BRIEF REPORT

Psychological Distress and Subjective Burden of Caregivers of People with Mental Illness: The Role of Affiliate Stigma and Face Concern

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Abstract The present study tested the mediating role of affiliate stigma on the relationships between face concern with psychological distress and subjective burden among caregivers of people with severe mental illnesses. One hundred and eight Chinese caregivers in Hong Kong were surveyed. Based on Baron and Kenny's (J Pers Soc Psychol 51:1173–1182, 1986) approach, affiliate stigma was found to serve as a partial mediator between face concern and caregiver distress and a full mediator between face concern and subjective burden. Cultural linkage of stigma and caregiver outcomes was identified, suggesting that researchers and practitioners should use a culturally sensitive approach to understand caregivers' experience and alleviate their stigma.

Keywords Caregiving · Affiliate stigma · Face concern · Subjective burden · Psychological distress

Introduction

Psychiatric stigma has been identified as a major barrier to adequate care among individuals with mental illness. Stigma not only affects the discredited individuals, it also impacts individuals who are closely associated with them. Previous studies referred to these public perceptions of the associates as courtesy stigma (Goffman 1963) or associative stigma (Mehta and Farina 1988). Rather than focusing on

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public views towards these associates, the present study focused on the internalization of stigma among associates of targeted individuals, specifically the caregivers of individuals with mental illness. To differentiate our proposed construct from courtesy stigma and associative stigma, we referred their self-stigma and its corresponding cognitive, affective, and behavioral responses of the associates as affiliate stigma (Mak and Cheung 2008).

Affiliate stigma refers to the extent to which associated individuals internalize the stigma of the general public towards the discredited. Consistent with prior conceptualization of stigma, it is composed of three interlocking psychological responses: *stigmatized cognition* (perceptions of lowered competence and worth than their peers due to the internalization of stigma), *affect* (feelings of shame, despair, and embarrassment as a result of the stigmatized status being internalized), and *behavior* (behavioral reactions as a result of internalized stigma such as withdrawal and self-denigration) (Corrigan and Watson 2002; Link and Phelan 2001; Mak and Cheung 2008). Caregivers of people with mental illness who have affiliate stigma may experience stronger distress and perceive a greater sense of burden in the caregiving process. They may feel shameful for having a family member with mental illness while obliged to take care of him/her. Thus, these caregivers may be subjected to feelings of strain and distress, as a result of their relationship with the discredited individuals and their caregiving role. Previous studies found that caregivers expressed a sense of burden and worry in caring for the carees, and experience stigma as a result of their associations with them (Phelan et al. 1998).

Affiliate stigma may be culturally salient among Chinese given their beliefs towards mental illness and their values of face concern. Research found that Chinese tended to emphasize biological roots of mental illness (Kung

2001) and might consider their ill relative as a "bad seed" and a disgrace to their family (Sue and Sue 1987), which may further exacerbate their stigma. As such, Chinese are likely to keep their ill relative as a family secret to avoid face loss.

Face concern is a culturally salient construct on social representations that may exacerbate the experience of affiliate stigma and dampen the well-being among Chinese. Face concern (*mianzi*) refers to one's desire to preserve and maintain his/her social image and social worth that is based on one's specific role within the interpersonal context (Hwang 1997–1998). Ho (1976, p. 883) further elaborated on the definition by asserting that "face extended to a person by others is a function of the degree of congruence between judgments of his[/her] total condition of life, including his[/her] actions as well as those of people closely associated with him[/her], and the social expectations that others have placed upon him[/her]." It is distinguished from *lian* or the meeting of moral and ethical standards set forth by one's social network and shame that one experiences when he/she falls short of meeting these moral demands (Ho 1976; Hwang 1997–1998). According to the face negotiation theory, "face is tied to the emotional significance and estimated calculations that we attach to our own social self-worth and the social self-worth of others" (Ting-Toomey 2005, p. 73). The present study focused on the impact of face concern in the form of *mianzi* on the experience of affiliate stigma, subjective caregiving burden, and psychological distress. Previous studies showed that face concern (*mianzi*) was significantly related to distress among Chinese Americans (Mak and Chen 2006), Hong Kong and Mainland Chinese (Mak et al. 2009). Thus, caregivers of people with mental illness who have strong face concern may be more sensitive to the psychiatric stigma endorsed by the public on their relative, influencing their own stigma experience as caregivers.

Caregivers with affiliate stigma may perceive a greater sense of subjective burden and distress in their caregiving experience, as stigma may have distorted their views towards the care-recipients and affect their relationships. Distinctive from the observable and concrete costs that are captured by objective burden, subjective burden revolves around caregivers' perceptions of their relationships with the stigmatized as well as the psychological impact that the caregiving experience has on the caregivers (Mak 2005). Based on focus groups and interviews, family members and caregivers reported being stigmatized based on their association with the stigmatized individuals, including people with mental illness (Angermeyer et al. 2003; Muhlbauer 2002; Östman and Kjellin 2002; Phelan et al. 1998; Schulze and Angermeyer 2003; Shibre et al. 2001). Thus, it was hypothesized that the cultural value of face concern would place caregivers at greater risk of developing affiliate stigma, which could further exacerbate their subjective burden and psychological distress. The purpose of this study was to investigate the mediating role of affiliate stigma on the relationships between face concern and psychological distress as well as subjective burden. Through this empirical investigation, we aimed to understand the cultural underpinning of stigma and the possible mechanisms by which caregivers' mental health is affected.

Methods

Participants

Participants of this study consisted of 108 Chinese caregivers of people with mental illness (20 men and 88 women) in Hong Kong. Over half of the carees were diagnosed with schizophrenia (57.4%, $n = 62$); 23.1% ($n = 25$) with mood disorders, 6.5% ($n = 7$) with anxiety disorders, and others (13.0%, $n = 14$). The caregivers had a mean ± SD age of 54.21 ± 13.20 years (range of 20–86 years). They were parents (38.9%, $n = 42$), spouse (12.0%, $n = 13$), children (24.1%, $n = 26$), siblings (23.1%, $n = 25$), or others (1.9%, $n = 2$). Majority of the caregivers (56.1%, $n = 61$) were unemployed. About 7.4% ($n = 8$) had no education; 37.0% ($n = 40$) had primary education, 39.8% ($n = 43$) had high school education, and 15.8% ($n = 17$) had tertiary education or higher. Compared with the Hong Kong monthly median household income of HK $18,705 (approx. US $2398) (Hong Kong Census and Statistics Department 2001), 53.4% of the caregivers had a family income below HK $10,000 (approx. US $1282); 28.2% between HK $10,001 and $30,000 (approx. US $1282 to $3846); and 18.5% above HK $30,001(approx. US $3846). They had been providing care for the carees for a mean ± SD of 8.85 ± 8.05 years, 3.35 ± 3.12 days per week and 5.28 ± 8.40 h per day. Ethical approval was obtained at the Chinese University of Hong Kong.

Procedure

Participants were recruited through non-governmental agencies and self-help organizations at various districts in Hong Kong. Advertisements were also made at caregiver support groups. Caregivers who were interested in participating signed up for the study. Inclusion criteria included (1) a minimum of one contact per week with the caree; (2) can read and write Chinese; and (3) aged 18 or above. To expand the pool of potential caregivers, the snowballing approach was used to recruit eligible caregivers referred by participants.

Eligible caregivers were surveyed at a location of their own choosing (e.g., service center, home) by one of the

four trained research assistants. At the beginning of each session, the research assistant explained the purpose of the study, and consent was sought prior to the commencement of the survey. The participants then completed the questionnaire at their own pace. The research assistant was available to answer any questions that the participants might have about the questionnaire.

Measures

Validated Chinese versions of the following questionnaires were used.

Face Concern   Face concern was measured by the 21-item Loss of Face Scale (Zane and Yeh 2002). It taps on concerns related to social norm violations or expectations that incur a loss of face to the self and to others. Sample items included "I maintain a low profile because I do not want to make mistakes in front of other people" and "I try to act like others to be consistent with social norms." Participants rated each item on a 7-point Likert scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Mean score was used with higher scores indicating greater face loss concern (Cronbach's alpha = .76). All items were scored in the direction of face loss concerns. The mean score was used. The LOF has been validated among Chinese, with satisfactory construct validity and reliability (Mak et al. 2009).

Affiliate Stigma   The 22-item Affiliate Stigma Scale was used to measure caregivers' internalization of stigma (Mak and Cheung 2008). The items measured the affective, cognitive, and behavioral components of affiliate stigma. Sample items included "Having a family member with mental illness makes me think that I am incompetent compared to other people" (*cognitive*); "I am under great pressure as I have a family member with mental illness" (*affective*) and "Given that I have a family member with mental illness, I've cut down the contacts with my friends and relatives." (*behavioral*). Participants rated each item on a 4-point Likert scale from (1) *strongly disagree* to (4) *strongly agree*. The mean score was used, with higher scores indicating higher levels of affiliate stigma (Cronbach's alpha = .94).

Psychological Distress   The psychological distress subscale of the Mental Health Inventory was used to measure participants' distress during the past month (Veit and Ware 1983). Being part of the National Health Insurance Study, the MHI had been extensively studied in different populations (Veit and Ware 1983) and had also been shown to have a good validity among Chinese (Liang et al. 1992). Participants rated each item on a 4-point scale, with higher scores indicating greater levels of psychological distress. Sample items included "During the past month, how much

of the time did you feel that you had nothing to look forward to?" and "Did you feel depressed during the past month?" The psychological distress subscale achieved excellent internal consistency in the present study (Cronbach's alpha = .82).

Subjective Burden   Subjective burden was measured by the Caregiver Burden Inventory (Novak and Guest 1989), which has shown to have good validity among Chinese (Chou et al. 2002). Subjective burden was assessed in five areas: emotional burden, social burden, time-dependent burden, developmental burden, and physical burden. Participants rated each item on a 5-point Likert scale from (1) *strongly disagree* to (5) *strongly agree*. Sample items included "Caregiving has made me physically sick", "my caregiving efforts aren't appreciated by others in my family", and "I wish I could escape from this situation." The mean score of all items was used, with higher scores indicating higher levels of subjective burden (Cronbach's alpha = .90).

Analytic Plan

Baron and Kenny's (1986) four-step procedure for testing mediation effects was used to test the effects of affiliate stigma on the relationships of face concern with psychological distress and subjective burden. Caregivers' age, gender, and household income were controlled for in the analyses.

Results

The mean affiliate stigma in present sample of caregivers was 2.31 (SD = .46). Among the three components of affiliate stigma, affective component had a mean of 2.66 (SD = .50), cognitive component had a mean of 2.21 (SD = .50), and behavioral component had a mean of 2.09 (SD = .52). All three components were highly correlated to each other (rs range from .71 to .78) and the total mean affiliate stigma score (rs = .91 to .92), Ps < .001.

The present study followed Baron and Kenny (1986)'s four-step procedure to test for the mediation effects. Caregivers' age, gender, and household income were entered into the first block to control for the effects of demographic variables. To meet the criteria for mediation, the predictor variable (i.e., face) first must be significantly associated with the outcome variables (i.e., psychological distress and subjective burden). This criterion was met according to the partial correlation analyses, which showed that face (M = 4.52, SD = .67) was significantly correlated with psychological distress (M = 2.95, SD = .71; r = .28, P < .01) and subjective burden (M = 2.90,

SD = .73; r = .33, P < .01). In the next step, the predictor variable must be associated with the potential mediating variable (i.e., affiliate stigma) significantly. This step was also supported by the significant correlation between face and affiliate stigma (r = .32, P < .01). Step 3 necessitated a simultaneous multiple regression, where the outcome variables were regressed on both the predictor variable and the potential mediating variable. This step required two features in the regression findings: (1) the potential mediator had to be a significant predictor of the outcome variable, and (2) the regression coefficients between the predictor and the outcome variables had to be reduced in relation to those in Step 1. To examine the effect of the potential mediating variable on the outcome variables, two separate regression analyses were conducted for psychological distress and subjective burden. None of the demographic variables were significantly related to psychological distress and subjective burden. Face concern explained 9 and 11% of variance in psychological distress and subjective burden, respectively. When affiliate stigma was entered into the regressions, it further explained 9 and 33% of variance in psychological distress and subjective burden, respectively. Whereas face concern continued to be significantly related to psychological distress after affiliate stigma was entered into the equation, it was no longer significantly related to subjective burden.

In the present study, the criteria in Step 3 were met for both variables. After controlling for the effect of face, affiliate stigma was significantly related to psychological distress ($\beta = .34$, $P < .01$) and subjective burden ($\beta = .67$, $P < .001$). In addition, the decrease in regression coefficients in face concern after affiliate stigma had been added to the equation were .10 for psychological distress and .22 for subjective burden, both of which suggested a mediating role of affiliate stigma. Step 4 required that the regression coefficients in Step 1 and Step 3 be significantly different. Results of two separate z tests (Baron and Kenny 1986) showed that the decreases in the regression coefficients are significant, indicating that affiliate stigma was a partial mediator ($z = 2.44$, $P < .01$) between face and psychological distress, and a full mediator ($z = 3.25$, $P < .001$) between face and subjective burden.

Discussion

The present study demonstrated the linkage between face concern, affiliate stigma, with subjective burden and psychological distress among Chinese caregivers of people with mental illness in Hong Kong. Affiliate stigma was found to partially mediate the relationship between face concern and psychological distress and fully mediate the relationship between face concern and subjective burden.

Extended from a recent study, which showed that the salient cultural value of face concern was associated with psychological distress (Mak and Chen 2006), the present study found that its negative relationships with burden and distress were mediated by affiliate stigma among caregivers of people with mental illness. In other words, caregivers with strong face concern tended to internalize psychiatric stigma, which was related to their experience of more psychological distress and subjective burden. This study provided preliminary support for the cultural explanation of heightened distress and burden among Chinese caregivers and highlighted the importance of face concern and affiliate stigma in understanding their caregiving experience.

The findings pointed to the importance of caregivers' cultural values and the relevance of affiliate stigma in understanding caregivers' distress and burden. Whereas affiliate stigma fully mediated the relationship between face concern and subjective burden, it only partially mediated the relationship between face concern and distress. One possible explanation for this difference may be that subjective burden is confined within the caregiving context, wherein their perception of the caregiving experience and responsibilities were more strongly influenced by the process of the internalization of psychiatric stigma. Thus, affiliate stigma fully mediated the relationship between face concern and subjective burden. In contrast, as both face concern and the internalization of affiliate stigma contributed directly to the caregivers' distress experience, a partial mediation relationship was found. Previous studies have already documented the positive relationship between face concern and distress, even when various stressors and social support were taken into account (Mak and Chen 2006). In order to protect their own social image and to maintain social order, people who are high in face concern may exert extraordinary pressure on themselves to avoid a range of potentially face-losing situations, which may further exacerbate their distress level. In this study, face concern was found to have both direct and indirect effect on psychological distress of the caregivers.

By attuning to caregivers' cultural beliefs and stigma experience, psychoeducation and mutual aid groups can provide a platform for caregivers to share their concerns, reduce the impact brought about by affiliate stigma and face concern, and reconsider the implications of having a family member with mental illness. Issues of face in relation to having a family member with mental illness can be discussed and processed. These discussions can potentially normalize their experience and empower caregivers to mobilize efforts against stigma, which in turn may positively influence carees' course of illness by strengthening caregiver-caree bonds.

Several limitations of the study should be born in mind when interpreting the current findings. First, its cross-

sectional nature precludes the establishment of causality among the variables. Longitudinal evaluation of the caregiver experience can shed light on causal mechanisms that dispose caregivers to develop affiliate stigma and subsequent burden and distress. Second, future study should attempt to collect a larger sample of caregivers to allow for the possibility of model testing using structural equation modeling. Third, the present study was conducted among Chinese caregivers in Hong Kong. Although face concern is salient among Chinese caregivers, it may also be prominent among caregivers of other ethnicities. Future studies should extend the present work in understanding stigma experience, caregiving, and well-being among culturally diverse caregivers of people with mental illness. Finally, the present study focused on socially oriented face concern (*mianzi*). Future study may examine morally-oriented face concern (*lian*) alongside with *mianzi* in order to investigate their relative importance and effect on caregivers' stigma and their psychological outcomes.

This study was one of the first attempts in linking specific cultural value in understanding caregivers' stigma and mental health. It sheds light on the impact of culture on caregiving and well-being and highlights the importance of stigma in understanding caregivers' experience. Not only should effective interventions be developed to alleviate stigma among caregivers, culturally sensitive services must also be implemented to capture the cultural underpinnings of their well-being and mental health.

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