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Short communication

Stigma never dies: Mourning a spouse who died of AIDS in China

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ABSTRACT

Stigma towards people with HIV (PHIV) can affect their family members. In this study of 68 HIV seronegative participants in China whose spouse died of AIDS, 35.3% reported prolonged grief. Stigma beliefs towards PHIV (i.e., belief that PHIV's death leaves the deceased, the family and society better off) predicted grief symptoms. Social campaigns to combat stigma and grief therapy to reconstruct the meaning of HIV-related death may be helpful to reduce suffering in HIV bereaved.

1. Introduction

Stigma not only affects people with HIV (PHIV) even after they die, but also extends to their family members. The effects of stigma related to the deceased PHIV on survivors have not been investigated. Guided by a social constructionist account of grief, this investigation examines being influenced by social conceptualization towards PHIV, the role of internal stigma on the grief manifestation in a Chinese sample of bereaved spouses.

Prejudice and discrimination towards PHIV are partly driven by moralistic attitudes towards illicit behaviors associated with HIV acquisition (Jeffries et al., 2015; Lee et al., 2014; Syvertsen et al. 2013). Notably, a significant group of PHIV in Mainland China acquired HIV when selling blood for economic reasons (Wu et al., 2001). Irrespective of a blameless means of contracting HIV, these HIV-infected plasma donors face significant discrimination in China due to the general fear of HIV contagion (Wu et al., 2001; Yan et al., 2012; Yu et al., 2009). In Chinese culture where the family is the central source of identity, the entire family is stamped with the HIV label after a family member is infected. Family members including children face ostracism and discrimination in education, employment, health care, insurance, and dating and marriage (Li et al., 2008). In addition, PHIV bring shame to their larger community, with economic and social consequences to entire villages (Cao et al., 2006); these consequences result in further loss of “face” of the families affected by HIV in this collectivistic culture.

An important variable in successful recovery from bereavement is the ability to construct a positive narrative of the deceased's life (Maercker et al., 1998), and HIV stigma, in particular the internal stigma perceived by family members, may inflict damage on this process. According to social constructionist models of grief, mourning is a contextual activity that takes into account the meaning of the deceased's life and death, as well as the post-death status of the bereaved affected by the collective conceptualization about the deceased (Neimeyer et al., 2014). Stigma-related beliefs formulated in the social context that promote the concept of PHIV as irrelevant and dispensable, whose death carries more positive weight than their lives, might well interfere with the development of the positive narrative about the deceased. This is particularly tragic among this group of PHIV whose infection resulted from their dedication to family interest. When the bereaved spouse internalizes social stigma of devaluing the life of PHIV, ambivalence regarding the deceased would be expected to be harder to resolve, enhancing the likelihood of protracted grief after the loss. We hypothesized that bereaved spouses who express higher levels of the belief that PHIV's death leaves the deceased, the family and community better off, would report more grief symptoms.

2. Methods

2.1. Participants

This is a cross-sectional survey conducted in a rural county in Henan Province, China. High mortality rate of HIV/AIDS-related death was reported in this area (Li et al., 2010). Among 22 villages with HIV prevalence greater than 10%, seven

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villages were randomly selected. Participants were (1) themselves HIV seronegative and (2) had a spouse who died from AIDS between six and 36 months prior to the study. Bereavement with a period of at least six-month is commonly used in grief studies to denote prolonged grief. A total of 68 participants were recruited with convenience sampling from June to October, 2011. The response rate was 82.9%. Written informed consent was obtained. Three interviewers who had received intensive training in conducting psychological surveys in the HIV affected populations conducted face-to-face interviews with each participant. Induced distress in the process was handled by experienced medical staff who have been providing psychological support for PHIV and their families. Ethics approval was obtained from the Ethical Review Board of the University of Hong Kong and City University of Hong Kong.

2.2. Measures

Demographic characteristics and duration since the spouse's death were recorded.

Stigma beliefs toward PHIV (shortened as *stigma beliefs*) was measured using three items constructed by the researchers based on interviews with bereaved family members relevant to narratives of PHIV's life versus death in qualitative explorations before this study. Stigma beliefs were assessed with the following three items: "PHIV are better off dead", "Their families are better off when PHIV die", and "The community is better off when PHIV die." These items were rated on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Exploratory factor analysis showed that these three items loaded onto a single factor, explaining 80.48% of the variance. Cronbach's α value was.92 in the present study.

Grief was measured by the Inventory of Complicated Grief with 19 items (ICG; Prigerson et al., 1995). Items include emotional and behavioral reactions that are related to separation distress and identity issues. The 19 items were rated on a 5-point Likert scale from 1 (never) to 5 (always). It has been used in the Chinese population (Chiu et al., 2010; Xu et al., 2014). A cut-off score of 30 has been recommended for prolonged grief disorder (Shear et al., 2006). Cronbach's α of the 19-item ICG was 0.89 in the present study.

3. Results

Table 1 shows that participants were mainly middle-aged, and had few years of education and low income, as would be expected in rural China. A 35.3% (24 out of 68) of participants reported grief scores of 30 or above. Participants with prolonged grief disorder obtained higher education and reported higher levels of stigma beliefs than the counterparts (Table 1).

Grief symptoms were positively associated with stigma beliefs ($r=0.37$, $p<0.01$). After controlling for duration since spouse's death, age, gender, education and family income, stigma beliefs significantly contributed to the variance in grief symptoms ($\beta=0.40$, $F(6, 61)=3.56$, increase of $R^2=0.13$, $p<0.01$).

Table 1
Demographic characteristics of the participants in the groups of normative mourning and prolonged grief disorder.

	Normative mourning (ICG scores <30) $N=44$, 64.7%	**Prolonged grief disorder** (ICG scores ≥ 30) $N=24$, 35.3%	p
	n (%) or Mean $\pm$ SD	n (%) or Mean $\pm$ SD	
Sex			0.61
Male	24 (54.5%)	11 (45.8%)	
Female	20 (45.5%)	13 (54.2%)	
Age (years)	51.27 $\pm$ 9.32	47.04 $\pm$ 8.13	0.07
Education			0.04
Elementary or lower	30 (68.2%)	10 (41.7%)	
Secondary or higher	14 (31.8%)	14 (58.3%)	
Family income (RMB)	1620.45 $\pm$ 470.32	1712.50 $\pm$ 549.56	0.47
Months since the spouse's death	23.34 $\pm$ 7.33	19.46 $\pm$ 9.69	0.07
Stigma beliefs towards PHIV	8.23 $\pm$ 3.75	10.38 $\pm$ 3.42	0.02
PHIV are better off dead	2.86 $\pm$ 1.34	3.58 $\pm$ 1.14	0.03
The families of PHIV are better off when PHIV die	2.80 $\pm$ 1.39	3.33 $\pm$ 1.24	0.12
Community is better off when PHIV die	2.57 $\pm$ 1.34	3.46 $\pm$ 1.25	0.01

1US$=6.1 RMB.

4. Discussion

The present cross-sectional study focused on AIDS-related bereavement in China. This investigation was guided by the theoretical formulation that gives stigma a role in interfering with the grief reactions. Our results showed that the bereaved spouses perceived substantial levels of stigma beliefs relevant to PHIV. The stigma beliefs were associated with prolonged grief symptoms. More alarmingly, more than one third of the participants reported prolonged grief disorder.

The present study specifically examines one component of stigma: beliefs about the dispensability of PHIV, and death as a burden–reduction solution for the affected families and community. These general beliefs would have a great impact on interpreting the life of the deceased. The deceased became infected with HIV when they donated plasma, mainly for financial reasons driven by the needs of their poverty stricken families. This is in stark contrast to the widespread culture of "not speaking ill of the dead", a custom shared by many cultures, that promotes ambivalence resolution and is covert from the loss of a loved one to death.

Our findings that stigma beliefs were positively associated with grief symptoms in the bereaved spouses expand our understanding of their suffering. In HIV prevalent areas, the dynamics may promote that the bereaved are pressured, explicitly or implicitly, to minimize the positive narrative of the deceased, relinquish attachment to the deceased, and interpret their meaning-making of loss as being "better off". Consistent with the social constructionist account of grief, their narrative of the deceased is constructed in compliance with the prevailing collective meaning of loss in the broader societal context (Mizota et al., 2006; Yick and Gupta, 2002) to view the death of the PHIV as a solution. This is incongruent with effective strategies of grieving which magnify the positive and reduce the negative characteristics of the deceased (Maercker et al., 1998). The negative narrative of the deceased as "better off dead" conceptualizes his or her life at best meaningless and at least dispensable, making it difficult for the survivor to heal after the pain of loss. Grief therapy offers an approach that might be helpful for these bereaved spouses. Therapeutic techniques such as using an "empty chair" allow imaginary conversations with the deceased with therapeutic guidance that addresses the struggle about conflicting narratives (Neimeyer, 2012). This therapeutic strategy has been effectively applied in Chinese bereaved samples, and would be particularly apt in helping HIV bereaved individuals (Chow and Chu, in press).

There are a few limitations in the present study. First, the sample size is relatively small. Second, the cross-sectional design hinders conclusion about the predictive effects of stigma beliefs on grief symptoms. Third, participants' grief was assessed exclusively by self-report. Structured clinical interviews and rating from informants may offer a more objective supplement. Fourth,

convenience sampling may result in an over-representative sample of participants with relatively low levels of grief, even though one third of the participants reported prolonged grief disorder.

The findings in the present study contribute to the knowledge about AIDS-related bereavement, by examining the role of stigma beliefs towards PHIV in grief symptoms. The results highlight that combatting stigma in the community and reconstructing the meaning of HIV-related death may be a strategy to reduce suffering in HIV bereaved.

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Contributors

Nancy Xiaonan Yu

Originated research questions and initiated the study. She was responsible for overall coordination, implementation, data collection and analysis, result interpretation, and manuscript writing.

Amy Y.M. Chow

Contributed to result interpretation and manuscript writing.

Cecilia L.W. Chan

Contributed to result interpretation and manuscript writing.

Jianxin Zhang

Monitored field work.

Sunita M. Stewart

Worked on the interpretation and formulation of the findings for this manuscript.

Conflict of interest

The authors declare that there are no conflicts of interest.

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