Applicability of the pre-death grief concept to dementia family caregivers in Asia

Tau Ming Liew[1]

Department of Geriatric Psychiatry, Institute of Mental Health, Singapore
Correspondence to: T. M. Liew, E-mail: tau_ming_liew@imh.com.sg

Objective: Pre-death grief is prevalent among dementia family caregivers. When unaddressed, it produces adverse outcomes. With its research primarily conducted in Caucasians, its applicability to non-Caucasians is uncertain. We explore the existence and the characteristics of pre-death grief in a multi-ethnic Asian population using an established pre-death grief scale—Marwit–Meuser Caregiver Grief Inventory (MM-CGI).

Methods: Seventy-two dementia family caregivers were recruited from a tertiary hospital. Existence of pre-death grief was shown by its measurability on MM-CGI, together with good internal consistency reliability and construct validity. Characteristics of pre-death grief were explored through multivariate linear regression of MM-CGI and by comparing MM-CGI scores with those from the original US study using one-sample T-test.

Results: In the Asian context, pre-death grief was measurable in a reliable and valid manner. Risk factors of pre-death grief included caring for patients with severe dementia, spousal relationship and secondary or below education. Influence of culture was palpable—Asians had more worries and felt isolation, and certain ethnicity showed more pre-death grief.

Conclusions: Pre-death grief is applicable even to the non-Caucasian population. It bears much similarity to that in Caucasians. Yet, its expression is modified by culture. Clinicians working with non-Caucasian populations need to be sensitive to its presence and to the influence of culture on its expression. © 2015 The Authors. *International Journal of Geriatric Psychiatry* published by John Wiley & Sons, Ltd.

Introduction

Traditionally, the emotional needs of dementia family caregivers are conceptualized with the transactional model of stress and coping (Lazarus and Folkman, 1984; Pearlin *et al.,* 1990). In this model, the focus is specifically on the emotion of stress, with emphasis on improving coping skills and lowering stress level. This has translated into caregiver services like disease education, skills training, stress management and respite care. However, stress is only one of the emotions experienced by caregivers, and there are a complex range of other emotions, such as guilt, denial, sadness and anger. From the recent evidence, this whole array of emotions can be better understood using the concept of pre-death grief (Blandin and Pepin, 2015).

Pre-death grief is the emotional response as dementia family caregivers mourn for the psychologically absent patient and anticipate impending losses (Blandin and Pepin, 2015). It is prevalent among dementia caregivers (Chan *et al.*, 2013) and can be more overwhelming than hands-on care issues (Frank, 2007). Caregivers who do not recognize the presence of pre-death grief tend to deny the losses they experienced and attempt to control the uncontrollable progression of dementia. They become more paternalistic in their communication with the patients and more authoritarian in making decisions related to the patients. Such

behaviours create inequity in the dyadic patient–caregiver relationship, with the caregivers feeling more helpless and the patients losing the sense of autonomy (Piiparinen and Whitlatch, 2011). With this understanding, it is not surprising that pre-death grief has been linked to negative consequences like caregiver burden (Holley and Mast, 2009), caregiver depression (Sanders and Adams, 2005; Chan *et al.,* 2013) and caregivers' desire to institutionalize the patient prematurely (Walker *et al.*, 1995).

However, the published literature on pre-death grief is derived primarily from the Caucasian population (Chan *et al.*, 2013). Because the expression of grief varies with culture (Eisenbruch, 1984), the applicability of pre-death grief is uncertain in distinct, non-Caucasian populations. This study investigates the existence (primary aim) and the characteristics (exploratory aim) of pre-death grief in a multi-ethnic Asian population using a well-established pre-death grief scale—the Marwit–Meuser Caregiver Grief Inventory (MM-CGI).

Methods

Study design

This study used a cross-sectional design.

Participants and procedures

Ethical approval was obtained from the Domain Specific Review Board of National Healthcare Group, Singapore.

Consecutive sampling at a psychogeriatric clinic was conducted from July to November 2014. Family caregivers who met the inclusion criteria were invited to participate in the study. The following inclusion criteria were used: (i) spouses or children of patient with dementia; (ii) caring for a patient with dementia not residing in nursing home; (iii) able to read in English; and (iv) aged at least 21 years. Participants completed self-administered questionnaires containing demographic information and MM-CGI. The other scales of related construct, such as Prolonged Grief Scale (PG-12), Zarit Burden Interview (ZBI) and Centre for Epidemiologic Studies Depression Scale (CES-D), were also included to contrast with MM-CGI.

Measures

Marwit–Meuser Caregiver Grief Inventory is a pre-death grief scale developed empirically from extensive qualitative interview of dementia caregivers (Marwit

and Meuser, 2002). Its 50 items are assessed through 5-point scales and summed to generate a total score and three subscale scores corresponding to the different dimensions of loss—personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation. In the original US study (Marwit and Meuser, 2002), MM-CGI showed high internal consistency reliability, with Cronbach's alpha ranging from 0.90 to 0.96. It also had good construct validity, with strong correlation with Anticipatory Grief Scale (Pearson's correlation coefficient, $r = 0.798$). Meanwhile, personal sacrifice burden subscale correlated with Caregiver Strain Index ($r = 0.730$), heartfelt sadness and longing subscale with Anticipatory Grief Scale ($r = 0.666$) and worry and felt isolation subscale with Well-being Scale ($r = -0.718$). The authors of MM-CGI proposed using one standard deviation above the normative mean of a population to indicate high pre-death grief and a need for further interventions. In the US population, this translates to cut-off scores of >175 for MM-CGI, >68 for personal sacrifice burden subscale, >59 for heartfelt sadness and longing subscale and >52 for worry and felt isolation subscale. Such normative values were not available for the Singapore population at the time of this study.

Prolonged Grief Scale is a 12-item pre-death grief scale for caregivers modified from a post-death grief scale, the Inventory of Complicated Grief. It is based on the diagnostic criteria of prolonged grief disorder proposed for ICD-11 (Prigerson *et al.*, 2009). Its first 11 items are rated on 5-point scales and summed to produce a quantifiable total score, while item 12 is scored dichotomously for the absence or presence of socio-occupational dysfunction.

Zarit Burden Interview is a 22-item instrument, rated on 5-point scales. It assesses the perceived burden experienced by caregivers of older persons (Zarit *et al.*, 1980). ZBI has five domains—burden in the relationship, emotional well-being, social and family life, finances and loss of control over one's life (Rankin *et al.*, 1994). ZBI has been validated in Singapore (Seng *et al.*, 2010), with good reliability and construct validity.

Centre for Epidemiologic Studies Depression Scale is a 20-item depression scale, assessed through 4-point scales. Its four domains are depressed affect, positive affect, somatic symptoms and interpersonal problems (Radloff, 1977). CES-D was previously validated in Singapore (Stahl *et al.*, 2008), with Cronbach's alpha of 0.70–0.79 and diagnostic performance of 64–82%.

The three dementia severities in the revised third edition of Diagnostic and Statistical Manual of Mental

Disorders (American Psychiatric Association, 1987) were used as a brief measure of dementia staging. From the three options, participants chose the description that best described the patient with dementia—still capable of independent living (mild stage), needs some assistance with daily living (moderate stage) or needs round-the-clock supervision (severe stage). This brief measure was previously shown to have reasonable agreement with Clinical Dementia Rating Scale ($\kappa = 0.56$–0.6) (Forsell *et al.*, 1992; Juva *et al.*, 1994).

Statistical analyses

If pre-death grief exists in the Asian context (primary aim), it should be measurable on MM-CGI with high internal consistency reliability and with convergent and discriminant validities consistent with the original Caucasian constructs (Marwit and Meuser, 2002). Internal consistency was assessed using Cronbach's alpha. Convergent and discriminant validities were assessed using Spearman's correlation coefficient with Bonferroni adjustment.

We had four hypotheses regarding convergent validity:

(1) MM-CGI measures the experience of pre-death grief. Therefore, it should show stronger correlation with another pre-death grief scale, PG-12, than with ZBI or CES-D.
(2) Personal sacrifice burden subscale captures the experience of individual losses due to caregiving. It resembles caregiver burden measured by ZBI and should correlate stronger with ZBI than with PG-12 or CES-D.
(3) Worry and felt isolation subscale measures the feelings of losing connection with others. It is a feature of grief reaction and should correlate stronger with PG-12 than with ZBI or CES-D.
(4) Heartfelt sadness and longing subscale resembles the traditional concepts of grief, that is, one's intrapersonal reactions to lost relationship. Hence, it should correlate stronger with PG-12 than with ZBI or CES-D.

We made two hypotheses regarding discriminant validity:

(1) Heartfelt sadness and longing subscale should correlate poorer with depression scale CES-D, consistent with ample evidence demonstrating the difference between grief and depression (Prigerson *et al.*, 2009).
(2) MM-CGI should correlate poorly with finances subscale of ZBI and positive affect subscale of CES-D, because they are distinctly different constructs.

The characteristics of pre-death grief (exploratory aim) were studied in two ways. First, linear regression was performed, with MM-CGI as dependent variable, to identify factors associated with pre-death grief. All variables with $p \leq 0.075$ in univariate regression were entered into multivariate regression, and variables with $p > 0.05$ in multivariate regression were removed through stepwise backward selections. Second, the mean scores of MM-CGI and its subscales were compared with those from the original US study (Marwit and Meuser, 2002) using one-sample T-test.

We calculated the sample size using Bonett and Wright's formulas (Bonett and Wright, 2000, 2015), setting the 95% confidence interval width at 0.2. Referencing to the original study (Marwit and Meuser, 2002), we expected the Cronbach's alpha of MM-CGI to approximate 0.90, corresponding to a minimum sample size of 11; Spearman's correlation coefficient between MM-CGI and PG-12 should approximate 0.8, corresponding to a minimum sample size of 72.

Results

We recruited 72 participants. Table 1 shows the basic demographics of the participants and the patients with dementia they cared for.

Cronbach's alpha, which measured the internal consistency of responses, was 0.97 for MM-CGI. Meanwhile, the Cronbach's alpha was 0.94 for personal sacrifice burden subscale, 0.92 for heartfelt sadness and longing subscale and 0.89 for worry and felt isolation subscale.

Contrasting among the three scales of PG-12, ZBI and CES-D (Table 2), MM-CGI expectedly correlated stronger with PG-12 (Spearman's $\rho = 0.79$, $p < 0.001$) than with ZBI or CES-D, while personal sacrifice burden subscale correlated stronger with ZBI ($\rho = 0.74$, $p < 0.001$), heartfelt sadness and longing subscale with PG-12 ($\rho = 0.76$, $p < 0.001$) and worry and felt isolation subscale with PG-12 ($\rho = 0.79$, $p < 0.001$).

As hypothesized, heartfelt sadness and longing subscale correlated poorer with CES-D ($\rho = 0.58$, $p < 0.001$). MM-CGI also correlated poorly with finances subscale of ZBI ($\rho = 0.37$, $p = 0.162$) and positive affect subscale of CES-D ($\rho = 0.33$, $p = 0.530$).

Table 1 includes the p values derived from univariate regression analysis of factors related to MM-CGI. In multivariate linear regression (Table 3), factors associated with higher MM-CGI score included caring

Table 1 Basic demographics of the caregivers and the patients with dementia they cared for ($n = 72$)

Variable	n (%)	p^a
Caregiver-related		
Age, mean (SD)	50.9 (11.6)	0.205
Duration of caregiving in years, mean (SD)	5.2 (4.0)	0.649
Female gender	42 (58.3)	0.206
Ethnic		**0.075**
Chinese	58 (80.6)	
Malay	9 (12.5)	
Indian/Eurasian/Others	5 (6.9)	
Marital status		0.219
Single	17 (23.6)	
Married	46 (63.9)	
Widowed/divorced/separated	9 (12.5)	
Employment status		**0.066**
Working part-time or full-time	47 (65.3)	
Not working	25 (34.7)	
Highest education		**0.027**
Tertiary	24 (33.3)	
Secondary or below	48 (66.7)	
Relationship with the patient with dementia		**0.075**
Child	67 (93.1)	
Spouse	5 (6.9)	
Staying with the patient with dementia	48 (66.7)	0.275
Frequency of caregiving		0.260
Daily	54 (75.0)	
At least once a week	14 (19.4)	
Less than once a week	4 (5.6)	
Status as primary caregiver	55 (76.4)	**0.056**
Patient-related		
Age, mean (SD)	79.6 (8.5)	0.828
Age at dementia diagnosis, mean (SD)	75.1 (8.4)	0.594
Duration of dementia diagnosis in years, mean (SD)	4.5 (3.4)	0.409
Female gender	56 (77.8)	0.545
Stage of dementia		**0.002**
Mild	5 (6.9)	
Moderate	28 (38.9)	
Severe	39 (54.2)	

SD, standard deviation; MM-CGI, Marwit–Meuser Caregiver Grief Inventory.
[a]p value derived from univariate linear regression, with MM-CGI score as the dependent variable. Boldfaced p values are ≤0.075.

Table 2 Spearman's correlation coefficient between the MM-CGI (total and subscale scores) and the other scales of related construct[a]

	PG-12	ZBI	CES-D
MM-CGI	0.79	0.75	0.69
Personal sacrifice burden subscale	0.68	0.74	0.64
Heartfelt sadness and longing subscale	0.76	0.63	0.58
Worry and felt isolation subscale	0.79	0.72	0.72

MM-CGI, Marwit–Meuser Caregiver Grief Inventory; PG-12, Prolonged Grief Scale; ZBI, Zarit Burden Interview; CES-D, Centre for Epidemiologic Studies Depression Scale.
[a]$p < 0.001$ for all the values in the table, after Bonferroni adjustment.

Table 3 The final model in multivariate linear regression, with MM-CGI score as the dependent variable. MM-CGI scores for the respective variables were also shown

Variable	MM-CGI score, mean (SD)	Beta coefficient (95% CI)	p
Ethnic			
Non-Malay	145.7 (31.2)		
Malay	169.3 (26.3)	22.1 (2.8–41.3)	0.025
Highest education			
Tertiary	134.5 (24.8)		
Secondary or below	155.7 (32.3)	17.7 (4.2–31.1)	0.011
Relationship with the patient with dementia			
Child	146.8 (31.6)		
Spouse	172.8 (17.4)	28.6 (4.5–52.7)	0.021
Stage of dementia			
Mild or moderate	134.9 (26.3)		
Severe	160.3 (31.1)	26.0 (13.7–38.3)	<0.001

MM-CGI, Marwit–Meuser Caregiver Grief Inventory; SD, standard deviation; CI, confidence interval.

for patients with severe dementia, spousal relationship, secondary or below education and Malay ethnicity. Employment and primary caregiver status both had $p > 0.05$ and were removed from the final model.

Table 4 compares the MM-CGI total and subscale scores between the current study and the original US study (Marwit and Meuser, 2002). The worry and felt isolation subscale score was 13.8% higher in this study ($p < 0.001$), while the rest of the scores were comparable with those of the USA (marginal difference of −4.4% to 3.7%).

Discussion

Prior to this study, there were uncertainties about the applicability of pre-death grief concept to the Asian population. In many ways, this study supported the existence of pre-death grief in Asia and attests to the universality of human emotions. We showed that pre-death grief was measurable in a reliable and valid manner, using an established pre-death grief scale of MM-CGI. The risk factors of spousal caregivers and advanced dementia reported here were similarly highlighted in a systematic review of the Caucasian

Table 4 Comparison of MM-CGI scores between the original US study (*n* = 166) and the current Singapore study (*n* = 72)

	USA, mean (SD)	Singapore, mean (SD)	Singapore, 95% CI	Difference in score, mean difference (%)	*p*[a]
MM-CGI total score	144.0 (31.6)	148.6 (31.5)	141.2 to 156.0	4.6 (3.2)	0.215
Personal sacrifice burden subscale score	54.3 (14.1)	56.3 (13.1)	53.3 to 59.4	2 (3.7)	0.189
Heartfelt sadness and longing subscale score	48.2 (11.1)	46.1 (10.4)	43.6 to 48.5	−2.1 (−4.4)	0.088
Worry and felt isolation subscale score	40.6 (11.9)	46.2 (10.3)	43.8 to 48.6	5.6 (13.8)	<0.001

MM-CGI, Marwit–Meuser Caregiver Grief Inventory; SD, standard deviation; CI, confidence interval.
[a]*p* value derived from one-sample *T*-test.

studies (Chan *et al.*, 2013). Even the MM-CGI total and subscale scores were largely comparable with those of the USA (Marwit and Meuser, 2002). These results suggest a need for clinicians to be attuned to the pre-death grief experience of dementia caregivers even in the non-Caucasian populations. This is particularly important because pre-death grief in dementia caregivers is commonly disenfranchised (Frank, 2007), and its expression is not generally acceptable in society. Unless the clinicians inquire about its presence, dementia caregivers are unlikely to volunteer such feelings and will suffer in silence until they experienced the irrevocable adverse effects of pre-death grief. By such time, it may be too late to intervene.

This study also demonstrated the palpable influence of culture on pre-death grief. Asian caregivers showed more worries and felt isolation, and certain ethnicity experienced more pre-death grief. To attune to the pre-death grief experience of caregivers, clinicians need to be mindful of the disparate presentations of pre-death grief in different cultures. In the example of Asian caregivers, strong expression of worries and felt isolation may be an indicator of underlying pre-death grief. Such cultural sensitivity is also necessary to tailor person-centred interventions and to better support the emotional needs of caregivers in multi-ethnic populations. The influence of culture on pre-death grief is an area worth further exploration in future researches.

The caregiver risk factors in this study (spouse, lower education and selected ethnicity) paralleled the predictors of complicated post-death grief from a systematic review (Chan *et al.*, 2013). Previous studies showed that greater pre-death grief is a key predictor of post-death complicated grief (Blandin and Pepin, 2015). Identifying shared risk factors between pre-death and post-death grief opens a window of opportunity to target efforts of case finding and early intervention in the pre-death setting. Such efforts can prevent the development of complicated grief following bereavement (Schulz *et al.*, 2006; Holland *et al.*, 2009).

One of the strengths of this study lies with the location where it was conducted. Singapore is a cosmopolitan city in Asia and holds a number of major Asian cultures, including that of the Chinese, Indian, Malay Muslim and Eurasian. This environment provided an opportune test bed to answer our research question on the applicability of pre-death grief in Asia. The results of this study have implications beyond the Singapore population alone. They alert readers on the likely presence of pre-death grief even in the other parts of Asia, and serve as an impetus for further researches on pre-death grief in Asia.

In this study, limited proportion of spousal caregivers participated because a number of them could only read in Chinese and not in English. We also restricted the number of variables entering multivariate regression so that the analyses remain valid given the sample size. Even with these two limitations, we have had reasonable evidence from this study to show that pre-death grief do exist among dementia family caregivers in Asia. We hope to better represent spousal caregivers and identify even more risk factors in our ongoing study involving Chinese MM-CGI and larger sample size.

Conclusion

In summary, pre-death grief is applicable even to the non-Caucasian population, and it is detectable with an objective scale like MM-CGI. Clinicians working with non-Caucasian populations need to be attuned to its presence and be sensitive to the influence of culture on its expression. Such postures are crucial to rein the adverse outcomes of pre-death grief.

Conflict of interest

None declared.

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Key points

- Pre-death grief is also applicable to dementia caregivers in a non-Caucasian population, and it is detectable with an objective scale like MM-CGI.
- To prevent the adverse outcomes of pre-death grief, clinicians working with non-Caucasian populations need to be sensitive to its presence and to the influence of culture on its expression.
- Identifying shared risk factors between pre-death and post-death grief allows targeted efforts of case finding and early intervention in the pre-death setting, thus preventing complicated grief following bereavement.

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