

# The Quality of Life and Caregivers' Burden among Caregivers of Psychiatric Patients: Evidence from Chongqing/China

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## Abstract

**Background:** Since the last few decades the disease burden caused by mental illness has been increasing. According to recent studies and reports, the disease burden caused by mental illness occupies the second rank of all non-communicable diseases. Studies show that the increase of mental illness in the general population goes together with the increases of multiple challenges within primary caregivers of psychiatric patients who are mostly family members of these patients. Like the rest of the world, in China, the increase of mental illness is becoming critical in different generations of the Chinese population. Many studies have been conducted on different topics related to caregiving psychiatric illness. Most studies have focused on psychosis illnesses such as schizophrenia and mood disorders. Psychological status and other related topics have been conducted in probably many if not all provinces of China. As per our knowledge to date, the psychological status such as quality of life, the caregiver burden of caregivers of multiple forms of psychiatric illness has been not yet studied in Chongqing. In this study, we aimed to investigate the quality of life, the caregiver burden, and Hopelessness within caregivers of psychiatric patients in three hospitals in Chongqing.

**Methods:** This study resulted on an on-going cross-sectional study in the psychiatry department of the first affiliated hospital of Chongqing medical university. The participants were males and female caregivers aged from 18-65 years old with no history of psychiatric illness caring for patients of all diagnosed forms of psychiatric illness. N=122. We used Chinese versions of Quality of Life (QoL), the Beck Hopelessness (BHS), and the Zarit caregiver Burden Interview (BIZ). Data analysis was performed using SPSS.

**Results:** The QoL was respectively presented as poor in 9% of participants. The high care burden was in 5.7% of caregivers while the severe despair was present in 7.7% and 12.8 with moderate despair while 23.4% have mild despair. Not having other help for caring for the patient, the frequency of hospitalization, daily living relation patient and caregiver and education of caregiver were significantly correlated with QoL  $P < 0.05$ . Similarly, patients having other diseases, caring for more than one patient, caregiver relation with the patient, and daily living relation patient and caregiver were significantly correlated with the BHS  $P < 0.05$ . The frequency of hospitalization and the total time caring for the patient in months have significantly correlated with BZI  $P < 0.05$ .

**Conclusion:** Psychological health of caregivers in Chongqing tends to be critical we recommended Chinese authorities especially policymakers in healthcare to reflect on primary mental healthcare and all concerned parties should increase effort in implementing strategies of increasing awareness of mental health, they must consider the found factors that influence challenges in caregivers and must act accordingly.

**Keywords:** Psychological health; Mental illness; Quality of life; Caregiver

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## Introduction

In approximately last two decades the World Health Organization reported that at least 450 millions of people were living with a mental health disorder [1]. Similar to the WHO report a meta-analysis survey conducted in 59 countries between 1980 to 2013 showed that the lifetime incidence of mental health disorders counts 29.2% in adults aged between 16-65 years old [2]. The reports showed by Chinese authorities in recent years levelled that in 2015 more than 173 million people were living with a mental disorder and in 2013 there was an estimate of 16 millions of Chinese diagnosed with serious mental illness [3,4]. The increase in prevalence of mental disorders especially serious mental disorders goes with the increase in challenges among caregivers of mental health patients who are mostly families of these patients [5-7]. The family care role started with the policy of deinstitutionalization where the family could play an active role in community care of relatives with serious mental illness, this approach was developed because the family could help in the treatment and improvement of the illness as family members were seen as source of social network, that can provide other needed support for the good benefit of the psychiatric patient [8]. In the recognition of caregiving role and challenges, the World Health Assembly in 2013 has adopted the comprehensive Mental Health Action Plan 2013-2020 to expand community based mental healthcare services and to change the attitude toward mental health illness in countries around the world, in this plan there were; to address education opportunities and income generation, housing and other social determinant of mental health which focused mainly on the role of caregivers of family member or relative with mental illness [9]. Like other countries, psychiatric patients are mainly treated in community based care in china and it is evident that the majority of psychiatric patients live and benefit assistance and care of their families or relatives in china with an estimate of 70% of patients [10,11]. Similar to other caregivers of psychiatric illness around the world, caregivers in china have reported challenges resulted to care and support that they provide to their sick relatives. The mostly reported challenges are caregiver burden, the social support and the quality of life, the physical and other psychological health and related problems [10-13]. Although, many topics on caregivers have been explored so far, there is a need to explore more especially in Chinese society where a given number of challenges may occur due to different causes which includes the change in time and the dynamicity of the society. In this study we aimed to investigate the quality of life and caregivers' burden among caregivers of psychiatric illness who were attending treatment in three different hospitals in Chongqing municipality.

## Methodology

This study is a party of an on-going project of caregivers of psychiatric patients at the first affiliated hospital of Chongqing medical university. Participants in this study have been recruited between January and August 2020, in departments of psychiatry

and mental health from three hospitals in Chongqing city (the first affiliated hospital of Chongqing medical university, first branch of the first affiliated hospital of Chongqing medical university and the university town hospital of Chongqing medical university). Data collectors and facilitators were mainly post-graduate students and teachers in the department of psychiatry and mental health. The study was designed to be cross sectional study. At the time of data analysis, 162 participants were recruited and accepted to respond to study questionnaires. We used internet based software in data collection; the QR code was available in psychiatric departments of all above three mentioned hospitals. Data collection facilitators helped in explanation of research purpose, participation criteria and the procedure for filling research tools. To meet the participation criteria, the participant should be; the caregiver who had; (i) provide care to a psychiatric patient diagnosed according to DSM 5 and/or Chinese classification of mental disorder (such as Depressive disorders, schizophrenia, epilepsy, anxiety disorders, any type of child or adolescent disorders, etc.) (ii) aged from 18 years, (iii) not presenting a sign or symptoms of mental or physical health during time of filling the tools, have ability to understand and fill or asked question into study tools.

## Tools

**General social demographic questionnaire:** A demographic questionnaire provided information on age, gender, marital status, educational level, area of residence, employment status, home monthly income, official relationship with patient, whether living with patients or not, health status of caregivers, knowledge about the mental illness, the mental health resources use and availability, the disease course and the total length of time and average number of hours per day spent caring for the patient. Whether the patient needs supervisor while taking medicine or other treatment, the living relation between patient and caregiver, the demographic survey also asked the caregiver to provide information on the family member under their care the number of children raised at home, whether there are other people helping the caregiver to take care of the patient, whether the caregiver has any other physical illness, whether the caregiver has been diagnosed with mental illness in past the medical bill payment, whether the family used to seek other treatment in past and now. Some demographic information such age, gender, marital status, employment, educational level of the patient was also asked to caregivers.

**The Quality of Life scale (QoL):** The Quality of Life scale (QoL) also known as (MOS-36) Medical Outcome Survey-36 is a self-report measure composed by 36-item Short Form (MOS SF-36) which is composed of eight sub-scales: Physical Functioning (PF), Bodily Pain (BP), Role Physical (RP), General Health (GH), Role Emotional (RE) Social Functioning (SF), Valitality (VT) and Mental Health (MH) [14]. Higher scores of each domain (range 0-100) indicate a higher perceived Quality of Life. Aggregating the mean of PF, BP RP and GH provided Physical Component Scores (PCS). Further, VT, SF, RE and MH provided Mental Component Scores (MCS)

[15]. The SF-36 is valid and reliable to use in China with the 0.66-0.88 for Cronbach's alpha coefficients, 91.4% for item convergent validity and 92.5% for item discriminant validity [16].

**The Zarit caregiver Burden Interview (ZBI):** The Zrit caregiver burden interview by origin is composed by 22 questions graded on scale from 0 to 4 it was developed by Zarit in 1980s [17]. According to the presence or intensity of any affirmative response, and it measure the caregiver's health, psychological well-being, social life, finances and relationship between the caregiver and the patient [18]. The zarit burden interview is valid and reliable to use in Chinese population with the Cronbach's alpha 0.89 [19].

**The Beck Hopelessness Scale (BHS):** The BHS was developed by Aaro T. Beck and his colleagues in 1974s in the therapy center of the psychiatric department in Pennsylvania University faculty of Medicine. Beck and his colleagues constructed this instrument based on pessimistic statements about the future selected from descriptions mentioned by patients. The scale is composed of 20 propositions that can be defined as true or false and they evaluate the scope of negative about the immediate and long-term future [20]. The replies are added to give a score of from 0 to 20, with a cut-off point at 9 or 10, depending on the population for which it was validated. The items that indicate hopelessness score 1 point, while those that do not indicate it score 0 points. The number of points measures the severity of hopelessness: 0-3 is minimum or normal, 4-8 is mild, 9-14 is moderate and 15-20 is severe [20,21]. The BHS is valid and reliable to be used in Chinese population the Cronbach's Alpha.96 [22].

## Statistical analysis

Data analysis was performed using SPSS. The descriptive statistics was used to figure out the demographic characteristics such us the n for each variable, the percentage the Mean (M) and Standard Deviation (SD). The logistic regression analysis was used to detect independent factors for psychological outcome as compared to Quality of Life scale (QoL), the BHS and ZBI. The  $P < 0.05$  was considered statistically significant (two-sided test).

## Results

Results in this study show that caregiver's respondents were aged from 18 and above 65 years old with the mean age of 50.47 median of 47.5 and SD of 12. Female caregivers were representing the majority of the rest of caregivers counting 72% while males are 27.9%. The education level of the majority of respondents was junior high school 31.1% approximately 67.2% of caregivers were parents of the patients 7% were offspring of the patient. 1.6% were caring spouse, 12.3% were grandparents while friends count 6.8%. The majority of them 24.6% were having the family income ranged between 5000-1000 RMB. Approximately 68.9% (n=84) of respondents were married the Han nationality was the highest number of caregivers 94.3% (n=115). Miao counts only 2.5% and Tujia 3.3%. 82% have no religion and remain percentage are either Buddhist 13.1% with a low percentage of other religions. At least 22% of respondents are self-employed,

14.4 are public servant (work for the government) and other less number is farmer 13.9% Worker in private institution 13.9% and unemployed counts 8%. The represented patients were aged in less than ten year and over 65 years old. The Mean 19.32 Median 17 SD 8.76 the majority of patients were female 71.1% (n=86) and male counting 28.9% patients were mostly single 86.1% (n=105). Married patients were 5.7%, divorced patients 2.5% and the majority 84% of them have student as their profession status, while 7.4% work for public institution 4.9% who work in private institution and 3.3% were farmers. The highest number in ethnicity was Han nationality 93.4% Tujia counts 4.9% and Miao 1.6% details on demographic characteristics of caregivers are seen in **Table 1**.

## Results of QoL, BHS, and ZBI

The Quality of life was seen to be normal in 25.5% of caregiver's respondents while 9% of caregivers were presenting the poor quality of life, 36.95% of caregivers have good quality of life and 28.7% had high quality of life. In terms of hopelessness, approximately 52.1% of caregivers have not enough symptoms for hopelessness which means that there were in normal range according to the scale, 27.4% have mild despair, 12.8% were in moderate range while 7.7% have severe symptoms. The caregiver burden was seen to be high in only 5.7% while 94.3% where presenting low care burden (**Table 2**).

## Comparison of QoL, BHS and ZBI with other variables

The comparison of QoL, BHS, and ZBI with different independent variables was performed using LR logistic regression model analysis. For the BHS model, the following independent variables were statistically significant as follow: the patient having other disease condition,  $P < 0.024$  (OR=-.530.95% CI=.372, 933). Caregiver taking care for more than one patient  $P < 0.05$  (OR.638 95 CI=1.001, 3.581). Education of caregiver  $P < 0.037$  (OR-.146 95%CI=.754, 991). The caregiver relation with the patient  $P < 0.004$  (OR.168 95%CI=1.054, 1.327) the daily living relation patient and caregiver  $P < 0.0001$  (OR.866 95%CI=1.675, 3.378). Similar to BHS, the ZBI model shows the statistically significant variables which are: the frequency of hospitalization of the patient  $P < 0.015$  (OR.37 95%CI=1.007, 1.070). which means as much as frequent the patient was hospitalized the hopelessness tends to increase from mild to severe on a certain statistical level, similarly, The frequency of taking care of the patient per month  $P < 0.007$  (OR.067 95%CI=1.019, 1.122). Meanwhile as the time the caregiver spends in caring increases despair increases negatively. As per the QoL Model not having other people to help taking care of the patient  $P < 0.041$  (OR-.386 95% CI=.469, 985), the frequency of hospitalization  $P < 0.0001$  (OR.219, 95%CI=1.106, 1.401). The daily living relation between patient and caregiver  $P < 0.043$  (OR-.327, 95%CI=.525, .990) education of caregiver  $P < 0.018$  (OR-.175 95% CI=1.030, 1337) were statistically significant. The details about the regression analysis are seen in **Table 3**.

**Table 1:** Demographic characteristics of caregivers.

Variable/Caregivers	n	%	Variable/Patient	n	%
<b>Age of caregiver</b>			<b>Age of patient</b>		
Mean 40.5 Median 42.5 SD 12			Mean 19.32 Median 17 SD 8.76		
<b>Gender of caregiver</b>			<b>Gender of patient</b>		
Male	34	27.9	Male	86	71.1
Female	88	72.1	Female	35	28.9
<b>Gender of caregiver</b>			<b>Gender of patient</b>		
Single	19	15.6	Single	105	86.1
Married	84	68.9	Married	7	5.7
Divorced	15	12.3	Divorced	3	2.5
Other	4	3.3	Other	6	3.3
<b>Education of caregiver</b>			<b>Education of caregiver</b>		
Elementary school or bellow	13	10.7	Elementary school or bellow	10	8.2
Junior high school	38		Junior high school	42	34.4
High school or technical secondary school	16	13.1	High school or technical secondary school	44	36.1
Junior college	22	18	Junior college	11	9.1
Bachelors or above	33	27	Bachelors or above	14	11.5
<b>Relation with the patient</b>					
Parent	82	67.2			
Child	9	7.4			
Spouse	2	1.6			
Siblings	6	4.9			
Grandparents	8	6.6			
Friend	15	12.3			
<b>Ethnicity of caregiver</b>			<b>Ethnicity of caregiver</b>		
Han	115	94.3	Han	114	93.4
Tujia	4	3.3	Tujia	6	4.9
Miao	3	2.5	Miao	2	1.6
<b>Religion of caregiver</b>			<b>Religion of caregiver</b>		
No religion	100	82	No religion	110	90.9
Buddhism	16	13.1	Buddhism	7	5.7
Taoism	2	1.6	Taoism	0	0
Christianity	2	1.6	Christianity	0	0
Other (Muslim, Hinduism etc.)	2	1.6	Other	4	3.3
<b>Caregiver's profession</b>			<b>Patient's profession</b>		
Student	14	11.5	Student	100	82
Work for private institution	17	13.9	Work for private institution	6	4.9
Farmer	17	13.9	Farmer	4	3.3
Public servant	18	14.8	Public servant	9	7.4
Self employed	27	22.1	Self employed	3	2.5
Unemployed	8	6.6	Unemployed	0	0
<b>Family Income/Months/RMB</b>					
≤ 1000 元	11	9.1			
Between 1001-3000 RMB	22	18			
Between 3001-5000 RMB	24	19.7			
Between 5001-10000 RMB	30	24.6			
Between 10001-15000 RMB	14	11.5			
> 15000 RMB	20	16.4			

**Table 2:** Results of QoL, BHS, and ZBI.

QoL	Frequency (%)	BHS	Frequency (%)	ZBI	Frequency (%)
Normal quality of life	31(25.5%)	Normal despair	61(52.1%)	Low care burden	115(94.3%)
Poor quality of life	11(9%)	Mild despair	32(27.4%)	High care burden	7(5.7%)
Good quality of life	45(36.9%)	Moderate despair	15(12.8%)		
High quality of life	35(28.7%)	Severe despair	9(7.7%)		

**Table 3:** Comparison of QoL, BHS, and ZBI with different independent variables.

Correlation of QoL and variables	B	P	Ex(B)	Ex(B)	95%CI
Not having other people caring for patient	-0.386	0.041	0.68	0.469	0.985
The frequency of hospitalization of patient	0.219	0.0001	1.245	1.106	1.401
Daily living relation patient and caregiver	-0.327	0.043	0.721	0.525	0.99
Education of caregiver	0.175	0.018	1.191	1.03	1.337
Correlation of BHS					
Patient having other diseases	-0.53	0.024	0.589	0.372	0.933
Caring for more than one patient	638	0.05	1.894	1.001	3.581
Education of caregiver	-0.146	0.037	0.865	0.754	991
Caregiver relation with the patient	0.168	0.004	1.183	1.054	1.327
Daily living relation patient and caregiver	0.866	0.0001	2.378	1.675	3.378
Correction of ZBI and variables					
The frequency of hospitalization of patient	0.37	0.015	1.038	1.007	1.07
Total time of taking care in a month	0.067	0.007	1.019	1.019	1.122

## Discussion

Understanding the psychological health and other health dimensions among caregivers of psychiatric illness in the community is one of needed key in sustaining the management of mental health in primary mental health care. Studies have shown importance of investigating this matter within different communities including some communities in China [5,12]. In this study we have investigated the Quality of Life, the Hopelessness and caregiver burden among caregivers of all forms of psychiatric illness in three different hospitals in Chongqing municipality/china. The quality of life among caregivers of mental ill persons has been explored in many other previous studies as these studies have shown, the whenever there is no opportunities for intervention in caring for caregivers of psychiatric illness, the quality of life becomes highly critical in a big number of caregivers [23-25]. In china the quality of life among caregivers of psychiatric illness has been studies in various studies [26]. In some instances the quality of life goes with the stigma burden and other psychological challenges within caregivers [11]. In this study the poor quality of life is seen only 9% of respondents making mining that the number is not too high, however another good number of respondents shows that their quality is quite normal (not good not bad) this might predict a culturally hiding of information and the shortage of sample size. However, we cannot absolutely confirm this argument. The predictors of the poor quality of life in the study were; caregiver who don't have other people who may help him/her in caring for the patient, the cooperation or bad relation between patient and his/her caregiver, the frequency of hospitalization of the patient meanwhile the patient is frequently hospitalized the quality of life of the caregiver tends to become poor similarly less education level plays a role in poor quality of life among caregivers in sample. Reflecting on such predictors, one may say that most of them are not surprising. Having a

relative or close one with psychiatric illness who is frequently need to be hospitalized and having none to help you caring for him or her and especially when symptoms may affect living relation could have an effect of ones' quality of life [11]. The most recommended intervention in such case would be the social support and the psychoeducation [27,28]. Theses interventions help in reducing multiple challenges which includes the above predictors in our sample. Thus in terms of social support assisting the caregiver in his daily tusker caring role, helping him/her financially and morally, would help the caregiver to live the normal life and cope with the demanding role of caring for a psychiatric patient [29]. The psychoeducation interventions also have been found to play a vital role in helping both patients and caregivers in overcome different challenges that are encountered in the illness course. Psycho education focus in teaching all concerned parties about mental illness its symptoms, its management and how family and the community should perceive or help a mentally affected person. These intervention have been adopted in some communities in china has been seen helpful [28]. It must also be sustained and used in many other provinces including Chongqing. Similar to the quality of life caregivers in this study have shown problems of hopelessness from mild to severe despair on a significant rate. Approximately 8% of respondents had severe despair while nearly 13% have moderate despair and 27% with mild symptoms of hopelessness. These numbers show that hopelessness symptoms among caregivers represent a serious matter within our sample. The predictors were; patient having other physical diseases, caregiver caring for other patient, the educational level of caregiver, the relation of the caregiver and the patient and daily living relation between caregiver and the patient. In terms of patient having other physical illness or condition some patient might have a comorbidity or the other chronic or non-chronic disease or condition that affects her/him

and further affects the caregiver in such case it is not uncommon for both the patient and caregiver to lose hope or becoming pessimist if no specific assistance is provided. The pessimism or loss of hope of caregiver may itself cause the stigma and other related challenges that may cause non-treatment adherence, lack of good cooperation between patient and caregiver and so on. Similarly, having more than one patient that caregiver should care for would not only affect psychological health of caregiver, but also the rest of social life. Therefore the recommendable intervention on these two points would be as the previously recommended intervention the sustained social support for caregiver, the psycho-education and when needed special financial assistance would be much helpful [30]. Furthermore, the level of education has been also seen significant meanwhile the education is at primary level hopelessness tends to become critical. For this matter educating people would help when teaching them mental health related issues as stated previously. This would give them insight on mental health thereby help them and the community to understand mental health as a quite ordinal illness that could affect any human being [31]. The same can work also when coping or caregiver and patient have bad daily living relation whether caused or not by psychiatric symptoms of the patient [32,33]. On point of caregiver burden this study shows that the majority of respondents have a significant rate of low care burden, approximately 6% of respondents have shown high care burden. Although the high care burden was seen on a quite low rate, there were predictors that would play a role such as needed time to take care of the patient per month and frequency of hospitalization mining that the more the patient get hospitalized the high the burden becomes and the more much time for caring increases the higher the burden becomes. In this case measures for lowering the burden should be in priorities for being investigated in further studies. In some known examples the positive coping mechanisms such as bereavement or doing religious activities, the active coping in the form of trying to do something about the situation to make it better, planning and acceptance of the illness or the situation, getting instrumental or material support or moral support like getting advice from others, reframing practices such as seeing something good in what is happening [34]. The lack of these mechanisms in caregivers with care burden would affect both patients and caregiver. When helping patients with mental illness workers should think about caregiving issues where possible, the must assess the possible challenges that caregivers are facing in daily life as related to the care they provide.

## Conclusion

This study shows that caregivers of psychiatric illness are facing challenges in their daily caring life. The challenges, particularly investigated are related to their psychological health, it is therefore seen that psychological health of caregivers tends to be in critical phase as a good number of caregivers tends to move from mild to severe considering the scales that were used in our investigation. The problems that were found have their predictors that could be said not be surprising in some cases. These predictors found as well as other variables that score a high negative percentage

should be on attention by health workers and all involved parties which the study has recommended the possible strategies to overcome the already known challenges and probable future coming challenges. Therefore, we insist that these following recommendations should need the attention for the community to overcome caregiving challenges thereby strengthening the strong community mental health. We recommend policy makers to further look at the issues of mental health of caregivers of psychiatric illness in China and decide by referring to Chinese culture. Generally, policy makers, health workers and the general population should be involved in sustained policy regarding mental healthcare in primary healthcare which includes specific attention of caregivers of psychiatric illness. Every member of the community especially healthcare professionals should respect and pay attention to the vital role of the caregivers of psychiatric illness in management of mental health within the community. The psycho-education or mental health campaigns are more needed and need to be improved. The entire community need to be educated about mental health in order to prevent the preventable psychological or psychiatric complications that may occur. Mental health profession should have a good habit of teaching and explain each case of mental illness to the concerned caregivers and the patients. The policy makers need to keep improving mental health resources and make them easily available. According to our sample, the further research must be conducted to explore the reasons of high prevalence of depressive symptoms in young generation in China. We recommend professions of mental health to further think about the caregiving and mental health not only caregivers of mental health but also in physical or other health condition.

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