

Assessing Long-term Services and Supports Recipients' Quality-of-Life and the Impact on Caregivers in Chengdu, China

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Abstract

This study investigates the quality of life (QoL) of long-term services and supports (LTSS) recipients and their caregivers in Chengdu, following the implementation of China's long-term care insurance (LTCI) system. The research utilized three ICEpop CAPability (ICECAP) instruments to evaluate the QoL of both groups and explored the association between the caregivers' QoL and that of the recipients. A total of 464 LTSS recipients and their caregivers were surveyed, yielding a response rate of 92.8%. Key findings indicated that physical and psychological health were the strongest predictors of higher QoL for both male and female LTSS recipients. Female recipients receiving home care experienced lower QoL, while for males, living with family or supporters was a significant predictor of QoL. Caregivers' QoL was associated with higher salary, lower education, and better health status, and it was also found to be positively linked to the QoL of LTSS recipients. The study concludes with recommendations for policymakers to consider gender-specific LTSS delivery and to increase salaries for caregivers as a means to improve QoL.

Keywords: long-term services and supports (LTSS), long-term care insurance (LTCI), quality-of-life (QoL)

1. Introduction

Long-term services and supports (LTSS) recipients were a vulnerable subpopulation in the healthcare systems globally. Various countries have developed well-directed policies, markets, and institutions to provide proper LTSS (Norton, 2016). Delivering LTSS also threatens caregivers' physical, psychological, emotional, and functional health (Kim H. *et al.*, 2012; Adelman R. D. *et al.*, 2014). Hence, China introduced a long-term care insurance (LTCI) system to support both LTSS recipients and their caregivers in 2016, hoping to promote their health status. Our target city of Chengdu, the largest municipality in southwest China, began to implement LTCI in 2017. Its LTCI system had 13,966,600 participants, 34,691 LTSS recipients, and 194 registered institutions by the end of 2021 (Chengdu Healthcare Security Administration Statistics, 2022, <https://cdyb.chengdu.gov.cn>). Studies have widely investigated LTCI's supportive effects (Feng Z. *et al.*, 2020; Chen, S. *et al.*, 2021; Chen, L. & Xu, X., 2020; Zhuang X, 2021; Lei, X. *et al.*, 2022; Zhou, W., & Dai, W., 2021; Li, Q. *et al.*, 2024; Han, Y., & Shen, T., 2022) and proved a positive impact on LTSS recipients and their caregivers in *quality-of-life* (QoL), burden, service utilization, healthcare expenditure, and patient satisfaction (Chen S. *et al.*, 2021).

Our study is the first empirical QoL assessment among LTSS recipients and their caregivers in Chengdu, while previous studies focused on cost-benefit association, financial sustainability, health benefits, recipients' hospitalization rate and survival rate (Zhang, Y., & Miao, F., 2022; Peng, R. *et al.*, 2022; Zeng, L. *et al.*, 2024;

Zhou, J. Q. *et al.*, 2023; Liu, H. *et al.*, 2023). We also put a focus on LTSS recipients than their caregivers, to address recipients' vulnerability. LTSS recipients and their caregivers' QoL were assessed by three instruments of the newly developed, preference-based, multi-attribute series of ICEpop CAPability (ICECAP) tools. The tool has a conceptual link to Amartya Sen's capability approach (Sen, A., 1993) and assesses participants' physical, psychological, social, and emotional perceptions. For LTSS recipients, we used the ICEpop CAPability Measure for Older People (ICECAP-O) as a general instrument and ICEpop CAPability Supportive Care Measure (ICECAP-SCM) to assess QoL for older adults in an end-of-life setting. For caregivers, we used the ICEpop CAPability Measure for Adults (ICECAP-A) for capability assessment. Responses to three instruments are 4-point Likert scale, which indicates the level of capability by 'always,' 'very often,' 'occasional,' and 'few.' These instruments have been translated from original English into Chinese, and the Chinese version has been validated (Xiong Y. *et al.*, 2023).

Our study further investigated the association with QoL among LTSS recipients and their caregivers. In addition, the association between the LTSS recipient's QoL and the respective caregiver's QoL was tested. The study findings will inform policymakers' future decisions.

2. Methods and Data

2.1 Study Population

500 LTSS recipients were stratified and randomized sampled from the population of 34,691 in Chengdu's LTCI system by the study date of December 31, 2021. 464 LTSS recipients and their corresponding caregivers completed the survey, with a response rate of 92.8%. For recipients, the valid responses to the ICECAP-SCM were 444, while ICECAP-O was 439. For caregivers, the valid responses to the ICECAP-A were 382. Only 360 ICECAP-A responses were identified with matched ICECAP-SCM and ICECAP-O responses.

2.2 Quality Control

Chengdu Healthcare Security Administration (CDHSA) approved, supported, and supervised the survey for QoL. CDHSA purposely developed a guideline and 120-minute, compulsory seminar to regulate and train survey investigators for quality assurance. All respondents had given written consent to the survey and authorization for secondary data use. CDHSA provided the private-access survey data for our study's analysis. The Institutional Review Board of Chengdu Medical College reviewed and approved the proper use of the survey data with document number (2023)043.

2.3 Variable Specification and Regression Models

For LTSS recipients, sociodemographic variables include age, gender, Hukou (Note 1), education level, marital status, social insurance UEBMI (Urban Employee Basic Medical Insurance) or URBMI (Urban Resident Basic Medical Insurance) enrollment, severity of disability, type of care received (home versus institutional), living alone or not, household income, exercises, and psychological status. For caregivers, sociodemographic variables include age, type of care delivered (home versus institutional), gender, Hukou, religious belief, education level, salary, health status, and tobacco or alcohol use.

The ICECAP-SCM, ICECAP-O, and ICECAP-A scores were rescaled to form a single-index-score variable (Coast J. *et al.*, 2008; Couzner L. *et al.*, 2013; Flynn, T. N. *et al.*, 2015). The index score ranged from 0 to 1, with the lower score associated with fewer symptoms and a higher QoL.

For both LTSS recipients and caregivers, we applied a series of multivariable ordinary least squares (OLS) linear regression models to test the QoL difference varying with sociodemographic variables. In the regression for recipients, age remained a continuous variable. Hukou, marital status, etc., remained dichotomous variables. The categorical variables education and household income were converted to dichotomous variables. Table 1 shows the details. In the regression for caregivers, all sociodemographic variables were converted to dichotomous variables. To test the association between the LTSS recipient's QoL and the respective caregiver's QoL, we applied a generalized linear regression model (GLM).

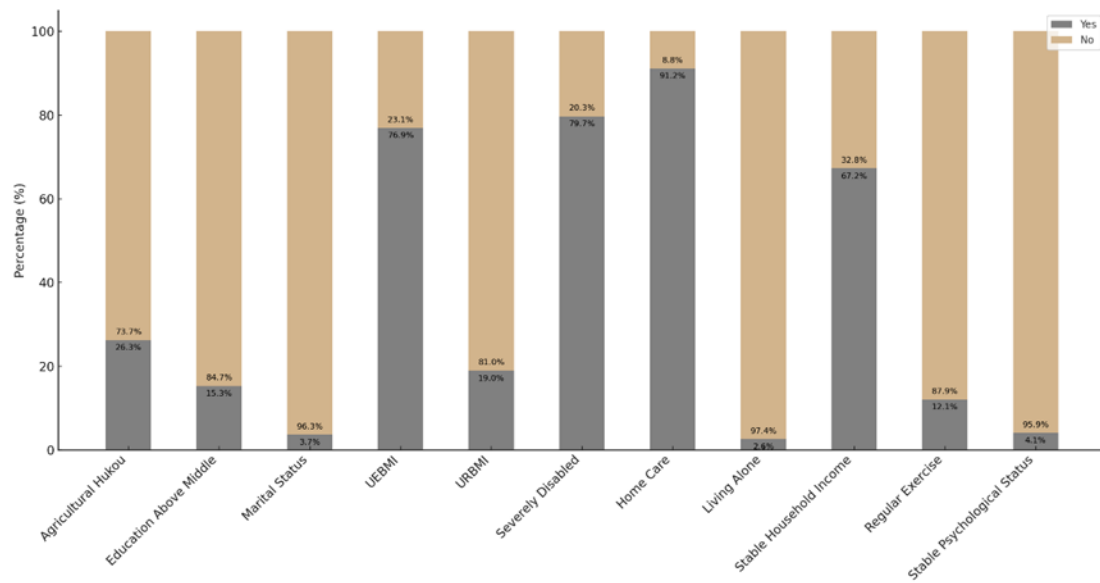
To present the findings and test gender differences for LTSS recipients, we purposely categorize them by all participants and gender groups. For all analyses, statistical significance was considered $p < 0.05$.

3. Results

3.1 Descriptive Statistics

The LTSS recipients' ages ranged from 19 to 106, with a mean of 77.06 (SD 14.20) for the 451 responses across the two instruments. In the following analysis, we removed 7 ICECAP-SCM and 12 ICECAP-O respondents who were under the age of 65. The recipients with agricultural Hukou were at 26.3%. 15.3% of recipients were

educated above middle school. 3.7% of the total recipients were married. 76.9% of recipients enrolled in the UEBMI program. 79.7% of them were evaluated as severely disabled LTSS recipients. 91.2% of them received LTSS at home. 2.6% of recipients lived alone. 67.2% of recipients had stable household income. However, only 4.1% of recipients had stable physical and physiological health. The descriptive statistics are shown in Figure 1 and Table 1.



Note: Age <65 removed from statistics (7 ICECAP-SCM and 12 ICECAP-O respondents)

Figure 1. Proportional Relations of Key Variables

Table 1. Descriptive Statistics

	N	mean	sd	min	max
ICECAP-SCM	444	0.43	0.19	0.00	1.00
ICECAP-O	439	0.64	0.20	0.00	1.00
Age	451	77.06	14.20	19.00	106.00
Agricultural Hukou (yes/no)	464	0.26	0.44	0.00	1.00
Education Above Middle (yes/no)	464	0.15	0.36	0.00	1.00
Marital Status (yes/no)	464	0.04	0.19	0.00	1.00
UEBMI (yes/no)	464	0.77	0.42	0.00	1.00
URBMI (yes/no)	464	0.19	0.39	0.00	1.00
Severely Disabled (yes/no)	464	0.80	0.40	0.00	1.00
Home Care (yes/no)	464	0.91	0.28	0.00	1.00
Living Alone (yes/no)	464	0.03	0.16	0.00	1.00
Stable Household Income (yes/no)	464	0.67	0.47	0.00	1.00
Regular Exercise (yes/no)	464	0.12	0.33	0.00	1.00
Stable Psychological Status (yes/no)	464	0.04	0.20	0.00	1.00

Note: 1) uncompleted responses excluded; 2) yes/no: 1=yes, 0=no.

3.2 Initial Statistical Analyses

For LTSS recipients, we further used a *t*-test to explore the QoL differentiation between gender groups. As shown in Table 2, we cannot conclude the gender differences in QoL by the lack of statistical significance.

Table 2. Difference between Gender Groups by *t*-test

Variables		Men		Women		difference
		N	mean	N	mean	
ICECAP-SCM	ICECAP-SCM Single Index	176	0.44	268	0.43	-0.01
	choice	172	0.64	258	0.59	-0.05
	love and affection	172	0.23	258	0.22	-0.01
	physical suffering	174	0.6	267	0.59	-0.01
	emotional suffering	173	0.36	257	0.32	-0.04
	dignity	170	0.28	256	0.33	0.05
	being supported	171	0.22	260	0.24	0.02
	preparation	166	0.72	246	0.71	-0.02
ICECAP-O	ICECAP-O Single Index	172	0.65	267	0.63	-0.02
	attachment	169	0.41	256	0.38	-0.03
	security	168	0.58	250	0.54	-0.04
	role	168	0.77	249	0.73	-0.04
	enjoyment	169	0.59	254	0.57	-0.02
	control	172	0.87	262	0.87	0.00

Note: 1) ***, ** indicate statistical significance at 99%,95% confidence intervals; 2) scores were normalized.

3.3 Main Regression Findings

For LTSS recipients, as shown in Table 3, Hukou, care setting, exercises, and psychological status were statistically significantly associated with QoL in an end-of-life setting by the ICECAP-SCM. These respondents with agricultural Hukou, receiving institutional care, and being physically and psychologically healthy had higher QoL than their counterparts. For males only, living with families or supporters was significantly associated with higher QoL. For females only, agricultural Hukou, residing in nursing homes, and physical and psychological health were significantly associated with higher QoL. In comparison, age and URBMI enrollment were significantly associated with lower QoL for females.

Table 3. Result of Multivariable Ordinary Least Squares (OLS) Linear Regression for ICECAP-SCM Single Index

	ICECAP-SCM Single Index		
	All	Male	Female
Age Above 65	0.001 (0.00)	-0.000 (0.00)	0.001** (0.00)
Agricultural Hukou	-0.053** (0.03)	-0.039 (0.05)	-0.062** (0.03)
Education Above Middle School	0.031 (0.03)	0.041 (0.04)	-0.008 (0.04)
Married	0.057 (0.05)	-0.010 (0.07)	0.096 (0.05)
UEBMI	-0.011 (0.06)	0.001 (0.09)	0.008 (0.06)
URBMI	0.109 (0.07)	0.075 (0.10)	0.157** (0.07)
Severely Disabled	-0.003 (0.02)	-0.000 (0.04)	-0.007 (0.03)
Home Care	0.092** (0.04)	-0.008 (0.06)	0.133*** (0.04)
Living Alone	0.054 (0.05)	0.180*** (0.04)	-0.031 (0.05)
Stable Household Income	-0.008 (0.02)	0.016 (0.03)	-0.013 (0.02)
Regular Exercise	-0.071*** (0.02)	-0.075 (0.04)	-0.082*** (0.03)
Stable Psychological Status	-0.122*** (0.03)	-0.067 (0.05)	-0.120*** (0.03)
Constant Term	0.297*** (0.09)	0.447*** (0.15)	0.197** (0.09)
R^2	0.108	0.066	0.203
N	440	176	260

Standard errors in parentheses

** $p < 0.05$, *** $p < 0.01$

For LTSS recipients, as shown in Table 4, marital status, exercises, and psychological status were statistically significantly associated with QoL by the ICECAP-O. Physical and psychological health were associated with higher QoL, while marriage was associated with lower QoL. For males only, physical and psychological health were significantly associated with higher QoL. For females only, receiving LTC at home was significantly associated with lower QoL.

Table 4. Result of Multivariable Ordinary Least Squares (OLS) Linear Regression for ICECAP-O Single Index

	ICECAP-O Single Index		
	All	Male	Female
Age Above 65	0.000 (0.00)	-0.000 (0.00)	0.001 (0.00)
Agricultural Hukou	-0.058 (0.03)	-0.041 (0.05)	-0.069 (0.05)
Education Above Middle School	0.027 (0.03)	0.057 (0.04)	-0.029 (0.05)
Married	0.090** (0.04)	0.073 (0.06)	0.092 (0.05)
UEBMI	-0.047 (0.07)	-0.017 (0.08)	-0.057 (0.13)
URBMI	0.037 (0.07)	0.102 (0.09)	0.010 (0.14)
Severely Disabled	0.006 (0.02)	-0.000 (0.04)	0.013 (0.03)
Home Care	0.061 (0.05)	-0.055 (0.06)	0.119** (0.06)
Living Alone	0.019 (0.07)	-0.071 (0.11)	0.093 (0.08)
Stable Household Income	-0.025 (0.02)	-0.013 (0.03)	-0.027 (0.03)
Regular Exercise	-0.083*** (0.03)	-0.132*** (0.04)	-0.042 (0.04)
Stable Psychological Status	-0.094** (0.04)	-0.145** (0.06)	-0.049 (0.06)
Constant Term	0.630*** (0.09)	0.747*** (0.13)	0.536*** (0.16)
R^2	0.073	0.154	0.074
N	435	172	259

Standard errors in parentheses

** $p < 0.05$, *** $p < 0.01$

For caregivers, as shown in Table 5, higher salary was statistically significantly associated with higher QoL, while higher education and poorer health were statistically significantly associated with lower QoL.

Table 5. Result of Multivariable Ordinary Least Squares (OLS) Linear Regression for ICECAP-A Single Index

	ICECAP-A Single Index
Age Above 60	-0.115 (-1.61)
Agricultural Hukou	0.080 (1.02)
Education Above Middle School	0.225*** (3.10)
Male	0.015 (0.21)
Religious Belief	0.201 (1.39)
Salary Above 3000	-0.408*** (-6.24)
Poor Health	0.759*** (4.59)
Institutional Care	-0.042 (-0.31)
Tobacco or Alcohol Use	-0.139 (-1.60)
R^2	0.1747
N	382

Standard errors in parentheses

** $p < 0.05$, *** $p < 0.01$

As shown in Table 6, higher caregivers' QoL was statistically significantly associated with higher LTSS recipients' QoL.

Table 6. Result of Generalize Linear Regression Model (GLM) for ICECAP-A and ICECAP-SCM/ICECAP-O Single Index

	ICECAP-A Single Index	
ICECAP_SCM Single Index	0.948*** (0.17)	
ICECAP_O Single Index		0.864*** (0.17)
R^2	0.0387	0.0403
N	360	360

Standard errors in parentheses

** $p < 0.05$, *** $p < 0.01$

4. Discussion

4.1 Gender Difference

For LTSS recipients, the results of our regression models implied that home care was associated with lower QoL by ICECAP-SCM in the end-of-life setting for both males and females. We suspected that access to formal care

or formal caregivers may influence the QoL difference in home care versus institutional care settings. Hellström, Y. *et al.* (2004) found that physical-health-related QoL among older adults receiving help from informal and formal caregivers was lower than those receiving assistance from only formal caregivers in the home care setting. Janssen N. *et al.* (2014) found that a lack of timely access to formal care resulted in unmet needs in patients with dementia. The unmet needs were associated with a lower QoL. We believed that these LTSS recipients residing in institutions in Chengdu had better access to formal caregivers than those cared for by informal caregivers at home. Better access reduced the unmet needs for formal care and was associated with higher QoL for LTSS recipients in institutional care settings.

In addition, we found that home care was associated with lower QoL for only females across two instruments, while a significant association for males did not exist. We suspected that access to proper LTSS may influence the QoL difference in females versus males. Cameron, K. A. *et al.* (2010) found greater health needs among female older adults than males with similar demographic and health profiles, but females had fewer economic resources. Hence, females used more volume and a higher proportion of home care than institutional care, which is explained by their greater needs and economic burden. With a similar assumption in the previous section, we believed that females had a greater gap to formal care or formal caregivers in home care settings in Chengdu, which caused greater unmet needs and was associated with a lower QoL than males.

4.2 Educational Level of Caregivers

Our study findings showed caregivers' lower QoL was statistically significantly associated with higher education levels, which is not consistent with results in previous studies. Rha, S. *et al.*, (2015) found that the caregiver's educational level was a positive contributing factor for the QOL. The agreement on the positive influence of education level is also proved by several studies (Kim, Y., & Spillers, R. L., 2010; Mosher, C. E., 2013). Meanwhile, in a few Asian studies, education level was not significantly associated with QoL (Effendy. C *et al.*, 2014; Yang, X *et al.*, 2012). We suspected that the reason for caused negative influence on QoL in our study was a result of the decrease in self-esteem through the caregiving experience. Nijboer, C., *et al* (1999) found that caregivers with a low educational level reported improvement in self-esteem and then affected their QoL. MacLean, D., & Kermodé, S. (2001) explain the relationship between QoL, health and self-esteem. They concluded high positive self-esteem scores were important in overall indices of QOL by substantial contributors to the "happiness" perceptions of caregivers. As to caregivers with higher education levels, we assume that they might experience decreased self-esteem in delivering LTSS resulting in lower QoL. Furthermore, we must clarify the reason caused the decreased self-esteem. We tend to agree with the possible explanation that caregivers with better socioeconomics (e.g. higher education level) perceive more differences between their prior professional role and the role of LTSS caregiver. Hence, caregiving may be perceived as less rewarding by caregivers with a higher education when compared with lower-educated caregivers (Nijboer, C., *et al*, 1999).

4.3 Predictors of Caregivers' QoL

Previous studies revealed factors that affect caregivers' QoL have established a wide range of physical, social, and psychological environmental factors, as well as demographic characteristics and resource inputs (Rand, S., & Fox, D., 2012). In our study, a few sociodemographic variables were tested with the association with QoL among LTSS caregivers, restricted by the accessible data and survey design. However, in further studies, there is a necessity to introduce an elevation instrument as a comprehensive description for caregivers. Hughes, S. L., *et al* (1999) proposed caregiver burden and discussed the relationship between caregiver burden and caregivers' QoL. Various studies also used caregiver burden as the description of caregivers and found its significance as a predictor. In further study, we tend to replace the currently limited sociodemographic variables with caregiver burden.

5. Limitation

This study had several limitations. First, only one-wave survey data were used, although it was carefully sampled, which could limit the significance of the findings. The cross-sectional nature of the data restricted the examination of cause-effect associations. So, multiple wave data will be used to explore the changes in QoL associated with sociodemographic variables. Second, limited sociodemographic variables were available in the survey, and only the gender difference among LTSS recipients of the hypothesized model was explored in this study. It implies that more research focusing on the difference between age groups and symptomatic groups is worthy of being conducted in the future. More importantly, the lack of incorporating any theoretical frameworks that guide the study into an understanding of the mechanisms leading some LTSS recipients and their caregivers to experience higher QoL and others not to. Wilson, I. B., & Cleary, P. D. (1995) proposed, and Ferrans, C. E. *et al.* (2005) revised conceptual farmwork that understanding the overall QoL was a result of general health

perception. The transition from the original individual's physical status to symptom and functional status and then the health perception was interacted by both environmental and individualized characteristics. Sociodemographic variables in studies must be more comprehensively included and categorized better to understand the cause of the difference in QoL. Third, only severely or moderately disabled LTSS recipients and their caregivers were supported by LTCI and participated in the survey, per Chengdu's policy, by the study date. The exclusion of individuals with mild disabilities might dilute the comprehensive understanding of both populations. Fourth, the Chengdu-specific study and findings limited the implications for policymakers in other cities of China.

Despite these limitations, our analysis raised concerns for domestic policymakers. It addressed the critical concerns of the most vulnerable subgroup within the vulnerable population. In addition, the ICECAP-SCM and ICECAP-O have a spiritual domain, which was believed to be one of the most essential aspects of QoL for LTSS recipients.

6. Conclusion

This study exploratory assessed the LTSS recipients and their caregivers' QoL in Chengdu, China. We found physical and psychological health were the strongest predictors of higher QoL for female and male LTSS recipients. For female LTSS recipients only, home care was associated with lower QoL based cross two instruments. For male LTSS recipients based on ICECAP-SCM only, living with or without their family or supporters was the single predictor of QoL. We also found physical and psychological health were the strongest predictors of higher QoL for female and male LTSS recipients. As to caregivers, higher QoL was statistically significantly associated with higher salary, lower education, and better health status. Furthermore, we proved higher QoL among caregivers was associated with higher QoL of the LTSS recipients. From our study findings, we suggest policymakers consider gender-specific LTSS delivery to improve LTSS recipients' QoL, by encouraging females receiving less home care. Meanwhile, policymakers could consider an increase in salary for caregivers as an effective intervention in improving QoL.

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Human Ethics and Consent to Participate declarations: This study was approved by the Chengdu Medical College IRB Committee, under approval number (2023)043. Informed consent was obtained from all participants prior to their involvement in the study.

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Note

Note 1. Hukou means household registration system in China. The hukou type is differentiated into “agricultural” and “non-agricultural”, which are usually referred to “rural” and “urban”. The Hukou status here is not referring to a person's current physical location but an occupational classification in labor market.

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