

# Anticipatory Grief among Chinese Family Caregivers of Patients with Advanced Cancer: A Cross-Sectional Study

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## ABSTRACT

**Objective:** The objective of this study was to explore the interrelationship between anticipatory grief (AG), caregiver burden, communication, preparation for death, and coping style. **Methods:** A convenience sample of 256 Chinese family caregivers of patients with advanced cancer were recruited from an academic cancer hospital between April 2018 and May 2019. This cross-sectional survey included the AG Scale, caregiver burden (Caregiver Reaction Assessment), communication (Caregivers' Communication with Patients about Illness and Death Scale), preparation for death, and coping style (Simplified Coping Style Questionnaire). Structural equation modeling tested the interrelation between them. **Results:** The final model fitted the data acceptably ( $\chi^2 = 25.79$ , degrees of freedom = 17,  $P = 0.08$ , root mean square error of approximation = 0.05, goodness-of-fit index [GFI]=0.98, adjusted GFI [AGFI]=0.95, parsimony GFI [PGFI]=0.46,

normed fit index = 0.94, comparative fit index = 0.98). Poor communication contributed to less preparation for death and caregiver burden, which further aggravate AG. Communication was positively associated with AG. In addition, communication and positive coping style interacted to further influence caregiver burden. **Conclusions:** Preliminary results supported the model and showed that poor communication, less preparation for death, and caregiver burden contributed to AG while positive coping alleviated AG. Findings suggest the need for further studies to explore effective intervention for communication, preparation for death, burden, and coping style of caregivers to ultimately alleviate AG.

**Key words:** Anticipatory grief, cancer, communication, family caregivers, proactive coping, social support, structural equation model

## Introduction

Anticipatory grief (AG) is defined as the process of mourning, coping, planning, psychosocial reorganization, and their interactions triggered by loss.<sup>[1]</sup> About one-third of family caregivers (FCGs) of patients with life-threatening diseases, such as cancer, experience AG.<sup>[2]</sup> While AG is posit

to be a natural progression when caring for terminally ill relatives, the effects are nonetheless debilitating for FCGs who must learn to cope during the process. This is especially significant given the increase in end-of-life home care.<sup>[3]</sup>

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The grief literature has grown exponentially since introduction of the concept by clinicians Cobbs and Lindemann following the Coconut Grove nightclub fire in Boston, USA, in 1942.<sup>[4]</sup> Research in AG has since expanded to encompass several social phenomena, albeit there are still only a few intervention studies focused on FCGs of patients with cancer.<sup>[3,5,6]</sup> The reason may be a lack of thorough understanding or consensus on the influencing factors of AG, focused on patients' disease-related and demographic factors.<sup>[7-15]</sup> Disease-related and demographic factors contribute to screening high-risk groups, but it is difficult to plan interventions which are conducive to improve AG.

The exploration of psychosocial factors is therefore important, as are studies that explore the relationship between psychosocial factors and AG.<sup>[16]</sup> Preparation for death, as a psychosocial factor, is usually defined as the present and future readiness of the impending death of a patient by the caregiver, and encompasses cognitive, affective, and behavioral dimensions.<sup>[17]</sup> Preparation helps to facilitate the grieving process and reduce the grief reaction.<sup>[18,19]</sup> A nationwide population-based cohort study showed that the preparation for death was associated with AG.<sup>[14]</sup> At the same time, caregiver burden, communication avoidance, and coping style were related to AG.<sup>[14,20,21]</sup> Although these studies provided opportunities for AG intervention, the mechanism of interaction between AG and these factors has not been clarified and so precise intervention tends to be unproductive.

In the real world, AG is not directly affected by a single variable but produced by the interplay of variables. Research showed that self-distraction of coping was related to caregiver burden.<sup>[22]</sup> Since AG was associated with caregiver's burden and coping styles, it can be hypothesized that coping styles mediate caregiver's burden and AG. In addition, it can also be inferred that caregiver's burden may be a mediator between preparation for death and AG, and between communication and AG. Studies have shown that less preparation for death means a greater care burden, as communication was significantly associated with caregiver burden.<sup>[23,24]</sup> Finally, at the patient's end-of-life, caregivers usually need a great deal of information to eliminate uncertainty and complete preparation for death. Communication is a prerequisite for doing this, and so good communication facilitates FCG's preparation for death.<sup>[25]</sup> Correspondingly, we hypothesized that preparation for death is a mediator between communication and AG. Unfortunately, no known research has tested these hypotheses and the mechanism.

This research was inspired by Stroebe's integrative risk factor framework for the prediction of bereavement

outcome, which indicates that five interlinked elements combine to describe and determine the sources of individual differences in adjustment to bereavement.<sup>[26]</sup> According to the literature review, we hypothesized that coping style, communication, preparation for death, and care burden are related to AG. At the same time, care burden is a mediator between preparation for death and AG, communication and AG, and coping style and AG [Figure 1]. Accordingly, this study aims to explore the interrelationship between these psychosocial factors and AG in order to lay the foundation for effective interventions to alleviate AG.

## Methods

### Study design

This was a descriptive cross-sectional research design, using a self-administered questionnaire to collect data on factors related to caregivers' AG: preparation for death, communication, care burden, and coping style. Ethical approvals were received from the institutional review board of Peking University Cancer Hospital, China, (Approval No. 2018KT25). All participants gave written informed consent.

### Participants

This cross-sectional descriptive study was conducted between April 2018 and May 2019. A convenience sample was recruited from an academic cancer hospital in Beijing, China. Inclusion criteria were as follows: (a) age  $\geq 18$  years, (b) primary FCG designate of a patient with stage IV solid tumor, (c) time of care lasting  $\geq 2$  months, (d) awareness of the patient's disease condition, and (e) volunteer for this study. We excluded persons unable to complete the questionnaire due to cognitive impairment, communication disorders, or weakness.

Of the 305 potential participants who were screened, 268 were recruited, and 256 were ultimately included in the final analysis [Figure 2].

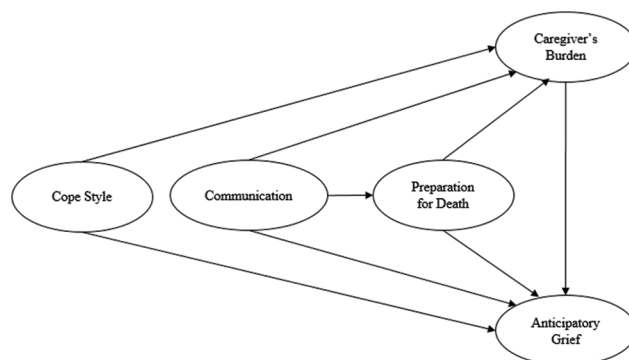


Figure 1: Hypothesized model

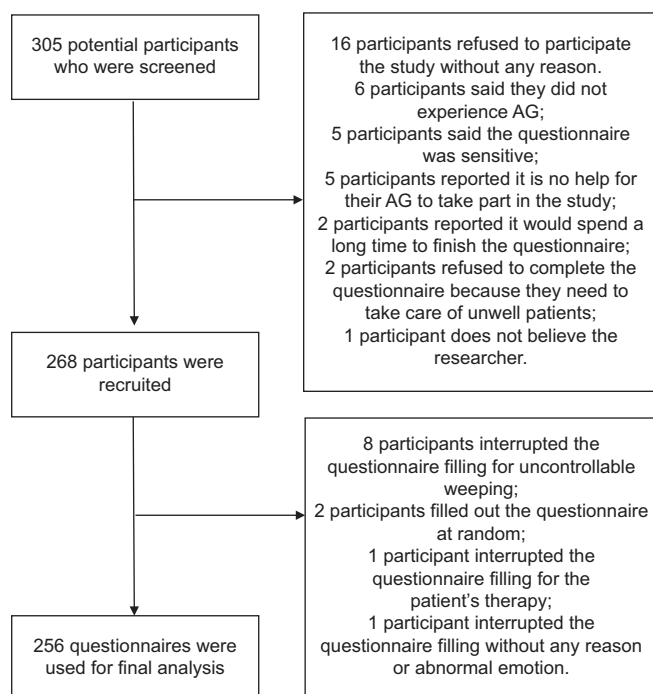


Figure 2: Sample inclusion flowchart

## Measurements

### Sociodemographic of caregivers and the disease of patients

A self-designed questionnaire was used to collect sociodemographic data of caregiver participants including age, gender, education, marital status, relationship with the patient, and patient's cancer types.

### Anticipatory grief

AG was assessed using the Chinese version of the AG Scale, which was developed by Theut and modified by Xin.<sup>[13,25]</sup> It consisted of 27 items, including seven subscales: guilt (4 items), anger (3 items), anxiety (4 items), irritability (4 items), sadness (4 items), feeling of loss (5 items), and decreased ability to function at usual tasks (3 items). The items were scored on five-point Likert scales that ranged from strongly disagree to strongly agree to measure the AG level. Higher scores reflected a higher level of AG. The content validity index (CVI) was 0.963, Cronbach's  $\alpha = 0.896$ , and Cronbach's  $\alpha$  for the subscales ranged between 0.788 and 0.896.<sup>[13]</sup>

### Caregiver burden

Caregiver burden was assessed using the Caregiver Reaction Assessment (CRA), which was developed by Given and modified by Zheng.<sup>[27,28]</sup> The CRA consisted of 24 items, including five subscales: impact on finances (3 items), impact on health (4 items), impact on schedule (5 items), lack of family support (5 items), and caregiver's esteem (7 items). The items were scored on five-point Likert scales that ranged from strongly disagree to strongly agree;

the average score of each subscale was calculated separately. Higher scores of the first four subscales reflected a heavier caregiver burden; higher scores of caregiver's esteem subscale reflected a lighter caregiver burden. The CVI for subscales ranged between 0.9 and 1.0, and the Cronbach's  $\alpha$  for subscales ranged between 0.612 and 0.732.<sup>[28]</sup>

### Coping style

Coping style was assessed using the Simplified Coping Style Questionnaire (SCSQ), which was developed by Xie and consisted of 20 items, including two subscales: positive coping and negative coping.<sup>[29]</sup> A score of 0 to 3 was given for never adopted, occasionally adopted, sometimes adopted, and frequently adopted. The higher score of a subscale meant a more inclination to choose this coping style. The test-retest reliability of the SCSQ = 0.89; the Cronbach's  $\alpha = 0.90$ , and the Cronbach's  $\alpha$  for subscales = 0.89 and 0.78.<sup>[29]</sup>

### Communication

Communication was assessed using the Caregivers' Communication with Patients about Illness and Death (CCID) Scale. The CCID consists of five items scored on a five-point Likert scale that ranged from "not at all" to "maximum yes" and measures the communication level between caregivers and patients concerning illness and death.<sup>[30]</sup> Higher scores reflected lower levels of communication. Cronbach's  $\alpha$  was 0.91. Following the Brislin model,<sup>[31]</sup> we translated the CCID. The CVI for the Chinese version of the CCID was 1.00, and Cronbach's  $\alpha$  was 0.847.

### Preparation for death

A single item based on previous studies of preparedness was used to measure this construct.<sup>[14,32]</sup> The single-item question "To what extent do you think you have prepared for the patient's death?" was used to directly measure caregivers' preparation for death. It was scored on a five-point Likert scale that included none, insufficient, sufficient, more sufficient, and complete.

### Data collection and statistical analysis

The researcher screened patients with advanced cancer through the Hospital Information Management System and then surveyed patients about who were their primary FCGs. Before entering the study, all participants were informed about the nature and the purpose of the study. They volunteered to participate and signed an informed consent form, and their autonomy to withdraw at any time of this study was respected. Participants were asked about uncompleted items to maximize the completeness of the questionnaire. Ultimately, final questionnaires that were  $\geq 90\%$  complete were included in the statistical analysis.

GPower 3.1 was used to test whether the sample size was sufficient. Wilcoxon–Mann–Whitney test was used to verify the test efficiency, with  $\alpha = 0.05$ , two tails, and an effect size of  $d = 0.5$ .<sup>[33]</sup> The power ( $1-\beta$ ) was 0.9999, thus verifying that the sample size was sufficient.

The IBM SPSS Statistics 22.0 (IBM Corp., USA) was used for data analysis. Less than 2% of the data were missing; results from Little’s MCAR test showed that these values were missing completely at random ( $P > 0.05$ ). The missing data were replaced by mean imputation. Descriptive statistics and Pearson correlation were used for statistical analysis. The hypothesized model [Figure 1] was tested using structural equation modeling (SEM) with IBM SPSS AMOS version 21.0 (IBM Corp., USA). We treated the ordered categorical variable preparation for death as a continuous variable.<sup>[34]</sup> Maximum likelihood estimation was used for parameter estimation. The ratio of cases to model parameters for SEM recommends should be more than 10:1.<sup>[35]</sup> In this study, 256 cases were available to test a model with 10 parameters for a ratio of 25:1, which was acceptable. The model fit indices were as follows: Chi-square ( $\chi^2$ ), degrees of freedom (*df*), *P* (probability level), root mean square error of approximation (RMSEA), goodness-of-fit index (GFI), adjusted GFI (AGFI), parsimony GFI (PGFI), normed fit index (NFI), and comparative fit index (CFI).

The critical value for GFI, AGFI, NFI, and CFI is 0.90 or higher.<sup>[35]</sup> Low values (between 0 and 0.08) for RMSEA and above 0.05 for PGFI indicate a good fitting model.<sup>[35]</sup> Low value ( $<5.00$ ) for  $\chi^2/df$  and low nonsignificant values are preferred.<sup>[35]</sup>

## Results

### Demographics of caregivers and the disease of patients

The demographics of caregivers and the disease of patients are shown in Table 1. Of all 256 participants, the average age was  $49.10 \pm 12.87$  and the majority were female (63.28%) and spouse of the patients (58.98%).

### Descriptions and correlations of major variables

The mean, standard deviation, and correlation of major variables are shown in Table 2. The variables followed the normal distribution. Caregivers experienced a moderate-to-upper level of AG. Caregivers had a high level of esteem and a mild lack of family support. Meanwhile, caregivers suffered moderate financial problems and mild health problems. The schedule was moderately impacted because of patient care. Caregivers exhibited both positive and negative coping but were more inclined to choose positive coping styles. Finally, caregivers rarely communicated the disease and death with patients and made little preparation for death.

**Table 1: Sociodemographic of caregivers and the disease of patients (n = 256)**

Items	n (%)
Age (years), Mean $\pm$ SD	49.10 $\pm$ 12.87
Gender	
Female	162 (63.28)
Male	94 (36.72)
Education	
Primary school or less	19 (7.42)
Junior high school	48 (18.75)
Senior high school	69 (26.95)
Junior college or above	120 (46.88)
Marital status	
Married	237 (92.58)
Other	19 (7.42)
Relationship with patients	
Spouse	151 (58.98)
Adult child	73 (28.52)
Parents	19 (7.42)
Others	13 (5.08)
Cancer types of patients	
Lung cancer	95 (37.11)
Colorectal cancer	42 (16.41)
Gastric cancer	37 (14.45)
Esophageal cancer	25 (9.77)
Head-neck tumors	21 (8.20)
Others	36 (14.06)

Analysis of the correlations revealed that there existed significant relationships between AG and other variables, and between impact on schedule and other variables. Caregiver’s esteem was significant related to impact on health, impact on schedule, lack of family support, and preparation for death. Impact on health was related to all caregiver burdens, communication, and AG. Impact on finances was related to positive coping, communication, preparation for death, AG, and all caregiver burdens except for esteem. Lack of family support was associated with all other variables except preparation for death. Positive coping was associated to negative coping, AG, and caregiver burden expect esteem. Negative coping was positively associated with AG, impact on schedule, lack of family support, and positive coping. Poor communication presented a significant correlation with severer AG and heavier caregiver burdens except esteem. Preparation for death presented a significant correlation with milder AG, lower esteem, less impact on schedule, and less impact on finances.

### Test of the hypothesized model

Although the hypothesized model fitted the data acceptably, the model fitting index was poor [ $\chi^2 = 26.462$ ,  $df = 16$ ,  $P = 0.048$ , Table 3].  $P < 0.05$  indicated that the model was inconsistent with the covariance data.

According to the literature review, clinical experience, and the principle of model modification, the hypothesized

Table 2: Descriptions and correlations of major variables

Variable	1	2	3	4	5	6	7	8	9	10
1. AG	1									
2. CE	0.30**	1								
3. IH	0.43**	-0.26**	1							
4. IS	-0.63**	0.32**	0.45**	1						
5. IF	0.44**	0.04	0.47**	0.46**	1					
6. LFS	0.41**	-0.15*	0.35**	0.36**	0.34**	1				
7. PC	-0.17**	0.11	-0.19**	-0.14*	-0.15*	-0.18**	1			
8. NC	0.20**	0.08	0.08	0.19**	0.12	0.21**	0.25**	1		
9. Com	0.41**	0.08	0.22**	0.29**	0.26**	0.14*	-0.12	0.07	1	
10. DP	-0.29**	-0.16*	-0.04	-0.17**	-0.14*	-0.03	0.09	-0.02	-0.12	1
Mean±SD	88.06±18.42	4.11±0.53	2.23±0.81	3.74±0.77	2.92±1.09	2.15±0.77	1.86±0.52	1.34±0.48	3.60±1.13	1.61±0.88

\*P<0.05, \*\*P<0.01. AG: Anticipatory grief, CE: Caregiver's esteem, IH: Impact on health, IS: Impact on schedule, IF: Impact on finances, LFS: Lack of family support, NC: Negative coping, PC: Positive coping, SS: Social support, Com: Communication, DP: Preparation for death, SD: Standard deviation

Table 3: Fitting indicators of the model

Fitting indicator	P	$\chi^2/df$	RMSEA	GFI	AGFI	PGFI	NFI	CFI
Reference standard <sup>[35]</sup>	>0.05	<5.00	<0.08	>0.90	>0.90	>0.05	>0.90	>0.90
The hypothesized model	0.048	1.65	0.05	0.98	0.94	0.43	0.94	0.98
The final model	0.078	1.52	0.05	0.98	0.95	0.46	0.94	0.98

RMSEA: Root mean square error of approximation, GFI: Goodness-of-fit index, AGFI: Adjusted GFI, PGFI: Parsimony GFI, NFI: Normed fit index, CFI: Comparative fit index

model was revised. The final model excluded a path than the hypothesized model: the direct path from preparation for death to caregiver's burden was suggested by covariance analysis and included one additional path: a direct path between positive coping and communication was suggested and seemed theoretically reasonable. The caregiver burden, as the latent variable, was fitted by subscales of impact on health, impact on schedule, impact on finances, and lack of family support, which accounted for 17.3% of the variation rate in the caregiver burden. At the same time, the coping style only indicated positive coping, excluding negative coping. The final model had a better fitting index [Figure 3,  $\chi^2 = 25.79$ ,  $df = 17$ ,  $P = 0.08$ , RMSEA = 0.05, GFI = 0.98, AGFI = 0.95, PGFI = 0.46, NFI = 0.94, CFI = 0.98].

Table 4 shows the path coefficient. Direct effect, indirect effect, and total effect were statistically significant ( $P < 0.05$ ). Caregiver burden and preparation for death mediated communication and AG. Communication had a significant positive direct effect on caregiver burden ( $\beta = 0.35$ ) and AG ( $\beta = 0.14$ ) and a significant negative direct effect on preparation for death ( $\beta = -0.12$ ). Preparation for death had a significant negative direct effect on AG ( $\beta = -0.19$ ), and caregiver burden had a significant positive direct effect on AG ( $\beta = 0.70$ ). Positive coping had a significant negative direct effect on caregiver burden ( $\beta = -0.19$ ) and was negatively associated with communication ( $\beta = -0.12$ ). Collectively, 62.7% of the variance in AG was explained by the final model.

## Discussion

This study explored the interrelationship between four psychosocial factors and AG in order to establish the groundwork for effective interventions to alleviate AG. We use SEM to show the causal relationships between these variables along with 256 FCGs of terminally ill cancer patients. The following is a discussion of findings:

The results indicate communication between advanced cancer patients and their caregivers had a direct effect on caregiver burden and preparation for death. Caregiver burden and preparation for death in turn had a direct effect on AG. Meanwhile, communication also directly affected AG. Positive coping was shown to have an indirect effect on AG through FCGs' burden and was associated with communication. Overall, the study provides an increased understanding of the interrelationship between AG, preparation for death, communication, caregiver burden, and positive coping. We posit that the findings may provide suggestions for health-care providers to help develop effective interventions to alleviate AG.

In this study, caregiver burden presented as economic pressure, disrupted schedules, health deterioration, and lack of family support. First, FCGs have to deal with the cycle of cancer diagnosis and treatment which could be long and expensive, and invariably lead to increased financial pressure.<sup>[36]</sup> Second, complicated cancer diagnosis and treatment process, as well as the continuous increase in care tasks, along with the deterioration of the patient's condition, result in FCGs needing to spend more time and energy on patient care.<sup>[5]</sup> This invariably disrupts the original life plan and contributes to poor health status. At the same time, social stigma of cancer being the result of bad behaviors affects not only the patients but also their caregivers.<sup>[37]</sup> As a result, the FCGs lack social support, including family support.<sup>[38]</sup> In addition, Chinese people's habit of self-containment inhibits proper social support for FCGs, further exasperating feelings of social isolation.

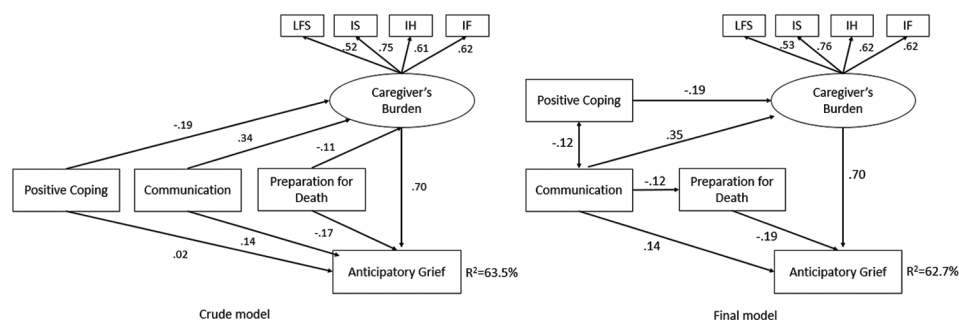


Figure 3: Test of hypothesized model

Table 4: Effect estimates of the final model

Path	Direct effect				Indirect effect				Total effect			
	Standard coefficients	SE	B (95% CI)	P	Standard coefficients	SE	B (95%CI)	P	Standard coefficients	SE	B (95%CI)	P
Com→DP	-0.116	0.061	-0.239-0.000	0.048	-	-	-	-	-0.116	0.061	-0.239-0.000	0.048
DP→AG	-0.189	0.045	-0.278-0.100	0.001	-	-	-	-	-0.189	0.045	-0.278-0.100	0.001
Com→AG	0.137	0.057	0.022-0.245	0.021	0.265	0.054	0.159-0.372	0.001	0.403	0.055	0.287-0.503	0.001
Com→CB	0.350	0.068	0.208-0.473	0.001	-	-	-	-	0.350	0.068	0.208-0.473	0.001
CB→AG	0.696	0.051	0.593-0.795	0.001	-	-	-	-	0.696	0.051	0.593-0.795	0.001
PC→CB	-0.187	0.066	-0.324-0.064	0.004	-	-	-	-	-0.187	0.066	-0.324-0.064	0.004
PC→AG	-	-	-	-	-0.130	0.045	-0.221-0.045	0.004	-0.130	0.045	-0.221-0.045	0.004

Com: Communication, DP: Preparation for death, AG: Anticipatory grief, CB: Caregiver's burden, PC: Positive coping, CI: Confidence interval

It is noteworthy that caregiver burden, as a mediator, was directly affected by communication and positive coping, which then affected AG. We also found that caregiver burden was positively associated with AG. This is probably because the heavier the caregiver burden, the heavier the physiological and psychosocial loss, in instances where loss causes AG. Here, the health-care provider could alleviate AG through intervening to alleviate the caregiver burden, through assistance, such as home-based palliative care, mindfulness-based stress reduction, and emotion regulation therapy.<sup>[39-41]</sup>

The result revealed communication between patients and their FGCs about cancer and death was positively related to caregiver burden, and caregiver burden was also positively related to AG. In traditional Chinese culture, talking about death is a taboo and people can often make decisions for others through the “principle of beneficence,” that means to protect others by force, commonly known as “for your own good.”<sup>[42]</sup> Hence, caregivers who are hesitant or ignorant about communicating with the patients to obtain their opinion, act as the agent and tend to make decisions for the patients based on their own understanding and perspective of the disease or from the perspective of social customs and concepts. Further, persons influenced by Confucianism believe that filial piety is measured by the length of life, often ignoring the quality of parents’ lives.<sup>[43]</sup> Consequently, it is common to see that adult children try their best to prolong the life

of parents regardless of financial resources, manpower, time, and parents’ quality of life in clinical practice. Poor communication increases unnecessary burden and AG. Conversely, poor communication exacerbates caregivers’ psychological distress (i.e., depression and emotional exhaustion), which may lead caregivers to experience high levels of AG.<sup>[14,44]</sup> It is suggested that health-care providers strengthen caregivers’ communication desire and skills, and conduct randomized-controlled studies to verify the effectiveness of interventions.

Interestingly, only positive coping had an indirect effect on AG through the caregiver burden. It is well known that coping is an important moderator between stress and outcomes.<sup>[45]</sup> The stressors for many FGCs came from the patient’s cancer diagnosis, disease progression, and death. Caregivers, who expressed positive coping actively, sought ways to relieve stress and engaged in activities that helped with distraction, as they struggled to cope, and/or sought advice from others, which helped to decrease the burden and thus moderate the severity of AG. The final model in our study displayed that positive coping was negatively related to AG. However, studies observed the interrelationship between coping, caregiver burden, and AG.<sup>[14,21,46]</sup> Thus, the relationship between the three needs to be confirmed by further research.

The results showed preparation for death mediated communication and AG. Barriers to end-of-life planning can include lack of knowledge, uncertainty about illness

prognosis, and ineffective communication.<sup>[19]</sup> FCGs who make little or no preparation for the patient's death may experience AG.<sup>[15]</sup> For example, families frequently experienced psychological distress and disturbance when attempting to manage or sort funeral affairs in the event of an emergency or unexpected death.<sup>[19]</sup> Less communication impedes patients' perception of illness and prognosis and caregivers' understanding of patients' wishes.<sup>[19]</sup> By communicating effectively with the patients, caregivers can arrange to handle patients' affairs before and after their death, thus reducing psychological distress and AG. It is suggested that health-care providers improve not only communication between caregivers and patients but also caregivers' knowledge and perception of patient prognosis and provide available resources through education and then improve the physical, psychological, and behavioral aspects of the caregiver's death preparation.

### Limitations

This study had a few limitations. First, this is a cross-sectional study, and so it confines explanations of the causal relationship between stated variables. Second, the study was conducted in one cancer center using convenience sampling to recruit participants, thus limiting generalization due to potential selection bias and the representativeness of the sample. Then, the measurement of death preparation is limited by the tools available and the need to develop a mature and comprehensive scale. Last, demographic variables were not included in SEMs, and the influence of demographic variables on AG may be further analyzed in future studies.

### Conclusions

This preliminary study supported the final model and showed that poor communication, less preparation for death, and caregiver burden contributed to AG while positive coping helped alleviate AG. Further studies should be conducted to explore effective interventions for communication, preparation for death, burden, and coping style of caregivers, to ultimately alleviate AG for FCGs in China and globally.

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Nil.

### Conflicts of interest

There are no conflicts of interest.

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