes for a negative and a positive patient experience. Themes from the lived experience responses for a negative patient experience included: "you treat me like a number or a problem, not a person"; "you take away my self-esteem, and hope"; "you don't consult me about my treatment"; "your response to me is medication"; "you allow your prejudices to influence how you treat me"; "you don't listen to me"; "you lock me away".

> *"I was often treated like a number…met with stone faces and cold attitudes. When I tried to communicate…they were already convinced that I was "crazy" and brushed off anything I had to say as just 'insane rambling'… I didn't feel safe in a place that was supposed to help me get out from my dark place."* Sweden

> *"I felt very scared and helpless…questioned my very existence… I would rather die. I felt like I was useless, had no reason to exist. I felt so sad and didn't feel valued."* Uganda

> *"Consulting a doctor, I had full confidence I will come out of the strange world I was in which was making me uncomfortable, but to my shock, I found she didn't want to listen to me, I was not a part in treatment process, whenever we went to the doctor, my husband would tell and she would prescribe the meds, so when I had marital issues, I didn't turn to her for help instead stopped my meds, headed for a full blown relapse, wandered to the next state, taken to police custody brought back home and when I resisted treatment, was thrashed by police in broad daylight in front of others, was administered ECT without my consent and involuntarily institutionalized which has left a deep emotional scar."* India

Themes from the lived experience responses for a positive patient experience included: "you give me a safe place where I feel supported, valued and loved"; "what I feel is real – you validate my feelings"; "you listen to me without interrupting"; "you give me control by involving me in decision-making"; "you give me tools I can use"; "you give me hope for a future when this is behind me"; "you communicate with me throughout".

"During one of my hospitalizations…I was on suicide watch…nurses were not just sitting with me, or imposing their views on me-they were allowing me to feel, supporting me as a human being with challenges, but who is loved and valued. That was a game changer in my healing." USA

"I still had the power to make decisions…I could still live and that all was not lost. I felt understood and valued like all normal people… there was still hope. This gave me the will to adhere to the treatment…I had been involved in the decision making." Uganda

"The doctor I worked with…explained each test before administering it…she was very friendly and non-judgmental. I felt comfortable talking to her...After testing was complete, she sent a detailed write-up of my results, spent an hour on the phone with me to discuss the results, and was consistently available via email to talk." USA

Derived from the lived experience responses in this study, an emphasis was placed on equality in mental health treatment that is necessary – equality of perception (mental health conditions perceived equal to physical health conditions), equality in funding (same attention and resources applied to mental health as with physical health), equality in access (non-discrimination on the basis of age, gender, race, income, diagnosis or geographic/ demographic location), and equality in patient rights (persons with mental health conditions' rights to be respected, listened to, consulted and informed about treatment options, the same as patients with physical health conditions). Lived experience respondents in this study further noted 4 key areas in which they wish to see improvement in mental health treatment, and included: human empathy; creating a safe space; respecting dignity and rights; and nurturing a sense of control and hope.

Persons with lived experience who had achieved recovery are able to utilise their own recovery stories to break down the stigma attached to mental health conditions and disorders. Research has shown that contact-based education such as sharing of recovery stories had a great impact on public understanding and sensitisation towards persons with lived experience. A study conducted by Thornicroft et al, on "Reducing stigma and discrimination: Candidate interventions" indicated that one of the strongest evidences for effective reduction in stigma and discrimination was through direct contact with persons with lived experience at individual level. [10] Having contact and engaging with someone who has overcome the adversities of living with a mental health condition, provides living proof to others experiencing the hardships of a mental health condition, that hope does exist.

Recovery stories presented at public platforms are able to place a human perspective of persons with lived experience – in my own experience of sharing my own recovery story, the most common responses that I have received was that "you don't look like you have schizophrenia" or "you don't sound like you have schizophrenia". These responses may be indicative of people creating false images of persons living with severe mental disorders such as schizophrenia, where there's a perception of such a person is violent and aggressive, talking to themselves and whose physical appearance relates to someone who is homeless. Much efforts had been made over the past years, even decades, to correct these false perceptions, but unfortunately the stigma attached to mental health and mental health conditions and disorders still exist. Therefore, greater effort should be made to include lived experience in anti-stigma campaigning.

The "Global Mental Health from a Policy Perspective: A Context Analysis" report[11] notes that there is a lack of evidence available on "mental health statistical realities and practical solutions, which hinders ability to persuade policy-makers to act" and further notes that the lack of data on the extent and severity of the situation in mental health and the lack of evidence of good practice,

scalable treatment activities and policy models are "largely lacking in the context of mental health in low- and middle-income country settings, and both can be linked to a lack of funding". Considering this gap in research, persons with lived experience can play a significant role – working alongside academic expert researchers in research projects, with their personal experiences and with their unique perspectives, they are able to relate to experiences of peers – this enhances engagement with service users. Persons with lived experience further are able to be involved in data collection, the development of research questions, objectives and evidence frameworks. Persons with lived experience can ensure that research outcomes are more widely and effectively disseminated, among interested peers and through, for example lived experience organisations and networks such as the Global Mental Health Peer Network (www.gmhpn.org) to use as advocacy tools.

The WHO Mental Health Atlas 2017[12] indicated a global average of 52% (of responding countries) who have formal collaborations with service user, family or caregiver advocacy groups – with this in mind, it poses an opportunity to governments to acknowledge the advantages of forming collaborations with lived experience organisations and networks to meet their international commitments in health, mental health, disability, human rights and sustainable development.

Empowerment and participation of persons with lived experience is acknowledged at international level as fundamental to advance the human rights agenda.[13] The Lancet Commission on Global Mental Health and Sustainable Development[14] which was launched in October 2018 at the Global Ministerial Mental Health Summit in London, UK, clearly places an emphasis on lived experience participation and role in advancing the global mental health agenda.

In response to the growing acknowledgement and evidence of the essential role of persons with lived experience discussed above, I founded the Global Mental Health Peer Network (GMHPN) which was formally established in 2018 as a global mental health care user organisation that functions as an entity of its own and that strives to ensure that the "voices" of persons with lived experience, wherever in the world, have the platform to share their experiences, views, opinions and perspectives in a well-established and sustainable structure. The idea was born from the Movement for Global Mental Health (www.globalmentalhealth.org) that envisioned the creation of a more diverse global mental health community that enhances the value of sharing initiatives and experiences; strengthening the "voices" of persons with lived experience and creating a platform for them to share their views, opinions and experiences; and finally, placing an emphasis on the importance of protecting and respecting the rights of persons with lived experience by promoting international treaties and both local and international human rights instruments. The GMHPN focusses on exactly that – the promotion of human rights, and with an emphasis on empowerment, recovery and peer support – where lived experience is the driving force behind NO stigma, QUALITY of life, EQUALITY and EQUITY. The GMHPN strives to promote and increase collaboration with mental health care user advocacy groups within countries, where lived experience could form the centre of consultative processes, especially in terms of policy and legislative reviews and development.

It is important that we create communities where persons with lived experience are valued as equal citizens of the world, free from stigma, discrimination, inequality and inequity, and where they are able to meaningfully participate in life and the future development of nations across the globe. Needless to say, collaborations with persons with lived experience and the groups representing them, forms an important component in response to achieve the United Nations' Sustainable Development Goals. The Lancet Commission on Global Mental Health made the case that the Sustainable Development Goals cannot be achieved without paying attention to mental health.

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