Psychosocial burden, approach versus avoidance coping, social support and quality of life (QOL) in caregivers of persons with dementia in Java, Indonesia: A cross-sectional study

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Abstract

Background: Dementia-caregiving causes severe distress and has a negative impact on caregivers’ health. This study examined the association of family caregivers’ psychosocial burden and quality of life (QOL), using the revised sociocultural model of stress and coping (rSMSC) (Knight & Sayegh, 2010), in an Indonesian sample.

Methods: Participants were family caregivers of persons with dementia living in Java, Indonesia. Caregivers completed the Burden Assessment Schedule (BAS), the WHOQOL-Bref, the Brief-COPE and the Multidimensional Scale of Social Support (MSPSS). Mediator analyses were performed to examine the association between psychosocial burden, OQL, social support and approach versus avoidance coping.

Results: 45 Indonesian family caregivers (M = 41 years, SD = 12.38; 77.8% female; 64.4% Cohousing) of persons with dementia ((M = 41 years, SD = 12.38) were involved. Caregivers’ psychosocial burden was negatively associated with their QOL. Avoidance coping showed a significant indirect negative effect of psychosocial burden on their QOL in the physical and psychological (partial mediations) and social domain (complete mediation). Approach coping and social support did not reveal significance in the mediation analyses.

Conclusion: Interventions for caregivers should integrate psychoeducation and training in the rSMSC, especially focusing on the benefits and harms associated with the different approach and avoidance coping strategies, on cultural values and their impact on the different coping styles, and how these variables are associated to physical, mental and social health.

Keywords: Caregiver, Dementia, Alzheimer, Stress Process Model, Mediation, Indonesia
Giving care for a person diagnosed with a mental disorder shows strong negative impacts on caregivers’ physical and psychological health [18, 19, 32], especially in caregivers’ of persons with dementia [13, 16, 34, 35], to a varying extent across cultural and ethnic groups [35]. The vast majority of the literature on caregiver-stress draws on Lazarus and Folkman’s [25] transactional model, adapted to caregiving by Pearlin, Mullan, Semple, and Skaff [31]. It describes that context variables (e.g. sociodemographics, clinical characteristics) and caregiving-demands (e.g. disruptive behavior) stimulate a negative appraisal of the stressor including subjective and/or objective burden, and thus affects caregivers’ health. Moderators and mediators are discussed in kind of coping styles and social support.

Especially context variables such as the type of dementia, the duration of the illness, caregivers’ age, gender, ethnicity, education, income, and cohabiting, as well as the relationship to the patient emerge as important factors associated with caregivers’ burden [6]. Caregiving-demands such as behavioral problems and psychological symptoms of persons with dementia (e.g. behavioral disturbances, functional status, neuropsychiatric symptoms) are consistently found with a moderate effect to influence caregivers’ burden [6, 12, 44]. Coping styles, however, are conceptualized and assessed differently and thus results emerge heterogeneous across studies and cultures [9]. Moos, Brennan, Fondacaro, and Moos [29] differentiate between approach coping (i.e. reappraisal, modification or solution of stressors) and avoidance coping (i.e. neglect of the stressor and/or its consequence). A systematic review by del-Pino-Casado et al. [9] found a positive relationship between avoidance coping and psychosocial burden, and a negative relationship with health-outcomes for caregivers of cognitive impaired older
relatives. They discuss avoidance coping in terms of a moderator or mediator, and in particular as an ineffective coping-style. Findings on approach coping are heterogeneous [9]. Social support serves as a buffer to negative effects of giving care [5]. Systemic reviews support this idea and demonstrate decreased burden if social support is available [44]. They also find a positive though smaller effect of social support on physical health [33]. In sum, the impact of caregiving-stressor on caregivers’ health depends on the evaluation of the stressor as negative, thus burdensome, and the occurrence of social support and coping as mediating variables. This model, however, is culture-bound to the European and US-American countries. Its applicability to different cultures and ethnic contexts has been called into question [10, 20]. Aranda and Knight [2] thus developed a sociocultural model of stress and coping (SMSC) complementing cultural values to Lazarus and Folkman’s [25] model. Ethnicity and cultural values are associated with the risk for health disorders, the appraisal of the stressors as burdensome as well as caregivers’ resources of social support and for coping successfully with challenging situations. Knight and Sayegh [23] propose a revision of the SMSC as they find cultural values to have an impact on the mediating role of social support and coping, rather than on negative appraisal. This revised version (rSMSC) is depicted in Figure 1.

The SMSC has been investigated in Korean, Korean-American [7], Canadian [8], African-American [22], Hispanic [39], Native American, Chinese. Asian-American [41] and European samples [26] with consistent findings of the caregiver stress and coping process across groups with behavioral problems, caregiver burden, coping-style, social support and health-outcome as the main variables [23].

Applying the SMSC in varying sociocultural contexts [2] demonstrates differences in
sociodemographic variables between ethnic minority groups living in the USA and US-Americans: ethnic minority groups were of younger age, had a less intimate relationship (e.g. spouse), provided more hours of care and had lower education and income. Ethnic minority groups reported better psychological though worse physical health compared to US-American caregivers. They also showed stronger beliefs about filial obligation, pronounced social support and higher use of cognitive coping. Though some years ago, the impact cultural values still was unclear [40], researches currently support the idea that studies on caregivers’ QOL among different cultural context and thereby possible differences in the moderating and mediating variables have to be seriously taken into account by the psychological and health sciences to support policy makers, service providers and clinicians in the development and proposition of culturally-specific interventions for caregivers [13].

Although the prevalence of dementia in Indonesia is expected to rise to 2.3 million cases until 2030, institutional and community-based care facilities are marginal and access to healthcare still remains a problem. Care is mainly provided within the family setting and by family members, strongly influenced by traditional familial piety and obligations. Research on this kind of caregiving and how caregivers in Indonesia manage caregiving-stress aiming at improving intervention to increase caregivers’ well-being still is scarce [36]. Research mainly addresses the prevalence and severity of dementia for institutionalized elderly [30] whereby a study in Maluku, Indonesia, reports high burden in 62,3% of those who give care to persons with dementia [42]. Putri and Riasmini [37] examine predictors of caregivers’ psychosocial burden and depression in Indonesia. They found contextual factors such as caregivers’ health, their civil status, income and relationship to the person with dementia, as well as caregiving associated factors such as memory and
behavioral impairments of the person with dementia, the number of caregiving tasks and caregivers’ satisfaction to be highly correlated with caregivers’ experienced burden and depression. Memory deficits and behavioral problems revealed the strongest prediction of caregivers’ burden. In addition, Kristanti et al. [24] found three themes to be identified in the lived experience of family caregivers of persons with dementia, i.e. problems with caregiving, dealing with problems, and beliefs in caregiving. In contrast to the SMSC, social support did not emerge as a significant aspect of caregivers’ burden and depression in the Indonesian population. These findings give first evidence that Indonesian caregivers of persons with dementia experience high psychosocial burden, most strongly predicted by behavioral problems of the ill person, and poor health (e.g. depression). The mediating role of different coping styles and social support as well as the association between caregivers’ appraisal of the experienced burden and their health status remains unclear.

aim

The rSMSC describes the mediation of caregivers’ psychosocial burden and their health status by how they manage the caregiving situation (i.e. coping styles) and how they feel supported by others (i.e. social support). Both mediators are understood as influenced by cultural values. Though the rSMSC has been investigated in different cultures, its application in Indonesia is still missing. Research on caregivers’ burden, however, is of high importance considering the Indonesian Ministry of Health’s national dementia plan 2016, which highlights the improvement of caregivers’ QOL. The purpose of this study thus was to examine the mediating role of coping styles and perceived social support in the association of
caregivers’ psychosocial burden and caregivers’ QOL. **H1:** We hypothesized that caregivers’ psychosocial burden will negatively predict their QOL, i.e. higher levels of psychosocial burden are expected to be associated with lower QOL. **H2:** We expected that coping styles will mediate the association between caregivers’ psychosocial burden and QOL, i.e. avoidance coping will be positively associated with psychosocial burden and negatively with QOL while approach coping will be negatively associated with psychosocial burden and positively with QOL. **H3:** We assumed that social support will mediate the association between caregivers’ psychosocial burden and QOL, i.e. higher levels of social support will weaken the direct influence of psychosocial burden on caregivers’ QOL.

design and method

Our cross-sectional study used paper-pencil self-report questionnaires. We recruited 50 caregivers. Inclusion criteria required (a) the non-paid family caregiver of a person diagnosed with dementia who stays at home, (b) an age ≥ 18 years, (c) living in urban areas of Jakarta or Yogyakarta, Indonesia, and (d) informed consent to participate in our study. Exclusion criteria referred to violations of the inclusion criteria. Participants were recruited from caregiver meetings in Yogyakarta and Jakarta or via social media networking (e.g. Facebook) organized by Alzheimer’s Indonesia, a non-profit organization that aims to improve the QOL of people with Dementia or Alzheimer, their families and caregivers in Indonesia. Those who were interested to participate in this study received detailed study information, informed consent forms and the questionnaires. Those who agreed to participate and gave informed consent were interviewed during caregiver meetings or afterwards at their home. The study was approved by the ethics committee of the Faculty of
Psychology, Universitas Gadjah Mada (Ref. #: 4573/SD/PL.03.07/XI/2016).

Measures. (1) Caregivers’ characteristics were assessed by those aspects which have been demonstrated to be relevant for caregivers’ psychosocial burden and QOL: including age, gender, education, civil status, relationship to the person with dementia, cohousing and ethnicity, as well as caregiving demands such as the age of the person with dementia, the type, duration, and severity of the illness [6]. (2) The Bartel Index [27] was used to assess the level of the ill persons’ impairment with 16 items. It measures activities of daily living (i.e. getting dressed, using the bathroom, making phone calls, working, taking over responsibility at home, administration of finances, doing errands as well as traveling alone to distant places) on a 3-point Likert-scale (1 = not at all dependent on the caregiver; 2 = sometimes dependent on the caregiver; 3 = always dependent on the caregiver). In this study, internal consistency was good with Cronbach’s α at 0.88. (3) The Burden Assessment Schedule (BAS) [43] assesses caregivers’ psychosocial burden with 20 items. This includes both objective and subjective burden in five domains (i.e. impact on well-being, impact on marital relationships, appreciation of caring, impact on relationships with others, perceived impact of the severity of the illness). The items are rated on a 3-point Likert-scale (1 = not at all; 3 = very much). Total scores > 20 indicate significant psychosocial burden. The Indonesian version [11] shows a good internal consistency with α at 0.89 for all items. In this study, we used the shortened version without the items specifically addressing married couple, with a good internal consistency of the total score with α at 0.85. (4) The Brief COPE [4] assesses approach and avoidance coping with 28 items rated on a 4-point Likert-scale (1 = I have not been doing this at all; 4 = I have been doing this a lot). The Indonesian version [1] shows excellent internal consistencies with α at 0.96 for
approach coping and $\alpha$ at 0.95 for avoidance coping. As proposed by Akbar [1], we removed items on alcohol and substance abuse to avoid culture-bound biases. In this study, internal consistency was good with $\alpha$ at 0.85 for approach coping and satisfactory with $\alpha$ at 0.70 for avoidance coping. (5) The *Multidimensional Scale of Perceived Social Support (MSPSS)* [47] measures perceived support from significant others, family, and friends with 12 items on a 6-point Likert-scale ($1 = \text{very strongly disagree}; 6 = \text{very strongly agree}$). The Indonesian version [1] shows excellent to good internal consistencies with $\alpha$ at 0.96 for significant others, $\alpha$ at 0.86 for family and $\alpha$ at 0.82 for friends. In this study, internal consistency was excellent with $\alpha$ at 0.94 for the total score, $\alpha$ at 0.93 for significant others, $\alpha$ at 0.90 for family and $\alpha$ at 0.81 for friends. (6) The *World Health Organization Quality of Life-Bref (WHOQOL-BREF)* [45] assesses caregivers’ QOL on four domains (i.e. physical health, psychological health, social relationships, environment) with 26 items on a 5-point Likert-scale. The Indonesian version [38] shows satisfactory to almost satisfactory internal consistencies with $\alpha$ at 0.77 for environmental QOL, $\alpha$ at 0.74 for physical QOL and $\alpha$ at 0.66 for psychological QOL. An exception was made by the domain of social QOL with $\alpha$ at 0.41. In this study, internal consistencies was good with $\alpha$ at 0.82 for environmental QOL, $\alpha$ at 0.80 for physical QOL, $\alpha$ at 0.77 for psychological QOL and $\alpha$ at 0.68 for social QOL.

*Statistical Analysis.* The analyses were conducted using IBM SPSS Statistics 20.0. Missing values were less than 5% for all variables and not missing completely at random, therefore they were deleted listwise. *Descriptive statistics* (i.e. means, standard deviations, frequency distributions) were used to describe the caregivers’ sociodemographic characteristics and caregiving demands. Pearson correlation was calculated to investigate associations between study variables. *Mediation analyses*
were used to examine whether QOL (WHOQOL-BREF) (physical, psychological, social, environmental; dependent variables Y) and psychosocial burden (BAS) (independent variable X) were mediated by coping (Brief COPE) (avoidance, approach) and social support (MSPSS) (mediator variables M). We used the Baron and Kenny [3] mediation method. To show the significance of a mediator, four criteria must be met: 1. X must be significantly related to Y (path c), 2. X must be significantly related to M (path a), 3. M must be significantly related to Y (path b), and 4. the relationship between X and Y (path c) must be reduced when including the mediator (path c’). We conducted the mediation analyses using the SPSS macro PROCESS developed by Hayes [17] with bootstrap estimates and 95% confidence intervals (CI) based on 10000 resamples to determine indirect effects. A mediator demonstrates significance in case of zero being not included in the 95% CI. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity.

Results

Out of the 50 recruited caregivers, 5 participants failed to complete the questionnaire due to living in far rural areas and time limitations after caregiver meetings. Our final sample thus included 45 caregivers. Caregivers were well-educated women in their mid-forties, more than half of them were Javanese and either employed, self-employed, or housewife and house husband, respectively. The majority of the caregivers lived together with the person diagnosed with dementia who most often was a parent with an age over 70 years on average. One-fourth of the persons suffered from Alzheimer disease and almost ten percent from vascular dementia. For the majority of the sample, the exact diagnosis of dementia was
unknown by the caregiver and most persons suffered from dementia for over 2 years. One-fourth of the caregivers participated regularly at caregiver meetings (Table 1).

There were significant negative relationships between psychosocial burden and all kinds of QOL. There were also significant negative associations between avoidance coping and all kinds of QOL, and a positive relationship with psychosocial burden. Approach coping was positively associated with environmental QOL. Social support revealed a significant association with social QOL and approach coping (Table 2).

**H1.** Higher levels of psychosocial burden were associated with lower levels of QOL. The regression analysis showed a significant negative effect of psychosocial burden on all four domains: physical QOL ($\beta_c = -0.50$, 95% CI [-1.25; -0.38]), psychological QOL ($\beta_c = -0.53$, 95% CI [-1.08; -0.36]), QOL in social relationship ($\beta_c = -0.31$, 95% CI [-0.93; -0.02]), environmental QOL ($\beta_c = -0.50$, 95% CI [-1.08; -0.33]). Psychosocial burden accounted for 25% of the variance in caregivers’ physical QOL, 28% in caregivers’ psychological QOL, 9% in caregivers’ QOL in social relationships and 25% of caregivers’ environmental QOL.

**H2.** There was a significant indirect effect of psychosocial burden through avoidance coping on physical QOL ($axb = -0.15$, 95% CI [-0.29; -0.04]), psychological QOL ($axb = -0.10$, 95% CI [-0.23; -0.02]) and QOL in social relationships ($axb = -0.10$, 95% CI [-0.25; -0.02]). The mediator could account for 30% of the total effect of psychosocial burden on physical QOL, for 20% of the total effect on psychological QOL and for 33% on QOL in social relationships. Because the direct effects on physical QOL ($\beta_{c'} = -0.35$, $F(2,42) = 17.02$, $R^2=.45$, $p < .01$) and on psychological
QOL ($\beta_c' = -.43$, $F(2,42) = 12.45$, $R^2 = .28$, $p < .01$) were not diminished in their significance by the total effect on physical QOL ($\beta_c = -.50$, $F(1,43) = 14.23$, $R^2 = .25$, $p < .01$) and on psychological QOL ($\beta_c = -.53$, $F(1,43) = 16.66$, $R^2 = .28$, $p < .01$), respectively, a partial mediation was demonstrated. For the mediation of avoidance coping on caregivers’ QOL in their social relationships, a complete mediation was demonstrated as the relationship between psychosocial burden and QOL failed significance when including avoidance coping as mediator ($\beta_c' = -.21$, $F(2,42) = 4.79$, $R^2 = .19$, $p > .05$; $\beta_c = -.31$, $F(1,43) = 4.51$, $R^2 = .09$, $p < .05$). (Figure 1). In contrast to our hypothesis, there was no significant indirect effect of psychosocial burden through avoidance coping on environmental QOL. Approach coping did not emerge as a significant mediator, and neither was significantly associated with psychosocial burden nor with QOL (a-path and b-path, n.s.) (Table 3).

**H3.** In contrast to our hypothesis, social support did not emerge as a significant mediator, and neither was significantly associated with psychosocial burden nor with any of the QOL domains (a-path and b-path, n.s.) (Table 3).

discussion

In this study, we investigated the mediating role of coping styles and perceived social support on the association of psychosocial burden and QOL in Indonesian caregivers of persons with dementia. In contrast to perceived social support and approach coping, avoidance coping emerged as a mediator of the association of psychosocial burden and social QOL (complete mediation), and physical as well as psychological QOL (partial mediation). Both approach and avoidance coping, and
perceived social support, did not show a mediating role with respect to environmental QOL. To our best knowledge, this is the first study applying elements of the rSMSC [23] in an Indonesian sample.

In accordance to the rSMSC and previous works in other cultures [23], the results in this study imply that higher caregivers’ psychosocial burden is associated with lower physical, psychological, social and environmental QOL in all domains. The strongest effects emerge on psychological QOL. Consistent to the literature [9], avoidance coping emerges to mediate the association between psychosocial burden and physical, psychological and social QOL in this study. Approach coping and social support, however, do not reveal statistical significance.

Our results thus support findings from previous work about the maladaptive effects of avoidance coping [9, 16, 25]. Our findings indicate that avoidance coping plays a major role in the context of caregivers’ psychosocial burden. Though it is used by caregivers with the aim to reduce stress by avoiding exposure to problems [29], they emerge with lower levels of QOL in all domains. The mediation was complete for avoidance coping affecting the impact of psychosocial burden on social QOL, and a partial mediation emerged for effects on the physical and psychosocial domain. Consequently, psychosocial burden still has some direct effect on caregivers’ QOL.

In accordance to Knight and Sayegh’s [23], this points to the role of alternative variables, such as distinct cultural values which have not been sufficiently assessed in our study, to explain variance in caregivers’ QOL.

There is a negative relationship between approach coping and psychosocial burden as known from the literature [9], though this association does not reveal significance. Results indicate a significant positive association of approach coping and environmental QOL which, however, did not demonstrate significance in the
mediation analysis. Approach coping, including strategies like acceptance or positive reframing of one’s situation, is defined as an attempt to actively solve problems so that stress will be reduced [29]. Our results call the impact of the stress-reducing effect of approach coping in Indonesian caregivers of persons with dementia into question. Given the irreversible degenerative progress of dementia accompanied by high levels of suffering [46], one might ask how otherwise effective approach coping in terms of positive reframing, active coping or planning is applicable for caregivers of persons with this illness. The higher mean value of avoidance coping compared to approach coping is not surprisingly. Harmony is an important cultural value in many parts of Indonesia [15] and thus open conflicts often may be avoided whenever possible. It needs to be discussed whether social desirability also may have influenced the caregivers’ response patterns in this study. In sum, it need to be further investigated whether approach and avoidance coping is an appropriate construct for the investigation of psychosocial burden and QOL in Indonesian caregivers. If additionally we take into account our small sample size, it would be worthwhile to investigate whether a replication of our study might be feasible in a larger population of Indonesian caregivers while controlling for social and cultural values. It also should be taken into account that we can increase our understanding of approach and avoidance coping while taking into account their different strategies in more detail (e.g. religion, humor, acceptance).

In contrast to van der Lee and colleagues’ [44] results and the rSMSC [23], but consistent to Putri and Riasmini [37], social support does not demonstrate a significant associations with psychosocial burden in the sample of Indonesian caregivers. It supports Kim, Sherman, and Taylor’s [21] assumption that in collectivistic orientated cultures, like Indonesia, people tend to seek out less social
support under stressful circumstances compared to individuals with an individualistic cultural background. The authors explain this idea by the caregivers’ striving for harmony as mentioned above, and by their need of implicit social support that is stimulated by a sense of belonging rather than actively sharing problems as assessed in our study. It thus should be discussed whether assessments such as the Multidimensional Scale of Perceived Social Support (MSPSS) serves as an appropriate while culture sensitive instrument for assessing social support in Indonesian. Future studies should concentrate on the implicit measurement of social support and cultural values, which may influence the perception and evaluation of social support [23].

*Limitations.* The generality of our study is limited by the use of a cross-sectional design and our small sample size. Results thus have to be interpreted with caution. The caregivers in our sample were well educated and recruited from caregiver-meetings in urban areas. Educated and wealthy parts of the population are more likely to have access to healthcare [36]. Future research thus should incorporate longitudinal designs with representative samples of caregivers also from rural parts of Indonesia. We used self-report questionnaires and social desirability may have stimulated unexpected response sets. Indirect assessments may reduce caregivers’ reactivity when answering the questionnaires. Matched control groups should also be taken into account for a better understanding of differences in dyadic coping with social stressors between significant and caregiving others of impaired versus healthy people [28]. We applied the rSMSC for the first time in an Indonesian sample while it should be discussed whether this model applies well in this. Future studies using the rSMSC should acknowledge culture-bound caregivers’ demands such as the psychosocial functioning of the person with dementia, family tightness
and looseness, independent versus interdependent self-construal, and religious as well as spiritual aspects [14] to better examine their influence on the mediating effect of the different coping styles and social support on the association of caregivers’ psychosocial burden to QOL.

implications

Dementia in Indonesia will be twice as high in about 15 years, whereby caregiving of people with this illness is most often provided by relatives and friends [36]. There thus is an inevitable need for the development and implementation of interventions facilitating caregivers’ psychosocial burden. Based on a small sample size, our study provides a first though preliminary step towards the examination of the rSMSC in an Indonesian sample of dementia-caregivers. It may provide first insights for policy makers and researchers into the psychosocial burden of Indonesian caregivers and how they try to cope with caregiving demands. Interventions should address avoidance coping as a maladaptive way of handling stressful situations though cultural values might implicitly stimulate this kind of coping rather than approach coping as the best solution. The tendency of a positive and not significant stress-reducing effect of approach coping found in this study also requires replication within a larger sample.

The World Alzheimer report 2016 concludes that caregiver-meetings in Indonesia, however, focus on the provision of information about dementia and caregiving as well as the networking for stronger social support. It should also include psychoeducation on approach and avoidance coping, on cultural values and their impact on the different coping styles, and how these variables are associated to physical, mental and social health.
Conclusion

The major strength of this study is that it provides information on psychosocial burden based on the rSMSC in an Indonesian sample of dementia-caregivers for the first time. It provides a replication of the association between psychosocial burden and health outcomes as found in other cultural groups. Considering the different coping styles, avoidance coping was the only mediator modeling the relation between psychosocial burden and QOL. Interventions for caregivers such as caregiver-meetings thus should integrate psychoeducation and training with respect to the benefits and harms associated with the different coping strategies. It should also include psychoeducation on approach and avoidance coping, on cultural values and their impact on the different coping styles, and how these variables are associated to physical, mental and social health.

abbreviations

QoL: Quality of Life
SMSC: Sociocultural Model of Stress and Coping
rSMSC: revised Sociocultural Model of Stress and Coping
BAS: Burden Assessment Schedule
MSPSS: Multidimensional Scale of Perceived Social Support
WHOQOL: World Health Organisation’s Quality of Life Scale

declarations

Ethics approval and consent to participate. The study was approved by the ethics committee of the Faculty of Psychology, Universitas Gadjah Mada (Ref. #: 4573/SD/PL.03.07/XI/2016).
Consent for publication. Not applicable.

Availability of data and materials. The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests. The authors declare that they have no competing interests.

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Authors’ contributions. CHS and SSK developed the study. SSK collected the data. CHS and SSK analyzed the data and wrote the first draft of this manuscript. SK gave access to participants and revised the first draft of this manuscript.

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**Tables**

**Table 1.** Means, standard deviations and frequency of caregivers’ characteristics
and caregiving demands
### Table 2

Means, standard deviations and intercorrelations of quality of life,

| Category                                                      | Total (n = 45) | M          | SD          |
|---------------------------------------------------------------|---------------|------------|-------------|
| **Age of caregiver**                                          |               | 41         | 12.38       |
| **Age of person with dementia**                              |               | 74         | 10.57       |
| **Gender (women)**                                           |               | 35         | 77.8%       |
| **Ethnicity**                                                 |               | 39         | 86.7%       |
| Javanese                                                      |               |            |             |
| Other                                                         |               | 6          | 13.3%       |
| **Education (≥ high school diploma)**                        |               | 45         | 95.7%       |
| **Housing**                                                   |               | 29         | 64.4%       |
| Cohousing                                                     |               |            |             |
| Separate                                                      |               | 14         | 31.1%       |
| **Relationship to person with dementia**                     |               | 25         | 55.6%       |
| Child                                                         |               |            |             |
| Spouse                                                        |               | 3          | 6.7%        |
| Other                                                         |               | 16         | 35.6%       |
| **Occupation**                                                |               | 16         | 35.6%       |
| Employed                                                      |               |            |             |
| Self-employed                                                |               | 9          | 20.0%       |
| Retired                                                       |               | 2          | 4.4%        |
| Housewife or house husband                                   |               | 10         | 22.2%       |
| Unemployed                                                    |               | 1          | 2.2%        |
| Other                                                         |               | 6          | 13.3%       |
| **Regular participation in caregiver meetings (yes)**         |               | 11         | 24.4%       |
| **Diagnosis of person with dementia**                        |               | 11         | 24.4%       |
| Alzheimer Disease                                             |               |            |             |
| Vascular Dementia                                             |               | 4          | 8.9%        |
| Dementia, type unknown by caregiver                           |               | 30         | 66.7%       |
| **Duration of the disease**                                  |               | 26         | 57.8%       |
| >2 years                                                      |               |            |             |
| **Level of impairment of person with dementia**               |               | 1.45       | 0.50        |
| (Barthel-Index)                                               |               |            |             |
psychosocial burden, coping styles and social support

| (1) QOL_phy | 3.64 | .58 |
| (2) QOL_psy | 3.53 | .48 |
| (3) QOL_soc | 3.32 | .55 |
| (4) QOL_env | 3.34 | .50 |
| (5) BAS | 1.43 | .36 |
| (6) COPE avoidance | 2.22 | .40 |
| (7) COPE approach | 3.18 | .43 |
| (8) MSPSS | 5.12 | .92 |

Note. QOL_phy: physical quality of life; QOL_psy: psychological quality of life; QOL_soc: quality of life in social relation environment; QOL_env: environmental quality of life; BAS: psychosocial burden; COPE: coping style; MSPSS: social support.

### Table 3: Regression results of mediation analysis

| Path | Avoidance Coping BC 95% CI | Approach Coping BC 95% CI |
|------|----------------------------|----------------------------|
|      | Path | \( \beta \) | LL | UL | F | \( R^2 \) | | \( \beta \) | LL | UL |
| QOL_phy | a | .32* | 0.0348 | 0.6906 | 4.97 | .10 | -.27 | -0.6907 | 0.03: |
|        | b | -.47** | -1.0361 | -0.3284 | 17.02 | .45 | .06 | -0.3005 | 0.44: |
|        | c’ | -.35** | -0.9640 | -0.1670 | 17.02 | .45 | -.48** | -1.2450 | -0.33: |
|        | c | -.50** | -1.2475 | -0.3783 | 14.23 | .25 | -.50** | -1.2475 | -0.37: |
|        | axb | -.15 | -0.2920 | -0.0414 | | | | | -0.01 | -0.1587 | 0.06: |
|        | ratio | .30 | 0.1010 | 0.6497 | | | | | .03 | -0.1299 | 0.41: |
| QOL_psy | a | .32* | 0.0348 | 0.6906 | 4.97 | .10 | -.27 | -0.6907 | 0.03: |
|        | b | -.32* | -0.7047 | -0.742 | 12.45 | .37 | .01 | -0.3166 | 0.29: |
|        | c’ | -.43** | -0.9336 | -0.2236 | 12.45 | .37 | -.53** | -1.0971 | -0.34: |
|        | c | -.53** | -1.0755 | -0.3642 | 16.66 | .28 | -.53** | -1.0755 | -0.36: |
|        | axb | -.10 | -0.2347 | -0.0212 | | | | | .00 | -0.0561 | 0.10: |
|       | QOL_soc |       |       |       |       |       |       |
|-------|---------|-------|-------|-------|-------|-------|-------|
|       | a       | b     | c’    | c     | axb   | ratio |       |
| ratio | .20     | 0.0461| 0.8722|       |       |       |       |
| QOL_soc |        |       |       |       |       |       |       |
| a     | .32*    | 0.0348| 0.6906| 4.97  | .10   | -.27  | -.6907|
| b     | -.32*   | -.8493| -.0297| 4.79  | .19   | -.06  | -.4671|
| c’    | -.21    | -.7811| 0.1419| 4.79  | .19   | -.32* | -.9815|
| c     | -.31*   | -.9339| -.0241| 4.51  | .09   | -.31* | -.9339|
| axb   | -.10    | -.2501| -.0170|       |       | .02   | -.0553|
| ratio | .33     | 0.0561| 1.3827|       |       | .05   | -1.3677|

|       | QOL_env |       |       |       |       |       |       |
|-------|---------|-------|-------|-------|-------|-------|-------|
|       | a       | b     | c’    | c     | axb   | ratio |       |
| ratio | .11     | 0.0263| 0.7538|       |       | .10   | -0.0221|
| QOL_env |        |       |       |       |       |       |       |
| a     | .32*    | 0.0348| 0.6906| 4.97  | .10   | -.27  | -.6907|
| b     | -.17    | -.5686| 0.1351| 7.95  | .27   | .19   | -0.0966|
| c’    | -.44**  | -1.0215| -.2291| 7.95  | .27   | -.45**| -1.0188|
| c     | -.50**  | -1.0811| -.3267| 14.16 | .25   | -.50**| -1.0811|
| axb   | -.06    | -.1742| 0.0130|       |       | -.05  | -0.2067|
| ratio | .11     | 0.0263| 0.7538|       |       | .10   | -0.0221|

Note: a: path X on M, b: path M on Y, c: total effect, c’: direct effect, axb: completely standardized indirect effect, physical quality of life, QOL_psy: psychological quality of life, QOL_soc: social quality of life, QOL_env: environmental

Figures
Figure 1

The revised Sociocultural Model of Stress and Coping (rSMSC), adapted from Knig
Figure 2

Standardized regression coefficients for the relationship between burden and qua