

VOICES FROM THE FIELD

Should wellbeing and distress be addressed by health policy and medical funding, or be understood outside of a medical framework?

Kanyi Gikonyo^a

^aUsers and Survivors of Psychiatry in Kenya (USPKENYA), Kenya. Corresponding Author – Email: kanyi.gikonyo@uspkenya.com

The term wellbeing encompasses several positive aspects of the quality of life from the perspective of health (mental and physical), security (physical, social, work, spiritual) education, occupation, housing, and finance (to name only the core ones). According to the World Health Organization, 32% of all years-lived with-disability globally are due to neuropsychiatric conditions, most commonly unipolar depression (11.8%), alcohol use disorder (3.3%), schizophrenia (2.8%), bipolar depression (2.4%) and dementia (1.6%) (WHO, 2005). Mental disorders are said to be highest in economically marginalized populations, especially the least educated, women and youth (Saxena, Thornicroft, Knapp, & Whiteford, 2007), with poverty, low education and food insecurity identified as key drivers (Lund et al., 2010; 2011). Yet mental health is neglected in country health budgets resulting in worrying “treatment gaps”. In low and middle income countries (LAMIC) between 75% and 90% of people with mental disorders are said not to receive medical treatment (Saxena et al., 2007; Patel, Boyce, Collins, Saxena, & Horton, 2011). Seventy percent of countries in Africa spend less than 1% of their health budgets on mental health (WHO, 2005).

A large literature on the global response to HIV/AIDS (Hanefeld, 2010), a key source of inspiration for the Global Mental Health Movement (Patel, et al. 2011), highlights how the uneasy interfacing of global and local systems of power and knowledge have often undermined efforts to manage the epidemic in the cases where interventions have failed to engage with the realities of target communities (Campbell & Cornish, 2010). Criticisms have been made of the prescriptive and top-down nature of the global funding architecture (Kelly & Birdsall, 2010), the subordination of local experiences of ‘health’ to ill-fitting international models of behaviour change and service provision, the positioning of communities as passive recipients of services rather than agents of their own health (Aveling, 2012), and the poor fit between donor and indigenous styles of response (Cassidy, 2010).

The concept of ‘local-global connectedness’ is a useful analytical tool for highlighting the spaces of engagement between self-styled ‘global’ actors and ‘local’ communities (Campbell, Cornish, & Skovdal, 2012). Local-global engagements refer to the flows of resources, knowledge and influence between global actors and the local communities targeted by their services and advocacy. The extent to which local communities are passive recipients of

external resources and influence, or able to use these to increase their control over their well-being, is hotly debated. To highlight the local reality and lived experiences of some of these issues, I will discuss the activities of an organization that I work for in Kenya.

The USPKenya Experience

Users and Survivors of Psychiatry in Kenya (USPKenya) is an NGO that was registered in Kenya in 2007 and currently operates on three levels:

1. Public Education and Awareness (From real people, real experiences)
2. Legislation and Policy Participation
3. Peer Support Group initiative (“Experts By Experience”)

The peer support group initiative currently operates in 4 counties in Kenya and is about 8 months old. The four counties in Kenya covered are Nairobi (50), Nyeri (50), Kiambu (15) and Nakuru (15), and within these counties there are about 5 groups (with the numbers indicated in the parentheses). USPKenya has adopted the human rights approach pegged on the recently promulgated Constitution of Kenya 2010, the CRPD and other legislative policies/bills that affect persons with mental health conditions (Psychosocial Disabilities).

Regarding the groups, especially in Nyeri and Kiambu Counties, we have adopted a holistic model of care for mental health due to the adverse effects of poverty that we have encountered. Some of the approaches we have taken are to encourage individual and group registration with the National Council for Persons with Disabilities (NCPWD), which is duly constituted under the Persons with Disabilities Act 2003 (PWD Act 2003) and born out of the additional obligations set by the UN Convention on the Rights of Persons with Disabilities (CRPD) of which Kenya ratified in 2008. The other aspect we considered, from a group level, is the registration with the Council to be identified and considered in the planning and disbursement of services and funds. The assumption here is that if people in distress are able to engage in some economic activities that can uplift their lives then they will be able to purchase medication, food and shelter - the most basic of needs to be met. We consider these as underlying determinants of health in the long-term because medication is not the only intervention for mental health conditions. We have come to see a three pronged approach to mental health care interventions. First and foremost, would be an intervention (if needed) at the biological/chemical level where applicable. Secondly, an intervention on a psychological side by counselors or psychologists. Thirdly, an intervention is required at the social level by use of peer-support groups to work on enhancing coping and social skills. Each of the three interventions are significant on their own, however they become potent when used together.

The peer support group is an inclusive sub-community within the wider community and seeks to reinforce best practices e.g. dealing with the side-effects of medications, complaints against mental health professionals, a sounding board for difficult situations, such as the inability to hold down a job or to complete education, socialization, matters of faith, problems with family members (carers), financial constraints, decisions to resign from work, or dilemmas of disclosing mental health difficulties to employers . The peer support group then taps into collective experiences where shortfalls in the mental health care system are highlighted and possible solutions suggested. These come from the different perspectives of different users, which would not usually be available to people, for example, a typical complaint is that the doctor doesn't listen or is dismissive. Here the session would establish the relationship between the user and doctor from the user perspective and explore whether the user provides the doctor with relevant feedback, taking into account that the user is an expert in themselves and their experiences. Finally, if the relationship between the professional and user is not working we recommend seeking another professional who is responsive to engagement. It is recommended that an ideal relationship should be open, cordial, and involve mutual respect and trust.

Another example is the dilemma of whether to disclose a mental health condition to one's employer or prospective employer. If a person does not disclose then it may come out later through an episode or hospital admission. If a person does disclose then the chances of discrimination are high, depending on the attitudinal bias of the prospective employer. There is no right or wrong answer here, and the groups encourage situational analysis and personal discretion. The prevailing thought is not to disclose and to ensure that performance benchmarks are high, such that in the event of hospitalization the merits of performance would out-weigh the discrimination. Though this in itself may put extra pressure and demands on people. Employment is key because it is a social determinant of health and is often linked to choice of where and with whom to live, access to health services, further study/training and many other aspects that are associated to wellness.

Another interesting development arising from the recently established devolved government system in Kenya has enabled some support groups to engage with their local governments at the grassroots level to waive the daily access market fees for those engaged in selling groceries or those who have small businesses related to the market. The local government has requested the group to come up with a proposal that they can actualize to exempt persons with mental health conditions from paying the rates to the local council, which enables people who live with distress to use this money for other needs to build up their often meager resources. This directly addresses some aspects of health stemming from poverty. And while it is not a panacea or elixir to life's challenges, it is a start.

One of our newest peer-support groups was born out of the issue of accessibility, due to the long distances that had to be covered and of the high transport costs to the County Support group. This led to the realization that the extra cost of the bus fare impacted on people's already limited purchasing power to access hospital care. Thus, the groups has engaged their local county government to bring the health services to their locality.

The PWD Act 2003 also entails benefits of Tax Exemption which would assist Persons with Psychosocial Disability (mental health conditions) to retain more earnings from employment or other sources of income. This is a non-medical approach that has been taken to pass concrete benefits that can influence the health of persons with disabilities. Article 260 of the Constitution of Kenya provides a definition of persons with disabilities to include mental illness, and which safeguards the registration and services from the State on the most Supreme legislation in Kenya. This will in turn see persons with psychosocial disability being able to claim their rights, and benefits and strengthens the Persons with Disabilities Act 2003.

Some members of the Nairobi and Nyeri support group have been denied tax exemption after registering with the National Council for Persons with Disabilities (NCPWD), and so we have engaged with the Kenya National Human Rights Commission (KNCHR) to pressure the Kenya Revenue Authority (KRA) through the NCPWD to issue a policy directive to relevant government bodies to comply with the Constitutional right to the benefit to ease the burden of living on those persons. This policy directive and shift creates jurisprudence that forms the basis for other applications from persons with disabilities, including those with mental health conditions. In all these examples, and thus, in much of the work addressed by USPKenya, are issues that the medical model alone cannot address.

In conclusion, the shift from the pure medical model to the social model of disability as envisioned by the CRPD, does not in any way invalidate the Mental Health Professionals. Is medication the be-and-end all determinant of health holistically? Wouldn't it be better to also evaluate the social determinants of health inclusively for wellbeing?

References

- Aveling, E. (2010). The impact of aid chains: relations of dependence or supportive partnerships for community-led responses to AIDS? *AIDS Care* 22 (Suppl. 2), 1588-1597.
- Campbell, C., Burgess, R. (2012). The role of communities in advancing the goals of the Movement for Global Mental Health. *Transcultural Psychiatry*, 49(3-4), 379-395.

- Campbell, C., Cornish, F. (2010). Towards a 'fourth generation' of approaches to HIV/AIDS management: Creating contexts for effective community mobilization. *AIDS Care*, 22, 1569-1579.
- Campbell, C., Cornish, F., Skovdal, M. (2012). *Health and Place*, 18(3), 447-694.
- Cassidy, R. (2010). Global expectations and local practices: HIV support groups in Gambia. *AIDS Care*, 22 (Suppl. 2), 1598-1605.
- Kelly, K.J., Birdsall, K. (2010). The effects of national and international HIV/AIDS funding and governance mechanisms on the development of civil-society responses to HIV/AIDS in East and Southern Africa. *AIDS Care*, 22 (Suppl. 2), 1580-7.
- Hanefeld, J. (2010). The impact of Global Health Initiatives at national and sub-national level - a policy analysis of their role in implementation processes of antiretroviral treatment (ART) roll-out in Zambia and South Africa. *AIDS Care*, 22 (Suppl. 1), 93-102.
- Lund, C., Breen, A., Flisher, A.J., Kakuma, R., Corrigall, J., Joska, J.A., Swartz, L., Patel, V. (2010). Poverty and common mental disorders in low and middle income countries: A systematic review. *Social Science and Medicine*, 71(3), 517-28.
- Lund, C., De Silva, M., Plagerson, S., Cooper, S., Chisholm, D., Das, J., Knapp, M., Patel, V. (2011). Poverty and mental disorders: breaking the cycle in low-income and middle-income countries. *Lancet*, 378(9801), 1502 – 1514.
- Patel V. (2002). Where there is no psychiatrist. *A Mental Health Care Manual*. London: Royal College of Psychiatrists.
- Patel, V., Boyce, N., Collins, P.Y., Saxena, S., Horton, R. (2011). A Renewed Agenda for GMH. *The Lancet*, 378, 1441-1442.
- Saxena, S., Thornicroft, G., Knapp, M., Whiteford, H. (2007). Resources for mental health: scarcity, inequity, and inefficiency. *Lancet*, 370(9590), 878-89.
- WHO. (2005). *Mental Health Atlas*. Geneva: WHO.