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RESEARCH ARTICLE

Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis

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National Medical Research Council, Grant/ Award Numbers: NMRC/CG/004/2013, NMRC/CSSSP/0014/2017 and NMRC/Fellowship/0030/2016; National University of Singapore **Background:** Caregivers of persons with dementia (PWD) can experience loss and grief long before the death of the person. While such phenomenon of pre-death grief (PDG) has been increasingly described, we are uncertain how it can be distinct from the well-studied construct of caregiver burden.

Objective: To determine whether there are differences in the risk factors of PDG and caregiver burden to aid in our understanding of the relationship between the two constructs.

Methods: Spouses or children of community-dwelling PWD were consecutively sampled from two tertiary hospitals. They completed questionnaires containing a PDG scale, a caregiver burden scale, and information related to the caregiver and PWD. Risk factors of PDG and caregiver burden were identified using multivariate regression, within which PDG and caregiver burden scores were jointly included as two separate dependent variables.

Results: We recruited 394 caregivers with a mean age of 53.0 years (SD 10.7), majority were Chinese (86.6%), children caregivers (86.3%), and primary caregivers (70.8%). In the regression analyses, we identified three risk factors which were shared by both PDG and caregiver burden (later stage of dementia, behavioral problems in PWD, and primary caregiving role) and three other risk factors which were unique to PDG alone (younger age of PWD, lower educational attainment of caregivers, and spousal caregiver).

Conclusions: The different risk factor profiles evidence a distinction between PDG and caregiver burden. They may possibly be distilled into a framework to direct our approach to PDG interventions, which may include using caregiver burden as an opportunity to initiate conversations on grief, exploring the various aspects of losses and encouraging adaptive coping.

KEYWORDS

burden, caregiver, dementia, pre-death grief, risk factor

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1 | INTRODUCTION

Caring for persons with dementia (PWD) can be stressful¹ and is not uncommonly associated with physical and emotional burden.^{1,3} Caregiver burden, in turn, has been shown to predict less desirable outcomes such as premature nursing home placement⁴ and mortality in PWD.⁵ For this reason, many of the current interventions are geared towards reducing the burden of caregivers² and improving their coping skills.⁶ However, there are other challenges that caregivers contend with which are not sufficiently addressed by interventions that focus primarily on burden and coping skills of caregivers. One of such challenges is the experience of loss and grief that is often faced by caregivers but less commonly recognized.⁷

Caregivers of PWD can experience bereavement long before the physical death of the person. They may show emotional, cognitive, and behavioral responses to the multiple *losses* in caregiving,⁸ which include the ambiguous *loss* due to increasing disconnectedness from the PWD who is physically present but psychologically absent, and the anticipation of future *losses* relating to the physical death of the person.⁹ Such experience of loss and grief in the pre-death context (which we refer to as "pre-death grief" (PDG) in this paper) is less recognized^{7,10} or understood, even though it can negatively impact the caregiver-PWD dyadic relationship¹¹ and has been associated with adverse effects such as caregiver depression,^{10,12} and caregivers' desire to institutionalize the PWD.¹³

While PDG has been increasingly described in the literature,^{7,12,14,16} we are still uncertain about how it may be distinct from the well-studied construct of caregiver burden, and whether PDG and caregiver burden are essentially analogous constructs that share similar risk factors. This is especially pertinent considering that prior studies had demonstrated a high correlation between PDG and burden, with correlation coefficients which were reported in the range of 0.66 to 0.76.^{9,17} In this study, we sought to contrast the risk factors of PDG and caregiver burden, and determine whether there are differences in the risk factor profiles that may aid in our understanding of the relationship between the two constructs.

2 | METHODS

2.1 | Participants and procedures

We consecutively sampled caregivers as they accompanied the PWD to the dementia services of the only two tertiary hospitals serving the North-Eastern population of Singapore. The inclusion criteria comprised (1) spouse or child of PWD, (2) caring for PWD who is residing in the community, and (3) age \geq 21 years. The recruitment criteria were predicated on our definition of family caregivers, which includes family members who are involved in the care of the PWD either directly or indirectly¹⁸; hence, we considered the act of accompanying the PWD to the dementia care services as an evidence of indirect involvement in the care of the PWD, which qualifies a person as a family caregiver. The recruitment process had a response rate of 87.8%. At the point of recruitment, the participants completed on-site

Key points

- Pre-death grief (PDG) has been increasingly described in dementia caregiving, but we are uncertain how it can be distinct from the well-studied construct of caregiver burden.
- The different risk factor profiles evidence a distinction between PDG and caregiver burden.
- The risk factors may possibly be distilled into a framework to direct our approach to PDG interventions.

a set of questionnaire comprising a PDG scale (Marwit-Meuser Caregiver Grief Inventory, MMCGI),¹⁷ a caregiver burden scale (Zarit Burden Interview, ZBI),¹⁹ and information related to the caregiver and PWD. Ethics approval was granted by the Domain Specific Review Board of Singapore.

2.2 | Measures

The MM-CGI is a PDG scale that was developed through extensive focus-group interviews with caregivers of PWD to capture the various aspects of losses experienced by caregivers.¹⁷ It has 50 items and includes statements such as "I've lost other people close to me, but the losses I'm experiencing now are much more troubling," "I'm angry at the disease for robbing me of so much," and "I have this empty, sick feeling knowing that my loved one is 'gone'." The items are self-rated by participants on 5-point Likert scales based on how much they agree with the statements (from 1 = strongly disagree to 5 = strongly agree) and summed to generate a total score ranging from 50 to 250. In previous studies, total scores >175 were reported to indicate high PDG which may require clinical attention.^{9,17} The ZBI is a 22-item scale that assesses the perceived burden experienced by caregivers of older persons.¹⁹ The items are rated on a 5-point Likert scale and summed to generate a total score ranging from 0 to 88.²⁰ According to the original test instructions,²⁰ a score range of 21 to 40 indicates mild burden, while 41 to 60 indicates moderate burden and 61 to 88 indicates high burden. In a more recent study,²¹ scores \geq 34 were reported to indicate significant burden that may require clinical attention. MM-CGI^{9,22,23} and ZBI²⁴ have previously been validated in our local population.

Key information on the caregiver and PWD was also captured in the study. The information was based on self-reports by the caregivers or obtained from the medical records when the caregivers were uncertain. Caregiver data included age, gender, ethnicity, marital status, employment status, educational attainment, relationship with PWD, co-residence with the PWD, duration of caregiving, frequency of caregiving, and primary caregiving role. Data relating to the PWD included age, gender, duration of dementia diagnosis, diagnosis of dementia before 65 years old, stage of dementia, and presence of severe behavioral problems. The stage of dementia was assessed based on the descriptors of the three dementia severities in the revised third edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R).²⁵ Participants chose the description that best matched WILEY Geriatric Psychiatry

the PWD–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 adequate agreement with Clinical Dementia Rating Scale (kappa 0.56-0.6),^{26,27} which is one of the most commonly used scale to stage dementia.^{28,29} It is also consistent with the dementia severity descriptions which were re-introduced in DSM-5,³⁰ after the absence of such staging descriptions in the preceding edition of DSM-IV-Text-Revision.³¹ The presence of severe behavioral problems was indirectly measured through the need for admission to the geriatric psychiatry ward, indicating behavioral problems that were too severe to be managed in the community setting.

2.3 | Statistical analyses

Multivariate linear regression³² was employed to identify factors associated with PDG and caregiver burden. Multivariate regression refers to the regression analysis that jointly models two correlated dependent variables (DV) on the same set of independent variables (IV) (that is, in simplified statistical terms, $DV_1 + DV_2 = IV_1 + IV_2 + IV_3 + IV_4 +$). This multivariate analysis allows us to test whether each IV has a significant effect against the two DV (modelled jointly) based on the joint *P*-value generated by the analysis.³²

We included both MM-CGI and ZBI as the two dependent variables in the multivariate regression model. Initially, we performed simple regression analyses (which regress each covariate against the two dependent variables) to identify potential covariates with joint *P*-values \leq 0.05. We then included these potential covariates in multiple regression analyses (which regress the potential covariates together against the two dependent variables) and removed covariates with joint *P*-values > 0.05 through backward variable selection method.³³ All analyses were performed with Stata (version 14).

3 | RESULTS

A total of 394 participants were recruited, with a response rate of 88%. The demographic information of the participants is presented in Table 1. The participants had a mean age of 53.0 years (SD 10.7). The majority were Chinese (86.6%), children caregivers (86.3%) and primary caregivers (70.8%). Mean MM-CGI score was 141.4 (SD 33.8), while mean ZBI score was 34.8 (SD 16.8). In the simple regression analyses, variables identified as potential risk factors (P < 0.05) (Table 1) included those relating to the caregivers (marital status, employment status, educational attainment, relationship with PWD, staying with PWD, frequency of caregiving, and primary caregiving role) and the PWD (age, gender, diagnosis of dementia before 65 years old, stage of dementia, and presence of behavioral problems).

The results of the final regression model are shown in Table 2. Three variables were significant risk factors of PDG but not caregiver burden (age of PWD, educational attainment and relationship with PWD). Another three variables were shared risk factors of both PDG and caregiver burden (stage of dementia, behavioral problems in PWD, and primary caregiving role), although stage of dementia had relatively stronger association with PDG than caregiver burden (standardized coefficient of 0.52 and 0.32, respectively), while primary caregiving role had relatively stronger association with caregiver burden than PDG (standardized coefficient of 0.39 and 0.23, respectively).

4 | DISCUSSION

This is the first study to compare the risk factors of PDG and caregiver burden and demonstrate the differences in risk factor profile between them. Three risk factors are shared by PDG and caregiver burden (later stage of dementia, behavioral problems in PWD, and primary caregiving role), while three other risk factors are unique to PDG alone (younger age of the PWD, lower educational attainment of caregivers, and spousal caregivers). The findings from this study provide evidence of a distinction between PDG and caregiver burden and support the notion that the two constructs are not the same.

Based on the risk factors identified in this study, we postulated a framework in Figure 1 which may potentially be useful to summarize and understand the relationships among the risk factors of PDG and caregiver burden. Most of the risk factors of PDG may possibly be conceptualized within the context of losses related to the past, present, and future.^{15,34} Spousal relationship possibly represents the loss of past relationship-spousal caregivers tend to have longer and more intimate bonds with the PWD,¹⁴ and may experience more grief reactions related to the loss of prior emotional closeness with the PWD.³⁵ Three of the variables (primary caregiving role, behavioral problems in PWD, and more severe dementia) are related to higher care responsibilities which increase the risk of caregiving burden-such constant struggle with caregiving burden can serve as an ongoing reminder to caregivers of the present reality of ambiguous loss, whereby the PWD may be physically present but is a vestige of what he used to be.^{9,15} Severe dementia and younger age of the PWD possibly represent caregivers' anticipation of future losses, such as the loss of the PWD through imminent death (related to severe dementia) or the potential loss of hopes and dreams that had been envisioned in the relationship with the PWD (related to the younger age of PWD).³⁴ Lower educational attainment has previously been linked to poorer coping strategies in individuals^{36,37}-it may have bearings on how caregivers cope with losses, which in turn can have consequences on whether the caregiving is affected by PDG.³⁸

The postulated framework in Figure 1 should be treated as hypothetical at present and will require further validation in future studies. Some of the constructs we proposed in Figure 1 (such as loss of past relationship, present reminder of ambiguous loss, anticipation of future loss, and coping strategies) had not been directly measured in the currently study and hence could not be further evaluated. Future studies should consider measuring each of the hypothesized constructs in Figure 1 and validating the proposed relationships using methods such as path analyses. If shown to be valid, the framework in Figure 1 may be a useful tool to guide interventions for PDG. For example, the approach to intervention may include using caregiver burden as an entry point to initiate conversations with caregivers on loss and grief; exploring the various aspects of loss related to the past, present, and future; and encouraging adaptive ways of coping with the losses (such as not avoiding grief reactions, finding new ways to remain connected

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TABLE 1 Demographic characteristics of caregivers and persons with dementia (*n* = 394), and the association with MM-CGI and ZBI in simple regression analyses

Variable	n (%)	Joint P-Value in Multivariate Regression ^a
Variables related to caregivers		
Age, mean (SD)	53.0 (10.7)	0.098
Female gender, n (%)	236 (59.9)	0.678
Ethnicity, n (%)		0.052
Chinese	341 (86.6)	
Malay	25 (6.3)	
Indian/Eurasian/others	28 (7.1)	
Marital status, n (%)		0.024
Married	271 (68.8)	
Single	94 (23.9)	
Widowed/divorced/separated	29 (7.3)	
Employment status, n (%)		0.005
Not working	123 (31.2)	
Working part-time	52 (13.2)	
Working full-time	219 (55.6)	
Educational attainment, n (%)		<0.001
Tertiary	125 (31.7)	
Secondary or below	269 (68.3)	
Relationship with PWD, n (%)		<0.001
Child	340 (86.3)	
Spouse	54 (13.7)	
Co-residence with PWD, n (%)	264 (67.0)	0.007
Duration of caregiving in years, mean (SD)	6.8 (6.7)	0.380
Frequency of caregiving, n (%)		<0.001
Daily, for at least 4 hours a day	211 (53.6)	
Daily, but less than 4 hours a day	79 (20.0)	
At least once a week	84 (21.3)	
Less than once a week	20 (5.1)	
Primary caregiving role, n (%)	279 (70.8)	0.001
Variables related to PWD		
Age, mean (SD)	79.5 (8.2)	<0.001
Female gender, n (%)	278 (70.6)	0.010
Duration of dementia diagnosis in years, mean (SD)	4.5 (3.5)	0.061
Diagnosis of dementia before 65 years old, n (%)	48 (12.2)	0.002
Stage of dementia, n (%)		<0.001
Mild to moderate	225 (57.1)	
Severe	169 (42.9)	
Severe behavioral problem, n (%)	22 (5.6)	0.001

Abbreviations: PWD, persons with dementia; SD, standard deviation.

^aP value derived from simple regression analyses, with each covariate regressed against the two joint dependent variables (MM-CGI and ZBI scores). Boldfaced P values are \leq 0.05.

with the PWD, and involving other family members in the grieving process). This approach bears much resemblance to the key strategies that have been employed in previous intervention studies for PDG,³⁹⁻⁴¹ which included^{22,39,41-43} (1) recognizing loss (by encouraging caregivers to tell the story of the PWD and identify painful emotions associated with the loss), (2) normalizing grief (by validating the expression of emotions, discouraging the avoidance of grief and helping caregivers to find ways to remain connected emotionally with other caregivers), (3) finding new ways to remain connected to the PWD (such as through celebrations, spiritual practices, humor, and therapeutic touch), and (4) addressing future losses (by focusing on plans for the future and painful future decisions associated with grief).

This study has several limitations. First, the participants were recruited from tertiary centers and may not fully represent community samples. However, this is less likely a problem in our context because majority of PWD in Singapore still receive dementia care from tertiary centers, and the two recruitment centres in this study are the only two dementia services that serve the population in the North-East of Singapore. Second, the proportion of spousal caregivers in this study were much lower than that of the children caregivers (Table 1). **TABLE 2** The final model in multivariate regression, with MM-CGI and ZBI scores as the dependent variables. Significant coefficients (with $P \le 0.05$) are highlighted in bold

	MM-CGI		ZBI		Joint P-Value
Variable	Standardized coefficient (95% CI) ^a	P-value	Standardized coefficient (95% CI) ^a	P-value	in Multivariate Regression
Age of PWD in years	-0.13 (-0.22, -0.04)	0.007	-0.08 (-0.18, 0.02)	0.100	0.022
Secondary or below education (ref: Tertiary education)	0.28 (0.09, 0.48)	0.004	0.10 (-0.11, 0.31)	0.355	0.003
Spousal relationship with PWD (ref: Children)	0.46 (0.18, 0.74)	0.001	0.05 (-0.25, 0.35)	0.756	<0.001
Severe stage of dementia (ref: Mild to moderate)	0.52 (0.34, 0.70)	<0.001	0.32 (0.12, 0.51)	0.001	<0.001
Behavioral problems in PWD	0.74 (0.35, 1.12)	<0.001	0.75 (0.33, 1.16)	<0.001	0.001
Primary caregiving role	0.23 (0.03, 0.43)	0.022	0.39 (0.18, 0.60)	<0.001	0.001

Abbreviations: CI, confidence interval; MM-CGI, Marwit-Meuser Caregiver Grief Inventory; PWD, person with dementia; ref, reference group in multivariate regression; ZBI, Zarit Burden Interview.

^aTo ease the comparison of results, the regression coefficients are standardized so that continuous variables included in the model have means of zero and standard deviations of 1.





Although it is possible that spousal caregivers may have been underrepresented, this is less likely considering our proportion of spousal caregivers (13.7%) were not vastly different from the 16.0% reported in a separate study based on nationally representative samples.⁴⁴ Had more spousal caregivers been recruited, we would expect that the association between spousal caregivers and PDG should remain similar but possibly become more precise (with a narrower 95% confidence interval in the odds ratio), considering that PDG has been consistently highlighted as the central theme for spousal caregivers in the literature.¹⁴ Third, as the scales were self-administered, it is possible that caregivers with lower literacy were under-represented. Fourth, we did not directly measure behavioral problems in PWD, and only had an indirect measure (the need for admission to geriatric psychiatry wards) to capture those with more severe behavioral problems. Fifth, the stage of dementia was assessed only based on self-reports by family caregivers, which may lack the precision of other staging instruments that also encompass objective assessments by the health care professionals. Last, the risk factors were derived from

cross-sectional samples which limit any conclusion on causal-effect relationships.

In summary, the risk factors identified from this study evidence a distinction between PDG and caregiver burden and support the notion that the two constructs are not the same. The risk factors can be further consolidated into a framework that can be useful to guide PDG interventions.

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CONFLICT OF INTEREST

None declared.

AUTHORS' CONTRIBUTIONS

All authors have read and approved the manuscript. Study concept and design: T.M.L. Acquisition of data: T.M.L., P.Y. Analysis of data: T.M.L., B.C.T. Interpretation of data: T.M.L., B.C.T., P.Y., G.C.H.K. Drafting of the manuscript: T.M.L. Revision of the manuscript: T.M. L., B.C.T., P.Y., G.C.H.K. Funding: T.M.L. Project supervision: T.M.L.

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