# LEVERAGING DIGITAL TECHNOLOGY TO CHALLENGE MENTAL HEALTH STIGMA IN WEST BENGAL: A PROTOCOL

**Ahmed Hankir[1,2,3], Sharmistha Ghosh[4], Syed Mustafa Ali[4],
Frederick R. Carrick[1,5,6,7] & Rashid Zaman[1,8,9]**

[1]*Centre for Mental Health Research in association with University of Cambridge (CMHR-CU), Cambridge, UK*
[2]*South London and Maudsley NHS Foundation Trust, London, UK*
[3]*Department of Psychiatry, Carrick Institute for Graduate Studies, Cape Canaveral, FL, USA*
[4]*Leeds and York Partnership NHS Foundation Trust, Leeds, UK*
[5]*Department of Neurology, Carrick Institute for Graduate Studies, Cape Canaveral, FL, USA*
[6]*Neurology, University of Central Florida College of Medicine, Orlando, FL, USA*
[7]*Medical Education, MGH Institute for Health Professions, Boston, MA, USA*
[8]*Hertfordshire Partnership University NHS Foundation Trust, UK*
[9]*Department of Psychiatry, University of Cambridge, Cambridge, UK*

### SUMMARY

   *Mental health related stigma is a pernicious phenomenon that permeates and pervades our world. As stigma continues to evolve so too must our approach to reduce it. This paper outlines a protocol that leverages the power of virtual contact and digital technology to challenge mental health related stigma in West Bengal, India.*

**Key words:** *mental health stigma - digital technology - explanatory models - mental illness - global mental health*

\* \* \* \* \*

*Sharmistha Ghosh composed a first-person narrative about her personal and professional experiences working in front-line psychiatry in the District of Purulia and the metropolis area of Kolkata, West Bengal, India. Below she discusses and describes the mental health related stigma that she witnessed and encountered whilst working as a psychiatry doctor in West Bengal.*

## INTRODUCTION

I am a medical graduate (MBChB) from Kolkata Medical College, West Bengal, India. I have also completed a Diploma in Psychiatric Medicine (DPM) from the Institute for Post Graduate Medical Education and Research in Kolkata. Upon qualifying from medical school, I worked as a Specialty Doctor in Psychiatry at the Institute for Mental Health Care, Purulia, West Bengal. I am currently a Core Trainee in the UK and I am a Member of the Royal College of Psychiatrists.

Working in front-line psychiatry in the metropolis area of Kolkata and the District of Purulia provided me with opportunities to assess and treat people with mental illness across the socioeconomic strata of society. During my training in psychiatry in West Bengal, mental health services were predominantly 'ageless'. I assessed and treated younger people with mental health difficulties brought by their parents. Conversely, I provided care to older people who presented with memory loss and who were brought in by their children. A common denominator in the aforementioned vignettes was the unwillingness of patients and their families to accept a mental health diagnosis and the insistence that a physical illness be identified as the chief cause of their symptoms.

I initially thought that the resistance to accept a psychiatric diagnosis was mainly because people in West Bengal were unaware of mental health issues. However, as I progressed with my training it became more apparent to me that the refusal to accept a psychiatric diagnosis was strongly influenced by the societal shame attached to mental illness. Below are a few anecdotes from my own personal and professional experiences.

A patient was brought to a psychiatric clinic by his relative. Whenever I saw this patient in my clinic, his relative almost always appeared stressed and anxious. When I shared my observations with the patient's relative, he immediately reacted in a defensive manner as if I was suggesting that he, too, might be experiencing some type of mental illness.

Patients were often referred to my outpatient psychiatry clinic by my medical colleagues. Patients with mental illness would commonly visit general medicine clinics complaining of somatic symptoms like chest pain or shortness of breath. These patients were often bewildered to receive a psychiatry referral after extensive tests and investigations effectively ruled out an organic cause of their symptoms. Many patients would simply refuse to accept that they have might a mental illness which, if and when confirmed, often resulted in non-adherence with their psychotropic medication.

Once a lady I met spoke about how her husband would behave in a bizarre manner and how he would express his delusional beliefs. I suggested to her that she bring him to the psychiatric clinic and that I would personally arrange for him to be reviewed however she politely declined the offer. She then unambiguously stated that if her neighbours discovered that they went to a mental health clinic, it would irrevocably damage their social standing and blemish their reputation.

I discussed the above examples with my colleagues and the consensus was that mental health stigma was a factor that might explain why patients with mental illness in West Bengal are often in denial. I find it deeply saddening that stigma is a major barrier to mental health care. I want to seize this opportunity to issue a clarion call that we must do everything in our power to reduce mental health related stigma in West Bengal and elsewhere in the world.

## Global Mental Health

On the 9th and 10th of October 2018, London hosted the inaugural Global Ministerial Mental Health summit. The Summit was comprised of six work-streams to showcase innovations from across the globe. Work-stream four was entitled, '*A Just Society: supporting societal shifts, tackling stigma and discrimination, creating inclusive societies…*' (https://mhfaengland.org/ mhfa-centre/news/global-mental-health-summit/).

The importance of challenging mental health related stigma cannot be over-emphasized. British Health Minister Matthew Hancock's Tweet below about the Summit supports this assertion:

*"Tell us what you think the world needs to break the stigma surrounding mental health using #TheWorldNeeds".* (https://www.trendsmap.com/twitter/ tweet/1041675690372939777).

Mental health stigma is a formidable barrier to mental health care on a global scale and despite the availability of effective treatment many people with mental illness throughout the world continue to suffer in silence (Mehta et al. 2015). As SG clearly illustrated in her poignant first-person narrative, West Bengal is certainly no exception.

## Mental Health Related Stigma in West Bengal

Arabinda Chowdhury and colleagues conducted a study to identify the indicators of stigma for a variety of mental health problems among laypersons and health care providers (HCP) in a rural community in West Bengal, India. The Explanatory Model Interview Catalogue (EMIC) was adapted and translated into the Bengali language and administered on a random sample of 21 laypersons and 17 healthcare providers (HCP). The interviews comprised of case vignettes depicting typical presentations of depression, somatoform disorders, deliberate self-harm, psychosis, hysteria and spirit possession. The study revealed that indicators of mental illness-related stigma were more prominent among Health Care Providers compared with laypersons. The authors conclude that anti-stigma programmes targeting Health Care Providers in West Bengal must be designed, developed and delivered (Chowdhury et al. 2000).

## Stigma, Shame and, 'Idioms of Distress'

Many Bengali patients who present to healthcare services with depressive illness do not report feeling sad, but rather express somatic symptoms such as generalized aches and pains, dizziness and difficulty in breathing and fatigue. This is partly due to the stigma attached to mental illness in West Bengal. Training on the 'idioms of distress' of depression (for example) can enable health care professionals to identify this disorder and to develop an appropriate treatment plan. Healthcare providers in West Bengal must also be trained about the stigma and shame attached to mental illness and how this can influence 'the idioms of distress' that people in their communities use for depression (Desai et al. 2017).

## Explanatory Models of Mental Illness in the Muslim Population in West Bengal

According to the 2011 Census of India, the West Bengal state has over 24.6 million Muslims, who form 27.01% of the state's population. Muslims form the majority of the population in three districts: Murshidabad, Malda and Uttar Dinajpur (https://www.livemint.com/ Politics/XkVYBX2IaBk5Sqf8yr2XMM/Hindu-population-declined-Muslims-increased-2011-census.html).

Any programme designed to challenge mental health related stigma targeting a given population must take into account the explanatory models of mental illness that that population formulates (Hankir et al. 2017, Hankir et al. 2017). We will now focus on the explanatory models that Muslims who experience psychological and/or behavioural disturbances formulate.

## Mental Illness in the Muslim population

The global Muslim population is estimated to be around 1.7 billion people (www.pewforum.org), which makes up about 24% of the world's population. According to the Pew Research Centre, this number is expected to rise by 73% by 2050, making it the fastest growing major religion in the world (www.pewforum.org).

As the global burden of mental illness grows at a staggering rate, Muslim populations continue to be an understudied demographic despite evidence of higher susceptibility. Asides from widely implicated reasons for psychological distress such as familial and inter-generational conflicts, economic challenges and crisis of identity (which all hold true), additional causes may include perceived discrimination, racism, bullying and the growing phenomenon of Islamophobia.

Studies have shown that although Muslim beliefs and ethnic sub-cultures are heterogeneous, there exists a proclivity to perceive them as a monolithic group which may be negatively stereotyped and subjected to significant interpersonal and structural discrimination (Jasinskaja-Lahti et al. 2006)

The core tenet of the Muslim faith, Islam, is that there is one God (the Arabic word for God, Allah, is used universally by Muslims, regardless of ethnic group or language of origin) and Allah causes everything including illness.

Historically speaking, the Muslim conception of illness, be it mental or physical, can be broadly divided into three categories, (a) theologically derived positions based upon the Quran and Prophetic traditions (b) theoretical concepts developed by Islamic philosophers and scholars and (c) beliefs of individuals and groups in traditional Muslim societies. These beliefs include definitions of illness, aetiology as well as treatments which may significantly differ from western philosophy of psychopathology as known today.

In Muslim cultures, mental illness may be perceived as a test or punishment from God (Abu-Ras et al. 2008). Belief in Qadr - or destiny (God's Will) as well as Tawakul – resilience derived from absolute reliance on God, play an integral role.

Asides from the theological conceptions mentioned above, cultural influences on presentation of symptoms and mental health problems also need to be considered. Due to the lesser stigma of physical symptoms as well as cultural idioms revolving around the physical body, mental health problems are often expressed as physical symptoms (Douki et al. 2007). In parallel, explicit mood symptoms such as hopelessness, self-deprecatory thoughts, and worthlessness, are uncommon; in particular, women ultimately diagnosed with depression frequently first present with "conversion" disorders and no self-recognition of psychological distress or sadness (Al-Krenawi et al. 2000). Additionally, normative cultural beliefs in the existence of jinn (evil spirits) may be confused with delusions of possession and control, and may prevent patients and family members from recognizing medical or psychiatric problems (El-Islam 2008). Significant cultural differences with respect to gender may also put women at risk of diagnosis and treatment of mental health problems in Muslim communities (Al-Krenawi 2005).

Interpretations of the causes of mental illness as a combination of both supernatural and social factors has been found in previous studies in Muslim majority countries in Southeast Asia as well as Pakistan (Azhar et al. 2000). Similar studies have noted attribution of mental illness to be a direct result of God's Will, divine punishment or Jinn possession in Muslim countries as well as Muslim immigrant and refugee populations (El-Islam 1982).

## The Power of Lived Experience

According to the results of a systematic review and meta-analysis on challenging the stigma of mental illness, social contact with someone who has recovered from mental illness is the most effective way of reducing stigma (Corrigan et al. 2012). Sara Evans Lacko and colleagues revealed that virtual contact (i.e. a film that contains a testimony from someone who has recovered from mental illness) is almost as effective as 'live' social contact at reducing mental health stigma. Evans-Lacko argues that film-based, anti-stigma interventions are more accessible and easier to scale-up than live social contact and are also cheaper and more cost-effective (Winkler et al. 2017).

Anjali is a mental health rights organization that works in three mental health hospitals in West Bengal. Anjali works with people who have suffered from mental health stigma.

The key objectives of Anjali are to:
▪ Create partnerships with local, state and national government to humanize mental health hospitals and systems.
▪ To end the stigma of mental illnesses within society and mainstream mental health services (http://www.anjalimentalhealth.org/).

## Protocol to Leverage Digital Technology to Challenge Mental Health Related Stigma in West Bengal

We propose to commission a short film targeting healthcare providers in West Bengal comprised of:
▪ An expert by lived experience.
▪ An expert by professional experience (i.e. a psychiatry doctor in West Bengal).

The clip would be educational and it would harness the power of virtual contact with someone who has lived experience of mental illness. It would contain information about mental health stigma and how this might influence the 'idioms of distress' that people with mental illness in West Bengal use. The clip would also be sensitive and respectful towards the explanatory models that Muslims formulate for psychological and/or behavioral disturbances.

The digital clip would be 5-17 minutes in duration. We will administer validated psychometric scales on healthcare professionals before and after exposure to the intervention to measure for any changes in stigma (i.e. Bengali Depression Stigma Assessment Questionnaire) (Wei et al. 2018).

We are pleased to share that we are in the final stages of securing funding to deliver an innovative programme that leverages the power of digital technology and virtual contact to challenge mental health related stigma in West Bengal using the protocol that we have outlined in this manuscript.

## References

1. *Abu-Ras W, Gheith A & Cournos F: The imam's role in mental health promotion: A study at 22 mosques in New York City's Muslim community. Journal of Muslim Mental Health 2008; 3:155-176*

2. *Al-Krenawi A; Mental health practice in Arab countries. Current Opinion in Psychiatry 2005; 18:560-564*

3. *Al-Krenawi A, Graham JR: Culturally sensitive social work practice with Arab clients in mental health settings. Health Soc Work 2000; 25:9-22*

4. *Azhar MZ & Varma SL: Mental illness and its treatment in Malaysia. In I. Al-Issa (Ed.), Al-Junūn: Mental illness in the Islamic world. Madison, CT, US: International Universities Press, Inc, 2000; pp. 163-186*

5. *Chowdhury A, Sanyal D, Salil K, Dutta S et al.: Stigma and mental illness: Pilot study of laypersons and health care providers with the EMIC in rural West Bengal, India December 2000. International Medical Journal 1994; 7:257-260*

6. *Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüsch N: Challenging the public stigma of mental illness: a meta-analysis of outcome studies. Psychiatric services 2012; 63:963-73*

7. *Desai G, Chaturvedi SK: Idioms of Distress. J Neurosci Rural Pract 2017; 8(Suppl 1):S94–S97. doi:10.4103/jnrp.jnrp_235_17*

8. *Douki S, Ben Zineb S, Nacef F & Halbreich U: Women's mental health in the Muslim world: Cultural, religious, and social issues. Journal of Affective Disorders 2007; 102:177- 189. http://dx.doi.org/10.1016/j.jad.2006.09.027*

9. *El-Islam MF: Arabic Cultural Psychiatry. Transcultural Psychiatric Research Review 1982; 19:5–24. https://doi.org/10.1177/136346158201900101*

10. *Fakhr El-Islam M: Arab Culture and Mental Health Care. Transcultural Psychiatry 2008; 45:671–682. https://doi.org/10.1177/1363461508100788*

11. *Hankir A, Khalil S, Wadood Q, Madarbukus D, Yunus HA, Bibi S, Carrick FR, Zaman R: The Federation of Student Islamic Societies programme to challenge mental health Stigma in Muslim communities in England: The FOSIS Birmingham study. Psychiatr Danub 2017; 29(Suppl 3):512-520*

12. *Hankir A, Pendegast H, Carrick FR, Zaman R: The Federation of Student Islamic Societies programme to challenge mental health Stigma in Muslim communities in Ireland: The FOSIS Dublin study. Psychiatr Danub 2017; 29(Suppl 3):279-284*

13. *Jasinskaja-Lahti I, Liebkind K & Perhoniemi R: Perceived Discrimination and Well-Being: A Victim Study of Different Immigrant Groups. Journal of Community & Applied Social Psychology 2006; 16:267-284*

14. *Mehta N, Clement S, Marcus E et al.: Evidence for effective interventions to reduce mental health-related stigma and discrimination in the medium and long term: systematic review. Br J Psychiatry 2015; 207:377-84. doi:10.1192/bjp.bp.114.151944*

15. *Wei Y, McGrath P, Hayden J & Kutcher S: The quality of mental health literacy measurement tools evaluating the stigma of mental illness: A systematic review. Epidemiology and Psychiatric Sciences 2018; 27:433-462. doi:10.1017/S2045796017000178*

16. *Winkler P, Janoušková M, Kožený J: Short video interventions to reduce mental health stigma: a multi-centre randomised controlled trial in nursing high schools. Soc Psychiatry Psychiatr Epidemiol 2017; 52:1549-1557. doi: 10.1007/s00127-017-1449-y. Epub 2017 Nov 3*

*Correspondence:*

*Ahmed Hankir, MBChB*
*South London and Maudsley NHS Foundation Trust*
*London, UK*
*E-mail: Ahmed.hankir@nhs.net*