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Abstract

Background: The main aim of this study was to determine the association between Behavioral and Psychological Symptoms of Dementia (BPSD) and caregiver burden, and the mediating role of coping strategy and personality style of caregivers to patients with dementia (PWD).

Methods: This cross-sectional study was conducted among 202 caregivers to PWD in home-based settings. Recruited caregivers were administered questionnaires regarding BPSD which was measured using Neuropsychiatric Inventory-Questionnaire (NPI-Q), caregiver burden using Zarit Burden Interview (ZBI), Brief COPE for coping strategies and Big-Five Inventory which measured personality traits.

Results: Majority of the caregivers were female (71.3%), aged 50 and above (55%), single (46%), married (43.6%), working full time (45%) while the rest work part time (22.3%), unemployed (7.4%) and retiree (25.2%), and majority were parents (58.9%) and spouse (18.3%). The duration of caregiving was less than a year (33.7%) while the rest are (02.6350-pts:

Background

Dementia is a neurodegenerative disorder that is progressive in nature involving the impairment of multiple higher cortical functions [1]. Symptoms of dementia comprise of two major groups which can be divided into cognitive symptoms and non-cognitive symptoms. Cognitive symptoms focus on impairment of memory, especially on learning of new material and short-term memory which is a key early symptom. Non-cognitive symptoms constitute of neuropsychiatric symptoms, also known as behavioral-psychological symptoms of dementia (BPSD). Behavioral symptoms are often identified based on observation of patients with dementia (PWD) such as physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing and shadowing [2]. Psychological symptoms are usually evaluated based on interviews with patients and informants which includes anxiety, depressive mood, hallucinations and delusions [3]. The emergence of BPSD can occur during any stage in dementia where patients demonstrate at least one type of BPSD [4]

Method

Research design

A cross-sectional research design was used in the current study.

Setting and participants

The primary scope of this study comprised of caregivers to patients who are registered under Alzheimer's Disease Foundation Malaysia (ADFM) centre in Petaling Jaya, Malaysia.

There were 202 caregivers who volunteered to join the study. They attended the weekly or monthly activities. Sample size was calculated using multivariate statistics which adhered to the sample size calculation of multiple regression analysis by Green [39] where $N > 50 + 8m$ in which N represented number of participants and m represented number of independent variables (i.e. Brief COPE with 14 independent variables and Big Five Inventory with 5 independent variables) thus, in total of 19 independent variables. Participants were recruited through purposive sampling who provided written consent to participate in the study. Following that, they were randomly selected from the list provided by the ADFM to proceed with parametric statistical analysis.

The inclusion criteria of caregivers included that they must be able to read and understand English and Malay language and aged 18 and above. The PWD of these caregivers must be registered under the association of ADFM and were previously diagnosed with mild to severe stages of dementia by a specialist working in a hospital. Caregivers comprised of family caregivers as well as formal caretakers such as housemaids or personal

coping strategies) (path a) and outcome (path c) and independent variable and mediator predicting the dependent variable (path c') which must be fulfilled in the results to support mediation. Figure 1 showed the hypothesized mediation effects of personality or coping strategies between BPSD and caregiver burden.

There will be four steps involved in conducting the mediation analysis. Steps 1 to 3 is conducted to establish that

(path a) signified that the regression of the BPSD se-

frequent type of BPSD exhibited by PWD (84.2%), followed by apathy (80.7%) and agitation (77.2%) as reported by caregivers (Table 2). Caregivers also implied that the least reported types of BPSD were elation (32.7%), followed by motor disturbance (57.5%) and appetite (59.4%) (Table 2). A previous study conducted in Malaysia showed that apathy was the most prevalent (83.2%), followed by agitation (60%) and sleep disturbance (53.8%) [7]. Past studies have concluded that neuropsychiatric symptoms in PWD are heterogeneous and essentially unpredictable in the presentation of emotional experience, thought content, perception and motor function which may explain the vast findings of research on prevalence of BPSD. However, despite the general discrepancy, there has been previous research where similar findings can be reported such as a study conducted by Mukherjee et al. [49] which highlighted that apathy/indifference was the most frequent (72.9%), followed by agitation/aggression (68.2%), and irritability/lability (59.8%). Aberrant motor behavior (31.8%), delusions (29%), and hallucinations (23.4%) were less frequent, while disinhibition (13.1%) and elation/euphoria (9.3%) were rare.

The pattern of previous findings is almost similar to the current research in which the three most frequent types of BPSD were reported accordingly while the least frequent types of BPSD were also highlighted in similar pattern with motor disturbance and elation being one of the least frequently reported BPSD. However, the results from other studies were inconsistent depending on different types of BPSD, the number of BPSD studied, environmental parameters and instrument used [5, 6, 17, 50, 51].

The pattern in which apathy is found to be one of the most common type of BPSD across several studies could be due to the presentation of the syndrome with reduced initiation and motivation, decreased social engagement, emotional indifference that could be misidentified with depression. PWD is rarely able to express pathological feelings of sadness, unhappiness, and preoccupation with depressing topics, hopeless (strongly associated with suicidal ideation) and loss of self-esteem [52]. As dementia progresses, other BPSD may predominate. Increased cognitive impairment was associated with more activity disturbances, hallucinations, agitation and sleep disturbances; however, delusions, affective disturbances, anxieties and phobias improved with worsening of the cognitive status [50]. Psychosis occurred more frequently with declining cognition and anxiety; depression were more common in younger patients [8].

In this study, the context of caregiving is primarily within vicinity of home-based settings which means that

support, venting, and positive reframing coping strategies were not mediator between relationship BPSD Severity and Total Caregiver Burden.

Discussion

The frequency of BPSD among patients with dementia in this study indicated that irritability was the most

focused on, thus, differences in reports as they varied in duration of their observation and presentation.

Table 3 indicated that Total BPSD severity score was significantly correlated with Total Caregiver Burden ($r = .199, p < .01$) which imply that the higher the se-

caregiver burden. Shaji et al. [17] reported that delusions, activity disturbances and aggression were perceived by caregivers to be more troublesome at times than memory deficits.

Current findings reported that there were a number of types of BPSD that were not significantly correlated to total caregiver burden which comprised of anxiety, elation and appetite. This could be explained by the fact that BPSD symptoms such as appetite is deemed less intrusive compared to delusion and agitation which includes physical violence. They cannot be easily dismissed by caregivers as they make them distressed, hence increase on

caregiving burden. Disruptive behaviors are more disturbing partly because of the adverse impact on the emotional connection between the caregiver and the care-recipient and partly because they exacerbate difficulties in other domains (e.g., caring for activities of daily living) [58].

Although disinhibition (61.4%) and motor disturbance (57.5%) were found to be one of the least frequently reported type of BPSD, the presentation of respective symptoms has been shown to have strong correlation with caregiver burden which could mean that the influence of BPSD on caregiver burden is not directly related to how common or frequently the symptoms are but

more of the underlying experiences of caregiving from the respective BPSD. Thus, it is to be underscored that the burden associated with BPSD is different for each symptom and does not always depend on frequency and severity of BPSD but could be extended to the nature of BPSD. These findings suggest that some symptoms, such as agitation/aggression and irritability/lability, as well as disinhibition and motor disturbance may affect the caregivers significantly, although their frequency and severity are low [54].

Mediating effect of coping strategies and personality styles Results reported conclude that majority of subscales in coping strategies mediate the relationships between BPSD and caregiver burden. Of coping strategies, self-distraction, active coping, planning and acceptance were found to mediate the relation between BPSD and caregiver burden whereas for personality styles, conscientiousness was the only subscale found to mediate the relationship. However, the mediation of endorsed coping strategies and personality style were all found to have partial mediation effect to the relationship.

In general, a given variable may be said to function as a mediator to the extent that it accounts for the relation between the predictor and the criterion. Mediators explain how external physical events take on internal psychological significance. The research model used in this study diagrams the mediating process by which the stressor precedes and influences the mediator and therefore affects the outcome [48].

The Multidimensional Stress-Process Model (SPM) posited how multiple stress factors contribute to negative outcomes for caregivers which was categorized into four types of variables that affect the well-being of caregivers: contextual variables, primary objective stressors, secondary stressors, and modulating variables. Based on the model, the most prominent primary stressors investigated are BPSD whereas coping strategies have a modulating function of different individual responses to the same care situation [59]. In a recent study that investigated the model also found that personality is one of the internal mediators to the relationship between primary stressor and outcome [60]; however, there has been lack of studies that have looked into the personality traits that have mediation effect in relation to BPSD and caregiving.

In the current research, it was reported that most coping strategies were found to mediate the relationship between BPSD and caregiver burden. This is supported by Lazarus [61] who argues that coping is a powerful mediator of the emotional outcome resulting from a stressful environmental transaction. Studies conducted by Folkman and Lazarus [62] highlighted that emotional state of the individual during the stressful encounter changed either positively or negatively based upon the type of

coping strategy that was used. Although current research is not investigating on the direction of association of specific coping strategies and personality style; however, it does reveal that with the inclusion of self-distraction, active coping, planning and acceptance as well as personality characteristic of conscientiousness, they signified to be partially accounted for the relationship between BPSD and caregiver burden.

According to Lazarus and Folkman [63], there is no clear guidelines on whether coping effort is deemed successful but instead is more dependent upon the caregivers' appraisal if the transaction with the environment was adequately resolved. This judgment is made based on the individual's personality characteristics, values, beliefs, and expectations related to the different factors involved in the encounter. Coping process and strategies selected are not inherently good or bad.

Based on the current findings, it reveals that most of the highlighted mediators are problem-focused strategies which include defining the problem, generating alternative coping strategies, and problem-solving. These strategies are not inherently good or bad. This study highlights that the most prominent primary stressors investigated are BPSD whereas coping strategies have a modulating function of different individual responses to the same care situation [59]. In a recent study that investigated the model also found that personality is one of the internal mediators to the relationship between primary stressor and outcome [60]; however, there has been lack of studies that have looked into the personality traits that have mediation effect in relation to BPSD and caregiving.

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individuals use to appraise stressful events and predispose them to cope in certain ways when they confront these events [31].

Abbreviations

AD: Alzheimer's disease; BFI: Big-Five Inventory; BPSD: Behavioral and Psychological Symptoms of Dementia; NPI-Q: Neuropsychiatric Inventory-Questionnaire; PWD: Patients with dementia; SPM: Stress-Process Model; SPSS: Statistical Package of Social Sciences; ZBI: Zarit Burden Interview

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Availability of data and materials

Not applicable.

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Authors' contributions

ADB, PS, and NCD conceived of the manuscript together and participated in planning the writing, workflow, and timeline. ADB wrote the first draft. NCD reviewed the first draft and offered substantial revisions, which PS and RR work on the discussion part. All authors have read and approved the final manuscript.

Ethics approval and consent to participate

The authors thanks the Ethical Committee of Universiti Kebangsaan Malaysia for the approval to conduct this study (Ethical Code: NN-2018-058). Written consents were obtained from all the participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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