

Person-centric, Rights-based approach for mental illness applicable vis a vis to all countries? Need to include caregivers and role of bystander in India.

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In every country, there exists a distinct mental healthcare system that encompasses the identification, assessment, and management of individuals with mental illnesses, as well as unique mental healthcare laws. These laws are formulated based on factors such as resource availability, the acceptability of the local population, affordability, legal considerations, and political influences. The less-discussed aspects revolve around culture and its impact on the aforementioned factors. Neglecting cultural aspects can result in reduced acceptability and a loss of trust in the system. Consequently, all stakeholders must adapt the necessary laws to suit their specific country. Failure to customize these laws is akin to attempting to fit a square peg into a round hole.

Cultural aspects in India that influence caregiving by family.

Caregiving is a multifaceted aspect of healthcare. The nature of caregiving in India significantly differs from that in Western countries. India, like many other Eastern nations, falls into the category of low-middle income countries (LMICs), sharing certain commonalities in healthcare systems influenced by shared ideologies. India boasts a rich cultural diversity, with its foundation deeply rooted in societal and familial values. These values serve as the driving force behind an individual's actions, desires, decisions, and way of life. More often than not every individual's personal, career, marriage, and all other decisions are usually taken at the family level. The need for approval from all is high. Hence, they foster harmony, and inter-dependence, and often follow patriarchal (though some are matriarchal) lineage, shaping holistic development and promoting mutual support.

In India, parents regard their children as a "blessing from God," resulting in an elevated sense of responsibility to ensure their care, even as they grow into adulthood. It's not unusual to encounter an elderly mother, frail and aging, accompanying her son to the hospital and taking care of him. Similarly, the general expectation is for children to care for their elderly parents, who are revered as equivalent to "God" to attain *Punya**.

Furthermore, Indian culture places great significance on various activities and categorizes them as good or bad. Providing care for an ill person is considered a virtuous act, not just pleasing to the elders within the family but also fulfilling a kinship obligation. Family members are driven to support individuals with mental illness due to feelings of closeness, belongingness, and interconnectedness (Guberman et al., 1992). This act brings about "good karma," garners praise, and brings support from other family members or friends. Conversely, neglecting the care of an ill person is viewed as morally wrong, inviting negative consequences (Karma)** and societal disapproval. The cultural imperative of acceptance and interdependence underscores the need to assist others and seek help when needed in return.

* *Punya* – In Hinduism, generally refers to virtue or merit, and the activities that allow one to acquire this attribute, in order to achieve liberation from *samsara*, the cycle of birth and death in the material world. ("Punya (Hinduism)," 2023)

** (in Hinduism and Buddhism) the sum of a person's actions in this and previous states of existence, viewed as deciding their fate in future existences. (Karma Meaning - Google Search, n.d.)

Caregiving

In both in-patient and out-patient settings in India, hospitals typically have a "healthy" individual accompanying the "ill" patient. This accompanying person is commonly referred to as a bystander, attender, onlooker, or informal caregiver, among other terms. The term "bystander" traditionally means a person who stands by and observes, but in a hospital context, it refers to someone present with the patient. Bystanders are typically close family members such as parents, siblings, grandparents, aunts, uncles, friends, and occasionally neighbors. Predominantly, these bystanders are often children, parents, or wives, and they are mostly female. Although the term "bystander" carries a passive connotation, in reality, they play a substantial role in caring for the person in need. An active bystander is one who proactively engages to bring about change.

When you walk through a hospital, you will observe anxious-looking bystanders rushing around for tasks such as registration, admission processes, scheduling scans, depositing samples for investigations, settling bills, collecting medications from the pharmacy, and carefully carrying cups of tea, coffee, or juice while attending to the needs of the sick. In addition to tending to the personal needs of their loved ones, they also assist nurses and hospital aides in caring for the sick person. This includes tasks such as changing diapers, positioning hands for IV lines, comforting the patient during procedures, notifying the nursing staff of any complications or deterioration, monitoring the IV drip, and sometimes pushing wheelchairs for consultations, investigations, and other activities. Alongside these responsibilities, bystanders actively seek to understand the nature of the illness, the treatment process, the expected duration of treatment, the need for follow-up care, symptoms of adverse effects, early warning signs of the illness, and monitoring.

In cases of in-patient care, aftercare often requires a caregiver to ensure treatment compliance, enhance social and occupational outcomes, reduce the risk of relapses, and improve the patient's overall quality of life. It's essential to acknowledge that bystanders or family members are typically the ones responsible for covering hospital bills.

However, the current facilities provided for bystanders often fail to meet basic living standards. Issues include a scarcity of drinking water, inadequate bed availability, poor sanitary conditions, and numerous other challenges. Moreover, bystanders often need to give up their responsibilities, jobs, and other commitments to care for the person requiring hospitalization. They provide physical, emotional, social, and financial support.

In India, 90% of persons with mental illness live with their family in the community and families take care of their basic needs (Chadda, 2001; Thara et al., 1994; Trivedi, 2009). Governmental and non-governmental institutions currently available cannot adequately meet the needs of the population requiring long-term or institutional care for individuals with mental illness. The government does not cover the entire cost of hospitalization for people with mental illness, and very few private insurers offer such coverage. The premiums for these insurances are often unaffordable for those with low or low-middle socio-economic backgrounds. This leaves health professionals with no choice but to rely extensively on the support of family and friends to facilitate treatment. Extensive literature supports the positive impact of involving family in the treatment process, including psychoeducation, family therapy, handling of expressed emotions, rehabilitation and process of reintegration across various psychiatric disorders (Bharat, 1991). Autonomy versus family-centered decision is one of the main connectors of differences between Western and Eastern societies (Gangadhar, 2013).

As bystanders play an active role in the entire process, implementing a person-centric and rights-based approach in India comes with challenges. If forcefully enforced, it could potentially jeopardize the support listed above, leading to increased suffering for individuals with mental illness or placing an even greater burden on already strained government resources, resulting in poor-quality care and uninhabitable living conditions.

The current Mental health policy of India, excluding the family a stepping stone to failure!

The Government of India ratified the United Nations Convention on the Rights of Persons with Disabilities in 2007. During the following decade, the Mental Health Care Act (MHCA) of 2017 was enacted. The MHCA adopts a Western approach of being person-centric, rights-based, with a strong focus on in-patient care. However, it notably lacks provisions for out-patient, post-discharge care or community reintegration (Rao et al., 2016). This stands in stark contrast to the deinstitutionalization movement, a noble concept that unfortunately neglects the crucial role of key stakeholders such as family, friends, and other relatives who serve as active and primary caregivers. This brings out a mismatch of a western concept enforced on Indian cultural dynamics (Pavitra et al., 2019). The exclusion of these caregivers increases the risk of families becoming disengaged and withdrawing their support, ultimately widening the treatment gap.

In our democratic and welfare-oriented society, it is imperative that governing laws and acts are not only synchronized but also aligned with our cultural values. The MHCA has provisions for both voluntary and involuntary admissions. Involuntary admissions are for PWMI who lack insight have impaired judgment and have symptoms of aggression or suicidal thoughts/actions, thus posing a high risk to themselves or others. In such cases, involuntary admission becomes necessary. The role of the family is straightforward when an Advanced directive/Nominated Representative has not legally been processed. However, in cases where the provisions related to Advanced Directives (AD) and Nominated Representatives (NR) are present, the decisions cannot be made without the NR and thus challenges when modifications to AD are required. The cumbersome process of filling out forms, applying to the Mental Health Review Board (MHRB), and waiting for their recommendations can lead to delays in intervention. The role of the family is a supportive or secondary role which is contrary to the cultural norms.

Furthermore, limiting the family's previous rights and role creates a more defensive approach among psychiatrists (Pavitra et al., 2019). While the act does not grant family members the right to take necessary actions, it does expect their involvement. This paradoxical situation results in a back-and-forth, reluctance to assume complete responsibility and a sense of helplessness among immediate caregivers.

Conclusion

In conclusion, the invaluable role of family members throughout all phases of care for Persons with Mental Illness (PWMI) cannot be overstated. Their involvement is not merely beneficial but essential in achieving the goals of inclusion and community integration for PWMI. When legal constructs exclude families from crucial decisions and caregiving responsibilities, it can lead to feelings of despair and overwhelming burdens in the caregiving process. To truly serve the best interests of PWMI, it is imperative that we recognize, appreciate, and encourage the role of families in in-patient, out-patient, and home care settings. The identification of the caregiver at home, will help identify whom to psycho-educate and give information on rehabilitation. The "voice" of a bystander should be accorded the same respect and consideration as that of a PWMI, for it is together, as a collective force, that we can provide the most effective care and support to those in need, fostering a more compassionate and inclusive society.

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