Surviving the stigma: lessons learnt for the prevention of COVID-19 stigma and its mental health impact

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Abstract

Purpose – *The spread of novel Coronavirus 2019 (COVID-19) has affected more than four million lives worldwide. Unfortunately, incidents of stigmatisation associated with COVID-19 are being reported worldwide. Studies conducted during and after public health emergencies because of communicable diseases have highlighted the development of stigmatisation and associated mental health consequences. This study aims to explore the past pandemics and current incidents of stigmatisation to understand COVID-19 stigma, its mental health impact and how they can be prevented by using primary and secondary prevention methods.*

Design/methodology/approach – *Researches were shortlisted using keywords such as ''infectious diseases and mental health'', ''COVID 19 stigma and mental health'', ''Contagious disease stigma'' and ''mental health of survivors''.*

Findings – *Studies conducted during and after public health emergencies because of communicable diseases have highlighted the development of stigmatisation and associated mental health consequences. The emphasis is on universal prevention of stigmatization. Early psychological intervention may reduce the long-term psychological effects of the illness and reduction of stigma may contribute to treatment.*

Originality/value – *This paper predicts the chances of stigmatisation that COVID-19 survivors may face and possible strategies to prevent it.*

Keywords *Stigma, COVID-19, Mental health impact*

Paper type *Viewpoint*

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Introduction

Stigma has a significant influence on mental health of the victim, his or her family, associated persons including health-care providers and society at large. It is defined as "attribute that is deeply discrediting" reducing the individual "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). The outbreak of novel Coronavirus 2019 (COVID-19) has been announced as the sixth public health emergency of international concern by the World Health Organisation (WHO, 2020). COVID-19 has infected more than 4 million people and more than 25,000 deaths have been reported worldwide (WHO, 2020).

Unfortunately, incidents of stigmatisation associated with COVID-19 are being reported worldwide. In Johannesburg, African reports by eNCA (2020) have indicated that the survivors of COVID-19 are struggling to reintegrate into the society. In Malaysia, a 32-year-old man in an interview reported being treated like a monster, despite his recovery (Chin, 2020). There are incidents reported in India about the stigma faced by COVID-19 survivors. A report published in the *Times of India* (2020) showed, individuals who recovered from

COVID-19, faced discrimination in their immediate surroundings in the state of Bihar. It was further reported that they were not allowed to move around with the excuse of contagious disease. In another report, published online, in Raipur, a 19 year old had to face criticism and received hate messages because she was tested positive (Pandey, 2020).

International organisations such as WHO, United Nations Children's Fund (UNICEF) and International Federation of Red Cross and Red Crescent Societies (IFRC) recognise prevalence of stigmatisation associated with COVID-19. They agree that the factors leading to stigmatisation include novelty of the virus, unknowns associated with the virus, the fear about the unknowns and associating the fear with "others". A guide has been jointly produced by the UNICEF, WHO and IFRC (2020), which addresses social stigma and its prevention associated with COVID-19. They pointed out that the pandemic has led to social stigma and discriminatory behaviours towards certain ethnic groups and those who have been in contact with the virus.

Mental health impact of stigmatisation of communicable diseases

Studies conducted during and after public health emergencies because of communicable diseases have highlighted the development of stigmatisation and associated mental health consequences (Lee *et al.*, 2007; Rubin and Wessely, 2020; Williams and Gonzalez-Medina, 2011). Diseases are stigmatised in circumstances where an individual is believed to be a cause of the disease, the nature of disease is terminal and degenerative, the disease seems to be communicable and adverse for others and the disease is physically apparent (qtd in Williams and Gonzalez-Medina, 2011). Obilade (2015) states that diseases such as leprosy, HIV/AIDS, tuberculosis, H1N1 and Severe Acute Respiratory Syndrome (SARS) had increased the fearfulness in people and those who suffered with any of these were stigmatised. Lee *et al.* (2005) reported that patients who had recovered from SARS felt being avoided by family, peers, colleagues and residents of the neighbourhood. They even faced barriers in accessing services and employment. Emotional disturbances were evident during SARS outbreak as well (Lee *et al.*, 2005). Kwek *et al.* (2006) in a 3-month follow-up study with survivors of SARS reported significant degree of impairment in health-related quality of life and mental functioning. Mak *et al.* (2009) in a longitudinal study post-SARS reported that at least one-third of patients suffered from psychiatric illness such as post traumatic stress disorder, depression and anxiety disorders and lower quality of life even after 30 months post-SARS and they suspected poor social support system and stigmatisation as maintaining factors of the psychological damage.

Even the survivors of Ebola virus disease were being stigmatised. The survivors of Ebola faced abandonment, lost livelihood, faced rejection by neighbourhood members or community places and even labelled as "Ebola people" (Obilade, 2015). In a systematic review on psychosocial distress among Ebola survivors, James *et al.* (2019) identified experiences of self- stigmatisation as one of the experienced phenomenon, in which feeling of embarrassment was associated with survivor status. Further, the survivors experienced discrimination and stigma in form of verbal abuse, eviction from their homes, not allowed to resume jobs, difficulty in buying or selling of commodities and not being permitted to visit public places.

Logie (2020) attempts to understand and address COVID-19 stigma through HIV research. It was pointed that labelling differentiates people and characterises them as "normal" from the "abnormal" other. Additionally, HIV research has thrown light regarding the complexity of stigma. Stigma, being intersectional (racism and poverty), social and ecological, is driven and facilitated. Stigma can affect our self-perception, mental health, alter our relationships, can have an impact on community cohesiveness and the way we interact with others.

Mental health impact of stigmatisation of COVID-19

As expressed in media reports, patients recovered from COVID-19 mostly feel they are not welcomed within the society (eNCA,2020; Chin, 2020; *Times of India*, 2020; Pandey, 2020). There is a feeling of social rejection or boycott. Stigma may be manifested in many ways such as complete social rejection, physical violence and mental torture. Possible reasons for rejection can be prompt messages for "social distancing" from various media sources, belief that the disease is not curable yet and that symptoms may reappear any time. Ministry of Health and Family Welfare, Government of India (MOHFW) (MOHFW, 2020) has also highlighted the increase in the level of stigmatisation during the current public health emergency. It has been stated "Public health emergencies during outbreak of communicable diseases may cause fear and anxiety leading to prejudices against people and communities, social isolation and stigma." (p.1).

Stigma associated with infectious diseases may be very stressful. Banerjee (2020) highlights that some of the common stress responses during the current phase are sleep problems, panic attacks, health anxiety, worry about illness and sometimes rise in substance consumption. With uncertainties associated with the current pandemic because of COVID-19, stigma with the disease is strengthened and to reduce the spread, strict measures such as lockdowns is increasing the fear among people. Quarantining for reducing the spread of corona virus is one of the primary measure. Rubin and Wessely (2020) highlighted that during previous quarantines, affected areas were socially avoided, the residents of these areas faced discrimination at workplace and their properties were also attacked.

Quarantining is associated with a mix of psychological reactions. Brooks *et al.* (2020) in a review explored the psychosocial impact of quarantine and identified stressors associated with pre-quarantine and post-quarantine. It was highlighted that tenure of quarantine, fear of infection, frustration, boredom, insufficient supplies, lack of information, financial constraints and stigma are the key stressors. It was emphasised that stigma was a post-quarantine stressor and a significant theme evident in the literature. There were reports wherein the people who had been infected because of the pandemic were avoided by others, social invitations were reduced, were treated with fear and suspicion and frequently witnessed critical comments of others.

Mental health morbidity is commonly reported during outbreak of infectious diseases, diseases leading to pandemic and diseases that require individuals or families to be quarantined. Hence, it is predicted that individuals suffering from COVID-19 or those who recovered from COVID-19 may experience mental health challenges and it may be maintained because of stigma associated with the disease.

WHO (2020) expresses its concern that due to the stigma, it is likely that people may not report the illness to avoid discrimination, delay access to health-care facilities and are likely to increase the spread of virus. Therefore, to avoid a high degree of stigma building with COVID-19, adequate and timely measures are needed.

Prevention of stigma associated with COVID-19

The guidelines produced by UNICEF, WHO and IRFC (2020) focus on universal prevention by encouraging all to trust the health-care services and to be empathetic with those suffering. Further, they suggest to avoid usage of language that have negative connotations that can increase stigmatisation; for instance, avoid attaching location or ethnicity with the disease, not to label the patients as victims or COVID-19 cases but address them as "people who have COVID-19", "people being treated for COVID-19", talk about "acquiring" or "contracting" the disease and not the terminology that creates the impression about blaming the people such as "transmitting COVID- 19". Some other ways suggested include encouraging spreading of facts and authentic information, involving social influencers such

as leaders, celebrities, involving community volunteers and boosting voices of those who have experienced the novel virus. The primary aim is creating a positive environment where people care for each other and are empathetic.

Logie (2020) suggests the application of HIV-related stigma-reduction interventions for COVID-19 stigma mitigation. She suggests provision of information by health-care providers, participatory learning through role-plays, discussions and games. On the other hand, Logie and Turan (2020) recommend exploration of long-term strategies for building empathy and social justice for current and future pandemics by balancing tensions between stigma mitigation and COVID-19 prevention.

For primary prevention, strategies such as educating the public about disease, grounds for quarantine and provision of health information can contribute to the reduction in stigmatisation about the disease in the society. The media can contribute in shaping the public attitude (Brooks *et al.*, 2020). Additionally, through news media and social media, positive stories of survivors and role of social support must be emphasised. Rumours or unvalidated information must be monitored and reliable sources must be identified. Messages of holding a non-judgemental attitude towards the patients and health-care providers must be dispersed. A feeling of compassion, hope and sensitivity must be inculcated to accept the current scenario, being hopeful about a positive future. This may further help in prevention of spread of mental health issues that can arise because of stigmatisation. Selective prevention programmes should target individuals that have increased risk, for instance those going for COVID testing and health-care workers.

Stigmatisation leads to development of mental health challenges and may act as a barrier in the intervention (Xiang *et al.*, 2020). Secondary prevention should aim to reduce the progression of a mental health disorder, through screening, early identification and brief treatment for COVID-19 survivors. Therefore, it is necessary to deal with stigma developing with survivors of COVID-19. Early psychological intervention may also reduce the long-term psychological effects of the illness and reduction of stigma may contribute to treatment.

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