Spouse and parent differences in caregiving experiences of people living with schizophrenia in rural China

Yu Yu

Xiangya Hospital Central South University

Tong-xin Li

Central South University Xiangya School of Public Health

Yi-lu Li

Central South University Xiangya School of Public Health

Dan Qiu

Central South University Xiangya School of Public Health

Shi-jun Xi

Central South University Xiangya School of Public Health

Shuiyuan Xiao (✉ shuiyuanxiao1503@163.com)

Xiangya Hospital Central South University

Jacob Tebes

Yale University School of Medicine

Research article

Keywords: Schizophrenia, family caregivers, caregiver burden, caregiving, parent, spouse

Posted Date: March 4th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-15828/v1>

License: This work is licensed under a Creative Commons Attribution 4.0 International License. [Read Full License](#)

Version of Record: A version of this preprint was published at BMC Psychiatry on May 12th, 2020. See the published version at <https://doi.org/10.1186/s12888-020-02633-w>.

Abstract

Background: To comprehensively examine and carefully compare caregiving experiences and impacts between spouse and parent caregivers for people living with schizophrenia in China.

Methods: A cross-sectional study was conducted in a sample of 264 community-dwelling primary family caregivers of people living with schizophrenia. Face-to-face interviews were conducted to collect information on caregiving activities, both objective and subjective burden, caregiver psychological distress including depression and anxiety, positive caregiving impact including caregiving rewarding feelings and family functioning between spouse and parent caregivers.

Results: Both types of caregivers report engaging in similar caregiving activities and report comparable levels of objective burden. However, parent caregivers report significantly higher subjective burden than spouse caregivers ($\beta=7.93$, 95%CI:2.13, 13.73), which is also reflected in significantly higher depression ($\beta=3.60$, 95%CI:1.09, 6.12) and anxiety scores ($\beta=2.37$, 95%CI: 0.08, 4.65), and reports of lower family functioning ($\beta=-1.61$, 95%CI: -2.73, -0.49). Despite these differences, both groups of caregivers report comparable rewarding feelings about caregiving.

Conclusions: The findings may be explained by the difference between subjective burden and objective burden, as well as the unique cultural and social characteristics of family caregivers in China. The study discusses implications for future intervention, particularly for parents as family caregivers. **Keywords:** Schizophrenia; family caregivers; caregiver burden; caregiving, parent, spouse

Background

Across the world, schizophrenia is a debilitating, persistent psychiatric disorder that adversely affects individuals with the disorder as well as their family members who provide support and care and support for people living with schizophrenia (PLWS) (1–3). Such family caregivers often serve as an extension of the mental health system in supporting people living with schizophrenia (PLWS) (4, 5). It is now recognized that globally, family caregiving is likely to grow for PLWS especially in lower and middle income countries with under-resourced mental health and social service systems (6). In China, the number of PLWS has increased significantly from 3.09 million in 1990 to 7.16 million in 2010 (7); over 90% live with their family and receive family care due to insufficient community resources (8).

Numerous studies across the world have shown that family caregiving for PLWS has a significant impact on caregiver burden, psychologic distress, family relationship and well-being, which also differs according to different types of kinship caregivers, such as spouses and parents (5, 9–13). Identifying impacts of caregiving and differences among family caregiver types may specify vulnerabilities to inform targeted interventions, but to date, evidence for differences in caregiving impact among family caregivers is either mixed or limited (14).

Among various caregiving impacts, caregiver burden has been the most extensively studied and widely reported outcomes across cultures (5, 9). Two types of burden have been identified: objective (e.g., manual tasks, household duties, etc.) and subjective (e.g., caregiver's perception of burden, distress, stigma, etc.), and each may be experienced as physical, mental, financial, or social demands(5, 9). Subjective burden has been found to be a major determinant of caregiver psychological distress, but objective burden, which usually depends on

specific caregiving activities, appears not to have a direct influence on distress (15). Conflicting evidence exists on caregiver burden between spouse and parents. For instance, the World Health Organization World Mental Health Surveys (6) have shown higher caregiver burden for spouses than parents across high- and upper-middle-income countries, yet higher caregiver burden for parents than spouses from lower or middle-income countries (16). One study on Chinese caregivers of PLWS found that parent caregivers reported higher burden than spouse caregivers (17), while another study of African caregivers of PLWS showed no significant difference in caregiver burden between spouse and parent caregivers (18). These results indicate that caregiver burden may be culture dependent and vary by country.

Psychologic distress of caregivers is another heated topic of caregiving impact in the literature, with depression and anxiety being the two most frequently reported health outcomes for caregivers in both qualitative and quantitative studies (19–25). Face-to-face qualitative interviews conducted with a diverse sample of US caregivers of PLWS showed that the most frequently reported impact of caring for a person with schizophrenia was feeling “emotional”, including feeling overwhelming, sad, frustrated, embarrassed, angry, stressed, anxious and worried, which have also been described by caregivers using analogies like “rollercoaster” “white-water rafting” and “feeling underwater” (23). Other quantitative studies consistently reported high level of psychological distress for caregivers, with prevalence of depression being as high as 79.84% (24) and anxiety as high as 84.1% (25). Comparison of psychological distress between spouse and parent caregivers showed inconsistent results. For instance, Chang et al. (26) compared both depression and anxiety between caregivers of serious mental illness (majority diagnosed as schizophrenia) in Taiwan and found no statistically significant difference between the two groups in either depression or anxiety, though parent caregivers exhibited slightly higher depression and anxiety scores than spouse caregivers. Similar results were also reported in Stanley et al.’s (21) study on caregivers of PLWS in India where no significant difference was seen based on parent/spouse status in terms of depression and anxiety. However, another similar study conducted in Singapore found much lower scores in the psychological domain in spousal caregivers as opposed to parental caregivers (22).

Finally, although most of literature has described caregiving as having negative effects, it is increasingly recognized that caregiving may have positive influences on both the caregiver and family (27). Caring for family member with schizophrenia may bring about positive transformation in caregiver’s life and can provide caregivers with positive inner feelings, such as improved self-admiration, self-affirmation, self-confidence, self-satisfaction and personal growth, which may be generally referred to caregiving rewarding feelings (15, 28). In addition, caregiving may also impact family functional dynamics and relationship in a positive way, especially in Asian countries with Confucian culture that attach great importance to familism and collectivism (29–33). Research have identified various aspects of positive family functional dynamics in caregiving families, including family cohesion, family connectedness, family resilience and family hardiness, which may be generally referred to as family functioning (32, 33). In well-functional families, all family members will actively work together to manage concurrent demands and utilize available resources in adapting challenges and adversities to achieve a degree of balance (32). Since research on positive impact of caregiving such as rewarding caregiving feelings and family functioning is limited, even less is known about the comparison in such positive impacts between parent and spouse caregivers.

Aims of the study

In view of the wide range of caregiving impacts and mixed/ limited evidence on their comparisons between caregiver types, it is both important and interesting to comprehensively examine and carefully compare such caregiving impacts between spouse and parent caregivers in a representative rural community of mainland China, which is underrepresented in caregiving research. To be specific, the current study will describe and compare caregiving activities, both objective and subjective burden, caregiver psychological distress including depression and anxiety, positive caregiving impact including caregiving rewarding feelings and family functioning between spouse and parent caregivers in a Chinese rural community.

Methods

Participants and Procedure

This study was conducted in Ningxiang County of Hunan province from November 2015 to January 2016. Our sample was recruited from the “Central Government Support for the Local Management and Treatment of Severe Mental Illnesses project”, also named the “686 program”, which is China's largest demonstration project for mental health services that seeks to integrate hospital and community services for serious mental illness (34, 35).

A one-stage cluster-sampling method was used to recruit participants from the 686 Program. First, three Towns and 1 Xiang (an administrative unit similar to a town but with lower socio-economic development) were randomly selected from Ningxiang County, and then followed by whole sampling within each Town/Xiang, leading to a total sampling frame of 55 representative communities/villages. A local primary care physician within each community/village assisted in identifying eligible participants based on a list of clients registered in the 686 Program. Eligibility criteria for primary family caregivers included: 1) a PLWS who is a family member who is registered in the 686 Program; 2) the PLWS meets criteria of the Chinese Classification of Mental Disorders-3 (CCMD-3) or the International Classification of Diseases-10 (ICD-10) for schizophrenia; 3) the primary caregiver is living with the PLWS and is responsible for caregiving; 4) the primary caregiver is older than 16 years of age ; 5) the primary caregiver is neither illiterate nor seriously sick and thus able to understand and communicate. A total of 352 primary family caregivers of PLWS were identified in the final sample.

The community/village primary care physician visited each study household with a member of the research team to obtain informed consent from the caregiver and PLWS. Both then completed a series of questionnaires (see measures below) in face-to-face interviews. All participants were reimbursed with small gifts equivalent to RMB ¥ 10 (approximately USD\$2) in return for their participation. Details of the subject recruitment process have been described elsewhere (36, 37).

Of the 352 participants approached, 327 participated in the interview (response rate: 93%). No significant differences in socio-demographic background were observed between those who did or did not agree to participate based on gender, age, marital status, and education (results not shown here). In the current study, only parents (n = 151) and spouses (n = 113) were included in the analyses, resulting in a final sample of 264.

Measures

Socio-demographic information. Demographic information of both the PLWS and the primary caregiver was collected on a questionnaire designed for this study, which included gender, age, marital status, occupation,

education, family financial status, and kinship between PLWS and the primary caregiver. For the primary caregivers, we also asked if there were any co-caregivers, dependents, physical illnesses, and how care had been provided for the PLWS.

PLWS functioning. The PLWS functioning was assessed using the Global Assessment of Function scale (GAF) (38) which assessed the person's overall social, occupational and psychological functioning in the past month from 1 (lowest) to 100 (highest). On the GAF, examples are provided for each ten-point interval. The GAF is an axis of the DSM-IV and is a reliable and valid measure of psychiatric functioning (38).

Caregiving activities. Concrete caregiving activities were assessed by four "Yes-No" questions asking if the respondent was involved with the following four aspects of caregiving activities for the PLWS: daily activities, medication management, hospital visits, and financial help. Responses of "no" were scored as 0, and "yes" as 1, and then followed by asking how often the respondent was involved with each caregiving activity, ranging from "occasionally" (scored as 1) to "always" (scored as 4). Detailed information about the questions and optional answers can be found in the S1 Appendix.

Objective burden. Objective burden was assessed using the Family Burden Interview Schedule (FBIS) (39) classified into six categories: financial burden, disruption of routine family activities, family leisure, family interactions, and effect on physical and mental health of others. The scale consists of 24 items rated on a 3-point Likert scale from 0 (no burden) to 2 (serious burden). The total score ranges from 0 to 48 with higher scores showing higher family burden. In the present study, the Chinese version of FBIS showed acceptable internal consistency with a Cronbach's α of 0.86 for the total scale and ranged from 0.63 to 0.86 for the subscales.

Subjective burden. Subjective burden was assessed using the Zarit Burden Interview (ZBI) (40). The ZBI consists of 22 items scored on a 5-point Likert scale from 0 (never) to 4 (nearly always), except for the final item on global burden, rated from 0 (not at all) to 4 (extremely). The total score ranges from 0 to 88 with higher scores indicating higher perceived burden (41, 42). In the present study, the Chinese version of ZBI showed acceptable internal consistency with a Cronbach's α coefficient of 0.89.

Caregiver depression. Caregiver depression was measured using the 9-item Patient Health Questionnaire (PHQ-9) (43), which consists of 9 items scored in 4-point Likert scale from 0 (not at all) to 3 (nearly every day). The total score ranges from 0 to 27, with higher scores implying more depressive symptoms, and a cut-off point of 10 differentiating depression and non-depression (44, 45). In the present study, the Chinese version of the PHQ-9 demonstrated good internal consistency with a Cronbach's α coefficient of 0.89.

Caregiver anxiety. Caregiver anxiety was measured by the 7-item Generalized Anxiety Disorder Scale (GAD-7) (46) which detects the primary caregiver's anxiety symptoms during the past two weeks. Each item is rated on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). The total score ranges from 0 to 21, with a cut-off point of 10 differentiating anxiety and non-anxiety (47). The Chinese version of the GAD-7 demonstrated good internal consistency in the current study with a Cronbach's α coefficient of 0.91.

Caregiving rewarding feelings. Positive feelings about caregiver were assessed using the caregiving rewarding feelings (CRF) scale which was designed for this study. The detailed development and validation process of the CRF has been described elsewhere(48). It consists of 12 items asking about a range of possible rewarding

feelings that caregivers may have during caregiving. Each “yes” response was scored 1 and “no” responses 0, with total scores ranging from 0 to 12; higher scores indicate more positive feelings in caregiving. The CRF showed acceptable reliability in the current study with a Cronbach's alpha of 0.77.

Caregiver perceived family functioning. Caregiver perceived family functioning was assessed using the Family Adaptation, Partnership, Growth, Affection and Resolve Index scale (APGAR)(49). It consists of 5 items scored in 3-point Likert scale from 0 (hardly ever) to 2 (almost always). The total score ranges from 0 to 10 with higher scores indicating higher satisfaction with family functioning. In the present study, the Chinese version of APGAR showed acceptable internal consistency with a Cronbach's α coefficient of 0.91.

Statistical Analysis

Data were analyzed using STATA software version 15.0. Data were examined missing values, influential values and outliers, skewness, and kurtosis. Frequencies and percentages were displayed for categorical variables, and means with standard deviations or medians with interquartile ranges (IQR) displayed for continuous variables. Group differences for continuous variables were tested using independent t-tests for normally distributed data or a Mann-Whitney U test for non-normally distributed data. Group differences for categorical variables were tested using Pearson's chi-square tests. Both univariate and multivariate linear regression were conducted to determine associations and predictors.

Ethical Considerations

This study was approved by the Ethics Review Committee of the Xiangya School of Public Health of Central South University in China. The interviewed participants were informed verbally and in writing of the study's purpose, their right to refuse to participate, and the voluntary nature of their participation. All participants provided written informed consent before the interviews.

Results

Sample characteristics

Table 1 describes characteristics of the PLWS and primary caregivers. The median age was 44 for the PLWS and 62 for caregivers. Slightly less than half of PLWS were female, married, with a primary education, and most were unemployed. PLWS functioning as measured by the GAF showed a median score of 42, indicating serious impairment of functioning. Slightly more than half of caregivers were female, employed, without co-caregivers and with additional dependents. Also, most caregivers were married, of a primary education and with some physical illness, and had been caring for the PLWS for many years (median = 15 years).

Table 1
Socio-demographic characteristics of care recipients and caregivers between two groups

Variables		Kinship types N (%) / Median (IQR)			z/χ2	p
		Total	Spouse (n = 113)	Parents (n = 151)		
Care recipients' characteristics						
Client functioning (GAF)	Median (IQR)	42 (5–90)	55 (11–85)	35 (5–85)	3.952	< 0.001
Age	Median (IQR)	44 (23–72)	53 (35–72)	38 (23–53)	10.422	< 0.001
Gender	Male	138 (52.27)	33 (29.20)	105 (69.54)		
	Female	126 (47.73)	80 (70.80)	46 (30.46)	42.143	< 0.001
Marriage	Married	115 (43.56)	113 (100)	115 (76.16)		
	Not married	149 (56.44)	0 (0)	36 (23.84)	152.481	< 0.001
Occupation	Employed	41 (15.53)	14 (12.39)	27 (17.88)		
	Not employed	223 (84.47)	99 (87.61)	124 (82.12)	1.486	0.223
Education	Primary	116 (43.94)	65 (57.52)	51 (33.77)		
	Middle	99 (37.50)	31 (27.43)	68 (45.03)		
	High	49 (18.56)	17 (15.04)	32 (21.19)	14.950	< 0.001
Caregivers' characteristics						
Age	Median (IQR)	62 (41–80)	57 (41–74)	64 (45–80)	-6.013	< 0.001
Gender	Male	123 (46.59)	77 (68.14)	46 (30.46)		
	Female	141 (53.41)	36 (31.86)	105 (69.54)	43.069	< 0.001
Marriage	Married	214 (81.06)	113 (100.00)	101 (66.89)		
	Not married	50 (18.94)	0 (0)	50 (33.11)	46.160	< 0.001
GAF: Global Assessment of Function scale *numbers in bold represents significant values at P = 0.05/0.01						

Variables		Kinship types N (%) / Median (IQR)			z/χ ²	p
		Total	Spouse (n = 113)	Parents (n = 151)		
Occupation	Employed	136 (51.52)	69 (61.06)	67 (44.37)	7.209	0.007
	Not employed	128 (48.48)	44 (38.94)	84 (55.63)		
Education	Primary	179 (67.80)	65 (57.52)	114 (75.50)	10.206	0.006
	Middle	59 (22.35)	35 (30.97)	24 (15.89)		
	High	26 (9.85)	13 (11.50)	13 (8.61)		
Family income (Yuan/ person.year)	Median (IQR)	3750 (0-25000)	5000 (0-25000)	3333 (0-16000)	1.329	0.184
Co-caregivers	No	153 (57.95)	81 (71.68)	72 (47.68)	15.277	< 0.001
	Yes	111 (42.05)	32 (28.32)	79 (52.32)		
Additional dependents	No	129 (48.86)	60 (53.10)	69 (45.70)	1.417	0.234
	Yes	135 (51.14)	53 (46.90)	82 (54.30)		
Physical illness	No	70 (26.52)	37 (32.74)	33 (21.85)	3.933	0.047
	Yes	194 (73.48)	76 (67.26)	118 (78.15)		
Length of caring(year)	Median (IQR)	15 (1–45)	19 (2–43)	14 (2–39)	3.049	0.002
GAF: Global Assessment of Function scale *numbers in bold represents significant values at P = 0.05/0.01						

We further compared the socio-demographic characteristics of PLWS and family caregivers for both spouse and parent caregivers. Compared to PLWS cared for by a spouse, family members cared for by a parent had lower functioning (median: 35 vs 55), were younger (median: 38 vs 53), were more likely to be male (70% vs 29%), were less likely to be married (76% vs 100%) and had higher educational attainment (66% vs 42%). Additionally, compared to spouse caregivers, parent caregivers themselves were older (median: 64 vs 57) and had fewer years of caregiving (median: 14 vs 19); were more likely to be female (70% vs 32%), had co-caregivers (52% vs 28%) and had a physical illness (78% vs 67%); they were also less likely to be married (67% vs 100%), employed (44% vs 61%) and with high school education (24% vs 42%).

Caregiving activities

Table 2 shows the type and frequency of care provided by the primary caregivers to the PLWS. Generally, most caregivers were actively involved with all four types of caregiving tasks, with participation ranging from 61% for financial help to 73% for medication management. For the frequency of each caregiving activity, a median frequency of 4 (always) was reported for all caregiving types except for daily activities (median frequency = 3). These results indicate that caregivers are frequently providing care to the PLWS in daily activities, medication management, hospital visits, and financial help.

Table 2
Caregiving activity involvement of parent and spouse caregivers

Variables		Kinship types N (%) / Median(IQR)			z/χ ²	p
		Total	Spouse(n = 113)	Parent(n = 151)		
Daily activities	No	103 (39.02)	45 (39.82)	58 (38.41)		
	Yes	161(60.98)	68 (60.18)	93 (61.59)	0.0542	0.816
	Frequency	3 (0–4)	3 (0–4)	4 (0–4)	-0.671	0.502
Medicine management	No	70 (26.52)	28 (24.78)	42 (27.81)		
	Yes	194 (73.48)	85 (75.22)	109 (72.19)	0.306	0.580
	Frequency	4 (0–4)	4 (0–4)	4 (0–4)	0.330	0.742
Hospital visit	No	78 (29.55)	33 (29.20)	45 (29.80)		
	Yes	186 (70.45)	80 (70.80)	106 (70.20)	0.0111	0.916
	Frequency	4 (0–4)	4 (0–4)	4 (0–4)	0.187	0.851
Financial help	No	104 (39.39)	40 (35.40)	64 (42.38)		
	Yes	160 (60.61)	73 (64.60)	87 (57.62)	1.321	0.250
	Frequency	4 (0–4)	4 (0–4)	3 (0–4)	1.042	0.298

A further comparison of caregiving activities between spouse and parent caregivers found no statistically significant difference in either their involvement or frequency in the four types of caregiving activities, indicating that parents and spouses were providing similar types of care for their loved one with schizophrenia.

Objective and subjective burden

Table 3 shows the comparison of both objective burden (as measured by FBIS) and subjective burden (as measured by ZBI) between spouse and parent caregivers, first using a simple two-sample t-test, followed by

multivariate regressions controlling for PLWS functioning, gender and education, and all caregiver demographics.

Table 3
Family burden and caregiving impacts between spouse and parent caregivers

Variables	Kinship types N (%) / Median(IQR)/Mean ± SD			z/t/χ ²	P*	Adjusted coef.	Adjusted p*	Adjusted 95% CI
	Total	Spouse(n = 113)	Parents(n = 151)					
Family Burden (FBIS 1–24)	26 (3–43)	22 (4–39)	27 (6–42)	-2.556	0.011	1.17	0.450	[-1.87, 4.21]
Caregiver burden(ZBI)	43.96 ± 18.25	40.81 ± 18.13	46.18 ± 18.07	-2.236	0.026	7.93	0.008	[2.13, 13.73]
Depression(PHQ-9)	9 (0–26)	6.5 (0–23)	12 (1–26)	-3.952	< 0.001	3.60	0.005	[1.09, 6.12]
Anxiety(GAD-7)	9 (0–21)	7 (0–21)	11 (1–21)	-3.541	< 0.001	2.37	0.042	[0.08, 4.65]
Caregiving rewarding feelings scale (CRF)	7 (5,9)	7 (5,10)	7 (5,9)	1.736	0.083	-0.62	0.239	[-1.64, 0.41]
Family functioning (APGAR 1–5)	6(4–9)	8(5,10)	6(3,9)	3.100	0.002	-1.61	0.005	[-2.73, -0.49]
FBIS: Family Burden Interview Schedule; ZBI: Zarit Burden Interview; PHQ-9: 9-item Patient Health Questionnaire; GAD-7: 7-item Generalized Anxiety Disorder Scale; CRF: Caregiving Rewarding Feelings; APGAR: Family Adaptation, Partnership, Growth, Affection and Resolve Index scale								
*numbers in bold represents significant values at P = 0.05/0.01								

For objective burden, no statistically significant difference in objective burden (FBIS) was found between spouse and parent caregivers in multivariate analyses, although parent caregivers reported significantly higher total objective burden scores in univariate analyses. However, for subjective burden, both univariate and multivariate analyses each showed higher subjective burden scores (ZBI) among parent caregivers than spouse caregivers (mean: 46.18 vs 40.18, $\beta = 7.93$, 95%CI:2.13, 13.73), indicating significantly higher subjective burden for parent caregivers (Table 3).

Negative and positive caregiving impact

Table 3 also shows the comparison of negative and positive caregiving impacts on caregivers between spouse and parent caregivers, first by a simple two-sample t-test, followed by multivariate regressions controlling for PS functioning, gender and education, and all caregiver demographics.

The negative impacts of caregiving include depression and anxiety symptoms as measured by PHQ-9 and GAD-7. In both univariate and multivariate analyses, parent caregivers reported significantly more depression symptoms (median: 12 vs 6.5, $\beta = 3.60$, 95%CI: 1.09, 6.12) and anxiety symptoms (median: 11 vs 7, $\beta = 2.37$, 95%CI: 0.08, 4.65).

The positive impacts of caregiving include caregiving rewarding feelings as measured by CRF and perceived family functioning as measured by APGAR. Although no statistically significant difference in caregiving rewarding feelings was found between spouse and parent caregivers, parents reported significantly lower family functioning in both univariate and adjusted multivariate analyses (median: 6 vs 8, $\beta = -1.61$, 95%CI: -2.73, -0.49).

Discussion

This study compared the caregiving experiences of spouse and parent caregivers of PLWS in China. The results show that both types of caregivers – parents and spouses – report engaging in similar caregiving activities and comparable levels of objective burden. However, parent caregivers report significantly higher subjective burden, which is also reflected in significantly higher depression and anxiety scores, and in reports of lower family functioning. Despite these differences, both groups of caregivers report comparable rewarding feelings about caregiving.

Although few studies have examined specific caregiving activities of primary caregivers, this study showed that parent and spouse caregivers are equally engaged in various aspects of caregiving, including daily activities, medication management, hospital visits, and financial help. These results are also consistent with the extensive literature showing caregiving to be a highly-demanding experience that requires family caregivers to devote considerable time, energy and resources to provide round-the-clock care to a PLWS, regardless of the specific activity (4, 5, 8, 9).

Parent caregivers reported significantly higher subjective burden than spouse caregivers, even though objective burden between spouse and parent caregivers was comparable. Considering the comparable engagement in caregiving activity between parent and spouse caregivers, it is not surprising that objective burden was also comparable between both of these two types of caregivers. However, statistically significant difference in subjective burden were found between parent and spouse caregivers despite their engagement in similar caregiving activities and reporting of objective burden. This is an important finding because it suggests that subjective burden may be especially critical to the “lived” experience of caregiving, and that what caregivers objective burden and what caregivers actually do may not fully reflect that experience. The consistent relationship between subjective burden and depression and anxiety scores also suggests a potential role for subjective burden in mediating the relationship between caregiving and health.(4, 50) That relationship should be examined in future longitudinal research with parent and spouse caregivers of PLWS.

Another intriguing issue raised by the present study is the intersection of family caregiving with the dominant belief in collectivism that is deeply rooted in Chinese culture. Family members in China attach great importance to specific roles and proper relationships among family members, thus maintaining family cohesion, harmony, and equilibrium(5, 51). As a result, different family members may perform similar caregiving tasks and experience similar objective burden since they are living in the same household and caring for the same person, yet their personal perception of burden may vary greatly due to the different role expectation they experience. For

instance, parents, especially mothers, are more likely to be blamed for a child's sickness since they are expected to give birth to healthy children and nurture them through their parenting role(52). A child with schizophrenia may contribute to marriage crisis and family conflict (27, 52, 53). The mother and father may blame each other for the child's condition, disagree about treatment plans, and argue about caregiving responsibilities. As a result, parents may perceive higher burden when caring for PLWS due to the sense of guilt, blame, and anger that results from their situation (27, 52, 53). In contrast, spouse caregivers may normalize caregiving as part of their marital role as reflected in their marriage vows, such as "in sickness and in health" or "until death do us part" (54–56). Thus, spouses may experience less conflict between their caregiver roles and other family and work-related roles they have, and thus experience less subjective burden (57, 58). Future research should examine directly the role of culture and family caregiving for PLWS.

Closely related to the above issue is the observed differences between spouses and parents is that parents generally reported being worse-off than spouse caregivers in both negative and positive caregiving impact. Relative to spouse caregivers, parent caregivers experienced more perceived burden as well as more depression and anxiety symptoms, and also reported lower perceived family functioning. These findings may also be explained by the unique family-oriented culture common in Asian countries that emphasizes family cohesion and harmony, with special focus on familism and filial piety (29, 51, 59). Chinese society is especially recognized for its strong sense of filial obligation, defined as: "the concept, desire, and behaviors of carrying on family line, being good, and obedient to, as well as taking care of one's parents". One key ideology of filial piety in China is the concept that "Bu Xiao You San, Wu Hou Wei Da" (There are three types of impieties, among which having no descendent is the worst) and "to have no posterity is unfilial"(60). In a Chinese society that is based on close-knit family relationships, children are seen as the only continuation of the family bloodline and they represent the future prosperity of the entire family(61–63). Also, children are expected to take care of their parents when they are old and frail (61–63). A child with schizophrenia in a family not only means that the family bloodline may be broken, but that the parents may have no one to depend on when they grow old. The situation is accentuated with the "one child per family" policy that has persisted for over three decades before it was abolished recently(64).

This study has several limitations. First, its cross-sectional design limits understanding differences among spouse and parent caregivers over time. Further longitudinal research is needed to better understand the processes related to caregiver kinship differences. Second, although our total sampling frame included various kinships including spouse, parents, siblings, children and others, we only were able to examine spouse and parent caregivers because of an insufficient sample size to examine other kinship types. Future research should consider examining differences across caregiver types.

Conclusions And Implications

In conclusion, our study found that parent caregivers were generally worse-off than spouse caregivers as regards to subjective burden, depression, anxiety and family functioning, although they reported similar caregiving activities, objective burden, and caregiving rewarding feelings.

These results have several implications with direction for future research. First, family intervention programs should consider taking into account kinship family dynamics when seeking to support family caregivers of PLWS. One promising approach is to offer family psychoeducation to family members of the PLWS as part of

ongoing treatment and rehabilitation (13, 65, 66). Such interventions may benefit from working with the entire family to enhance impact. Second, intervention programs that target individual caregivers may need to address the specific vulnerabilities of parent caregivers of PLWS, such as increased subjective burden, depression, and anxiety, and reduced family functioning. And third, this study suggests that it may be particularly useful to incorporate cultural values and beliefs in understanding the family processes at work for family caregivers of PLWS. Although our study was conducted in mainland China, our findings are relevant to other countries, especially those that share Confusion beliefs common to Asian culture.

Declarations

Ethical approval and consent to participate:

Ethical approval was obtained from the Institutional Review Committee of the Xiangya School of Public Health of Central South University. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants gave written informed consent before participation of the study.

Availability of data and materials:

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interest:

The authors declare that they have no competing interests

Funding:

This work was funded by a grant from the National Natural Science Foundation of China (Grant Number 71804197) and the China Scholarship Council (CSC) in support of the first author.

Authors' contributions:

YY, TL, SYX and JKT contributed to the conception and design of the study, YY, TL, YL, DQ, and SJX contributed to the research conduction and data collection, YY, TL and YL contributed to data analyses and interpretation. YY drafted the article while TL, YL, DQ, SJX, SYX and JKT critically appraised it and revised it. All authors approved the final version of manuscript for submission and publication and agreed to be accountable for all aspects of the work.

Acknowledgement

The authors are grateful to the families that participated in this study for sharing their experiences. The authors also appreciate the assistance of the health and family planning bureau of Ningxiang County, the government of the Towns of Liushahe, Shungfupu, and Yutan as well as the Xiang of Chengjiao, for their administrative support, and the village/community physicians that assisted in home visits to each household in the rural areas of Ningxiang County, Hunan province.

Abbreviations

PLWS

people living with schizophrenia

CCMD-3

Chinese Classification of Mental Disorders-3

ICD-10

International Classification of Diseases-10

GAF

Global Assessment of Function scale

FBIS

Family Burden Interview Schedule

ZBI

Zarit Burden Interview

PHQ-9

9-item Patient Health Questionnaire

GAD-7

7-item Generalized Anxiety Disorder Scale

CRF

Caregiving Rewarding Feelings

APGAR

Family Adaptation, Partnership, Growth, Affection and Resolve Index scale

IQR

Interquartile Ranges

References

1. Giel R, de Arango MV, Hafeiz Babikir A, Bonifacio M, Climent CE, Harding TW, et al. The burden of mental illness on the family. Results of observations in four developing countries. A report from the WHO Collaborative Study on Strategies for Extending Mental Health Care. *Acta Psychiatr Scand.* 1983;68(3):186-201.
2. Roick C, Heider D, Toumi M, Angermeyer MC. The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: a longitudinal analysis. *Acta Psychiatr Scand.* 2006;114(5):363-74.

3. Parabiaghi A, Lasalvia A, Bonetto C, Cristofalo D, Marrella G, Tansella M, et al. Predictors of changes in caregiving burden in people with schizophrenia: a 3-year follow-up study in a community mental health service. *Acta Psychiatr Scand Suppl.* 2007(437):66-76.
4. Suro G, Weisman de Mamani AG. Burden, interdependence, ethnicity, and mental health in caregivers of patients with schizophrenia. *Family process.* 2013;52(2):299-311.
5. Chan SW. Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of psychiatric nursing.* 2011;25(5):339-49.
6. (WFMH) WFMH. *Caring for the caregiver: Why your mental health matters when you are caring for others.* Woodbridge VA: WFMH. 2010.
7. Chan KY, Zhao FF, Meng S, Demaio AR, Reed C, Theodoratou E, et al. Prevalence of schizophrenia in China between 1990 and 2010. *J Glob Health.* 2015;5(1):010410.
8. Phillips MR, West CL, Shen Q, Zheng Y. Comparison of schizophrenic patients' families and normal families in China, using Chinese versions of FACES-II and the Family Environment Scales. *Fam Process.* 1998;37(1):95-106.
9. Awad AG, Voruganti LN. The burden of schizophrenia on caregivers: a review. *PharmacoEconomics.* 2008;26(2):149-62.
10. Magliano L, Fadden G, Fiorillo A, Malangone C, Sorrentino D, Robinson A, et al. Family burden and coping strategies in schizophrenia: are key relatives really different to other relatives? *Acta Psychiatr Scand.* 1999;99(1):10-5.
11. Sin J, Murrells T, Spain D, Norman I, Henderson C. Wellbeing, mental health knowledge and caregiving experiences of siblings of people with psychosis, compared to their peers and parents: an exploratory study. *Soc Psychiatry Psychiatr Epidemiol.* 2016;51(9):1247-55.
12. Valiakalayil A, Paulson LA, Tibbo P. Burden in adolescent children of parents with schizophrenia. The Edmonton High Risk Project. *Soc Psychiatry Psychiatr Epidemiol.* 2004;39(7):528-35.
13. Hadrys T, Adamowski T, Kiejna A. Mental disorder in Polish families: is diagnosis a predictor of caregiver's burden? *Soc Psychiatry Psychiatr Epidemiol.* 2011;46(5):363-72.
14. Pinquart M, Sorensen S. Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychol Aging.* 2011;26(1):1-14.
15. Kate N, Grover S, Kulhara P, Nehra R. Caregiving appraisal in schizophrenia: a study from India. *Soc Sci Med.* 2013;98:135-40.
16. Shahly V, Chatterji S, Gruber MJ, Al-Hamzawi A, Alonso J, Andrade LH, et al. Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. *Psychol Med.* 2013;43(4):865-79.
17. Yu W, Chen J, Hu J, Hu J. Relationship between Mental Health and Burden among Primary Caregivers of Outpatients with Schizophrenia. *Fam Process.* 2018.
18. Alexander G, Bebee CE, Chen KM, Vignes RD, Dixon B, Escoffery R, et al. Burden of caregivers of adult patients with schizophrenia in a predominantly African ancestry population. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation.* 2016;25(2):393-400.
19. Wittmund B, Wilms HU, Mory C, Angermeyer MC. Depressive disorders in spouses of mentally ill patients. *Soc Psychiatry Psychiatr Epidemiol.* 2002;37(4):177-82.

20. Boye B, Bentsen H, Ulstein I, Notland TH, Lersbryggen A, Lingjaerde O, et al. Relatives' distress and patients' symptoms and behaviours: a prospective study of patients with schizophrenia and their relatives. *Acta Psychiatr Scand*. 2001;104(1):42-50.
21. Stanley S, Balakrishnan S, Ilangovan S. Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *J Ment Health*. 2017;26(2):134-41.
22. Jeyagurunathan A, Sagayadevan V, Abdin E, Zhang Y, Chang S, Shafie S, et al. Psychological status and quality of life among primary caregivers of individuals with mental illness: a hospital based study. *Health Qual Life Outcomes*. 2017;15(1):106.
23. Gater A, Rofail D, Tolley C, Marshall C, Abetz-Webb L, Zarit SH, et al. "Sometimes It's Difficult to Have a Normal Life": Results from a Qualitative Study Exploring Caregiver Burden in Schizophrenia. *Schizophrenia research and treatment*. 2014;2014:368215.
24. Yusuf AJ, Nuhu FT. Factors associated with emotional distress among caregivers of patients with schizophrenia in Katsina, Nigeria. *Soc Psychiatry Psychiatr Epidemiol*. 2011;46(1):11-6.
25. Yikilkan H, Aypak C, Gorpelioglu S. Depression, anxiety and quality of life in caregivers of long-term home care patients. *Arch Psychiatr Nurs*. 2014;28(3):193-6.
26. Chang CC, Yen CF, Jang FL, Su JA, Lin CY. Comparing Affiliate Stigma Between Family Caregivers of People With Different Severe Mental Illness in Taiwan. *J Nerv Ment Dis*. 2017;205(7):542-9.
27. Shiraishi N, Reilly J. Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary. *Soc Psychiatry Psychiatr Epidemiol*. 2019;54(3):277-90.
28. Kulhara P, Kate N, Grover S, Nehra R. Positive aspects of caregiving in schizophrenia: A review. *World J Psychiatry*. 2012;2(3):43-8.
29. Choi Y, Kim TY, Noh S, Lee J, Takeuchi D. Culture and Family Process: Measures of Familism for Filipino and Korean American Parents. *Fam Process*. 2018;57(4):1029-48.
30. Bhugra D. Cultural identities and cultural congruency: a new model for evaluating mental distress in immigrants. *Acta Psychiatr Scand*. 2005;111(2):84-93.
31. Zhang AY, Yu LC, Draguns JG, Zhang J, Tang D. Sociocultural contexts of anthropophobia: a sample of Chinese youth. *Soc Psychiatry Psychiatr Epidemiol*. 2000;35(9):418-26.
32. Hsiao CY, Tsai YF. Caregiver burden and satisfaction in families of individuals with schizophrenia. *Nursing research*. 2014;63(4):260-9.
33. Chien WT, Chan SW, Morrissey J. The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of clinical nursing*. 2007;16(6):1151-61.
34. Ma H. Integration of hospital and community services-the '686 Project'-is a crucial component in the reform of China's mental health services. *Shanghai archives of psychiatry*. 2012;24(3):172-4.
35. Good BJ, Good MJ. Significance of the 686 Program for China and for global mental health. *Shanghai archives of psychiatry*. 2012;24(3):175-7.
36. Yu Y, Tang BW, Liu ZW, Chen YM, Zhang XY, Xiao S. Who cares for the schizophrenia individuals in rural China - A profile of primary family caregivers. *Compr Psychiatry*. 2018;84:47-53.
37. Yu Y, Liu ZW, Tang BW, Zhao M, Liu XG, Xiao SY. Reported family burden of schizophrenia patients in rural China. *PloS one*. 2017;12(6):e0179425.

38. Association. AP. Diagnostic and statistical manual of mental disorders. 4th ed (DSM-IV). Washington DC:APA. 1994.
39. Pai S, Kapur RL. The burden on the family of a psychiatric patient: development of an interview schedule. *The British journal of psychiatry : the journal of mental science*. 1981;138:332-5.
40. Zarit SH, Orr, N.K., & Zarit, J.M. . *Families under stress: Caring for the patient with Alzheimer's disease and related disorders*. New York: University Press. 1985.
41. Tang B, Yu Y, Liu Z, Lin M, Chen Y, Zhao M, et al. Factor analyses of the Chinese Zarit Burden Interview among caregivers of patients with schizophrenia in a rural Chinese community. *BMJ open*. 2017;7(9):e015621.
42. Yu Y, Liu ZW, Zhou W, Chen XC, Zhang XY, Hu M, et al. Assessment of Burden Among Family Caregivers of Schizophrenia: Psychometric Testing for Short-Form Zarit Burden Interviews. *Front Psychol*. 2019; 9:2539.
43. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. *Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire*. *Jama*. 1999;282(18):1737-44.
44. Manea L, Gilbody S, McMillan D. A diagnostic meta-analysis of the Patient Health Questionnaire-9 (PHQ-9) algorithm scoring method as a screen for depression. *General hospital psychiatry*. 2015;37(1):67-75.
45. Liu ZW, Yu Y, Hu M, Liu HM, Zhou L, Xiao SY. PHQ-9 and PHQ-2 for Screening Depression in Chinese Rural Elderly. *PLoS One*. 2016;11(3):e0151042.
46. Spitzer RL, Kroenke K, Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006;166(10):1092-7.
47. Schalet BD, Cook KF, Choi SW, Cella D. Establishing a common metric for self-reported anxiety: linking the MASQ, PANAS, and GAD-7 to PROMIS Anxiety. *Journal of anxiety disorders*. 2014;28(1):88-96.
48. Yu Y. Study on family burden and experiences of primary caregivers of schizophrenia in community. *Central South University Thesis*. 2016.
49. Smilkstein G. The family APGAR: a proposal for a family function test and its use by physicians. *The Journal of family practice*. 1978;6(6):1231-9.
50. Chiou CJ, Chang HY, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. *Arch Gerontol Geriatr*. 2009;48(3):419-24.
51. Park M. Filial piety and parental responsibility: an interpretive phenomenological study of family caregiving for a person with mental illness among Korean immigrants. *BMC Nurs*. 2012;11:28.
52. Young L, Murata L, McPherson C, Jacob JD, Vandyk AD. Exploring the Experiences of Parent Caregivers of Adult Children With Schizophrenia: A Systematic Review. *Arch Psychiatr Nurs*. 2019;33(1):93-103.
53. Wiguna T, Ismail RI, Noorhana SR, Kaligis F, Aji AN, Belfer ML. Family responses to a child with schizophrenia: An Indonesian experience. *Asian J Psychiatr*. 2015;18:66-9.
54. Chappell NL, Dujela C, Smith A. Spouse and adult child differences in caregiving burden. *Canadian journal on aging = La revue canadienne du vieillissement*. 2014;33(4):462-72.
55. Yu MY, Shim W. Couples with schizophrenia "becoming like others" in South Korea: marriage as part of a recovery process. *Fam Process*. 2009;48(3):429-40.
56. McCoy A, Rauer A, Sabey A. The Meta Marriage: Links Between Older Couples' Relationship Narratives and Marital Satisfaction. *Fam Process*. 2017;56(4):900-14.

57. Beeson RA. Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Arch Psychiatr Nurs*. 2003;17(3):135-43.
58. Lin IF, Fee HR, Wu HS. Negative and Positive Caregiving Experiences: A Closer Look at the Intersection of Gender and Relationships. *Fam Relat*. 2012;61(2):343-58.
59. Campos B, Kim HS. Incorporating the cultural diversity of family and close relationships into the study of health. *Am Psychol*. 2017;72(6):543-54.
60. Li YZ, Liu HD, Cao JR. [A brief analysis of the ideology of filial piety about "No descendant is the worst among three impieties."]. *Renkou Yanjiu*. 1981(4):25-9.
61. Yu Yu S-YX. Loss of Only Child Family in China: Psychological Effect *Journal of General Practice*(Los Angel) 2015;3(201).
62. Wu MH, Chang SM, Chou FH. Systematic Literature Review and Meta-Analysis of Filial Piety and Depression in Older People. *J Transcult Nurs*. 2018;29(4):369-78.
63. Li M, Dong X. The Association Between Filial Piety and Depressive Symptoms Among U.S. Chinese Older Adults. *Gerontol Geriatr Med*. 2018;4:2333721418778167.
64. Zeng Y, Hesketh T. The effects of China's universal two-child policy. *Lancet*. 2016;388(10054):1930-8.
65. Kulhara P, Chakrabarti S, Avasthi A, Sharma A, Sharma S. Psychoeducational intervention for caregivers of Indian patients with schizophrenia: a randomised-controlled trial. *Acta Psychiatr Scand*. 2009;119(6):472-83.
66. Rammohan A, Rao K, Subbakrishna DK. Religious coping and psychological wellbeing in carers of relatives with schizophrenia. *Acta Psychiatr Scand*. 2002;105(5):356-62.