Stigma towards mental illness in South Asian communities: A summary of three studies

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Abstract: Social workers work with many disadvantaged and stigmatised groups. People with mental health problems have been stigmatised for centuries. In the last few decades attempts have been made to reduce levels of stigma in the general population, such as with the Time to Change program in the United Kingdom. Yet, there is so much about stigma we still do not understand, which has been referred to by Smith as stigma's 'dark matter.' For instance, how do levels of stigma vary among different cultures? In this paper we consider what affects stigma in South Asian populations. After a short review of the literature in Sri Lanka, Pakistan, and India, we describe three studies we have conducted in this area. The first was a quantitative online survey, that used a previously published vignette to assess elements of stigma in 425 participants. The second comprised interviews with 15 people of South Asian heritage. The third was a community engagement event which brought together 99 mental health professionals and community activists for a hybrid educational event. The three studies are presented and discussed. Some tentative conclusions are offered.

Keywords: stigma towards mental illness; South Asia; community engagement; attribution questionnaire

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Introduction. The issue of stigma and the South Asian context

Mental health stigma can be shaped by cultural factors (Yang et al., 2007), and due to the prevailing cultural norms, the type and degree of stigmatisation may differ (Warner, 1996). Cultural factors also play a significant role in shaping the experience of stigma (Corrigan et al., 2011). Link and Phelan (2001) describe five interrelated components that encompass the construct of stigma. Discrimination, labelling, negative attributes, separation, and status loss. Likewise, discriminatory behaviour, insufficient knowledge, and prejudicial attitudes are elements incorporated at the core of stigma (Thornicroft et al., 2007). There are four social-cognitive processes that Corrigan (2004) specified to describe stigma. They are cues, discrimination, prejudices, and stereotypes. Discrimination is commonly highlighted in describing stigma. Stigma leads to discrimination, which may occur at interpersonal and structural levels (Fink and Tasman, 1992; Link and Phelan, 2001). There are two forms of experience of stigma, which are interrelated. These two forms are public stigma and self-stigma (Corrigan, 2005; Corrigan and Watson, 2002).

Guthrie, Abraham, and Nawaz's (2016) report on a 28-year-old Afghan woman includes the role of her religious and cultural background. These significantly influence how individuals perceive, interpret, and assimilate psychotic experiences; people of any religious faith or no faith at all may have beliefs about possession.

Lim, Hoek, and Blom (2015) conducted a systematic literature review, reviewing the medical literature on 'Jinn' as an explanatory model in the context of psychotic disorders. Their results showed that among 47 case reports, 66% of the cases reported a definite biomedical diagnosis and 45.2% of those cases involved a schizophrenia spectrum disorder.

Research suggests greater stigmatisation in Asian countries (Corrigan et al., 2011; Ng, 1997; Patel et al., 2010), and education and cultural factors may explain some of the stigma in these countries (Mungee et al., 2016; Ng, 1997). According to Musyimi et al. (2016), misfortunes, and social and cultural ideas of illness are deeply embedded in the concepts of the causation and treatment of mental illness. A review of the literature suggests that, in Asian communities, the perception of mental illness as a reflection of a flaw in the family is linked to the collectivistic nature of Asian societies (Abdullah and Brown, 2011). Disproportionally higher levels of stigma are observed in Asian countries towards people with mental health conditions than in Western countries (Lauber and Rössler, 2007; Ta et al., 2016). Culturally linked stigma regarding the utilisation of mental health services was seen among South Asian communities in both the UK and the US (Ali et al., 2005; Cinnirella and Loewenthal, 1999; Gilbert et al., 2004; Inman et al., 2007; Randhawa and Stein, 2007; Tabassum et al., 2004), which may prevent people from seeking help. The following review will focus on the ethnic, cultural, and religious stigma associated with mental health conditions among South Asian populations, specifically Sri Lanka, Pakistan, and India.

Sri Lanka

Some of the most common beliefs about the causality of mental health conditions in Sri Lankans are around '*Gods and Devils*', paying for past mistakes, and spirits such as their dead relative taking them over and causing mental health conditions (Samarasekare, Davies, & Siribaddana, 2012). Samarasekare and colleagues reported stigma towards family, stigmatising behaviours and negative attitudes in Sri Lankan communities that were associated with mental health. Stigmatising attitudes, for example, that mental health conditions are dangerous, erratic, and a sign of personal weakness, were found in a survey conducted among 119 Sri Lankan carers of people with experience of depression and schizophrenia (Ediriweera et al., 2012). In a cross-sectional study examining the stigmatising attitudes of undergraduate students in Sri Lanka towards their peers with depression, male students reported more negative attitudes towards their peers in the 'Dangerous-Undesirable' dimension of the stigma scale used. On the 'Weak-not-Sick' dimension females participants perceived depression as having a *'weakness'* and not a *'sickness'* (Amarasuriya et al., 2015). Nevertheless, in 2007 the National Mental Health Survey of Sri Lanka showed that among the general population, the desire for socially distancing from people with

mental health conditions was low (Institute for Research and Development, 2007).

Fernando et al. (2010) found that Sri Lankan doctors and undergraduate medical students reported higher levels of stigma towards people with experience of depression, alcohol, and drug addiction. They also endorsed the attitude that people with experience of schizophrenia were to blame for their condition, and they should *'pull themselves together'* (Fernando et al., 2010, p. 737). However, a recent study conducted with 743 final-year medical students in Sri Lanka reported a more positive attitude towards psychiatry (92.2%) and 22.2% of students considered psychiatry as a potential career choice (Baminiwatta et al., 2020).

Pakistan

Research on mental health stigma with medical students in Pakistan found contradictory results. One study found negative attitudes towards people with experience of depression, schizophrenia, and alcohol and drug problems (Naeem et al., 2006). However, Waqas et al.'s (2014) study comparing medical and non-medical students, found that more positive attitudes towards mental health conditions were reported by medical students than students from a non-medical programme. A recent study (Husain et al., 2020) conducted in Pakistan with healthcare professionals, healthcare students, and the general public, found that all three groups reported higher scores on stigma towards mental health conditions than physical health problems. While females had lower stigma scores than males, higher stigma scores were associated with the age 30-plus age group.

India

Prejudice towards people with mental health conditions as being aggressive and dangerous exists among South Asian countries, especially in India (Kermode et al., 2009; Lauber and Rössler, 2007). Lower education and religious factors were associated with people socially distancing themselves from individuals with mental health conditions (Zieger et al., 2016). Kishore et al. (2011) assessed the beliefs, myths, and perceptions of mental health conditions and help-seeking behaviour among medical professionals ($N = 76$) and the general population in rural ($N = 180$) and urban ($N = 180$) areas of Delhi, India. Most medical professionals and half of the participants from urban areas considered mental health conditions as a disease, whereas only 31.6% of participants from rural areas believed mental health conditions as a disease. Some 76.6% of participants from the rural area reported they would be comfortable talking to someone with a mental health condition. Whereas 59% of participants from urban areas, and 69.7% of medical professionals reported they were comfortable conversing with someone who had a mental health condition.

Most participants in the sample believed people who have traumatic or emotionally disturbed childhoods have a higher risk of having a mental health condition. Almost half of the participants from the general population (urban, 48.6% and rural, 45%) and 63.1% of medical professionals believed that having a lower socioeconomic status led to a higher risk of developing a mental health condition. Some also believed that having a higher education or IQ (urban 32.8%; rural 37.3%; medical professionals 30.3%) increased the risk of mental health condition. Fewer participants believed that having less sexual desire and masturbating excessively increased the chances of developing a mental health condition (Kishore et al., 2011).

When asked about the causes of psychiatric disorders, most participants from the Kishore et al. (2011) study reported imbalances in neurotransmitters, and increasing awareness of patients towards their emotions could facilitate their treatment. Some regarded polluted air, loss of semen/vaginal secretions, God punishing them for past sins, witchcraft, and planets and stars as the causation of psychiatric disorders. While 33.7%, 40%, and 7.9% of participants from urban, rural areas, and medical professionals respectively reported psychiatric disorders are untreatable, some believed they can be treated by faith healers (urban 26.1%; rural 31.6%; medical professionals 11.8%), or by leaving the patient alone (urban 4.4%; rural 6.5%; medical professional 6.6%) (Kishore et al., 2011).

Thara and Srinivasan (2000) assessed the presence and the degree of perceived stigma among primary caregivers of patients with a diagnosis of schizophrenia in Chennai. Most participants (35%) had no explanation for the causation of schizophrenia in their family members. Fewer participants implicated hereditary, biological functioning, substance abuse, or supernatural forces (7%). Some stigmatising aspects include fear of rejection by neighbours, the need to hide the facts and marriage. Additionally, Hindus report a higher level of stigma than Christians and Muslims (Thara and Srinivasan, 2000).

A study comparing pharmacy students from India with students from Australia, Belgium, Estonia, and Latvia found that higher blame for depression (31.3%) and schizophrenia (16.5%), was found in the Indian pharmacy students' sample (Bell et al., 2008). With 400 undergraduate students enrolled in private medical schools in Gujarat, India, researchers Vankar, Prabhakaran, and Sharma (2014) found the existence of high stigma of the causation of depression and discrimination against colleagues with depression. Depression was seen as a sign of weakness and most female students had a strong belief of not wanting to work with a student with depression. Similarly, Böge et al. (2018) found higher levels of perceived stigma were observed among female participants, while high levels of perceived stigma were also overall observed among the general population from five metropolitan cities in India. Namely, Chennai (N = 166), Hyderabad (N = 139), Kolkata (N = 158), Lucknow (N = 183), and Mumbai (N = 278).

Most people with mental health conditions feel ashamed due to the stigma created by myths and misconceptions about mental health conditions, therefore

preventing them from seeking help (Kishore et al., 2011). Understanding a client's cultural and religious background and creating awareness among mental health professionals about religious and cultural beliefs that may be widely held, will aid in forming therapeutic alliances, therefore enhancing assessment, and making a clearer diagnosis and treatment (Guthrie et al., 2016). Lim et al. (2015) suggested tailoring interview techniques, which would aid in acquiring specific information about the sociocultural context of patients' complaints, coping mechanisms, and symptomatology, which could ultimately promote clinical engagement. Support services could be provided for the unique problems in nations through greater comprehension of the stigma experienced by the carers (Fernando et al., 2017). Moreover, the differences in how stigma is elicited in different countries signify the importance of analysing stigma scales for their psychometric properties before applying them to a given culture. We now report on three linked studies we have conducted into stigma towards mental health problems in South Asian populations.

Study 1. Investigating stigma using a quantitative survey.

A cross-sectional, cross-cultural, mixed-method online questionnaire survey with open-ended questions and standardised scales was conducted among people of different South Asian heritage. The study aimed to explore the stigmatizing beliefs, attitudes, and actions toward mental health conditions currently existing in the South Asian community among the general population. Ethical approval for the studies was granted by the University of Greater Manchester.

Participants

Table 1
Demographic characteristics of the sample (N= 525).

Variable		N (%)
Gender	Female Male	414 (78.9) 111 (21.1)
Age	18 – 25 26 – 33 34 – 40 41+	372 (70.9) 91 (17.3) 26 (5) 33 (6.3)
Marital Status	Single (never married) Married, or in a civil partnership. Divorced	380 (72.4) 138 (26.3) 7 (1.3)

Education Level	Less than a high school diploma 'O'level 'A'level Associate degree (e.g., AA, AS) Bachelor's degree (e.g., BA, BS) Master's degree (e.g., MA, MS, Med) Doctorate or professional degree (e.g., MD, DDS, PhD)	20 (3.8) 24 (4.6) 114 (21.7) 21(4.0) 260 (49.5) 66 (12.6) 20 (3.8)
Employment Status	Employed full-time Employed part-time Unemployed and currently looking for work Unemployed not currently looking for work Student Retired Homemaker Self-employed Unable to work	134 (25.5) 31 (5.9) 21 (4.0) 12 (2.3) 301 (57.3) 2 (0.4) 10 (1.9) 12 (2.3) 2 (0.4)
Income Level	My income is not sufficient to meet my needs. My income is sufficient to meet my needs. My income is more than sufficient to meet my needs.	222 (43.4) 262 (49.9) 35 (6.7)
Religious Affiliation	Islam Hindu Buddhist Christian Atheist Agnostic Sikhism Roman Catholic Jain None Other	347 (66.1) 126 (24) 2 (0.4) 9 (1.7) 4 (0.8) 6 (1.1) 5 (1.0) 1 (0.2) 3 (0.6) 14 (2.7) 8 (1.5)
South Asian Heritage	Maldives India Sri Lankan Pakistan Nepal Bangladesh Afghanistan Pakistan and India	143 (27.2) 166 (31.6) 4 (0.8) 171 (32.6) 12 (2.3) 26 (5.0) 1 (0.2) 2 (0.4)
Formal Diagnosis	Yes No	74 (14.1) 451 (85.9)
Family History of Mental Health diagnosis	Yes No	123 (23.4) 402 (76.6)

Measures

Demographic questions included age, gender, marital status, education level, employment, satisfaction with income, religious affiliation, nationality, South Asian heritage, and country of residence.

Mental health questions included whether they had a formal diagnosis, family history of mental health conditions, and beliefs about the cause and treatability of mental health conditions. Lastly, whether they experienced or witnessed stigma associated with mental health conditions.

Attribution Questionnaire (Corrigan et al., 2003), a 21-item measure with six constructs, namely, personal responsibility belief (3 items, Cronbach's alpha = 0.70). Emotional responses included pity (3 items, α = 0.74), anger (3 items, α = 0.89), and fear (4 items, α = 0.96). Helping and rejection responses, helping (4 items, α = 0.88), and coercion-segregation (4 items, α = 0.89) are rated on a 9-point Likert scale. Additionally, seven 'Yes' or 'No' statements regarding familiarity with mental illnesses.

The Meet Sally Vignette, as described by Feeq and colleagues (2014), was utilised. With the permission from the original author, the vignette was slightly adjusted for this research. The vignette stated 'New York City,' which was changed to 'Your city,' denoting participants' city of residence. The second edit was from 'Walkman' to 'Headphones'. It is a vignette that is culturally neutral and describes a psychiatric episode of a 15-year-old living with her father. The cause of the mental health condition is unspecified.

Self-esteem was measured using Rosenberg's (1965) self-esteem questionnaire with 10 items, where items 2, 5, 6, 8, and 9 were reverse-coded. Participants were asked to indicate how strongly they agreed or disagreed with each statement.

Results

The questionnaire was completed up to the open-ended questions by 525 participants, of whom 523 responses were included in a geographical mapping (see, www.samhstigma.my.canva.site), where individual responses to the cause of mental health conditions, perception about treatability and treatment of mental health conditions, and accounts of witnessed or experienced stigma are mapped against respective South Asian heritage.

The most common understanding of the cause of mental health, among the plethora of reasons, included biopsychosocial factors such as genetics, environment,

stress, and trauma, especially in childhood. About 40 participants could not provide an explanation for the cause of mental health questions; this may perhaps be their lack of mental health literacy. Some responses include '*demonic*', '*strict culture, parents, and religion*', '*feeling dissatisfaction with all aspects of one's life*', '*lack of communication*', '*being away from the religion*', '*less faith and lack of love*', and '*people not minding their own business*'.

One participant had a comprehensive response to their perception of mental health conditions: '*Mental health conditions are multifaceted and influenced by a combination of factors. Biological factors, such as genetic predispositions or imbalances in brain chemistry, play a role. Environmental factors, including traumatic experiences or chronic stress, can contribute to their development. Psychological factors such as individual coping mechanisms and cognitive patterns, also impact mental well-being. Additionally, social factors like socioeconomic status, cultural influences, and access to resources have an influence. It is important to recognize that mental health conditions are not caused by a single factor, but rather emerge from a complex interplay of various elements.*' – Bangladeshi, 35-year-old male.

Most participants (*N*= 451) did not have a formal diagnosis or a family history (*N*= 402) of a mental health condition. Some 95.4% of participants believed mental health conditions could be treated; the 24 who responded '*No*' to the treatability of mental health conditions argued that mental health conditions could not be cured but could be managed with proper professional help. However, some responded with, '*It is something you are born with*', '*never seen it [mental health treatments] work*', and '*by morning walks, by attaching our self with nature, do dua [prayer] and zikr [supplication] if Allah almighty permits*'.

Most responses to those who said '*Yes*' to the treatability of mental health conditions highlighted therapy, medication, support, love, and kindness. The role of society was mentioned in a few of the responses, e.g., '*… in your society other people do not help the mentally unstable person as much as he needs. If we can help him in a better way, we can take him towards a normal life*'. The society we live in plays an important role in feeling a sense of normality for people with a mental health condition.

'Have more faith in the creator', 'praying,' and *'by doing things which make you feel relax[ed]'* were some treatment suggestions from those who said *'Yes'* for the treatability of mental health conditions. One respondent stated that '*for those who do not speak English, mental health is nothing*'. Highlighting that it is vital to understand what the treatments of mental health conditions are and the importance of translating information about mental health into South Asian languages.

In terms of experienced or witnessed stigma, 114 participants reported experiencing stigma, 131 reported witnessing stigma, and 278 reported neither experiencing nor witnessing mental health stigma. Words and phrases such as '*crazy*', '*insane*', '*mad*', '*idiots*', '*psycho*' '*attention seeking*', '*acting*', '*pretending*', '*faking it*', '*dramatic*', '*excuse*', '*overreacting*', '*just a phase*', '*lack of faith*', '*not religious*', '*just get over it*', '*selfish*', '*weak*', '*not real*', '*avoid responsibility*', '*lazy*', and '*made fun of*' are recurring

throughout the description of events participants had reported either experiencing or witnessing mental health stigma. These words and phrases were used by family, close relatives, and friends in schools, workplaces, and society.

The secrecy, or denial and avoidance, '*Hush hush; we do not talk about it,*' that exists around mental health prevents people from seeking help. For example, '*family asking to keep their [self-harm] scars and stories hidden*', '*… no daughter of theirs is 'mad' and needs to go to a doctor*', '*when relatives asked about said person, the mother said the person was on holiday*', and '*I have seen that mental health issues are kept secret within families due to fear of judgement.*'

Lack of understanding about mental health, '*Was told to go off antidepressants because depression is 'not real''*, further deprives people of getting proper help. Alternative sources are warranted for the cause of mental health conditions such as '*punishment for bad karma*', '*sins*' or '*evil eye*', and therefore, seeking a traditional approach, such as '*instead of taking her to therapy they are taking her to the temple to get rid of the evil spirit*' and '*the patient complained that she is possessed by some evil spirit because she wanted to kill her newborn with a pillow*'.

People with experiences of mental health conditions are not only '*being unfairly judged, avoided, or marginalised, perpetuating misconceptions about their capabilities or character*', they also '*stay in denial about their illness through their whole life, living in that fear.*' They also hide that they were getting professional help, *'I had to tell my family that I was taking a study class when I started therapy',* because they are being told *'medication should be avoided', 'no need to seek help for mental disorders'* by their families.

There is a generational difference and gender roles in play in the understanding of mental health conditions. For example, *'people saying that the new generation is making up issues over small, small, things and then calling it anxiety and depression,*' and '*boys cannot cry.'*

A total of 425 participants completed the attribution scale, and 417 participants completed the self-esteem scale. Demographics showed higher familiarity scores with mental health conditions included Maldivians (M = 3.53, SD = 1.97, N = 116), females (M= 2.88, SD = 1.94, N = 335), participants in the age group 26 to 33 (M = 3.53, SD = 2.11, N = 68), married or in a domestic partnership (M = 3.00, SD = 2.04, N = 107), having a doctorate or a professional degree (M = 4.17, SD = 1.80, N = 12), and participants with an income that was not sufficient to meet their needs (M = 2.98, SD = 2.12, N = 176).

Table 2
Mann-Whitney U-test between mean scores of subscales with high and low scores of familiarity with mental health conditions.

	Personal_Responsibility_Mean	Pity_Mean	Anger_Mean	Fear_Mean	Helping_Mean	Coercion_Segregation_Mean
Mann-Whitney U	19200.500	21048.000	19581.000	19325.500	16921.000	17143.000
Wilcoxon W	31761.500	33609.000	32142.000	31886.500	52699.000	29704.000
Z	-1.550	-.037	-1.246	-1.451	-3.412	-3.234
Asymp. Sig (2-tailed)	.121	.971	.213	.147	**<.001**	**.001**

a. Grouping Variable: Levels of familiarity with mental illness.

Table 2 shows Mann-Whitney U-test of mean scores of personal responsibility beliefs, pity, anger, fear, helping, and coercion segregation with dichotomised scores of 'familiarity with mental health,' where a total score between 0 to 3 (*N*= 267) is considered low familiarity and a score of 4 to 7 (*N* = 158) is considered a high familiarity with mental health conditions. Statistically significant difference was observed between the mean scores of the subscales of helping and coercion-segregation. Table 3 presents the mean and standard deviation for each subscale variable across the high and low familiarity with mental health conditions. Results showed people with higher familiarity with mental health are more willing to help, and those with lower familiarity are likely to discriminate against people with mental health conditions.

Table 3
Mean and standard deviation for each subscale variable across high and low scores of familiarity with mental health conditions.

	Levels of familiarity with mental illness	Mean	Std. Deviation
Personal_Responsibility_ Mean	Low Familiarity (0-3)	**3.78**	1.85
	High Familiarity (4-7)	3.51	1.86
Pity_Mean	Low Familiarity (0-3)	6.57	1.81
	High Familiarity (4-7)	**6.60**	1.81
Anger_Mean	Low Familiarity (0-3)	**2.84**	1.80
	High Familiarity (4-7)	2.61	1.70
Fear_Mean	Low Familiarity (0-3)	**3.25**	2.00
	High Familiarity (4-7)	2.97	2.02
Helping_Mean	Low Familiarity (0-3)	5.69	1.96
	High Familiarity (4-7)	**6.37**	1.79
Coercion_Segregation_ Mean	Low Familiarity (0-3)	**3.70**	1.96
	High Familiarity (4-7)	3.11	1. 90

From the three statements about personal responsibility beliefs, the second statement asked how controllable participants thought the cause of the condition presented in the vignette was. It was rated on a scale of 1= not at all under personal control to 9 = completely under personal control. The scores were categorised into three groups, which are scores between 1-3, low 4-6, moderate, and 7-9, high belief about the controllability of the cause of the mental health condition described in the vignette used. Participants who ranked high in their belief that the condition was under the personal control of the person in the vignette scored higher on anger (M = 3.26, SD = 2.13), fear (M = 3.75, SD = 2.34), coercion and segregation (M = 4.11, SD = 2.19), and helping (M = 6.21, SD = 1.83). Based on Kruskal-Wallis analysis, these differences were significant. *Anger*, X^2 (2.425) = 21.972, p <.001, *Fear*, X^2 (2.425) = 26.811, p <.001, *Coercion-Segregation*, X^2 (2.425) = 29.808 p <.001, and *Helping*, X^2 (2.425) = 9.552, p = 0.008.

The first and third statements in the personal responsibility subscale asks whether it is the person in the vignette's fault that she is in her present condition and how responsible respondents think she is for her present condition. These statements were rated on a scale of 1 to 9. Tables 4 and 5 show the correlation between the scores on these two statements and the mean scores on pity, anger, fear, helping, and coercion-segregation.

Table 4
Spearman's rho Correlation analysis between personal responsibility belief (fault), and pity, anger, fear, helping, and coercion-segregation (N= 425).

Personal Responsibility Belief (Fault). (M= 2.87, SD = 2.38)	Pearson Correlation	Significance (2-tailed)
Pity (*M* = 6.58, *SD* = 1.81)	-.093	.055
Anger (*M*= 2.27, *SD* = 1.76)	.452**	<.001
Fear (*M*= 3.14, *SD* = 2.00)	.413**	<.001
Helping (*M* = 5.94, *SD* = 1.92)	-.193**	<.001
Coercion-Segregation (*M* = 3.48, *SD* = 1.95)	.450**	<.001

**. Correlation is significant at the 0.01 level (2-tailed).

Table 5
Spearman's rho Correlation analysis between personal responsibility belief (responsible), and pity, anger, fear, helping, and coercion-segregation (*N*= 425).

Personal Responsibility Belief (Responsible). (M= 3.46, SD = 2.29)	Pearson Correlation	Significance (2-tailed)
Pity (*M* = 6.58, *SD* = 1.81)	-.108*	.026
Anger (*M*= 2.27, *SD* = 1.76)	.378**	<.001
Fear (*M*= 3.14, *SD* = 2.00)	.327**	<.001
Helping (*M* = 5.94, *SD* = 1.92)	-.144**	.003
Coercion-Segregation (*M* = 3.48, *SD* = 1.95)	.402**	<.001

**. Correlation is significant at the 0.05 level (2-tailed)*
***. Correlation is significant at the 0.01 level (2-tailed).*

Participants with lower familiarity with mental health conditions had a higher mean score of self-esteem (*M* = 27.83, *SD* = 5.35, *N* = 260) than those who had a higher familiarity (*M* = 26.90, *SD* = 6.14, *N* = 157). Independent samples *t*-test showed that the difference was not statistically significant, *t* = 1.619, df = 415, *p* = 0.053, (one-tailed).

Discussion of Study 1

Understanding the perceived stigma is crucial for developing targeted mental health interventions and reducing the treatment gap. It is also essential to assess the public's attitude towards mental health treatment to identify the barriers to care and improve help-seeking behaviour. Investigating cultural differences in mental health beliefs aids in the development of culturally sensitive mental health services and improves treatment outcomes. Examining cultural factors that contribute to mental health stigma can enhance understanding and lead to culturally sensitive mental health interventions. Investigating the differences, influences, and relationships between demographic factors such as age, gender, and education level and mental health stigma can inform age-specific educational and intervention strategies and guide the development of educational programs to combat and reduce stigma in South Asian countries. It can also help tailor educational approaches to address specific biases and perceptions more effectively. The second study takes a qualitative approach.

Study 2. A qualitative approach to understanding stigma

The qualitative study was conducted to understand the *lived experience* of stigma among people with a mental health condition in the South Asian population. A total of 15 interviews were conducted online over Zoom. The participants were 18 years and older, from a South Asian background, and had a formal diagnosis of a mental health condition. The semi-structured interview questionnaire was adapted from Howe, Tickle, and Brown's (2014) qualitative study. There were 11 participants identified as female and four identified as male. Participants' descriptions and highlights of their interviews are presented in Table 6.

Table 6
Interview participant's descriptions

	Participant description.	Highlights.
1	Female, diagnosis of nonverbal learning disorder. Indian heritage residing in the US.	Misdiagnosis of ADHD & ASD Has a sibling with ASD. Her parents are accepting of her sibling's therapy and medication but not of her. Advocates for mental health.
2	Male, diagnosis of bipolar. Indian heritage residing in the US.	The father is a psychiatrist; however, since the diagnosis, there has been no contact between them. His father prescribed him antidepressants. The therapist triggered mania without proper diagnosis and medication. Creating awareness about mental health through a podcast.
3	Female, psychology MSc student diagnosed with premenstrual dysphoric disorder. Indian heritage residing in India.	Father had experienced schizophrenia. However, the family is not accepting of her diagnosis. Has great insight about her diagnosis. Experienced stigma by association. A helpful therapist. Brother witnessed a panic attack, but he did not help. Sister has a depression diagnosis and fears judgment.
4	Female, undergrad student, anxiety, MDD. Indian heritage residing in Canada.	Stigma and discrimination experienced at school. The family does not have an understanding of her diagnosis and provides no support. They are against her use of medication. She found hope and support through the community.
5	Female, university student, schizoaffective with bipolar type 1. Indian heritage residing in the US.	Four misdiagnoses. Stigma experienced through negative labelling of schizophrenia.

6	Female, Doctorate in Clinical Psychology, diagnosis of generalised anxiety disorder. Indian heritage residing in the US.	Car accident, her mother died by suicide, and another death by suicide in the extended family. Stigma experienced from seeking support, trying to navigate South Asian culture and views of mental health
7	Female, chartered accountant. Obsessive compulsive disorder and ADHD diagnosis. Bangladeshi heritage residing in the US.	Diagnosed at the age of 8, followed by two misdiagnoses later. Her father is a pharmacist, but he discouraged her from taking antipsychotic medication. Experienced harsh environment in school. She is reluctant to share her diagnosis at the workplace.
8	Female, grief-led post-traumatic stress disorder. Indian heritage and residing in the US.	Father goes to therapy. Received negative attitude from mother. She did disclose to close friends about her diagnosis; however, she is afraid to share at the workplace because of potential consequences. She shared the positive impact of therapy and barriers to help-seeking and ran a podcast to create awareness about mental health.
9	Male, diagnosed with depression, and is a psychotherapist in training. Indian, Hindu background, living in the UK.	He struggled with not being taken seriously. Relatives offered unsolicited advice and remedies. His father tells people his son works with crazy people.
10	Male, diagnosis of depression, anxiety, and PTSD. Indian heritage and residing in the US.	Volunteers at mental health events. Side effects of medication. Highlighted issues in healthcare that prevented early intervention. Lost hope in therapy. The struggle of not having a therapist from the same cultural and ethnic background.
11	Female. Mechanical engineer. Diagnosed with ADD and dysthymia. Indian heritage residing in the US.	Multiple diagnoses and consulted several psychiatrists for opinions on the diagnosis. Suicidal episode leading to hospitalisation. Good experience with medication; however, struggling with parents about taking medication. Has a podcast.

12	Female, college student. Diagnosis of anxiety, PTSD, panic, major depression, and emotionally unstable borderline personality disorder. Indian heritage residing in Canada.	Family's involvement in treatment hindered recovery. The professional support received was unhelpful. Supportive friends provided support to seek help including financially. Side effects of medication. Sexually abused by a teacher.
13	Female. OCD diagnosis. Psychology master's student, Indian heritage, living in India.	Father is a psychiatrist. History of OCD in the family. Supportive friends and family.
14	Female, Sociology graduate, diagnosis of major depressive disorder and OCD. From Punjab, India. Residing in Sacramento, US.	Multiple diagnoses and exposure to multiple psychiatric treatments, including EMDR and CBT. Cousin died of an overdose.
15	Male, diagnosed with depression. Indian heritage and residing in India.	Health anxiety, physical health struggles, motorbike accident, grief, and prostitution.

ADHD = Attention Deficit Hyperactivity Disorder, ADD = Attention Deficit Disorder, OCD = Obsessive Compulsive Disorder, ASD = Autism Spectrum Disorder, PTSD = Posttraumatic Stress Disorder, EMDR = Eye Movement Desensitisation and Reprocessing, CBT = Cognitive Behavioural Therapy

Discussion of Study 2

Most of the participants are from the South Asian diaspora in the US. It is noteworthy to highlight that several of the participants came from a psychology background. Moreover, they are raising awareness on an individual level through podcasts and sharing their personal experiences. It is important to mention that despite having a mental health diagnosis, these participants are studying, working, and earning. The themes emerging from the interviews include the participants' experience and understanding of their diagnosis, the impact of the diagnosis, their experiences with mental health treatment and help-seeking behaviour, social support and disclosure of their diagnosis, and the meaning and experience of stigma, as well as how to challenge stigma in their opinions.

Some participants experienced multiple misdiagnoses, but it did not prevent them from seeking proper care. *'I went and asked five other psychiatrists. I made a lot of appointments.'* While some participants benefited from having a diagnosis, others did not. *'Benefit of the diagnosis was that it just suddenly placed things into like a lot of contexts.' 'I used to be in therapy, but I have lost faith in therapy.*' Apart from financial challenges and accessibility to mental health care, participants highlighted the struggle of finding therapists who are from the same ethnic background or someone who understood their own cultural and religious beliefs. Although there are a few who, because of their past experiences, felt discouraged from seeing a therapist from the same community or cultural background. *'I am like I don't know how to overcome cultural barriers to communicate to them [therapist]s.*'

Participants reported struggling to disclose their diagnosis to family, friends, at workplaces, educational institutes, and romantic partners due to fear of judgment and rejection. *'I think the negative aspects was kind of telling people, because schizoaffective has the 'schizo' term in it.' 'My mom was like dad already had a mental disorder. Why do you want like another diagnosis for yourself?*'

The participants used words such as 'shame,' 'silence,' 'hatred,' 'labelling,' and 'judgment' to describe what stigma meant to them. The role of media portrayal of mental health and people with mental health diagnoses was also highlighted. *'Inability to look at the objective facts because of some preconceived notions.' 'An unfair judgment, opinion placed on something.*' Stigma is a double-edged sword, where not only does it prevent help-seeking behaviour, but it also leads to further deterioration in their conditions. *'Stigma definitely held me back for all these years, because there was a refusal to sort of see what the signs of mental illness were.*'

While it took so much effort and struggle for some participants to seek proper help, they were then stigmatised because of their choices of mental health treatment. Therapy and counselling were looked at favourably, whereas medication was frowned upon. Some participants did not disclose their diagnosis or the treatments they were seeking hence, they did not experience any stigma due to their mental health diagnosis. *'My family was hesitant when I first told them, like my parents, they didn't want me to take medication, even though my dad is a pharmacist. He just, I guess he just had a stigma. He takes a cardiac medication himself. He just had a stigma with like medication for mental health. He discouraged me from taking it.*'

Therefore, it is important to challenge the stigma against mental health conditions, not only on an individual level. Some suggestions by the participants include education, creating awareness, listening, self-acceptance, community building, and accepting everyone as they are as a way we can challenge stigma. Exploring the impact of stigma and help-seeking behaviour among people with a diagnosis of a mental health condition is essential for creating a targeted intervention that encourages mental health service utilisation. Investigating the effects of acculturative family distancing on mental health can inform strategies to bridge cultural gaps and improve family support. Additionally, examining the correlation between

social support and mental health can help identify protective factors that promote well-being in the South Asian community. We now turn to Study 3 which was a community engagement event.

Study 3. Hosting a community engagement event.

The one-day conference, co-organised by the researcher and her director of studies, Professor Jerome Carson, with the support of the Research and Doctoral College and the School of Psychology, University of Greater Manchester was held on October 14, 2024. The conference was titled '*Shifting Perceptions: Breaking the Stigma*.' The conference was delivered both in person and over Zoom from 9:30am to 5:00pm. The conference presentations were divided into four sessions, with lunch and tea breaks provided for the attendees. A total of 15 presentations were given at the conference, of which four were online recorded presentations, a presentation from the CEO of Chiron Care, and the CEO from MedEquip4Kids – a children's charity presented about their mental health project among primary and high school students, the Hummingbird Project. Two of the speakers were research students, and the rest were mental health professionals from South Asian backgrounds.

The three keynote speakers were among the top three psychiatrists from South Asian backgrounds in the United Kingdom. They were Professor Dinesh Bhugra, Professor Nusrat Husain, and Professor Subodh Dave.

Professor Bhugra presented on the geopolitical determinants of mental health, Professor Husain confronted mental health stigma in the cultural context of Pakistan and Professor Dave addressed stigma about mental illness in healthcare workers. Other presentations included 'Understanding and Managing Mental Health Stigma in Pakistan,' by Professor Dr Amina Muazzam. 'The role of clinical leaders in breaking the stigma,' by Professor Kishen Neelam, and 'Understanding mental health stigma in Sri Lanka,' by Dr Chathurika Kannangara.

'Mental health support and alleviating stigma in patient populations in India', was an online presentation by Dr Bhavani Prakash. Suicide Prevention within the South Asian Community was an online presentation by Dr Dimple Patel. 'Silent Sufferers: Reframing how we address men's mental health', was another online presentation by Ankur Varma. 'Gender differences in public stigma about mental health and psychological help-seeking among Maldivians, was an online presentation by Fathimath Lamha Ahmed.

Two presenters who travelled from the United States, Mrinal Gokhale, discussed her two self-published books on first-person accounts of people with mental health conditions in the South Asian diaspora in the US. The books are titled, *Saaya Unveiled: South Asian Mental Health Spotlighted* and *Taboo: South Asian Mental Health Stories*. Arpita Sharma, founder and creator of Rethink Desi and a data analyst,

presented how storytelling serves as a transformative tool for breaking stigma. The researcher (Aishath Shahama) presented about the challenges and barriers to recruiting participants for mental health research.

Discussion of Study 3

All the conference attendees were asked to participate in a short survey with questions about mental health conditions. Options of online and paper/pencil were given. Outside the conference lecture theatre, there was a sticky note board where attendees could leave a message of what they wanted to say to a person with a mental health condition (*N*= 41). The conference was recorded and shared upon request. A booklet was prepared with all the presenters' details and presentation summaries. A website (https://samhstigma.my.canva.site/) was launched by the researcher, which included the research details and studies.

A total of 99 participants registered for participation, comprising 69 in-person and 30 online participants. Sixty-two attendees were present in person, and thirteen joined online via Zoom on the day. Practitioners, stakeholders, educators, and a diverse group of individuals attended the conference. The collective message that the attendees of the conference left for people with a mental health condition was that you are not alone, you are loved, you matter, and they are listening, they are there to support, understand, and help you. It included messages of hope, empowerment, and encouragement to be resilient and seek help. '*It is okay not to be okay*.' '*This does not define you*.' '*It may not seem like it, but it will pass*. '*Be kind to yourself*', and '*Trust yourself, you will get there*.' '*Your best is great, but either way, you are amazing*.' '*There is always hope. Sometimes it's just hidden for a moment*.'

'*Nothing about us, without us*.' It is the epitome of a community engagement programme in challenging mental health stigma and creating awareness (UNICEF SBC Guidance, n.d.). Some key aspects of community engagement include collaboration, participation, empowerment, and trust-building. To ensure effective results and inclusivity, community engagements are utilised in social accountability, health promotion, and community engagement (World Health Organization, 2020) Community engagement in mental health can offer several advantages, including improved social connections, increased empowerment and confidence, access to support networks, and reduction of stigma (World Health Organization, 2024). Approaches such as education and awareness, social contact, empowerment, and advocacy can collectively foster a supportive environment where conversations about mental health can be normalised and encourage help-seeking behaviour, influence policy and system impact, promote social inclusion, improve mental health literacy, and sustain attitude and behaviour changes (Castillo et al., 2019; McDowell et al., 2023; Semrau et al., 2024).

Conclusions

We started off this paper with a short review of the stigma literature in South Asian populations, focusing on Sri Lanka, Pakistan, and India. There is a suggestion that levels of stigma towards the mentally ill may be higher in South Asian populations than in Western societies. We then reported on three empirical studies that looked at the issue of stigma using three different methodologies.

Study 1 used an online questionnaire with an established vignette to examine six constructs linked to mental illness. These were personal responsibility beliefs, the emotional responses of pity, anger, and fear, being helping or rejecting, and coercion or segregation. Some 425 completed the Attribution Scale. Participants who had low familiarity with mental illness were more likely to feel that the mentally ill should be segregated. Similarly, if participants felt that the person was responsible for their mental illness, they were likely to be less pitying and more fearful.

Study 2 featured 15 interviews with people of South Asian heritage who had lived experience of mental health problems. Of these nine was based in the United States, three in India, two in Canada and interestingly only one in the UK. Five of the interviewees were involved in educating the public about mental health problems, either through writing about mental health or delivering podcasts. The interviews provided revealing insights into the lives of these individuals. Family attitudes were sometimes very negative, and some participants felt that they had to hide details of their conditions from loved ones. Therapy and counselling were looked on favourably, but medication less so.

Study 3 was a hybrid community engagement event that was live streamed to the United States and India, but with more participants attending in person. Two speakers travelled across from the United States and one Professor came over from Pakistan. There was a strong representation of South Asian psychiatrists, with three attending who had both national and international profiles. The main message coming out of the event was that people with mental health problems are not alone, they matter and there are always people who are willing to listen and help. It just may be difficult to find them sometimes.

So, what conclusions can we draw from these studies for the benefit of social workers? Firstly, it is important to understand the model of mental illness that families might believe. If they believe that mental illness is caused by evil spirits and that the only solution is to consult faith healers, they will be resistant to biopsychosocial models of mental illness. Secondly, these beliefs may affect willingness to engage with therapeutic approaches. Medication may be something that families may be reluctant for their sons or daughters to take. Thirdly, we need to work with community leaders to ensure that interventions are culturally sensitive and that services are accessible. We have much to learn from each other.

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