

Enacted Stigma Influences Bereavement Coping Among Children Orphaned by Parental AIDS: A Longitudinal Study with Network Analysis

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Purpose: The study aims to understand how enacted stigma influences bereavement coping at the style (scale) level and the specific pathways at the strategy (item) level.

Methods: The longitudinal data of 755 children orphaned by parental Acquired Immune Deficiency Syndrome (AIDS) in rural China were used. Grief processing and deliberate grief avoidance were measured at wave 1 (baseline) and wave 2 (one-year follow-up) to reflect bereavement coping in the contexts of being with family members, being with friends, being with community members, and being alone. Enacted stigma that measured at wave 1 was used to assess the experienced stigma of these AIDS-orphaned children. Network analyses were run following regressions.

Results: Controlling for demographics and baseline-level bereavement coping, multivariate regressions revealed that enacted stigma at wave 1 significantly predicted grief processing and deliberate grief avoidance at wave 2. Network analyses showed that, for grief processing, stigma increased searching for meaning alone and with friends and expressing feelings to community members, which then provoked the same strategy across contexts. Meanwhile, stigma triggered the deliberate grief avoidance network by initially suppressing the expression of feelings to community members.

Conclusion: Enacted stigma contributes to bereavement coping. Stigma stirs up complex feelings but forces AIDS-orphaned children to suppress expressions, and it increases needs to process grief through meaning making but cuts supporting forces by promoting avoidance. Interventions are imperative to reduce stigma, improve emotion regulation, and facilitate meaning making for people bereaved by stigmatized deaths.

Keywords: enacted stigma, bereavement coping, AIDS, orphans, network analysis, parental loss

Introduction

Stigma is the “co-occurrence of labelling, stereotyping, separation, status loss, and discrimination”¹ Stigma experienced by an individual could be categorized into enacted stigma (overt), perceived stigma (awareness of others' attitudes), and internalized stigma (inner shame and self-discrimination).^{2,3} For people who lost loved ones to Acquired Immunodeficiency Syndrome (AIDS), all types of stigma are salient in their bereavement experiences.⁴⁻⁶ Such stigma is especially harmful for children due to their frailty.⁷ Children orphaned by parental AIDS (AIDS-orphaned children) are usually ignored, rejected, and referred to in derogatory manners⁸ as people fear about infection through contact with them and interpret their misbehaviors as being like their deceased parent.⁷ Responding to stigma with silence, secrecy, and withdrawal, AIDS-orphaned children's perceived social

support drops, psychological distress increases,⁹ and self-hatred¹⁰ grows. All these factors add an immense weight to the already overwhelming process of bereavement for children.¹¹

Stigma links to a series of negative bereavement outcomes. Higher perceived stigma relates to more intense global psychological distress,¹² depression,⁵ trauma, and problematic grief¹³ among people bereaved for stigmatized death. Among them, grief deserves greater attention because it is the most direct outcome of bereavement.¹⁴ For people whose loved ones died from AIDS, more intense grief was found to be cross-sectionally associated with perceived stigma in South Africa¹⁵ and internalized stigma in China.⁶ Despite their meaningful findings, previous studies have mainly focused on stigma's impacts on bereavement outcomes (eg, grief intensity) rather than bereavement coping (eg, grief processing and deliberate grief avoidance). Moreover, little attention has been given to the influence of enacted stigma. Theoretically, enacted stigma was found, among people stigmatized by epilepsy,¹⁶ breast cancer,¹⁷ and same-sex sexual behavior,¹⁸ to be the source of the perceived stigma and internalized stigma that induced psychological distress and poor adjustment. Practically, as a subjective indicator that could be measured by specific behaviors and events, enacted stigma could be easily identified to inform in-time intervention. Under such circumstances, it would also be meaningful to investigate the role of enacted stigma in bereavement.

Bereavement Coping and Its Social Nature

Bereavement coping refers to “processes, strategies, or styles of managing the situation in which bereavement places the individual”.¹⁹ From the social constructionism perspective, bereavement coping processes involve both social and individual levels, and they manifest in a specific cultural and historical frame.²⁰

Bereavement coping includes grief processing and deliberate grief avoidance.²¹ Grief processing means to accept the reality of loss, experience the pain, adjust to life without the deceased person, emotionally relocate the deceased person and move on, and deliberate grief avoidance is to avoid all reminders of the loss on purpose to prevent the sufferings of moving forward without the loved one.²¹ Both processing and avoidance styles shape bereavement outcomes.²² Grief processing correlated longitudinally with more severe distress and poorer perceived health among the bereaved,²³ and deliberate grief avoidance was found to contribute to the persistence of complicated grief.²⁴

Bereavement coping has an inherent social nature. People's coping styles differ across social contexts. For instance, both Chinese and American bereaved individuals showed less grief processing with friends than with family or while alone.²⁵ In addition, bereaved individuals adjust their styles according to perceived social acceptance of public mourning displays.²⁶ People bereaved for stigmatized deaths are very cautious about disclosing to people around them,²⁷ and some express grief to strangers in online forums instead.²⁸

Although it has been developed in previous studies that both stigma and bereavement coping share significant links with bereavement outcomes,^{6,15,22} whether stigma influences bereavement coping has never been explored. Moreover, bereavement coping was viewed as a single construct and analyzed mainly at the style (eg, processing/avoidance) rather than the strategy level (eg, search for meaning to process grief/not talk about the deceased to avoid process grief), and its social nature is rarely considered. Given that the social context of bereavement coping is important and that stigma has the potential to influence bereavement coping at the strategy level, it is important to understand how specific coping strategies are linked with risk factors, such as stigma and how social contexts make a difference.

The Network Perspective

From a network perspective of psychopathology, mental disorders are not single latent constructs but networks of symptoms that mutually interact and are reciprocally reinforcing,²⁹ and symptom construct rather than reflect disorders.³⁰ In a network model, symptoms are represented by nodes, and between-symptom connections are shown as edges.³⁰ Major life events could activate disorder networks through specific symptom nodes, and different events trigger the same disorder network through distinct pathways.³¹

In recent years, network analyses have been applied to see links between coping strategies and adaptation outcomes.³² Among bereaved earthquake survivors in China, maladaptive coping strategies such as self-blame linked positively with post-traumatic stress disorder symptoms, while adaptive coping strategies such as positive reframing linked closely with post-traumatic growth elements.³³ Until now, links between risk factors, such as stigma and bereavement coping have never been studied with the network approach.

The Present Study

In previous studies,^{6,15} how stigma influences bereavement coping was underexplored, and the strategy-level mechanism from stigma, specifically enacted stigma, to bereavement coping remains unknown. Social contexts in which coping takes place have not received enough attention, longitudinal analyses are rare, and most explorations focused on adults. Addressing all these gaps, the present study intended to investigate the influence of enacted stigma on bereavement coping at both the style and strategy levels. A longitudinal design was adopted, and context-related bereavement coping was measured among AIDS-orphaned children.

Materials and Methods

Study Design and Participants

The present study was part of a larger research project on the psychological adjustment of children affected by parental human immunodeficiency virus (HIV)/AIDS.³⁴ The current study included 755 AIDS-orphaned children aged between 6 and 18 years. Children's understanding of the five elements of death, namely universality, irreversibility, causality, nonfunctionality, and noncorporeal continuation, gradually develops with age.³⁵ From 6 years on, most children can understand the five subcomponents to varying degrees,³⁶ and those who had bereaved for family members have a more mature understanding.³⁷ In this case, it is assumed that children in the present study are capable of comprehending the death-related topic under discussion and answer reasonably regarding their bereavement coping. Detailed information on the sample and recruitment is reported elsewhere.^{34,38} Briefly, the children were recruited from community settings (orphanages and family or kinship care settings) in two rural counties in central China where a large number of residents were infected with HIV due to unhygienic blood collection.³⁴ One child per family was randomly recruited. Baseline data were collected from 2006 to 2007 (wave 1), with follow-ups after 1 year (wave 2) and 2 years (wave 3). Interviewers read questions for children who were too young or had limited literacy and recorded their oral responses.

Regarding the sample size, at least 55 participants were needed for the multivariate analysis (G*Power:³⁹ two tails, 8 predictors, effect size $f^2 = 0.15$, $\alpha = 0.05$, power = 0.80) and 500 for the 29-node network analysis.⁴⁰ Therefore, at least 500 participants were needed for this study. Data from the first two waves were used in the analyzes, since bereavement coping (dependent variable) was not measured in wave 3. There were 755 orphans at wave 1, and 552 of them reported bereavement coping at wave 2. This manuscript followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for reporting observational studies.⁴¹

Variables and Measures

Enacted stigma was measured by the scale that Zhao et al³⁴ developed specifically for children affected by HIV/AIDS. The 14-item scale in Chinese focuses on whether the children had experienced some stigmatization acts and prejudice from others and the consequences of such stigmatization and prejudice (eg, "physically abused by other people or other kids" and "I was hurt by how people looked at me or talked to me") (1 = never, 5 = always). The Cronbach's α for enacted stigma in wave 1 (ES_1) was 0.869 in this study.

Bereavement coping was measured by the 18-item grief processing scale and the 10-item deliberate grief avoidance scale by Bonanno et al.²³ The grief processing scale measures the frequencies of using five strategies, namely, thinking about the deceased, searching for meaning, having positive memories of the deceased, talking about the deceased, and expressing feelings about the deceased. The deliberate grief avoidance scale measures frequencies of three strategies, including avoiding thinking about the deceased, avoiding talking about the deceased, and avoiding expressing feelings. All eight strategies were phrased in the contexts of family members, friends, and community members. All strategies except talking about the deceased and expressing feelings about the deceased were measured in the context of being alone. The 28 bereavement coping (processing and avoidance) items were measured with a 5-point response option (from 1 = "almost never" to 5 = "almost constantly"). The Cronbach's α for wave 1 grief processing (GP_1), wave 1 deliberate grief avoidance (GA_1), wave 2 grief processing (GP_2), and wave 2 deliberate grief avoidance (GA_2) were 0.920, 0.873, 0.928, and 0.895, respectively.

For demographics, age, sex, orphan type (single orphan or double orphan) and living condition (in an orphanage or with family) of the AIDS-orphaned children, as well as the education levels and occupations of both parents, were recorded. A family

socioeconomic status (SES) score was calculated as the sum (ranging from 0 to 4) of the education score (1 = greater than elementary school, 0 = others) and occupation score (1 = engaged in a nonfarming occupation, 0 = others) of each parent.⁴²

Statistical Analysis

First, descriptive analyses were run for all variables in SPSS. *T*-tests were run to detect differences between the retained participants and dropouts in age, family SES score, and ES₁, GP₁, and GA₁ scores, and chi-square tests were used to test differences in sex, orphan type, and living condition. Correlational coefficients between ES₁, GP₁, GA₁, GP₂, and GA₂ were calculated.

Second, two multivariate regressions were run in the R package mice with GP₂ and GA₂ as the dependent variables, ES₁ as the independent variable, and age, sex, orphan type, living condition, family SES, GP₁, and GA₁ as control variables. Orphan type and living condition were transformed into dummy variables. Missing data were handled with multiple imputation.

Third, a network model was estimated using the R package bootnet. The model involved the ES₁ node (total score) and the 28 GP₂ and GA₂ nodes (item score). The network analysis was run following the steps proposed by Epskamp, Borsboom and Fried.⁴³ The relationship between two nodes was calculated after controlling for the influence of all other nodes. Sparse Gaussian graphical models with the graphical lasso were adopted,⁴⁴ and the tuning parameters were chosen using the extended Bayesian information criterion (EBIC). Bootstrapping (nBoots = 1000) was used to test centrality stability and edge differences. Full Information Maximum Likelihood was applied to deal with missing data. Afterward, a 36-node model that contained an additional seven control variable nodes (age, sex, orphan type, living condition, family SES, GP₁, and GA₁) was run following the same steps of the 29-node model to explore whether the stigma-coping network structure changes profoundly after control variables are involved.

Results

Descriptive Analysis

The 755 AIDS-orphaned children (male: $n = 403$, 51.4%; female: $n = 352$, 46.6%) were 13.16 of age on average ($n = 752$, Range: 6–18, $SD = 2.20$) at wave 1, and 453 and 180 of them were single and double orphans, respectively. A total of 76.7% ($n = 579$) of them lived with family, while 23.3% ($n = 176$) lived in orphanages. The mean family SES score was 1.77 ($n = 612$, Range: 0–4, $SD = 1.15$).

No difference existed between the retained participants and dropouts in sex, ES₁, GP₁, or GA₁ scores. However, the dropouts were older ($t = 1.868$, $df = 750$, $p < 0.001$) and had lower family SES scores ($t = -0.293$, $df = 610$, $p = 0.005$), and they were more likely to be single orphans (84.1% VS 76.4%, $X^2 = 4.276$, $df = 1$, $p = 0.046$) and live with family (87.2% VS 72.8%, $X^2 = 17.134$, $df = 1$, $p < 0.001$). The outcomes of the descriptive analyses and correlational analyses are in Table 1. ES₁ significantly correlated with GP₂ and GA₂.

Multivariate Regressions

The two regressions with GP₂ and GA₂ as the dependent variables generated similar findings (Table 2). After controlling for age, sex, orphan type, living condition, family SES, GP₁, and GA₁, higher ES₁ significantly predicted higher GP₂ ($B = 0.222$, $p = 0.017$, $R^2 = 0.210$) and higher GA₂ ($B = 0.124$, $p = 0.023$, $R^2 = 0.101$).

Table 1 Descriptive and Correlational Analyses (Total Score)

	N	Range	M	SD	2	3	4	5
1: ES ₁	673	14–60	22.20	7.87	0.201***	0.337***	0.124**	0.148**
2: GP ₁	617	18–89	47.16	14.19		0.343***	0.394***	0.039
3: GA ₁	666	10–50	20.51	8.39			0.055	0.204***
4: GP ₂	520	18–90	39.92	13.70				0.245***
5: GA ₂	526	10–50	17.95	7.75				

Notes: *0.01 ≤ $p < 0.05$, **0.001 ≤ $p < 0.01$, *** $p < 0.001$.

Abbreviation: ES, enacted stigma; GA, deliberate stigma; 1, wave 1; 2, wave 2.

Table 2 Detailed Finding of Multivariate Regressions

	GP ₂	GA ₂
Estimates		
ES ₁	0.222**	0.139*
Age	-0.222	0.487*
Sex (female VS male)	4.496***	1.85*
Living condition (family care VS orphanage)	2.936*	-0.648
Orphan type (single VS double)	-2.601	-1.879
Family SES	-0.303	0.408
GP ₁	0.364***	-0.032
GA ₁	-0.196**	0.169**
R ²	0.210	0.101
Adjusted R ²	0.202	0.091

Notes: *0.01 ≤ p < 0.05, **0.001 ≤ p < 0.01, ***p < 0.001.

Abbreviation: ES, enacted stigma; GA, deliberate grief avoidance; 1, wave 1; 2, wave 2.

The Network Analysis

In the 29-node model, 133 out of the 406 edges were nonzero, and their mean weight was 0.032. The maximum drop proportions to retain a correlation of 0.7 in at least 95% of the sample were 0.75 and 0.75 for edge and strength, respectively. According to the criteria by Epskamp, Borsboom and Fried,⁴³ the model was reliable. [Figure 1](#) shows the distribution of strategies (blue edges have positive weights, and red edges have negative weights). Edge characters can be found in [Figure S1](#) of the [Supplementary Document](#).

In [Figure 1](#), grief processing items form separate strategy-based clusters. One strategy in a specific context was more likely to link to the same strategy across contexts rather than other strategies in the same context. However, deliberate grief avoidance items formed one general network, and they were linked across both strategies and contexts.

Four bereavement coping items shared nonzero edges with enacted stigma: H4.2P (Search for some reason, meaning, or way to make sense of the loss alone), H2.2P (Search for some reason, meaning, or way to make sense of the loss with friends), H3.7P (Show feelings about the deceased parent with community members), and H3.8A (Avoid showing feelings about the deceased parent with community members). Bootstrap analysis detected no significant differences among the four edge weights.

From the findings about the network distribution of grief processing items and deliberate grief avoidance items (how grief processing items link to each other) and these items' links with the stigma node (how enacted stigma links to specific grief processing items), two stigma-processing pathways (stigma – searching for meaning alone/with friends – searching for meaning across contexts; stigma – feeling expressions with community – feeling expressions across contexts) and one stigma-avoidance pathway (stigma – avoidance of feeling expressions with community – all avoidance strategies across contexts) were identified.

Network analysis of the 36-node model generated similar findings in terms of node distribution, edge weight and node strength, and model reliability to the 29-node model. Detailed outcomes of the 36-node model are shown in the [Supplementary Document](#) and [Figure S2](#) demonstrates its symptom distribution.

Discussion

Using large-sample (n = 755) longitudinal data from Chinese AIDS-orphaned children, this is the first study to reveal the influence of stigma on bereavement coping. Combining multivariate regressions with network analysis, explorations were conducted at two distinct levels, and attention was given to social contexts. At the style level, higher enacted stigma significantly predicted more grief processing and deliberate grief avoidance in the AIDS-orphaned children one year later. At the strategy level, stigma triggered two networks in specific pathways. Our findings contribute greatly to the theoretical understanding of the effect of stigmatized deaths on bereavement and support the use of network analysis in future studies in the field.

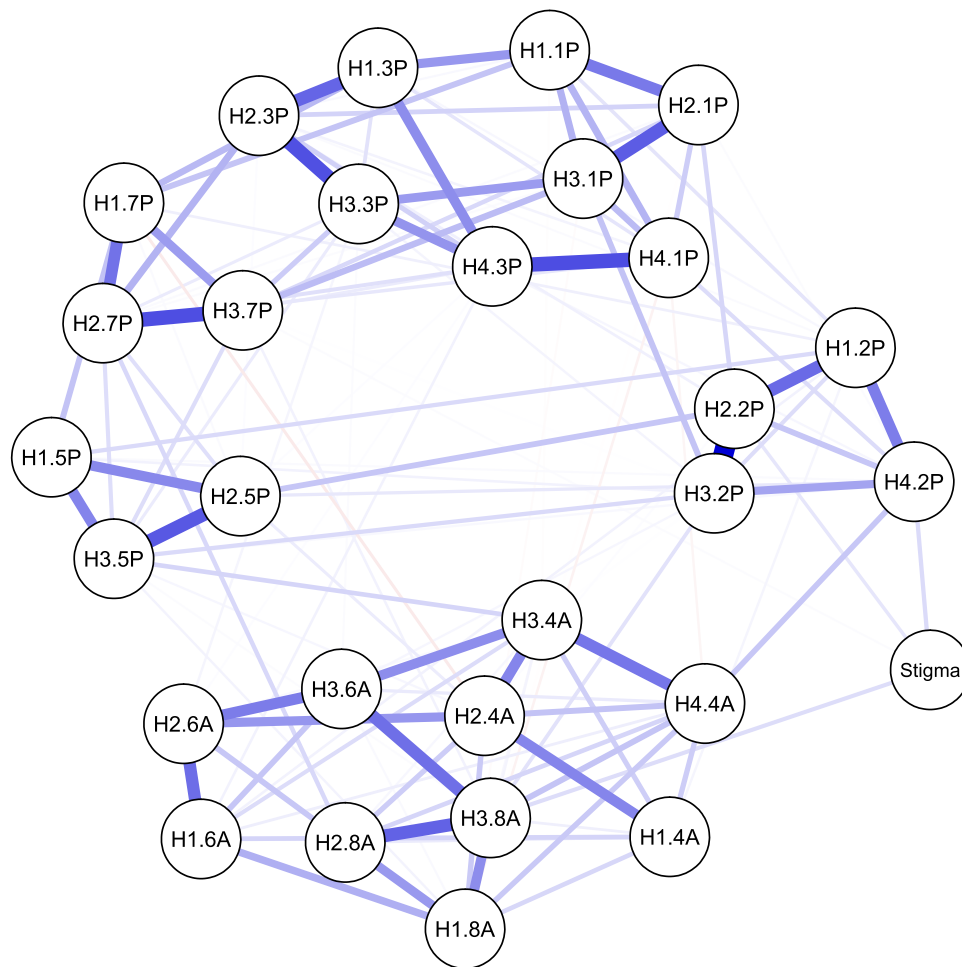


Figure 1 Symptom network of enacted stigma and bereavement coping.

Notes: Blue edges have positive weights, and red edges have negative weights. Edge thickness is proportional to the edge weight. Processing: 1P: Think about your deceased parent; 2P: Search for some reason, meaning, or way to make sense of your loss; 3P: Have positive memories of your deceased parent; 5P: Talk about your deceased parent; 7P: Show your feelings about your deceased parent. Avoidance: 4A: Avoid thinking about your deceased parent; 6A: Avoid talking about your deceased parent; 8A: Avoid showing your feelings about your deceased parent. Contexts: H1: Family member; H2: Friends; H3: Community members; H4: Alone. Stigma: Enacted stigma.

The Style Level

The style-level findings show that how orphans are treated in their social network influences how they deal with bereavement. The developmental challenges of incomplete individuation and dependency on caregivers⁴⁵ and the lack of coping experiences⁴⁶ make children especially susceptible to adverse environmental conditions.

In previous studies, both stigma¹² and bereavement coping styles, such as grief processing and avoidance were found to link positively with negative bereavement outcomes.⁴⁷ By revealing stigma's predictive effects on bereavement coping, present findings indicate coping's potential mediating role in the relationship between stigma and bereavement outcomes.

The Strategy Level

In the network model, while grief processing is linked mainly within the same strategy across contexts, avoidance could be triggered across both strategies and contexts. Processing grief is especially difficult, exhausting, and confusing for children,⁴⁸ so they may find it easier to try one coping strategy at a time. In contrast, when trying to avoid reminders of the loss, distance should be kept from any relevant clues, including emotions, thoughts, and conversations.

The Stigma-Processing Pathway

For grief processing, enacted stigma mainly connected to searching for meaning. Facing stigmatized deaths, children can have contradictory feelings of anger and abandonment as well as love and affection towards their deceased parents,⁴⁹ and

meaning making may help form counternarratives.⁵⁰ Moreover, meaning making may help children construct continuing bonds to gain strength through inner guides (“What would he or she suggest that I do?”)⁴⁶ to deal with enacted stigma.

Stigma-triggered meaning making began in contexts where AIDS-orphaned children were alone and with friends. Making sense of the loss alone would be safe. When support is needed, the rest of the grieving family may be too sad to provide help, while peers who are not directly involved with the death are more available.⁵¹

Enacted stigma also leads to more feeling expression, starting when AIDS-orphaned children are with community members. Stigma could serve as a loss reminder that evokes grief reactions.⁵² Since most of the stigma experiences measured in this study (eg, physical abuse or being called bad names by others) were more likely to be enacted by community members than family or friends, more grief reactions would be stirred up in those contexts. As sustaining emotions during bereavement are particularly hard for children,⁴⁵ more expression is inevitable. This, in turn, could increase feeling expressions across contexts.

The Stigma-Avoidance Pathway

Although enacted stigma brings unavoidable feeling outbursts, it also contributes to intentional feeling suppression. Stigma triggers the whole avoidance network through “avoiding expressing feelings with community members”. This makes sense because a gradual avoidance process should start from with the most sensitive topic and the least intimate group. Avoidance measures like social withdrawal and emotion suppression may be used to manage embarrassment and stigma.⁵³

A Paradox

The two pathways revealed a paradoxical picture. Enacted stigma stirs up complex feelings in orphans but forces them to suppress expressions. It creates stronger needs for meaning making but cuts supporting forces by promoting avoidance. Similar difficulties were vaguely mentioned in previous qualitative explorations regarding stigmatized deaths.⁵⁴ For the first time, this study revealed how such a paradox forms quantitatively at the style and the strategy levels.

Limitations

As participants were recruited from a specific group in a certain region and only one type of stigma was measured, the generalizability of the findings is limited. In addition, the data are not recent enough. Nevertheless, as the study focused on the relationships between variables rather than the prevalence, the findings may not have been seriously distorted.

Practical Implications and Future Studies

In practice, it is imperative to reduce the HIV/AIDS stigma through public education and awareness, and support should be provided to bereaved individuals who suffer from enacted stigma to reduce alienation, shame, misunderstandings, and ambiguity.⁵⁵ Preventing enacted stigma from interfering with people’s acceptance of the death and moving on with the loss is of paramount importance, for which meaning-oriented interventions could be applied.⁵⁶ For children, practitioners could involve the surviving parent or primary caregivers to promote adaptive coping towards stigma and grief.⁵⁷

Future studies could explore the style-level and strategy-level mediation pathways of “stigma – bereavement coping – grief outcomes”. Investigating the moderation effects of some protective factors that could buffer the negative effects of enacted stigma would also be useful. Interventions with randomized controlled trial designs could aim to break the link between enacted stigma and maladaptive bereavement coping. Moreover, the dyadic coping between the surviving parent and the child under the shadow of stigma would also provide insights.

Conclusion

Enacted stigma influences bereavement coping. At the style level, higher enacted stigma significantly predicted more grief processing and deliberate grief avoidance in the AIDS-orphaned children one year later. At the strategy level, enacted stigma stirs up complex feelings but forces AIDS-orphaned children to suppress expressions, and it increases the need to process grief through meaning making but cuts supporting forces by promoting avoidance. Interventions are imperative to reduce enacted stigma, improve emotion regulation, and facilitate meaning making for people bereaved by stigmatized deaths.

Abbreviations

AIDS, acquired immune deficiency syndrome; HIV, human immunodeficiency virus; PTSD, post-traumatic stress disorder; SES, socioeconomic status.

Data Sharing Statement

The data that support the findings of this study are available from the corresponding author, Dr Peilian Chi (email: peilianchi@um.edu.mo) upon reasonable request.

Ethics Approval and Informed Consent

The present study complies with the Declaration of Helsinki. All procedures involving human subjects were approved by the Institutional Review Boards or the research ethics committee at Wayne State University (HIC# 099205B3F), Henan University (1R01MH76488-01), and University of Macau (MYRG2017-00173-FSS). For children's participation, written assent or oral assent was obtained from the children, and written or oral consent was obtained from their caregivers or legal guardians.

Consent for Publication

The authors confirm that the details of any images, videos, recordings, etc., can be published, and that the persons providing consent have been shown the article contents to be published.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report there are no competing interests to declare.

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