

Risks and mitigating factors in psychosocial adjustment of spousal caregivers of people with dementia

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Author Note

Dr Frank Lai coordinated the whole study and developed the research idea. He executed the research plan and monitored the progress. Dr Frank Lai and Dr Cynthia Lai both had substantially contributed to the conception and design of the work, analysis, and interpretation of research data. Ms. Elaine Yan and Ms. Wing Tsui had conducted the literature review. Mr. Daniel Chan and Ms. Moon Wong assisted in data collection, including the arrangement for interventions for participants. Ms. Kathy Yu and Ms. Wing Tsui assisted in the literature search and served as the blinded assessors in the study. They had helped in the earlier drafts of the manuscript and assisted in subsequent revision of the text. Ms. Sharon Wong had addressed the questions raised by our reviewers and solidified our arguments through the provision of supporting evidence, and in editing and reviewing the manuscript prior to its final submission. They have thus had contributed significant to the paper's intellectual content. All authors have agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The authors report no declarations of interest.

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Abstract

By applying the Stress Process Model to examine the characteristics of people with dementia and their spousal caregivers, this study aims to identify the potential risk and mitigating factors of psychosocial adjustment among the spousal caregivers. We recruited 80 care recipient-caregiver couples in Hong Kong and examined the relationships of socio-economic, care recipient's, and caregiver's factors with spousal caregivers' psychosocial adjustment. It was found that care recipients' cognitive functions were associated with caregivers' reported frequencies of their behavioral and psychological symptoms of dementia (BPSD) ($r = .30, p = .008$), and caregivers' perceived burden of caregiving ($r = -.54, p = .008$). Caregivers' quality of life was associated with their perceived caregiving burden ($r = -.82, p = .001$) and self-efficacy ($r = .32, p = .001$). Upon further examining the caregiving model with these parameters, a significant multivariate general linear model was found with ($F(1, 12) = 13.06, p = .001, \text{partial eta square} = .70, \text{observed power} = .99$). Moreover, female caregivers reported higher sense of caregiving stress and poorer quality of life than male caregivers. This study found that the cognitive functions and BPSD of care recipients with dementia and perceived level of caregiving burden are strongly associated with degrees of psychosocial adjustment among their spousal caregivers. The self-perceived caregiving role in a family is also a possible confounding factor contributing to the perceived caregiving burden. To support in-home caregiving of people with dementia, strategies to empower spousal caregivers to execute their caregiving roles are recommended.

Keywords: caregivers, dementia, psychosocial adjustment, quality of life

Background

We are living in an era when the world's aging population is rapidly expanding. The importance of family caregivers has been receiving increasing attention since last decade (Gitlin et al., 2014; Huang et al., 2009; Huang et al., 2015; Ready et al., 2007). The World Health Organization has underlined the need to apply health-in-all-policies and interventions, whole-of-society, and multisectoral approaches for this group of caregivers (WHO, 2018). With longer lifespans and limited caregiving resources from the affected ones' own children, some of whom are even childless, caregiving for older adults has become the main responsibility of their spouses. Caring for older adults with dementia has always been a family endeavor (Brodaty & Donkin, 2009; Rippon et al., 2019), and spousal caregivers play a crucial role in caring for people affected by dementia in the community (Chung & Lai, 2003).

Care of dementia produces changes in the affected families and these changes affect the psychosocial well-being and health of the caregivers (Campbell et al., 2008; Chan & Chui, 2011; Cheng, 2017). Subjective caregiving burden (e.g., perceptions of psychological distress, depression, anxiety, demoralization, and generalized loss of personal freedom attributed directly to caregiving) may affect the quality of caregiving (Lawton et al., 1989). It is important to identify the risks and mitigating factors of psychosocial adjustment in spousal caregivers for people with dementia. This understanding is essential for carer policy and caregiving intervention development.

The Stress Process Model (SPM) explained the dynamic nature in stress development (Pearlin et al., 1990) and caregivers' psychosocial adjustment (Chan & Chui, 2011) under various stresses which are best to describe the situation of those dementia population and their caregivers (Hepburn et al., 2001). The SPM has been commonly adopted in psychosocial research and indicates bidirectionality in the relationship between personal characteristics and environmental properties that affect individuals' psychosocial adjustment (Cohen & Lee, 2007; Pashby et al., 2009; Tebb & Jivanjee, 2000) and bidirectionality relationship in SPM had been identified as an important components in care-giving to older people with dementia (Elliott et al., 2010; Hepburn et al., 2001). The SPM has been used to examine the stress levels, coping strategies and quality of life for caregivers of people with dementia (Roth et al., 2009). When caregivers experience higher levels of stress, poorer caregiving outcomes and thus worsened psychosocial adjustment may be resulted (Aneshensel et al., 1995; Pinquart & Sorensen, 2005, 2007). Through the SPM, the underlying factors attributable to either personal or environmental characteristics, which could influence caregivers' psychosocial adjustments, can be studied (Pearlin et al., 1990). This enables the identification of potential risks and mitigating factors to caregiving for people with dementia as well as their associations and contributions to caregiver's perceived level of burden in dementia care (Hepburn et al., 2001; Pinquart & Sorensen, 2005, 2007). In this study, we hope to gain an insight of the application of the SPM outside of the western world, and through the lens of an ever-growing aging population within the Chinese community. The trend of burning-out in caregivers can be alleviated if there is better understanding on their stress and psychosocial adjustment (Costello et al., 2019).

Psychosocial adjustment refers to the psychosocial accommodation of a person to a life-altering event or transition (Mosby, 2006). It has been postulated that good psychosocial adjustment is associated with lower burden, higher family satisfaction and greater perception of social support in family caregivers (Gallagher et al., 2011; Lopes Dos Santos et al., 2020). The capability in psychosocial adjustment could be reflected by the perceived well-being of a person when he or she encounters stress. Besides, psychosocial adjustment acts as a mediator between the health of a caregiver and the stress factors related to care (Swedish Council on Health Technology, 2008). Caregivers' quality of life would be jeopardized if their psychosocial adjustment in caregiving is poor (Cheung et al., 2020; Morley et al., 2012; Pereira & Soares, 2015; Rippon et al., 2019; Serrano-

Aguilar et al., 2006). Therefore, identification of the risks and mitigating factors to psychosocial adjustment of spousal caregivers is important. It is found that these factors have not been sufficiently studied within the Chinese population. Noting the significance of such area of focus both in helping caregivers improve their quality of life and in bringing to light the gaps that exist in our current policies and intervention development, there is a great need to study the underlying factors affecting caregivers' psychosocial adjustments within our local context. In doing so, our study extends the previous literature and contributes to the broadening of such examination related to dementia caregiving from an international perspective.

According to the SPM, the caregivers' stress process comprises of several domains that are interrelated with one another, including the socioeconomic, primary, and secondary stressors to which they are exposed. Literature suggested caregivers from disadvantaged backgrounds can struggle more in socioeconomic stressor by health illiteracy and lower accessibility to healthcare information. This can make it more difficult for people to access the dementia care they need (Jones, 2017). The socioeconomic stressor refers to the background and context of stress. The primary stressor refers to problems stemming directly from the care recipients, whereas the secondary stressor refers to the caregivers' role strains and intrapsychic strains. Therefore, in this study, socio-economic factors, care recipient's factors and caregiver's factors were all incorporated into the ecological model of caregivers' psychosocial adjustment. Socio-economic factors are composed of a few interrelated conditions, such as individuals' socioeconomic backgrounds (Law & Kwok, 2019; Zacharopoulou et al., 2019), and their knowledge about the availability of community resources for caregivers (Resciniti et al., 2020; Vogel et al., 2017). Adverse socioeconomic factors include lower levels of education, social classes and incomes that contribute to the poor qualities of care for those with dementia among the Chinese population (Chan et al., 2013; Chen et al., 2016). Moreover, men and women may approach their caregiving roles differently. While men seem to consider caregiving as more of a task, women may take it as a role to be taken more comprehensively (Baker & Robertson, 2008a; Russell, 2001). A better understanding of the socio-economic factors that influence dementia caregivers can facilitate future policies and intervention development.

The specific care recipient's factors include the physiological, behavioral and psychological conditions of care recipients (older adults with dementia). Physiologically, poorer cognitive functioning increases the risk of functional decline (Dodge et al., 2006) and mortality (Bassuk et al., 2000). Behavioral and psychological symptoms of dementia (BPSD) include symptoms of disturbed perception, thought content, mood, or behaviour, that frequently occur in patients with dementia. Behavioural Symptoms are usually observed by others, and include problems of physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, cursing/swearing, and 'shadowing'. Psychological Symptoms are usually included anxiety, depressed mood, hallucinations, and delusions. These would result in deteriorated communication ability in people with dementia. BPSD are integral parts of the dementia syndrome (Kar, 2009), and are associated with a more rapid rate of cognitive decline and greater impairment in activities of daily living. BPSD would hinder the interactions between the dementia caregivers and their recipients. BPSD would also increase morbidities and burdens, jeopardize caregivers' quality of life, and increase the costs of care (Kar, 2009). BPSD would also induce stress that results in negative effects of the emotional state and sense of burden in their caregivers (Kar et al., 2006). However, there is a lack of evidence of this factor as a potential key risk to caregivers' psychosocial adjustment in the Chinese population.

Caregiver's factors include knowledge and self-efficacy. Caring for a person with dementia requires the caregiver's knowledge of the trajectory and appropriate care related to dementia. Having adequate knowledge about dementia is associated with lower levels of perceived burden and less severity of depression of caregivers, as well as higher quality of caregiving for older adults with

dementia (Resciniti et al., 2020). Caregiving self-efficacy is conceptualized as the belief that an individual can perform confidently and capably in each situation as a caregiver (Zhang et al., 2014). Caregiving self-efficacy has been regarded as an important determinant of emotional and behavioral responses to stressors (Grano et al., 2017). Theories of caregivers' self-efficacies have explained the variabilities that exist in family caregivers' behavior and abilities to cope with the stressors in caregiving. A strong caregiver's self-efficacy is found to have positive implications on his or her quality of life, mental and physical health (Gilliam & Steffen, 2006). However, these potential mitigating factors of psychosocial adjustment were under-explored among Chinese caregivers (Ko et al., 2008; Lee & Tang, 2015).

Gender difference had been believed to influence the amount and type of care provided, access to social support and resources that may alleviate caregiver strains, and appraisal of the caregiving experience (Brodaty & Donkin, 2009; Pearlin et al. In various cultures and societies, women played a dominant role in providing care for frail family members (Langner & Furstenberg, 2020; Rippon et al., 2019; Schulz et al., 2003), whereas the role of male caregivers should be emphasized and collected more attention in dementia care research (Sun, 2014). Moreover, the degrees of self-efficacies, in relation to gender, showed influences the abilities of caregivers in taking care of their care recipients effectively (Pöysti et al., 2012).

This study aims to evaluate the relationships between socio-economic factors, care recipient's factors and caregiver's factors to spousal caregivers' psychosocial adjustment, to note if there would be difference between male and female caregivers, as reflected by their reported quality of life. It is hypothesized that these factors would contribute to caregivers' psychosocial adjustment. The findings of this study would be beneficial to policy makers and service providers in determining the future direction of support to be provided to caregivers of older adults with dementia.

Methodology

Participants

To enable the study of all three factors related to the socio-economic, caregiver, and care recipient aspects, both the caregivers and their care recipients had to be invited to take part in our assessments. Eighty caregiver-care recipients couples were recruited through poster advertisements at six district-based day activity centers in Hong Kong. Written consents were sought from all participants. The inclusion criteria were: (a) family caregivers aged between 65 and 80, and (b) being able to understand verbal and written Chinese instructions. To eliminate the co-founding care-giving burden apart from cognitive impairment, care-recipients with major physical dysfunctions, such as stroke and head injuries, were excluded. Approval was given by the university research ethics committee and the study was conducted according to the Declaration of Helsinki.

Of those recruited, 33 were male caregivers and 47 were female caregivers, with their spouses as care recipients. The caregivers' ages ranged from 65 to 82 (mean = 71.41; SD = 5.04) while those of care recipients ranged from 65 to 80 (mean = 70.40; SD = 4.00). In terms of their education levels, the caregivers reported having received 3.5 to 13.5 (mean = 6.99; SD = 2.11) years of education. With respect to their health conditions, these caregivers were asked for the number of chronic diseases they had (mean = 1.89; SD = 1.32). Data were also collected regarding their family circumstances, including their sources of financial support, family support, as well as the number of children they have. Financially, they were supported through social security (n = 16), from their family (n = 31), or by using their own savings (n = 33). Only a quarter of these couples received family caregiving support from their offspring or domestic helpers, either during the day (n = 8) or at night (n = 12).

Most of these couples had one to two children ($n = 49$), while others had none ($n = 15$) or three or more children ($n = 16$) (Table 1).

Procedures

The study was conducted in three low-income districts in a Cantonese speaking community (Census and Statistic Department, 2015; Census and Statistics Department, 2016). These districts were selected because this study was part of the pilot review on care giving needs in preparing the development of a district health centre for older people with dementia. The target participants were recruited by convenient sampling from a support group for family caregivers who were taking care of older adults with dementia. The support group organized a monthly face-to-face educational program for the spousal caregivers. Centre staff from each of the collaborating day activity centres assisted with the identification and invitation of eligible caregivers based on the participation criteria provided by the researchers. Caregivers received the questionnaire surveys that covered questions on their socio-economic backgrounds, conditions of the care recipients, their self-efficacies in caregiving and their psychological wellbeing. The assessment lasted for approximately 30 minutes.

Measuring instruments

Psychosocial adjustment of caregivers

- (1) **The Short Form 36 version 2 (SF-36) (Dong et al., 2017).** The psychosocial adjustment of the caregivers was measured by the Short Form 36 version 2 (SF-36) (Dong et al., 2017). It is a 36-item self-reported questionnaire that covers eight health domains, with which the participant had to answer questions such as “Does your health now limit you in lifting or carrying groceries?”. Domains encompassing physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP), and general health perceptions (GH) are grouped under the physical component summary (PCS). On the other hand, vitality (VT), social functioning (SF), role limitations due to personal or emotional problems (RE), and emotional well-being (MH) are grouped under the mental component summary (MCS). Scores of each domain range from 0 to 100, with higher scores defining more favorable health statuses. The SF-36 had been proven useful in monitoring population health, estimating the burden of different diseases, monitoring outcomes in clinical practice, and evaluating treatment effects (Dong et al., 2017). The internal consistency reliability (Cronbach's α) was 0.92 (range 0.74-0.93), and all item-subscale correlations in the SF-36 showed satisfactory convergent and discriminant validities.

Socio-economic factors

- (2) **Self-report of socio-economic conditions.** The sub-components of caregivers' socio-economic factors were obtained from their self-reports. Each self-report includes the caregiver's age, gender, educational level, health conditions (number of chronic diseases the caregiver had), financial support for the couple's daily living, number of children, and availability of family support (Aneshensel et al., 1995; Bierhals et al., 2017; Bleijlevens et al., 2015).

Care recipient factors

- (3) **The Montreal Cognitive Assessment - Hong Kong Version (HK-MoCA) (Wong et al., 2009).** The HK-MoCA was applied to examine the care recipients' cognitive functions, scores ranged from 0 to 30, with higher score indicates better cognitive function. The HK-MoCA

was used to evaluate visuospatial functions, naming ability, attention and working memory, language, abstraction, and orientation abilities, which composes of items such as trails making, clock drawing, digit span and vigilance tests. The ICC of the HK-MoCA for the 2-week test-retest and inter-rater reliability was 0.96 and 0.87 respectively ($p < 0.001$ for both). Cronbach's α coefficients for internal consistency between the item scores was 0.72. In this study, the HK-MoCA was conducted by an occupational therapist.

- (4) **The Revised Memory and Behavior Problem Checklist (RMBPC) (Fuh et al., 1999).** The RMBPC was applied to examine the care recipients' cognitive abilities and **their behavioral and psychological symptoms of dementia (BPSD)**. Caregivers were required to report the frequencies of the care recipients' BPSD and their reactions towards them using the RMBPC. This is a 24-item caregiver report comprising of BPSD items such as "Repeated questions" that measures one's observable problematic behavior with a 4-point Likert's scale (0 = never occurred, 1 = not in the past week, 2 = 1 to 2 times in the past week, 3 = 3 to 6 times in the past week, 4 = daily or more often) and one's reaction to these problems (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, and 4 = extremely). The RMBPC **scores ranged from 0 to 96, with lower score indicates lower frequency of memory and behaviour problems. The instrument** covers three domains of problematic behaviours of older adults with dementia, namely memory-related problems, depression, and disruptive problems (Fuh et al., 1999). The RMBPC was significantly correlated with the Geriatric Depression Scale (GDS) (Brink & Niemeyer, 1992) score ($r = .36, p = .001$). The Cronbach's α for frequency and reaction scores were .82 and .90 respectively. The test-retest reliabilities of the total frequency and reaction scores were significantly correlated, and the overall correlations were .89 for frequency ($p < .001$) and .74 for reaction ($p < .001$).

Caregiver factors

- (5) **Questionnaire on knowledge about caregiving and community-based services (QK).** QK contains seven self-reported questions, **with dichotomous response as either yes or no option;** namely (1) the prevalence and patterns of functional limitations, both physical and cognitive, (2) medical conditions and recent medical problems, (3) use of health care services, (4) kinds and amounts of formal and informal long-term care services used, (5) demographic characteristics like age, race, sex, marital status and **source of personal** income, (6) public and private expenditures for health care services, and (7) housing and neighborhood characteristics. **QK was** adapted from the framework of the National Long-term Care Survey (NLTC) (Kinosian et al., 2018). These questions were used to examine caregivers' knowledge about caregiving and their utilization of community-based services (e.g., respite care service, out-reaching services, home-based care, home-delivered meal services, housekeeping services, transportation services, and support group services).
- (6) **The Revised Caregiving Self-Efficacy Scale (C-RCSSES) (Zhang et al., 2003).** The Chinese version of the C-RCSSES is a 27-item self-report scale, **with a total score that ranges from .00 to 1.00,** containing items such as "To assist with daily personal hygiene.", that assesses five self-efficacy factors of a caregiver: i) responding to problematic behavior; ii) obtaining support; iii) management of the household, personal and medical care; iv) regulating mood related to caregiving; and v) gathering information about symptoms, treatment, and healthcare. All the Cronbach's α for internal consistency between the items and the overall scores were over 0.80. The 4-week test-retest reliability coefficients ranged from .64 to .85.

- (7) **Chinese version of the Zarit Burden Interview Scale (CZBI) (Ko et al., 2008).** The CZBI was applied to measure caregiving stress. The CZBI is a self-reported 22-item questionnaire using the 5-point Likert's scale, scores ranged from 0 to 110, with lower score indicates lower level of burden in care. This instrument includes questions such as "Do you feel that your relative asks for more help than he/she needs?", that are used to measure a caregiver's stress through the reflection of his/ her own feelings of over-sacrifice, care recipients' dependence on the caregiver, negative emotions associated with caregiving, his/ her own feelings of inadequacy, and uncertainty about the care recipient's future. Its Cronbach's α for internal consistency was 0.89 (95% CI: 0.86–0.91). Moreover, the CZBI demonstrated good concurrent validity with the Caregiver Activity Survey (CAS) (Marin et al., 2000), with Spearman's $r = .47, p < .001$.

Statistical Analysis

Descriptive analyses of socioeconomic, care recipients' cognitive and behavioural symptoms, caregivers' knowledge about caregiving and the availability of community-based services, their self-efficacy and subjective caregiving burden were carried out. Then, correlative analyses of care recipient's and caregiver's factors were conducted. As we have multiple dependent variables stemming from various stressors and that our data was heteroscedastic in nature, multi-variate General Linear Model (GLM) analyses of these factors were performed to examine their relationships with caregivers' psychosocial adjustment. Effect sizes of specific significant effects were reported in partial eta square. All analyses were conducted using SPSS IBM v23 with significance value set at $p < 0.05$.

Power analysis was performed for calculating a priori sample size by using G*Power based on the reference study (Lee & Tang, 2015; Wong et al., 2019) with key parameters' pooled effect size $f^2 = 0.3$, level of statistical significance = 5%, and estimated power = 0.8. G*Power indicated that with these variables, a sample size of 55 was needed. Taking 10% attrition rate, 62 subjects were targeted.

Results

We recruited 80 caregivers (33 males and 47 females) that had a large variance (SD= 4.44 years) in education levels. Their general health conditions were good as reflected by the number of chronic diseases they had (1.89 ± 1.32). Financially, the couples were mostly supported by their families or their own savings (82.5%). The sex-ratio and average age of the care recipients and caregivers, and years of education received are depicted in Table 1.

As displayed in Table 2, the level of cognitive impairment in the care recipients is mild as reflected by the HK-MoCA score (19.30 ± 1.27). As reflected by the RMBPC, the frequency of care recipients' behavioural symptoms is moderate (58.82 ± 1.31 in male care-recipients and 59.35 ± 1.09 in female care-recipients). There was significant effect for sex, $t(78) = 7.89, p = .02$, female caregivers' reactions to these symptoms are noted on the high trend (63.89 ± 1.21) than male caregivers ($58.78 \pm .99$).

As summarized in Table 3, the caregivers' self-reported knowledge about caregiving and the availability of community-based services were reflected by the 7-item QK. Male caregivers showed better knowledge on caregiving and community resource, $t(78) = 4.28, p = .03$, Cohen's $d = 2.04$. Moreover, there were significant effect for gender, $t(78) = 9.23, p = .03$, Cohen's $d = 2.38$, in caregiving self-efficacy, male caregivers reported their higher self-efficacy ($.55 + .07$) than female caregivers ($.33 + .11$). Moreover, in their perceived burden in care. There was significant effect for

gender, $t(78) = 2.42$, $p = .04$, female caregivers reported their higher burden (65.25 ± 2.87) than male caregivers ($M = 56.85$, $SD = 3.99$).

Correlation between care recipient and caregiver factors

Correlative analyses of care recipient's and caregiver's factors were conducted. As depicted in Table 4, we found that the cognitive function score (HK-MoCA) is associated with the reported frequency of behavioural symptoms in the care recipients (RMBPC) with $r = .30$ and $p = .008$, and the perceived burden of caregiving ($r = -.54$, $p = .001$), but not so much with the caregivers' self-efficacy (RCSES) with $p > 0.5$.

Caregivers' perceived burden (CZBI score) is negatively correlated with the frequency of care recipients' behavioral symptoms (RMBPC) ($r = -.30$, $p = .03$), their knowledge of caregiving and community-based services ($r = -.29$, $p = .001$), and their self-efficacy in caregiving ($r = -.27$, $p = .001$). It was discovered that caregivers who experience less caregiving burden are more likely to report better quality of life ($r = -.82$, $p = .000$). An individual's self-efficacy is positively correlated with his/ her own quality of life ($r = .32$, $p < .001$).

The data were analysed based on random-effects model. The random effects assumption is that the individual-specific effects on psychosocial adjustment are uncorrelated with the independent variables. In this study, the general linear model (GLM) was used to identify component of variation. The order of terms in the GLM for caregivers' psychosocial outcome were care-recipients' factors and caregivers' factor (the order corresponds to the questionnaire design structure). Multi-variate GLM analyses of these factors were performed to examine their relationships with caregivers' psychosocial adjustment. With the gender of caregivers as co-variate, a significant multivariate GLM was collected with $F(1, 12) = 13.06$, $p = .001$, with partial eta square = .70 and observed power = .99. Moreover, there is significant interaction effects between care recipients' factors and caregivers' factors. Regarding the cognitive function of care recipients, the multivariate GLM was collected with $F(1, 12) = 2.68$, $p = .005$ with partial eta square = .324 and observed power = .96, while that of the behavioral symptoms of care recipients was $F(1, 12) = 2.05$, $p < .05$ with partial eta square = .324 and observed power = .88. Regarding caregivers' self-efficacy, the multivariate GLM was collected with $F(1, 12) = 2.77$, $p = .004$ with partial eta square = .33 and observed power = .97, while their perceived burden of caregiving was $F(1, 12) = 13.06$, $p = .001$ with partial eta square = .70 and observed power = .99. GLM analysis summary is depicted in Table 5.

Furthermore, caregivers' gender reveals significant differences. Results of the independent sample t-tests indicate that significant gender differences exist in terms of the caregivers' quality of life ($t = 2.04$, $p = .05$, 95% C.I. : .04-3.47), self-efficacy in caregiving ($t = 4.34$, $p = .01$, 95% C.I. : .05-.14), and perceived burden of caregiving ($t = -2.06$, $p = .04$, 95% C.I. : -6.35 -.11)

Discussion

Building on the SPM, to identify the potential risks and mitigating factors of psychosocial adjustment among spousal caregivers of people with dementia, we examined the socio-economic factors, care recipient's factors and caregiver's factors and evaluated their effects on the caregivers' psychosocial adjustment, as reflected from their self-reported quality of life. Our findings suggested that there was a significant association between care recipients' cognitive functioning and their frequency of BPSD as reported by their caregivers, and which contributed significantly to caregivers' perceived burden. The aspect of caregiving burden was further examined together with the caregivers' levels of self-efficacy, both of which were noted to have a correlation with one's own quality of life.

Multivariate GLM analyses was also performed based on the caregiving model involving the socio-economic, care recipient, and caregiver factors, which produced significant results. Additionally, gender differences were also found to play a significant role, with female caregivers reporting higher sense of caregiving stress and poorer quality of life than male caregivers.

Conditions of psychosocial adjustment of caregivers

Compared with the quality of life of the general Chinese population aged 65 or above in 2003 (Li et al., 2003), our recruited caregivers of people with dementia showed remarkably lower levels of quality of life. Undoubtedly, this lower quality of life among the spousal caregivers is alarming. However, it can be partially explained by the relatively lower socio-economic statuses among the recruited participants of this study, who came from three low-income districts in Hong Kong. It is recommended that future research should be conducted to carry out further studies involving larger groups of subjects with a wider socio-economic spectrum.

Risk factors of psychosocial adjustment of caregivers

(a) *Cognitive function and BPSD symptoms*

Our findings indicate a significant correlation between the examiner-rated cognitive functions (HK-MOCA) score and the reported BPSD symptoms by the caregivers. Moreover, BPSD significantly correlates with perceived burden of caregiving. This can be explained by the degeneration of cognitive and communicative functions of people with dementia, which significantly affects their communication skills and hinders their interactions with their caregivers (Richardson et al., 2013).

(b) *Perceived caregiving burden*

Furthermore, the current study echoes with previous research that the level of caregiving burden experienced by a family caregiver is associated with his/ her quality of life (Cheung et al., 2020; Thomas et al., 2006). Consistent with previous studies (Goren et al., 2016), our findings indicate that caregiving burden is linked to a few negative psychosocial outcomes. Our study of Chinese caregivers supports the notion that caregivers who experience higher caregiving burden are more likely to report poorer quality of life and with higher anxieties than caregivers with lower caregiver burden or non-caregivers (Lavela & Ather, 2010; Roth et al., 2009). In this study, female caregivers reported with higher burden than male caregiver. The gender-role socialization perspective suggested that appraisal of caregiver burden may be partially explained by women's greater ease in expressing feelings (Lee & Tang, 2015). . This perspective could partially explain our findings when female caregivers showed more negative emotion, more feeling of inadequacy and more feeling of over-sacrifice in the caregiving process.

Female caregivers who perceive higher levels of caregiving burden are more likely to report lower degrees of psychological wellbeing. On the other hand, male caregivers with less perceived caregiving burden reported lower caregiving distress, better general mental health, lower levels of depressive symptoms, higher levels of subjective well-being, higher life satisfaction, and greater purpose in life.

(c) *Family support*

With smaller family sizes, longer lifespans, and limited caregiving resources as depicted in Table 1, spousal caregivers for older adults with dementia have become the only source of caregiving in the Chinese community. Previous research suggested that traditional Chinese values are the major predictors of caregiver burden (Chan & Chui, 2011; Chau et al., 2013). Lack of family members' support is a clear but unresolvable social phenomenon in Hong Kong (Chau et al., 2013; Wong &

Chau, 2006). Therefore, appropriate social support to caregivers is undoubtedly essential in alleviating the caregiving burden and improving the quality of life of caregivers. Understanding of caregivers' experience can also help service providers design effective interventions to alleviate their burden.

(d) Gender

With this study, significant gender differences were found across quality of life, self-efficacy, and perceived burden of the caregivers. This can be explained by male caregivers may face more challenges due to gender role conflict, which is associated with the psychological stress experienced by men during the caregiving process (Baker & Robertson, 2008). Literature further suggested that men manage stress differently from women because men had been more socialized to delegate whereas women tend not to delegate responsibilities (Lee & Tang, 2015; Wong et al., 2019). Additionally, when men are able to maintain satisfactory intimate relationships, this helps alleviate their caregiving burden. Furthermore, a strong sense of coherence (the ability to comprehend a situation and cope) also helps lessen the amount of burden they perceive (Ashley & Kleinpeter, 2002).

This study further indicates that female caregivers showed more negative emotions in caregiving, stronger feelings of over-sacrifice, and greater feelings of inadequacy than male caregivers, as reflected in our 12-month evaluation. As suggested in the existing literature, regardless of cultures and societies, women have always played a dominant role in providing family care (Langner & Furstenberg, 2020; Rippon et al., 2019; Schulz et al., 2003). Therefore, according to the gender-role socialization perspective, it is suggested that the appraisal of caregiver burden may be partially explained by women's greater ease in expressing their own feelings (Lee & Tang, 2015). Moreover, the significantly negative emotions of female caregivers can be explained by the fact that they are more likely to be exposed to their subjective caregiving stressors than male caregivers, as stated by the caregiver stress theory (Baker & Robertson, 2008b; Lee & Tang, 2015). It was further suggested that men and women manage stress differently, because men had been more used to delegating responsibilities in caregiving activities whereas women tend not to do so (Akinola et al., 2017; Lee & Tang, 2015; Wong et al., 2019). This type of coping behavior was identified as an important factor for individuals' caregiving efficacy (Akinola et al., 2017; Collie et al., 2005; Cox et al., 2006).

Mitigating factors of caregivers' psychosocial adjustment

(a) Self-efficacy

Female caregivers with poor self-efficacy were found to be more vulnerable to caregiving stress than male caregivers. This phenomenon echoes with previous studies that female caregivers reported more suffering and had more clinical symptoms than male caregivers (Brodaty & Donkin, 2009; Campbell et al., 2008; Langner & Furstenberg, 2019; Pereira & Soares, 2015; Tang et al., 2013). This symptomatology has been more frequently reported among caregivers in different studies (Ferrara et al., 2008; Gallagher et al., 2011). With male caregivers, they always reported fewer depressive symptoms, less distress, and higher sense of coherence than female caregivers. When men report depressive symptoms, they are strongly associated with the care recipients' neuropsychiatric symptoms (Välämäki et al., 2009). Romero-Moreno et al. (2011) suggested that there was moderating effect of caregivers' self-efficacy in managing their feelings of distress and burden. Self-efficacy was further shown to have a moderating effect on the relationship between caregivers' burden and distress involving caregivers' psychological and emotional well-being (Gallego-Alberto et al., 2017; Gallego-Alberto et al., 2019).

(b) Knowledge about caregiving and community-based services

In this study, male caregivers reported with better knowledge on caregiving and community resource. Caregivers' knowledge about caregiving and the resources available to them have been believed to be in support of caregivers' abilities to counterbalance the negative and deleterious effects to which caregiver stress and burden had on them (Pearlin et al., 1990). Accessibility of resources are particularly important since caregiver's role intensifies in response to the progression of the disease condition (Baker & Robertson, 2008b). A more strategic plan should be planed for female caregivers to enhance their use of social and community resource.

Interestingly, some studies indicated that caregivers' knowledge about caregiving and community-based services had insignificant contribution to the prediction of stress outcomes and lesser impact on individuals' quality of life (Chung & Lai, 2003; Schulz et al., 2003; Sun, 2014). The inconsistent findings can be partially explained by the greater amount of self-reported knowledge on caregiving and community-based services as reflected by the QK (as shown in Table 3), and the comparatively convenient access to community resources as Hong Kong is a relatively small city. It is also possible that our participants were younger when compared with previous studies that had reported an average age of 70 or above (Ferrara et al., 2008; Pöysti et al., 2012), and were more capable of obtaining information and community services that they need. This phenomenon had also been reported in previous studies, as it has become easier to obtain information and knowledge nowadays (Wittmeier et al., 2018), such as using online platforms (Piraino et al., 2017). Therefore, the accessibility of information about caregiving and community-service would be helpful in reducing the stress of caregivers.

Based on the conceptual framework of the SPM, we have adopted it within our local Chinese context and set out to provide an extensive analysis of how the socio-economic, care recipient, and caregiver factors affect caregivers' psychosocial adjustment within the Chinese community. In addition to showcasing our findings which highlight the factors that impact Chinese caregivers' stress and quality of life, our conclusions drawn were also aligned with what the existing literature from other parts of the world suggest, thus providing further evidence in support of the SPM in explaining the dynamic nature of caregivers' psychosocial adjustment and stress development.

There are several limitations with this study. First, the quality of life of care recipients was assessed by their caregivers. This measure leaves the results open to a person's own interpretation, which may in turn lead to either overestimation or under-estimation of the actual quality of life of the care recipients. Second, the findings regarding the magnitude and significance of gender differences would have benefited from further examination using a population involving larger sample sizes, wider socio-economic statuses and with more scrutinized research methodology, such as the stratified random sampling method. Third, while our study supported the notion that there is a general lack of family caregiving support, a quarter of the participants did report obtaining either daytime or night-time support from their offspring or domestic helpers (Table 1). However, we did not document the specific amount of family support received by this group of spousal caregivers. Fourth, the study sample was recruited from poor neighbourhoods in Hong Kong, and the sample income would have enough variation to note any effect in stress of care. Nevertheless, we only got the information on the source of caregivers' personal income and cannot analyse the full picture of incomes in relation to their stress in care. Future research that seeks to further explore both the family support and the financial aspects should include the regularity, duration and financial support received by these caregivers to enable better quantification of their results.

Irrespective of the study limitations, however, it was evident that spousal caregivers of older people with dementia were under a lot of stress that were coming from different facets of their everyday lives, which could influence their psychosocial adjustment and ultimately affect their quality of life. To better support these caregivers, it is important to empower them through evidence-based

interventions, such as multicomponent interventions that involve educating caregivers on coping skills, to reduce the amount of distress they experience (Roth et al., 2009). To make this a less solitary journey for them, more resources should be allocated to the provision of explicit supportive services, since social support has been recognized to play a significant role in contribution to the success of one's ability to take up his/ her caregiving role. Furthermore, gaining emotional support from others and adopting other relevant coping skills that are emotion-focused would help alleviate any depressions and anxieties they may have, as well as help strengthen their appraisals of their own social supports and networks (Gallagher et al., 2011).

Conclusion

This study affirms that cognitive decline, and behavioral and psychological symptoms of dementia are the major sources of stress among caregivers of older people with dementia. Caregiving research across the world indicate that most family caregivers are women. Female caregivers are more vulnerable to caregiving stress than male caregivers. Moreover, they also reported poorer quality of life than male caregivers. In general, spousal caregivers who perceive lower levels of caregiving burden are more likely to report better quality of life than those who perceive higher levels. With high caregiving demands, the psychosocial well-being and health of dementia caregivers are prone to be negatively impacted. When not properly managed, their subjective caregiving burden may affect the quality of caregiving, thus creating a vicious cycle which would only worsen with time. This study suggests that care for older people policy makers and service providers should prescribe more evidence-based interventions to offer more practical assistance and education to the highly strained caregivers by equipping them with appropriate coping skills as well as expanding the level of social support they can have access to and enable them to take up their caregiving role more effectively.

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Table 1

Socio-economic Characterisite of Participants

Sociodemographic	Caregivers		Care-recipients	
	<i>n</i>	%	<i>n</i>	%
Gender				
Female	33	41	47	59
Male	47	59	33	41
Educational level				
Primary school	48	60	55	69
Middle school	15	19	18	23
High school/some college	15	19	5	6
University or postgraduate degree	2	2	2	2
Number of Children ^a				
Childless	15	19		
With one to two	49	61		
With three or more	16	20		
Financial Support to the Family ^a				
Social Security	16	20		
Support from Family	31	39		
Own Saving	33	41		
Care Support to the Family ^a				
With day-time support (from offspring or home-helper)	8	10		
With night-time support (from offspring or home-helper)	12	15		
No support at all	60	75		

Note. *N* = 160 (*n* = 80 for caregivers; *n*=80 for care-recipients). Caregivers were on average 71.41 years old (*SD* = 5.04); Care-recipients were on average 70.40 years old (*SD* = 4.00)

^a Reflects the number and percentage of participants answering “yes” to this question.

Table 2

Results of Care-recipients' Factor

Care recipients' Factor	Care-recipient Male		Care-recipient Female		<i>t</i> (78)	<i>p</i>	Cohen's <i>d</i>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Cognitive Function								
Hong Kong Montreal Cognitive Assessment (HK-MoCA)								
	19.30	1.27	19.25	1.45	1.23	.35	0.02	
Behavioral Sign and Symptoms of Care-recipients								
Revised Memory and Behavior Problem Checklist (RMBPC)								
Memory	(Frequency)	16.13	1.33	16.30	1.41	0.98	.56	.12
	(Reaction)	16.10	1.57	16.35	1.62	1.23	.61	.15
Disruption	(Frequency)	15.51	1.16	16.77	1.29	.89	.67	1.03
	(Reaction)	15.47	1.23	16.45	1.35	.92	.87	.75
Depression	(Frequency)	21.07	5.64	20.87	5.56	.72	.52	.04
	(Reaction)	20.85	4.87	21.21	4.79	.92	.79	.07
Other symptoms	(Frequency)	9.80	1.03	9.83	.98	.91	.62	.03
	(Reaction)	9.65	.99	9.87	.89	.89	.71	.23
Total	(Frequency)	58.82	1.31	59.35	1.09	.92	.67	.44
	(Reaction)	63.89	1.21	58.78	.99	7.89	.02*	4.62

Note. Mean parameter values for each of the analyses are shown for the male care-recipients ($n = 33$) and female care-recipients ($n = 47$), as well as the results of *t* tests (assuming unequal variance) comparing the parameter estimates between the two groups.

Table 3

Caregiver's Factor

Care-givers' Factor	Care-givers Male		Care-givers Female		<i>t</i> (78)	<i>p</i>	Cohen's <i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Knowledge about caregiving and community-based services^a							
Questionnaire of knowledge caregiving and community-based services (QK)	3.89	.95	2.21	.67	4.28	.03*	2.04
Caregiving Self-efficacy							
Revised Caregiving Self-Efficacy Scale (RCSES)	.55	.07	.33	.11	9.23	.03*	2.38
Caregiving burden							
The Chinese version of the Zarit Burden Interview Scale (CZBI)	56.85	3.99	65.25	2.87	8.23	.04*	2.42
Psychosocial Adjustment							
Short Form 36 version 2 (SF-36)	24.63	2.18	20.47	1.61	9.68	.04*	2.17

Note. ^a Reflects the number of participants answering “yes” or “no” to this question. Mean parameter values for each of the analyses are shown for the male caregivers (*n* = 47) and female caregivers (*n* = 33), as well as the results of *t* tests (assuming unequal variance) comparing the parameter estimates between the two groups.

Table 4

Correlation Matrix for Study Variables

	n	M	SD	1	2	3	4	5	6
Cognitive Function of Care Recipients (HK-MoCA)	80	19.23	1.36						
Frequency of Behavioural Symptoms of Care Recipients (RMBPC)	80	16.13	1.33	r = .30 **					
Caregivers' Knowledge and Understand of Resources (QK)	80	4.57	1.06	r = -.11	r = .18				
Caregivers' Perceived Burden of Care (CZBI)	80	57.06	4.66	r = -.54 **	r = -.30 **	r = -.29 **			
Caregivers' Self-efficacy in Caring (C-RCSES)	80	.55	.09	r = .08	r = .04	r = .16	r = -.27 *		
Caregivers' Psychosocial Adjustment (SF-36)	80	30.78	7.72	r = .40 **	r = .30 **	r = .37 **	r = -.82 **	r = .32 **	

Note. *p<.05, **p<.05

Table 5. GLM analysis summary^a

Measure ^b	GLM model results ^c		
	<i>F</i> (1, 12)	partial η^2	power
Cognitive function of care-recipients	2.68***	.32	.96
Behavioral symptoms of care recipients	2.05*	.32	.88
Caregivers' self-efficacy	2.77**	.33	.97
Perceived caring burden	13.06***	.70	.99

^a The type of GLM computation refers to the order in which items are brought in.

^b The model component refers to the term brought in last.

^c P values were computed by using GLM estimates: * $p < .05$, ** $p < .01$, *** $p < .001$.