Research Article

Serial Multiple Mediation of Mastery and Sleep Quality in the Relationship between Caregiving Burden and Anxiety among Parental Caregivers of Children with Leukemia in China

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Objective. The emerging literature on caregiving posits that anxiety is fairly prevalent and could vary with factors such as caregiving burden, mastery, and sleep quality. Little work has explained the possible dynamics between those variables. This study therefore aims to investigate the multiple serial mediations of mastery and sleep quality in the relationship between caregiving burden and anxiety among Chinese parental caregivers of children with leukemia.

Method. Data were taken from a convenient sample (n = 342) from a nonprofit organization that provides psycho-social support to oncological patients and their families nationwide in China. The following standardized self-reported questionnaires were administered to parents of children with leukemia: Zarit Care Burden Scale, Personal Mastery Scale, Insomnia Severity Index, and Generalized Anxiety Disorder. A serial multiple mediation model (PROCESS model 6) was employed to test the mediation hypothesis.

Result. It was demonstrated that caregiving burden was positively and significantly correlated with caregivers’ anxiety. Bootstrap analyses indicate that there were direct and indirect effects of caregiving burden on anxiety, and it was mediated by mastery. In addition, sleep quality mediated the effects of caregiving burden and mastery on anxiety, respectively.

Conclusion. Taken together, for parental caregivers of children with leukemia in China, caregiving burden is a primary stressor and can trigger anxiety. Low mastery and poor sleep quality are the secondary stressors that could lead to negative psychological outcomes for the caregiver.

1. Introduction

Leukemia is a malignant cancer that seriously threatens the physical health of children [1]. Each year in China, approximately 15,000 children are newly diagnosed with leukemia [2]. In terms of care, it is emphasized in Chinese society that the whole family engages in caring for the sick children, and parents usually bear the responsibility as the primary caregivers [3]. Parental caregivers may experience negative consequences on financial resources, household activities, health, and leisure. Apart from the objective burden, parental caregivers of children with leukemia may also experience severe subjective burden [4, 5].

Anxiety symptoms are prevalent among parental caregivers. It has been reported that nearly 50% of caregivers of patients with cancer are at a high risk of anxiety [6]. Parental caregivers could be anxious about the outcomes of sick children’s medication, operation, radiotherapy, chemotherapy, and rehabilitation [7]. Indeed, caring for children with leukemia may be associated with heavy subjective burden on parental caregivers, which may negatively affect their mental health. Despite the growing research in
caregivers’ anxiety [8, 9], there is a lack of attention to the psychological well-being of parental caregivers of children with leukemia in China. Moreover, the relationship between caregiving subjective burden and anxiety among those caregivers needs further exploration [10]. Caregiving burden is a multidimensional concept and is often treated as the primary stressor for the general caregivers in the stress process model [11, 12]. In general, the caregiving burden can significantly elevate caregiver anxiety. However, according to a systematic review, the effect of caregiving burden on caregiver anxiety varies across groups [8]. In addition, caregiving burden as a primary stressor can generate multiple secondary stressors that can also impact caregiver anxiety. However, less attention has been paid to the role of secondary stressors in the relationship between caregiving burden and anxiety [13].

Sleep quality is considered a predictor of caregiver anxiety. One systematic review shows that up to 76% of the population of general caregivers reported poor sleep quality [14]. Similar findings exist among parents caring for their sick children, such as when one study discovered caregiver anxiety significantly correlated with sleep quality among parents of children with cerebral palsy [15]. This is mainly because poor sleep quality can negatively affect caregiver activities, which can lead to poor medical outcomes of sick children. Consequently, the anxiety level of caregivers could increase [16]. Another study in China also suggested that family caregivers’ sleep problems and anxiety were prevalent, and moderate to severe anxiety was caused by sleeplessness [17].

In terms of the relationships between caregiving burden, sleep quality, and caregivers’ psychological well-being, to our best knowledge, only one study conducted among general community caregivers confirmed the mediating role of sleep quality between caregiving burden and anxiety [9]. This is due to the positive effect of better sleep quality in maintaining the caregiver’s physical and mental health [18]. Poorer sleep quality also acts as a secondary stressor, resulting in severe consequences for the caregiver. Numerous studies have focused on the mediating effects of caregiver sleep quality in the relationship between caregiving burden and psychological well-being [9, 19], but little is known about the role of sleep quality in that relationship in the case of parental caregivers of children with leukemia.

Some researchers suggested that caregivers’ greater sense of mastery predicts lower anxiety [13, 20]. Mastery is an internal resource of individuals, and it refers to the degree to which one experiences control over what goes on in one’s life [21, 22]. That is, a lack of mastery may increase psychological distress among caregivers [23].

According to the stress process model, caregiving burden can reduce the caregiver’s ability to master; thereby, lower mastery is a secondary stressor that has negative impacts on caregivers [18, 24]. Many studies have confirmed the effect of caregiving burden on mastery [25, 26]. Moreover, previous studies found that mastery plays a mediating role in the relationship between caregiving burden and psychological distress [27, 28]. According to these findings, mastery is likely to mediate the effect of caregiving burden on psychological well-being, but anxiety has been relatively neglected. Therefore, it needs to further verify whether mastery can play a mediating role between care burden and anxiety.

The link between caregiving burden, mastery, sleep quality, and anxiety is complex and poorly understood. For the most part, mastery [29] and sleep quality [19] are significantly correlated with caregiving burden. However, the effects of mastery and sleep quality on caregiver anxiety were not consistent [18]. Although high mastery and good sleep quality are viewed as personal resources of caregivers, prior studies showed that sleep quality significantly affected caregivers’ experiences of unhealthy days due to physical health and/or mental health issues, while mastery did not [18]. In addition, there is a lack of research on how mastery affects caregivers’ sleep quality. We found only one study suggested that mastery has a significant effect on sleep quality among caregivers [30]. Few studies considered both mastery and sleep quality in the context of caregiving burden and anxiety [31].

Parents are usually the primary caregivers of children with leukemia, and the continuous process of caregiving can have a detrimental impact on their mental health. According to the stress process model, caregivers with heavy caregiving burden may perceive low mastery, thus reducing their sleep quality and further lead to anxiety. This study aimed to examine the mediating effect of mastery and sleep quality in the relationship between caregiving burden and anxiety among parents caring for children with leukemia in China. Therefore, we hypothesized that (1) caregiving burden is positively associated with anxiety; (2) mastery mediates the positive link between caregiving burden and anxiety; (3) sleep quality mediates the positive link between caregiving burden and anxiety; and (4) mastery and sleep quality play a chain mediating role between caregiving burden and anxiety sequentially.

2. Methods

2.1. Participants and Procedures. A cross-sectional design and convenient sampling method were adopted in this study. We used WeChat, an instant messaging and social media mobile app, to conduct an online survey. All participants were service utilizers of Diai Home, which is a nonprofit organization located in Beijing that provides psycho-social support to oncological patients and their families nationwide. Diai Home disseminated the survey information to its service utilizers through WeChat and recruited participants. Service utilizers were told they were voluntary to take part in, and whether to participate in this survey or not was not associated with the services they could receive from Diai Home. Eligible participants were parental caregivers of children (0–18 years old) with leukemia. At the first window of this online survey, there was an information statement for participants to indicate and agree to participate. A total of 397 questionnaires were collected. Among them, 55 were omitted because their children were older than 18 or did not suffer leukemia. Eventually, 342
questionnaires were valid and included in the analysis. All patients suffered from acute leukemia, either acute myeloid leukemia or acute lymphocytic leukemia. This study was approved by the committee on Human Research Publication and Ethics, Renmin University of China.

2.2. Measures

2.2.1. Caregiving Burden. The Zarit Care Burden scale (ZCBS) was used to assess the participants’ caregiving burden [32]. ZCBS evaluates the stress endured by the caregivers who care for those who are ill or injured. Consistent with the Zarit Burden Interview (ZBI) [33], ZCBS is also the classic scale for measuring caregiver burden, which focuses primarily on the subjective burden. It has been used in numerous studies to assess the caregiving burden of caring for children with leukemia [34, 35]. The Chinese version of ZCBS has a high reliability [36]. The scale comprises 22 questions (e.g., “Do you think patient asks for more help than he/she needs?” “Do you think you are afraid of patient’s future?” and “Do you think you are suffering in social life?”) with a Likert-type rating scale, ranging from 1 = never to 5 = nearly always. The total score ranged from 22 to 110, with higher scores indicating a greater burden [33]. Cronbach’s alpha for ZCBS was 0.926.

2.2.2. Mastery. The Personal Mastery Scale (PMS) was used to assess the sense of mastery among the caregivers [37]. This scale consists of seven items that assess caregivers’ belief that they have control over their life circumstances. For example, “There is really no way I can solve some of problems I have,” “I have little control over the things that happen to me,” and “I can do just about anything I really set my mind to do.” The responses are graded on a 4-point scale ranging from “strongly agree” to “strongly disagree.” The negatively worded items require reverse coding prior to scoring, resulting in a score range of 7 to 28, with higher scores indicating higher levels of mastery. Cronbach’s alpha for this tool was 0.816.

2.2.3. Sleep Quality. Insomnia Severity Index (ISI) was used to assess sleep quality among the participants [38]. ISI is a 7-item self-report questionnaire that examines sleep quality in the previous month. The specific items evaluate the severity of difficulties with sleep onset, sleep maintenance, and early morning awakening; sleep dissatisfaction; interference of sleep problems with daytime functioning; noticeability of sleep difficulties by others; and sleep-related worries [39]. A 5-point likert scale (1 = one; 5 = very severe) is used to rate each item, with total scores ranging from 7 to 35. A higher total score indicates more severe sleep difficulties. Previous studies have determined that Chinese versions have adequate psychometric properties [40, 41]. In our research, Cronbach’s alpha was 0.936.

2.2.4. Anxiety. The Generalized Anxiety Disorder (GAD-7) questionnaire was used to assess the anxiety among the caregivers during the previous two weeks [42]. Caregivers were asked to rate how often they had been bothered by problems such as feeling nervous or anxious, unable to manage or stop worrying, over-worrying, having trouble relaxing, and getting quickly irritated or feeling afraid [43]. The total score range for the GAD-7 is 0 to 21, with each item scored on a scale of 0 = not at all to 3 = nearly every day, and higher scores indicate higher anxiety levels. In China, this tool has received widespread validation [44]. The internal consistency of GAD-7 in this sample was high (Cronbach’s alpha = 0.944).

2.3. Statistical Analysis. The data were analyzed using the statistical software package SPSS 25. The background characteristics of the samples, including the parental caregiver and their ill child, were presented using descriptive analysis. Pearson’s correlation analysis was employed to determine the relationships among caregiving burden, mastery, sleep quality, and anxiety. A multivariable mediation analysis was carried out to develop a mediating model of these variables. This approach allows for the inclusion of an independent variable (caregiving burden), a dependent variable (anxiety), and two sequential mediator variables (mastery and sleep quality). The SPSS PROCESS macro (model 6) was used to calculate the total, direct, and indirect effects [45]. The total effect refers to the association between the caregiving burden and anxiety when mastery and sleep quality are not taken into account. For the multiple mediation analysis, the indirect effects are the effects of the caregiving burden on anxiety via mastery or sleep quality. A 95% confidence interval (CI) was calculated with 5,000 bootstrapping resamples. The mediating effects are statistically significant if zero does not fall within the confidence interval range [46].

3. Results

Table 1 shows the characteristics of the overall sample and each subgroup. The sample consisted of 342 respondents in total, aged between 24 and 54 with an average age of 37.79 years. The sample was primarily female (61.11%), with less secondary education (62.57%), married (90.06%), and engaged in agricultural activities (74.27%). Most participants were rural residents (57.89%). The mean of caring hours per day was 16.89 (SD = 7.02). Regarding the characteristics of the children, 26.90% were the only children, and the proportion of boys (64.62%) was higher than girls (35.38%).

The mean scores for anxiety, caregiving burden, mastery, and sleep quality are presented in Table 2. Table 2 also shows the results of Pearson’s correlation analysis. Caregiving burden was positively associated with anxiety (r = 0.433, p < 0.001). In addition, caregiving burden was inversely related to mastery (r = -0.424, p < 0.001) and positively correlated with sleep quality (r = 0.344, p < 0.001), which means that the heavier the caregiving burden, the worse the caregiver’s mastery and sleep quality. Both mastery (r = -0.435, p < 0.001) and sleep quality (r = 0.605, p < 0.001) were significantly correlated with anxiety.

The multiple linear regression analysis revealed significant relationships between the independent variables,
investigated whether mastery and sleep quality can mediate the path between caregiving burden and anxiety in a sequential manner. The indirect effects of caregiving burden on anxiety through mastery and sleep quality were also statistically significant (standardized estimate = 0.009, CI = 0.002, 0.017), confirming that caregiving burden positively affected anxiety via mastery and sleep quality in serial.

4. Discussion

In this study, we tested the relationships between caregiving burden, mastery, sleep quality, and anxiety among parental caregivers of children with leukemia in China. Particularly, we examined the mediating role of mastery and sleep quality in the relationship between caregiving burden and anxiety.

Our results indicated that caregiving burden, directly and indirectly, affects anxiety among parental caregivers. For the direct effects, this study shows that caregiving burden significantly elevated caregiver anxiety symptoms. This is consistent with the theoretical hypothesis of the stress process model [11, 12], and it is also consistent with previous empirical evidence [8, 10]. Generally, the responsibility to care for a child with leukemia is a primary stressor for parents and has an adverse effect on their mental health. Caregivers’ anxiety increases along with caregiving burden. Our finding indicated that reducing subjective caregiver burden may help reduce caregivers’ anxiety. Previous studies on caregiving behaviors of parental caregivers of children with leukemia in China have focused on coping strategies [48], psychological well-being [5], and quality of life [49]. We expanded previous findings by focusing on the specific pathways that caregiving burden affects anxiety.

Regarding the potential mediators or indirect effects, this study confirmed that sleep quality mediates the association between caregiving burden and anxiety. On the one hand, sleep quality was independently associated with caregiver anxiety which is in line with former studies [14, 17], and on the other hand, a more substantial caregiving burden diminishes caregivers’ sleep quality and further elevates their anxiety [50]. Sleep disruption is a prevalent symptom reported by caregivers triggered by caregiving burden [9], and it can lead to caregivers’ executive dysfunction and role strain [14]. Thus, poor sleep quality mediates the effect from caregiving burden on anxiety [51].

Mastery has been linked to caregiver outcomes in a variety of prior studies [20, 52]. Lower mastery is a major risk factor of poor physical health for parents of children with developmental disabilities [52]. Greater mastery is linked to lower anxiety symptoms among dementia caregivers [20]. Previous research also showed mastery mediates the relationship between caregiving burden and depression symptoms [12]. Caregivers’ mastery, as an intrinsic psychological resource, is prone to fluctuate when caregivers’ duties are fulfilled [12]. When caregivers are exposed to stressful events, mastery not only exerts a buffering effect but also is directly affected by the stressful event. Thus, the ongoing care process will weaken the caregivers’ sense of mastery. Thus, the sense of mastery mediates the relationship between caregiving burden and anxiety.

<table>
<thead>
<tr>
<th>Variables</th>
<th>N (%) or M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age</td>
<td>37.79 (5.69)</td>
</tr>
<tr>
<td>Caregiver gender</td>
<td>Male 133 (38.89%), Female 209 (61.11%)</td>
</tr>
<tr>
<td>Residence</td>
<td>Urban 144 (42.11%), Rural 198 (57.89%)</td>
</tr>
<tr>
<td>Education</td>
<td>Less than secondary 214 (62.57%), Secondary and above 128 (37.43%)</td>
</tr>
<tr>
<td>Marriage</td>
<td>Married 308 (90.06%), Unmarried 34 (9.94%)</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>Very bad/bad 102 (29.82%), Moderate 191 (55.85%), Good/very good 49 (14.33%)</td>
</tr>
<tr>
<td>Current work</td>
<td>Peasant 254 (74.27%), Nonpeasant 88 (25.73%)</td>
</tr>
<tr>
<td>Only child</td>
<td>Yes 92 (26.90%), No 250 (73.10%)</td>
</tr>
<tr>
<td>Child gender</td>
<td>Male 221 (64.62%), Female 121 (35.38%)</td>
</tr>
<tr>
<td>Caring hours per day</td>
<td>16.89 (7.02)</td>
</tr>
<tr>
<td>N (%) or M (SD)</td>
<td>342</td>
</tr>
</tbody>
</table>

Table 1: Background characteristics of the sample (n = 342).
In line with previous research [30], this study showed a significant correlation between mastery and sleep quality, suggesting that a lower level of mastery is correlated to worse sleep quality. Simpson et al. found that mastery and sleep quality on caregivers’ health were inconsistent, i.e., the two did not work together [18]. However, the present study showed that both mastery and sleep quality can affect caregivers’ anxiety. This suggests that for parents of children with leukemia, high mastery and good sleep quality can serve as resources for coping with psychological distress. More than that, mastery may also have an indirectly effect on anxiety through sleep quality. This implies the importance of mastery in maintaining a better sleep quality and thus relieving anxiety among caregivers.

The primary strength of this study is it demonstrated that mastery and sleep quality play multiple mediating roles between caregiving burden and anxiety. In prior studies, mastery and sleep quality were mediators between caregiving burden and mental health, separately [9], while few studies tested the linkage between them or explored the dynamic of their effects. This study provided a more comprehensive analysis of the process as well as the direct and indirect effects of caregiving burden on anxiety symptoms. The contribution of the results of this study is to expand the researchers’ theoretical understanding of mastery and sleep quality in the stress process model. On the one hand, secondary stressors, triggered by caregiving burden, play a mediating role in the relationship between the primary stressor and the caregiver’s psychological well-being. On the other hand, there are interactions between secondary stressors.

The findings also have important implications for practitioners. This study implies the necessity to facilitate healthcare workers to identify and reduce parental caregiving burden. Particularly, in order to maintain caregivers’ high levels of mastery, some related services could be considered, such as to provide knowledge of caregiving, as well as the information of the benefits, risks, and accessibility of treatment options [53]. Moreover, caregivers may need assistance to be clear about their personal values to make decisions for children [54, 55]. Emotional support to caregivers could also be helpful to relieve emotional isolation [56]. Additionally, it would be beneficial to build supportive communities for parental caregivers to acquire financial and social resources they need [57].

4.1. Study Limitations. This study has a couple of limitations to recognize. First, respondents are heterogeneous in the progression of the children’s disease and treatment. Since the caregiving burden and psychological features can vary a lot, the findings could have been more specific with a more homogeneous study sample. Second, since our study adopted a cross-sectional design, it is difficult to draw valid causal relationships between variables. Third, the relatively small sample influenced the power of the tests, although the tests were performed via bootstrap. Finally, in the context of

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean</th>
<th>SD</th>
<th>ZBCS</th>
<th>PMS</th>
<th>ISI</th>
<th>GAD-7</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZBCS</td>
<td>58.84</td>
<td>18.69</td>
<td>1</td>
<td>-0.424***</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>PMS</td>
<td>16.44</td>
<td>3.19</td>
<td>-0.068***</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>ISI</td>
<td>20.84</td>
<td>7.13</td>
<td>0.063***</td>
<td>-0.301***</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>GAD-7</td>
<td>16.98</td>
<td>5.70</td>
<td>0.433***</td>
<td>-0.435***</td>
<td>0.605***</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. N = 342, * p < 0.05, ** p < 0.01, *** p < 0.001.
China, except for parental caregivers, it could be common that other family members and kin participate in taking care of the sick children throughout phases of treatment, and some of them bear the primary caregiving responsibilities. Further research on their caregiving burden and well-being is warranted.

5. Conclusion

This study provided empirical evidence that caregiving burden is a primary stressor and can trigger anxiety among parental caregivers of children with leukemia in China. Low mastery and poor sleep quality can be treated as secondary stressors leading to negative psychological outcomes for the caregivers. Practitioners can use the findings to enhance the psycho-social support of this vulnerable group by connecting needed resources and facilitating supportive communities to reduce their caregiving burden, improve their sense of mastery, and assist children in their treatment and rehabilitation phases.

Data Availability

The datasets used during the current study are available from the corresponding author upon reasonable request.

Disclosure

The sponsor of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the study.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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