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Perceived burden and quality of life in Chinese caregivers of people with serious mental illness:

A path analysis

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Abstract

Background: In China, family members take on the major responsibility of caring for people with serious mental illness (SMI). Caring for a family member with SMI can result in numerous consequences for the caregiver. The aims of this study were to investigate perceived caregiver burden and quality of life (QOL) among Chinese family caregivers for people with, to assess the role of social support as a mediator between caregiving and QOL, and to test whether the proposed conceptual model can explain the pathway of how caregiving influencing perceived burden and QOL.

Methods: In the current cross-sectional study, 231 family caregivers were recruited and independently interviewed using the Chinese version of the WHOQOL-BREF, Hospital Anxiety and Depression Scale, Social Support Rating Scale, and Family Burden Interview Schedule as outcome measures.

Results: The path analysis model provided a good fit for the data ($\chi2$ [7] = 13.96, p = 0.052, CFI = 0.910, TLI = 0.875, IFI = 0.912, RMSEA = 0.068), with all individual paths significant at $p < 0.05$. Caregiving time spent in SMI patients was re-

lated directly with family burden. Caregivers' depressive symptoms were related directly levels of family burden and QOL. All other significant variables were related indirectly with family burden and QOL, social support plays the role of mediating effects.
Conclusions: Study findings show that social support can be regarded not only as a protective factor in reducing the caregiving burden for family caregivers, but also in promoting caregivers' QOL.

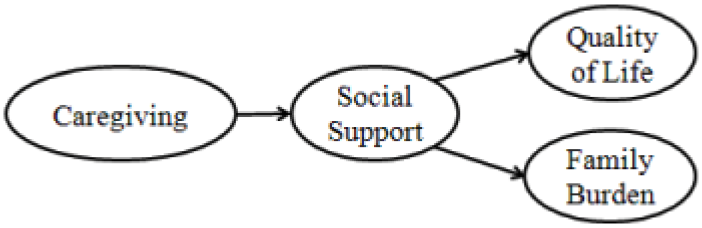
Keywords: Family caregivers; Serious mental illness; Caregiver burden; Quality of life; Path analysis

Introduction:

Caring for a family member with SMI can result in numerous consequences for the caregiver [1,2]. Caregivers may experience considerable adverse effects on their quality of life (QOL), as well as adverse health effects such as distress [1]. Caregivers could also experience a range of negative emotions, impacting both their physical and mental health [2]. This impact of caregiving has been conceptualized as caregiver burden [2]. Caregiver burden has been associated with caregivers' depressive symptoms and inadequate social support [3,4]. Previous research found that insufficient social support was the most significant predictor of caregiver depression, followed by caregiver burden [5]. Chan [6] indicated that social support appears to be an important protective factor in caregiver burden in diverse cultures.

This study investigated the mediating role of social support as a major protecting factor, determining the influence of caregiving on caregivers' perceived burden and quality of life (QOL). The conceptual model guided this study is illustrated in Fig. 1. The aims of this study were to investigate perceived caregiver burden and QOL among Chinese family caregivers for people with SMI, to assess the role of social support as a mediator between caregiving and QOL, and to test whether the proposed conceptual model can explain the pathway of how caregiving influencing perceived burden and QOL.

Fig. 1. The research model



Methods

Subjects

The SMI patients who met the following inclusion criteria were invited to participate in the study upon their planned discharge: (1) Chinese adults ages 18 to 65, (2) suffering from schizophrenia and/or other psychotic disorders, using the consensus diagnosis according to DSM-5, and (3) voluntary consent. Eligible family caregivers were recruited on the day of SMI patients' discharge from hospital. Caregivers who were interested in participating signed up for the study. Inclusion criteria included (1) caregivers who have spent two hours or more each day looking after the discharged patients; (2) one caregiver per patient; and (3) age 18 or above.

Measures

Measures included in this study consist of five parts: 1) The Socio-demographic sheet was used to collect participants' age, gender, relationship with the patient, marital status, employment status, education level, monthly income, health status, length of time as a caregiver, and average number of hours per week spent caring for the discharged patient; 2) The World Health Organization Quality of Life – Brief Form (WHOQOL-BREF)

(Chinese version) was used to measure the quality of life in subjects; 3) The Hospital Anxiety and Depression Scale (HADS) was used to measure the psychological health of subjects; 4) The Social Support Rating Scale (SSRS) was used to measure social support of subjects; and 5) The Family Burden Interview Schedule (FBIS) was used to assess caregiver burden of subjects.

Data collection and analysis

This study was approved by studied hospitals' Ethics Committee. Written consent was obtained from participants before data collection. Data were collected from May - July 2014. Trained research nurses collected the data in face-to-face interviews, on the day of patients' discharge from hospital. Data were analyzed using SPSS and AMOS for Windows, version 20. Statistical significance was set at 0.05. The findings would be summarized by descriptive statistics, correlation and path analysis.

Results

Subject characteristics

A total of 231 family caregivers were recruited in this. Most patients were suffering from schizophrenia or schizophrenia spectrum disorder, while the remaining subjects were experiencing psychotic disorders or major depressive disorders. Participants' ages ranged from 18 to 73, with a mean age of 45.46 (SD=13.18). The detailed characteristics of family caregivers were listed in Table 1.

Table 1 Demographic and clinical characteristics of participants (N=231)

Characteristics	
Age (Years)	Mean (SD) = 45.46 (13.18)
Gender	
Male	115 (49.8)
Female	116 (50.2)
Relationship	
Parents	109 (47.2)
Spouse	58 (25.1)
Sisters/Brothers	43 (18.6)
Others	21 (9.1)
Marital status	
Never married	21 (9.1)
Married or cohabited	190 (82.3)
Divorce/separated	16 (6.9)
Others	4 (1.7)
Employment status	
Employed	122 (52.8)
Unemployed	58 (25.1)
Others (housewife, retired, student)	51 (22.1)
Education level	
Primary school or below	51 (22.1)
Secondary school	115 (49.8)
University/Tertiary education	65 (28.1)
Health status	
Very good	149 (64.5)
Good	66 (28.6)
Poor	6 (2.6)
Very poor	10 (4.3)
Length of time as family caregivers (days)	Mean (SD) = 31.15 (70.28)
Hours of contact with patients per week	Mean (SD) = 59.62 (62.31)

Means of measurement outcomes

Means of measurement outcomes was listed in Table 2. With regards to QOL by WHOQOL-BREF, caregivers indicated a higher perceived QOL in the domains of environmental and physical health, than in the areas of psychological health and social relationships. Concerning symptom severity by HADS, family caregivers had more severe psychological symptoms of depression, than anxiety-related symptoms. In terms of social support by SSRS, caregivers perceived better subjective support than objective support and support use degree. In terms of a sense of care burden, the most common burden perceived by caregivers was financial.

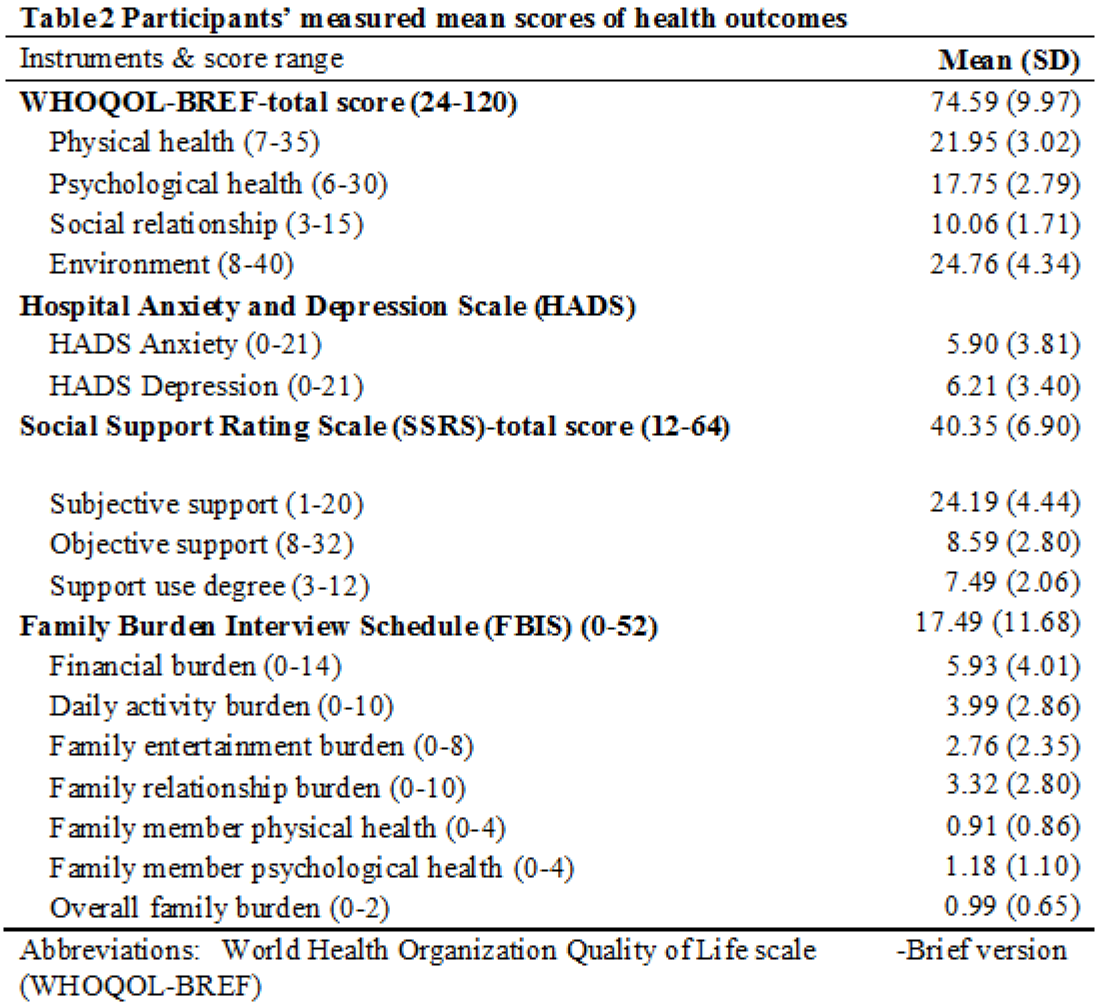


Table2 Participants' measured mean scores of health outcomes

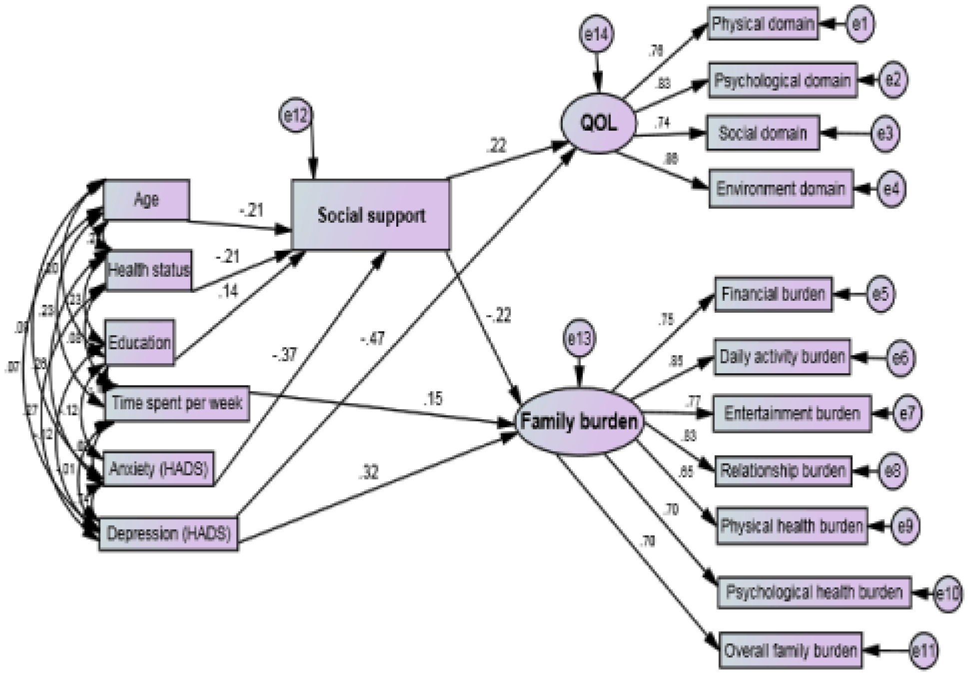
Instruments & score range	**Mean (SD)**
WHOQOL-BREF-total score (24-120)	74.59 (9.97)
Physical health (7-35)	21.95 (3.02)
Psychological health (6-30)	17.75 (2.79)
Social relationship (3-15)	10.06 (1.71)
Environment (8-40)	24.76 (4.34)
Hospital Anxiety and Depression Scale (HADS)	
HADS Anxiety (0-21)	5.90 (3.81)
HADS Depression (0-21)	6.21 (3.40)
Social Support Rating Scale (SSRS)-total score (12-64)	40.35 (6.90)
Subjective support (1-20)	24.19 (4.44)
Objective support (8-32)	8.59 (2.80)
Support use degree (3-12)	7.49 (2.06)
Family Burden Interview Schedule (FBIS) (0-52)	17.49 (11.68)
Financial burden (0-14)	5.93 (4.01)
Daily activity burden (0-10)	3.99 (2.86)
Family entertainment burden (0-8)	2.76 (2.35)
Family relationship burden (0-10)	3.32 (2.80)
Family member physical health (0-4)	0.91 (0.86)
Family member psychological health (0-4)	1.18 (1.10)
Overall family burden (0-2)	0.99 (0.65)

Abbreviations: World Health Organization Quality of Life scale -Brief version (WHOQOL-BREF)

Testing the research model by path analysis

Relevant correlation and regression analyses were conducted before performing the path analysis. Only significant ones were kept in the path analysis. As shown in Fig. 2, the model (Fig. 2) provided a good fit for the data ($\chi2$ [7] = 13.96, p = 0.052, CFI = 0.910, TLI = 0.875, IFI = 0.912, RMSEA = 0.068), with all individual paths significant at $p < 0.05$. Caregiving time spent in SMI patients was related directly with family burden. Caregivers' depressive symptoms were related directly levels of family burden and QOL. All other significant variables were related indirectly with family burden and QOL, social support plays the role of mediating effects. In other words, caregivers' age, health status, education levels and anxiety symptoms had no direct relations to family burden and QOL, and social support mediated the effect of caregiving on family burden and QOL.

Fig.2 Summary of the standardized path coefficient representing effects of caregiving characteristics and social support on family burden and QOL.



Discussion

By the path analysis, the severity of depression was negatively associated with caregivers' QOL. Previous research reported that Chinese caregivers of people with schizophrenia with higher psychological distress were found to have a higher caregiving burden [7]. Hence, relevant interventions to promote Chinese family caregivers' psychological health are urgently required. Additionally, education levels had indirect relation to QOL. Among Chinese community, obtaining a high level of education is valued. To some degree, individuals with an increased education level may often have a greater financial income and better working opportunity. Thus, higher education levels were associated with better QOL among Chinese family caregivers. Another significant indirect relation was weekly hours spent caring for the family member with SMI associated with caregiver burden. Longer hours spent caring for the SMI patient indicate a perception of higher levels of burden , especially for employed caregivers dealing with both work-related issues and providing care for a family member with SMI. Previous research found that many family caregivers had to quit their job or retire early in order to take care of family members with mental illness [8]. Thus, unemployment or early retirement could result in financial difficulties for these family caregivers.

Furthermore, health status had indirect effects in family burden and QOL. One would expect that having good health when providing care for a family member with SMI would lead caregivers to experience a lighter burden. Obviously, greater objective demand burden requires family caregivers to put more effort into performing daily assistance activities, supervising patients' behaviour and providing financial assistance in caring for SMI patients. In consequence, the QOL of caregivers was significantly affected. Similar to previous research, social support is one of the protective factors when providing care for a family member with schizophrenia [3,6]. This study also found that social support can be regarded not only as a protective factor in reducing the caregiving burden for family caregivers, but also in promoting caregivers' QOL.

Several study limitations should be taken into account. First, the convenience sampling method limits the generalizability of study findings. Further studies, at multiple sites and across regions, should be conducted.

Second, this study only recruited stabilized SMI patients, so replications of the current findings among family caregivers for acutely ill and ambulatory SMI patients is necessary. Finally, the current study only reported and assessed study outcomes at a single point in time. In consequence, the causality of relationships between social-demographic variables, caregiver burden and QOL could not be explored. However, this study is ongoing, with a year follow-up to be conducted with these family caregivers for people with SMI.

Although this study has several limitations, its findings have important practice implications. Lower levels of social support were a significant protecting factor for higher caregiver burden and lower levels of QOL among Chinese family caregivers of people with SMI. Hence, providing caregiver support (e.g. support from friends or other family members) might prove beneficial. In addition, providing caregivers with knowledge about SMI is essential, since an increase in knowledge about SMI might help reduce caregivers' sense of burden [9]. Furthermore, caregivers experienced high levels of depressive symptoms, which negatively influenced their QOL. More services, such as family psycho-education, support groups and individual counselling should be developed, with the goal of improving caregivers' psychological health and QOL [7].

Implications for future research include the potential for developing and implementing effective intervention strategies to reduce caregiver burden and improve caregivers' QOL. For example, intervention strategies to improve communication between mental health service providers and families should be developed. Health policy makers should provide relevant resources, such as financial assistance with care for family caregivers, and it is important that health policy fully recognizes the role of family caregivers as a healthcare resource in caring for people with SMI [10].

Conclusions

Study findings show that social support can be regarded not only as a protective factor in reducing the caregiving burden for family caregivers, but also in promoting caregivers' QOL.

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