WWS Mak 麥穎思
F Cheung 張妙清
J Woo 胡令芳
D Lee 李德誠
P Li 李頌基
KS Chan 陳健生
CM Tam 譚卓賢

A comparative study of the stigma associated with infectious diseases (SARS, AIDS, TB)

Key Messages

1. Quantitative and qualitative approaches were used to elucidate the psychosocial processes operating in SARS, HIV/AIDS, and tuberculosis.
2. The impact of stigma was examined from three perspectives: (1) the general public (public stigma), (2) target individuals afflicted with stigma (self-stigma), and (3) affiliates of the target individuals (affiliate stigma).
3. Three dimensions of stigma were assessed: (1) cognition (stereotypes and beliefs about the target), (2) affect (prejudicial attitudes and feelings toward the target), and (3) behaviour (discrimination toward the target).

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The Chinese University of Hong Kong, Shatin, NT, Hong Kong SAR, China:
Department of Psychology
WWS Mak, F Cheung
Department of Community and Family Medicine
J Woo
Department of Psychiatry
D Lee
Department of Medicine, Queen Elizabeth Hospital, Kowloon, Hong Kong SAR, China
P Li
Haven of Hope Hospital, Tseung Kwan O, Kowloon, Hong Kong SAR, China
KS Chan
Yuen Chau Kok Chest Clinic, Shatin, NT, Hong Kong SAR, China
CM Tam

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Principal applicant and corresponding author:
Dr Winnie WS Mak
Department of Psychology, The Chinese University of Hong Kong, Shatin, NT, Hong Kong SAR, China
Tel: (852) 2609 6577
Fax: (852) 2603 5019
E-mail: wwsmak@psy.cuhk.edu.hk

Introduction

Stigma can be defined as an attribute linking a person to a set of undesirable characteristics that may lead to prejudice and discrimination. Infectious diseases are considered stigmatising.[1] Stigma causes psychological suffering (eg shame and isolation) in afflicted individuals and families, compromises efforts to provide effective health care, and fosters discrimination in societies. Stigma may also directly affect the course and outcome of the stigmatised medical condition, by increasing stress or decreasing access to effective treatment.[2] For example, individuals with the stigmatising condition may delay treatment for fear of being labelled with the condition, or they may avoid treatment because the treatment setting has been made so undesirable that they may be discouraged from seeking help. In HIV/AIDS, stigma has been shown to be associated with self-esteem and depression.[3] Given the impact of stigma on health, research is needed to guide desirable public health interventions for the reduction of stigma. This can be done by comparing the features of stigma between different diseases, understanding the phenomenon of stigma and its psychosocial correlates within particular sociocultural contexts, documenting the burden of stigma on those afflicted as well as their associates, and evaluating the process of stigmatisation over time and in response to the course of the diseases, interventions, and social change.[4]

Limited research has been done on the stigma associated with infectious diseases among Chinese, and work done in other societies may not be extrapolated to the Chinese population because of cultural differences. Local studies examining attitudes toward people with mental illness[5-9] and with HIV/AIDS[10,11] tend to be descriptive in nature and have focused on public perceptions. Small-scale ethnographic case studies have been carried out among SARS sufferers. Media reports suggest that SARS and HIV are both stigmatising conditions, which result in self-barricading and social rejection of those in contact with SARS sufferers, and hiding of information by those who have contracted HIV from contaminated blood products.[12] There have also been anecdotal reports of people losing their jobs because they have family member(s) with SARS. In view of the rapidity of spread and the serious consequences, both in terms of mortality and subsequent protracted physical and psychological morbidity, observed during the recent SARS epidemic, considerable stigma may be attached to SARS. To assess the extent of SARS stigma, other stigmatising infectious diseases (ie HIV/AIDS, tuberculosis [TB]) may be used as a benchmark for evaluating the phenomena. Both the differences and commonalities observed across these conditions can enlighten researchers about psychosocial sequelae such as reduced self-esteem, social disadvantages, or changes in health-seeking behaviours. All of these have implications for the design of relevant public health interventions. Furthermore, stigma must be understood from multiple perspectives (self-stigma, affiliate stigma, public stigma) so that interventions aiming to reduce stigma can target each condition from multiple levels. Responses by the general public, potential stigmatisation of associates of the affected person (family members, friends, healthcare workers), and internalisation of stigma by the affected persons are all important processes that stigma reduction programmes need to address. Measures may include legal action, changes to the health care system, support from the public, professionals, and family members, and self-care and understanding of those affected.

Aims and objectives

1. Explore the sociocultural and psychological underpinnings of public, self-, and affiliate stigma;
2. Identify social-cognitive processes that are germane to the adoption and maintenance of stigma;
3. Examine the effects of stigma by accounting for individuals' well-being and social opportunities; and
4. Compare the magnitude of stigmatisation and its related outcomes among SARS, HIV/AIDS, and TB.

Methods

Qualitative study

A total of 90 participants were interviewed for 19 focus groups: 17 for public stigma, 22 survivors/patients and 11 caregivers for SARS, six survivors/patients and eight caregivers (including non-government organisation service providers and health care professionals) for HIV/AIDS, and 20 survivors/patients and six caregivers for TB.

Quantitative study

Public stigma

A telephone survey was conducted between September and October 2004, to assess levels of public stigma related to SARS, HIV/AIDS and TB among Hong Kong residents. Telephone numbers were drawn randomly from a pool of seed numbers based on the most recent residential telephone directories, which contained almost all residential telephone numbers in Hong Kong. To capture unlisted numbers, the last two digits of the number selected were deleted and replaced by two random numbers generated by computer. If the household could not be reached, two more follow-up calls were made at different hours. The interviews were conducted between 6 and 10 pm on weekdays and 2 to 9 pm on Saturdays to avoid under-sampling of students and employed individuals. One eligible household member aged 18 to 65 years whose birthday was the closest to the interview date was invited to participate in each residential unit. The selected participant was interviewed about one of the above three infectious diseases, based on random assignment, and the interview was conducted in Cantonese. A total of 3011 participants took part in the interview, of which 1007, 1001, and 1003 participants were questioned about HIV/AIDS, SARS, and TB, respectively. The response rate, defined as the number of complete interviews divided by the total number of households containing an eligible person contacted, was 45.5%, 47.3%, and 50% for HIV/AIDS, SARS, and TB, respectively.

Self-stigma

Patients with one of the three health conditions were interviewed twice in a 6-month interval. They were recruited using the following methods: (1) recovered SARS patients identified from a list provided by the Hospital Authority: first-wave data from 147 ex-SARS patients and second-wave data from 106 ex-SARS patients were collected. (2) People with HIV/AIDS attending government AIDS clinics and major non-government organisations such as the Hong Kong AIDS Foundation: first-wave data from 150 people with HIV/AIDS and second-wave data from 119 people with HIV/AIDS were collected. (3) People with TB from hospitals (Tai Po Hospital) as well as chest clinics (Yuen Chau Kok): first-wave data from 148 people with TB and second-wave data from 85 people with TB were collected.

Trained interviewers sought informed consent from the participants by explaining the purpose of the study, confidentiality of the data, and rights of the participants. Interviewers conducted the interview at a location preferred by the participants and on completion of the questionnaires, participants were paid HK$50 or a coupon equivalent as compensation for their time.

Affiliate stigma

Patients who participated in the study and agreed that their primary caregivers may be contacted for collateral information were asked to identify, at most, three family members who regularly provide care for them. Identified affiliates were contacted by a research assistant and asked to participate in the study to explore their experience of caring for individuals with SARS, HIV/AIDS or TB. The caregivers were interviewed twice in a 6-month interval. The following data were collected: (1) SARS caregivers: first-wave data from 74 ex-SARS caregivers and second-wave data from 64 ex-SARS caregivers were collected. (2) HIV/AIDS caregiver: first-wave data from 7 HIV/AIDS caregivers were collected and no second wave data collection due to small sample size in the first wave. (3) TB caregivers: first-wave data from 57 TB caregivers were collected and no second wave data collection due to small sample size in the first wave.

The interviews were conducted at locations selected by the participants who were paid HK$50 or a coupon equivalent to compensate for their time.

Results

Qualitative study

Public stigma focus group findings: physical and psychological avoidance was the most common reactions toward people known to have infectious diseases (SARS, HIV/AIDS, and TB). Most participants were knowledgeable about the modes of transmission of the infectious diseases under study. Attribution of stigma was somewhat different between SARS/TB and AIDS. This might be because people with SARS/TB were not generally seen as being responsible for contracting the disease whereas HIV infection is viewed as a self-inflicted, avoidable consequence.

The SARS focus group findings: quite a number of participants reported apathetic attitudes and avoidant behaviours from doctors during their in-patient stay. They also reported avoidance from family, friends, colleagues, and neighbours after recovery. Many perceived barriers to service access and employment after recovery. Emotional disturbances were reported quite frequently, including worries, anxiety, and a sense of helplessness.

The HIV/AIDS focus group findings: compared with the two other groups, it was much more common for people with HIV/AIDS to maintain secrecy as they regarded AIDS a highly stigmatised disease. All agreed that HIV-related stigma is rooted in biased publicity about the nature of the disease, judging it from a moralistic point of view. Actual and anticipated rejection by others predisposed people with HIV/AIDS to feel self-hatred, humiliated and to withdraw.

The TB focus group findings: no participants reported stigma in medical settings, though interpersonal avoidance by family members, friends/relatives, and neighbours is still common. Quite a number of participants believed public fear of TB has been reduced by better knowledge about the disease.

Quantitative study

For the telephone survey about public stigma toward SARS, HIV/AIDS, or TB, path-constrained structural equation models were compared. The attribution model (internal controllability, responsibility and blame) was predictive of an increased level of self-stigma (CFI=0.92, RMSEA=0.04). The MANOVA results indicated that the high- and low-stigma groups showed significant differences in attitudes to policy across the three diseases. The low-SARS stigma group expressed more favourable attitudes toward government policies on prevention, public education, research, and anti-discrimination than their high-SARS stigma counterparts. As for HIV/AIDS, significant differences in attitudes were found only in attitudes to policies on prevention, public education, and anti-discrimination. Finally, differences in attitudes between low- and high-TB stigma groups were found only in attitudes to policies on prevention, public education, and research.

Data from first-wave SARS survivors and their caregivers were analysed to elicit the relationship between their self-stigma. Caregiver strain was a significant mediator between affiliate self-stigma and survivor self-stigma among 51 dyads.

First- and second-wave people with HIV/AIDS findings: structural equation modelling was used to analyse the data. The results indicated (CFI=0.97, RMSEA=0.08) that the attribution model (personal responsibility, stability, and personal controllability) was not predictive of self-stigma. A higher level of self-stigma led to a decreased level of social support, and eventually a higher level of mental distress.

In terms of medication adherence for people with HIV/AIDS, using the conventional adherence rate, only 12 (11.8%) of participants reported having missed/altered medication in the past 4 days. However, using a more comprehensive assessment, only 27 (26.5%) of participants were classified as adherers. Intentional non-adherers had worse mental health, higher level of self-stigma, and higher score in avoidant coping than adherers and unintentional non-adherers. They also scored higher in physical symptoms than adherers.

Discussion

The telephone survey results indicate that public stigma is greatest toward HIV/AIDS, followed by TB then SARS. Using multi-sample structural equation modelling, the attribution model with internal controllability, personal responsibility, and blame were found to be applicable across the three diseases for explaining stigma. Knowledge about the disease had no significant effect on stigma. Participants with less stigmatising views had significantly more favourable attitudes toward government policies related to the diseases.

Data from the 119 people with HIV/AIDS indicated that although the linkage between the attributions of control, responsibility, and blame was confirmed, the relationship of blame to self-stigma was not significant. Self-stigma was found to dampen social support and lead to psychological distress half a year later.

Data from 143 SARS survivors indicated that self-care self-efficacy completely mediated the effects of perceived medical staff support and perceived family/friends support on mental health status.

Regression analyses on data from 51 dyads of SARS survivors and their caregivers, indicated that affiliate self-stigma served as a partial mediator between patient self-stigma and caregiver strain.

Conclusions

This study is an important attempt to understand the attributional mechanisms of stigma toward infectious diseases. It challenges the adequacy of attributional factors as a means of understanding self-stigmatisation and demonstrates the impact of stigma on psychological adjustment among people with HIV/AIDS. It is also the first attempt to understand long-term psychological adjustment in SARS survivors. These findings may be applicable to other infectious disease outbreaks because they inform about psychosocial factors that may be important to long-term recovery. Caregivers for patients with higher self-stigma are at risk of greater internalisation of stigma and caregiver strain.

Stigma reduction and promotion of public awareness should focus not only on knowledge but also cognitive representations of illness and interpersonal contact to alleviate stigma. Along with providing psycho-education and information about treatment and medication, family-based interventions should focus on the self-stigma imposed on patients and caregivers.

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