Destigmatizing day-to-day practices: what developed countries can learn from developing countries

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The nature of and threshold for stigma associated with mental disorders appears to be different between developed and developing countries. Decreasing stigma can be achieved through a combination of the best Western educational and media strategies and the systematization of some important lessons from developing countries. At the macro-level, this involves: societal changes leading to being more inclusive and re-integrating people with mental illness into our communities; finding socially useful and culturally valued work roles for such marginalized people; re-extending our kinship networks, and re-valuing contact with people with mental illness and learning from their experiences. At the micro-level, this involves developing more destigmatizing day-to-day clinical practices, including: more holistic appraisal of disorder, abilities and needs; therapeutic optimism; a strengths orientation; engaging family and redeveloping an extended support network; celebration of age appropriate rites of passage; invoking the language of recovery; valuing veterans of mental illness as "spirit guides"; promoting consumers' community living as full citizens; engaging and involving the local community in taking responsibility for their own mental health.

Key words: Stigma, developed countries, developing countries, mental health literacy, destigmatizing practices, recovery, strengths orientation, therapeutic optimism

The WPA has embarked over the last several years on a programme to challenge stigma associated with schizophrenia in both developed and developing countries. It is the objective of this programme to have both a common core strategy and a common resource data base. However, there is also an unusual commitment to encourage and support developing countries to utilize local knowledge and methods in generating their own culturally congenial anti-stigma initiatives.

This paper summarizes what developed countries can learn from developing countries in order to diminish stigma associated with mental disorders, elaborating on a prior study (1).

IS THE NATURE OF AND THRESHOLD FOR PSYCHIATRIC STIGMA DIFFERENT BETWEEN DEVELOPED AND DEVELOPING COUNTRIES?

Comparative studies by the World Health Organization (WHO) (2-4) have demonstrated a better long-term outcome for schizophrenia in developing countries, particularly in rural regions. These findings still generate some professional contention and disbelief, as they challenge outdated assumptions that people generally do not recover from schizophrenia and that the outcomes of Western treatments and rehabilitation must be superior. However, these results have proven to be remarkably robust, on the basis of international replications and 15 to 25 year follow-up studies (5).

Explanations for this phenomenon are still at the hypothesis level, but include: a) greater inclusion or retained social integration in the community in developing countries, so that the person maintains a role or status in the society; b) involvement in traditional healing rituals, reaffirming communal inclusion and solidarity; c) availability of a valued work role which can be adapted to a lower level of functioning; d) availability of an extended kinship or communal network, so that family tension and burden are diffused, and there is often low negatively "expressed emotion" in the family.

The parallels in Western society include evidence (6) that rates of apparent recovery from schizophrenia increase in periods of industrial "boom", when the job market expands, and decrease during industrial worldwide depressions, when the job market shrinks. Possible explanations of this phenomenon are: a) that having a job allows a person with schizophrenia to disappear from clinical attention; b) that access to regular work is a culturally valued role which promotes recovery and healing; c) that clinicians and the community perceive the possible clinical needs of a mentally ill person more benignly (i.e., with less stigma) if the individual has a regular job. Probably all three elements are at play to some extent.

The WPA Stigma Programme has identified a number of factors in the developing world which promote greater tolerance and community support for people with serious mental illness (7). These include: a) the absence of large-scale institutional care from the traditional mental health care system; b) the rural agrarian nature of the society; c) the strength of the extended family system; d) explanatory models which place the cause of the illness outside the patient; e) the fact that symptoms of psychosis are more readily reversible and outcome from schizophrenia better in the developing world.

Indeed, psychiatrists working in developing countries have often noted the low level of stigma attached to mental disorder (7). Among Formosan aboriginal tribesmen, in contrast to the Chinese in Taiwan, mental illness is free of stig-

ma (8). Sinhalese families freely refer to psychotic family members as "pissu crazy" and show no shame about it; tuberculosis in Sri Lanka is more stigmatizing than mental illness (9). In Nigerian and Malaysian villages, the label "madman" or "crazy" is applied only to violent and highly disruptive people; others with schizophrenia are tolerated as eccentric, and may well be considered functional and marriageable (6). Moreover, as the experience of leprosy also demonstrates, public attitudes to illness can tell disabled people how to behave. This "moral map", once established, is often perpetuated for reasons having little to do with the disease itself (9). In some societies (e.g., Nigeria, Tanzania) leprosy is regarded as just another potentially debilitating illness, while in India it is highly stigmatized, leading to segregation, divorce, shunning and beggar status (9).

Biological explanations do not necessarily lead to more hopeful and less stigmatized outcomes. In some campaigns, the more solely biological treatments are promoted, the more fear and social exclusion result (10). The public often find that biological explanations for mental illness are difficult to understand and that these explanations imply that mental illness is essentially unchangeable despite the occasional effects of "miracle drugs". Educational programmes which place more emphasis on understandable causes and interventions to which the public can relate personally (e.g., understandable reactions to life events, trauma and deprivations, and interventions such as stress reduction, cognitive-behavioural and family strategies) improve perceptions of mentally ill people, particularly on the "safe-dangerous" and "predictability" dimensions (10). Such approaches arguably also allow communities to no longer feel helpless in the face of mental illness.

Luhrmann (11) shows how Western psychiatrists, while trying to destigmatize psychiatric illness by promoting its "medical" nature, have participated in the destruction of what attracted many of them to the profession in the first place: the chance to personally engage and heal. Western psychiatrists appear to have lost their souls, she argues, to the quest for the "fixable perfect brain" and the economic imperatives of the pharmaceutical industry and managed care.

WHAT CAN DEVELOPED COUNTRIES LEARN FROM DEVELOPING COUNTRIES IN GENERATING EFFECTIVE METHODS OF CHALLENGING STIGMA ASSOCIATED WITH MENTAL DISORDERS?

What can we learn from developing countries in our struggle against stigma associated with mental disorders?

We can learn not to segregate people with mental illness behind high walls or away from the community, so that we can retain knowledge and experience of living with such people in our midst. This accords with studies which demonstrate an improvement of attitudes and a lowering of stigma where communities have direct experience of meeting and living with people with mental illness, and feeling they can make a difference by helping such people (10).

We can learn to be inclusive of people with mental illness, integrating them into our communities. We can also learn to restructure our societies to find meaningful, socially useful and culturally valued roles for people with mental illness and other marginalized groups. In most instances (though not all), this means real pay for real work.

We can learn to reach out from our nuclear families and re-extend our kinship networks to share out the practical experience and stresses of caring, and to feel that "you are not alone" and should not feel that yours is a shunned or pariah household.

We can learn to listen to the content of experiences of psychosis, and assist individuals to discern, distil or explore possible real meanings which resonate for them and their loved ones in these experiences. Accordingly, an episode of mental illness may not just be seen as a terrible life disruption or waste of time, but as an existentially useful crisis or turning point in their lives (13). They may then resolve to live differently in terms of drug intake, stress management and co-operation with treatment.

We can learn that stigma associated with mental disorders is not fixed, indelible or universal, but is culturally applied. Therefore it is not immutable, and it is worth struggling to find culturally congenial ways of challenging it. Australia's Aboriginal people and New Zealand's Maori people with mental illness have had to contend with "double-whammy" stigmatizing and discrimination, due to dispossession and devaluing as indigenes by white society, as well as being colonized and controlled by mental health services (13). We have generally provided culturally inappropriate aversive, devaluing, spirit-breaking and poorly accessible care, with recent exceptions (13). We may well contribute to better outcomes by the direct consulting of such consumers and their families for their perceptions of care, as well as incorporating traditional cultural healing practices and/or reconciling our interventions to them.

Decreasing stigma associated with mental disorders can be achieved through a combination of the best of Western educational and media strategies and honouring, amplifying and systematizing important lessons from developing countries. This may include wider communal involvement in addressing external (psycho-social-cultural) causal or precipitating factors (e.g., losses, lack of meaningful role, spiritual crises) rather than just relying on internal biological explanations and treatments.

DESTIGMATIZING DAY-TO-DAY PRACTICES

Destigmatizing principles guiding day-to-day practice can be derived from developing countries, and combined with evidence-based interventions from developed countries. A preliminary, fairly speculative and incomplete list of such practices is summarized in Table 1.

In terms of holistic assessment, Engel's (14) bio-psycho-

Table 1 What developed countries can learn from developing countries to destigmatize day-to-day practices

- Assessing and reviewing the whole person, employing the bio-psycho-socio-cultural-spiritual paradigm *rather than* assessing and reviewing a purely biological disease, treating disembodied symptoms, intervening on fragmentary biological sub-systems.
- Externalizing symptoms and joining to challenge them *rather than* internalizing symptoms and impairments.
- More focus on consumer's role restoration, strengths, abilities. Defocus on patient's role dysfunction, weaknesses, disabilities.
- Engaging and involving consumer's immediate family, extended kinship network, proxy family and/or socio-cultural network, in a context of confidentiality and privacy rights *rather than* performing "parentectomy" or dismissing family as "toxic", denying access by family to treatment team, deciding who "the patient" should mix with.
- Orienting services towards progression through and celebration of age-appropriate rites of passage *rather than* "maintenance" programmes, retaining in a timeless limbo of often hostile dependency.
- Encouraging the re-claiming of the authorship of one's own story in more empowering and hopeful terms, and the language of recovery, potential continual growth, and expectation of improvement. Challenging the objectifying and alienating assumption that "your case notes define you" and the self-fulfilling prophecy of poor outcome embedded in the language of chronicity.
- Valuing veterans of mental illness as spirit guides and consumer consultants *rather than* devaluing them as perpetual dependents and life-long patients.
- Promoting healing and recovery by community living as a full citizen, culturally valued (work) role, and "in vivo" rehabilitation *rather than* institutional warehousing, play-work or just minding, and "in vitro" rehabilitation in artificial environments.
- Working by consumers' sense of time, sense of readiness to take the next step or leap, or "woodshedding" (non-linear tacit mode of change) *rather than* by service providers' "clock", sense of impatience or resignation, or linear predictable sense of change.
- Invoking consumer's sense of agency and control, self-determination and choice from a range of interventions, and therapeutic optimism *rather than* professional control and colonization, "vocational ownership" (we know what is best for you), and therapeutic pessimism.
- Engaging and involving the local community in taking responsibility for their own mental health (e.g., by local action groups or teams) *rather than* leaving it to authorities and mass-media campaigns, allowing the belief that "it is about them, not us".
- Teaching mental health literacy to the community and health professionals, and challenging stigma *rather than* tolerating communal and professional ignorance, media stereotyping, discrimination and stigma.

social model could be expanded into a bio-psycho-socio-cultural model to encompass cultural dimensions, including the micro-culture of family or kinship, and the macro-culture of communal perceptions, including stigma and consequent discrimination. Arguably, the spiritual domain fits within the cultural dimension with both micro-personal and macro-communal mindsets and expressions. No clinical assessment or review of an apparently delusional or deeply distressed person should be deemed complete without direct and (if possible) collateral inquiry regarding these factors.

A holistic conception of mental health involves not just the absence or overcoming of mental illness, but addressing all the qualitative dimensions of well-being, including optimizing physical health, engagement with family and social networks, and meaningful roles within one's community. Rebuilding whole lives underpins recovery. This entails mobilizing not only external expertise, but also local community knowledge, inclusion and participation.

"Externalizing" of symptoms is a principle promoted by narrative therapists (15) to challenge the traditional clinical metaphor, which can lead you to internalize your symptoms and impairment. Rather than inadvertently being inducted into the belief that you are a bunch of symptoms and an impaired or indelibly flawed person, "externalization" strategies help you to objectify the problem and think of it as separate to your identity. The symptom or diagnosis no longer defines you, and it becomes just another obstacle to your life, which you, your family and the clinician can join in challenging and overcoming.

A "strengths" and "abilities" orientation rather than the usual clinical focus on symptoms, impairments and disabilities as "weaknesses" allows you to see and value the positive qualities of this particular person. Bringing such strengths to their attention allows them to use sustained ability components to compensate for or overcome disability components of their condition. This rationale has been codified for such use in the Life Skills Profile (16), a functional ability/disability outcome measure, which scores in the direction of strengths. Therefore ratings charts (e.g., histograms) can be readily shared with clientele and families to both monitor and encourage recovery. Rapp (17) has developed a strengths orientation model for case management, which can be made compatible with the fidelity criteria for assertive community treatment teams.

Re-instilling hope for a sense of growth throughout life entails regaining or relearning the long-eroded cultural resource or tool of knowing how to progress through and celebrate age-appropriate rites of passage. With loss of communal guidance through rites of passage or life transitions, these have become buffeting and stressful and potential points of breakdown, while families may remain stuck in life, e.g., as perpetually dependent offspring of ageing parents. Meanwhile "chronic" patients remain in a timeless limbo of backward custodial care, backstreet neglect, or "maintenance stream" rehabilitation adult-minding programmes (13).

Recovery work re-emphasizes for severely mentally ill individuals the life-enhancing potential of story-telling and of reclaiming authorship for their lives. By learning how to retell their story in more hopeful and empowering terms than the dominant story in the clinical file, service users and families can choose a destiny other than one which perpetually lives out a psychiatric career (18).

"Woodshedding" (19,20) encapsulates how initial improvement following an episode of psychiatric disorder may apparently halt for frustratingly long periods. In such a seemingly static phase, the person may be busily processing internally, may be valuably acquiring subtle increments of self-esteem, competence, stamina, and social skills. Perhaps better regarded as a regulatory mechanism, the recovering person may need this period to muster suf-

ficient strength to overcome the next hurdle, e.g., demands of a new job or leaving the hospital or parental home.

Strauss' detailed observational studies leading to the construct of "woodshedding" provide a rationale for attending to and respecting a person's readiness or preparedness for significant or even radical changes. Readiness may not fit the service provider's timetable or imposed clinical "clock" of goal attainment. The service user's timeframe of readiness to change must take preference (21).

"Therapeutic optimism" invokes a mindset which acknowledges evidence of far greater recovery from schizophrenia than hitherto considered possible, even without special intervention. These more favourable prospects are further enhanced by cognitive-behavioural strategies and by optimizing both family and communal inclusion and expectations, as well as other cultural factors associated with better prognosis and reducing stigma. "Therapeutic optimism" has an evidence base, and relevant skills can be learned, taught and operationalized, as demonstrated in programmes of early intervention in psychosis (22). Developing and nurturing local action groups, committees or teams has been the method used by the WPA Stigma Programme (23) to mobilize local participation expertise and knowledge to enhance communal mental health literacy and challenge stigma.

CONCLUSION

If public attitudes can tell people how to behave, providing them a moral map of how to be ill, then we can contribute as service providers to a moral map pointing to how to recover, how to overcome obstacles in life such as mental illness, and to share our common aspiration and life expectation of being able to retain full membership of our community while continuing to learn, develop and grow in life.

Acknowledgements

The author is grateful to Sylvia Hands for assistance with the manuscript, and to Vivienne Miller, Liz Newton, Garry Walter, Ernest Hunter, David Shiers and Susannah Rix for help with the content.

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