



Quality of life and social support of older adults caregivers and care recipients in high social vulnerability

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Abstract

Objective: to compare quality of life and social support between older adults caregivers and care recipients. **Method:** observational, cross-sectional and quantitative study, carried out with 112 older adults registered in five Family Health Units in a context of high social vulnerability in a city in the interior of São Paulo, Brazil. Sociodemographic, care and health variables, social support by the *Medical Outcomes Study Social Support Scale* and quality of life by the *WHOQOL-bref* and *WHOQOL-old* were evaluated. For data analysis, Pearson's Chi-Square, Mann-Whitney and *Spearman's* Correlation tests were used. **Results:** There was a significant difference between the participants for material support ($p=0.004$) and physical domain of the quality of life scale ($p=0.002$). Older adults caregivers have lower material support scores and better perception of the physical domain of the quality of life scale when compared to care recipients. Furthermore, there was a direct and moderate correlation between quality of life and social support of older adults ($p<0.001$), that is, the higher the score on the social support scale, the higher the score on the quality of life scale. **Conclusion:** adults caregivers presented lower material support scores and better perception of the physical domain of the quality of life scale compared to care receptors. Actions related to expanding the amount of significant relationships of caregivers can be useful for improving social support, with consequent improvement of the other aspects involved in quality of life.

Keywords: Social Support. Quality of Life. Aged. Caregivers. Social Vulnerability.

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INTRODUCTION

Amid increased longevity and a predominance of chronic diseases, older individuals can experience difficulties carrying out activities of daily living (ADLs) and, consequently, may require the help of caregivers¹. Caregivers provide support and encouragement to perform these ADLs². On a national level, there is a growing number of older individuals who care for other older people, where the spouse is often the only option for delivering care³.

Older caregivers in a situation of high social vulnerability are more exposed to a lack of resources, where this can negatively impact their health and quality of life, besides affecting the care provided⁴.

In the context of care, older adults may have specific health needs, highlighting the need to study aspects that can improve quality of life and health in aging. In this respect, social support is an important determinant of health and disease⁵ and can enhance quality of life in both older caregivers and care recipients⁶.

Quality of life (QoL) is fundamental for humans throughout all stage of the life span and is associated with well being, health, satisfaction and perception on life in psychological, physical and social domains⁷. Remaining active, enjoying social support and performing activities with autonomy are important elements contributing to good quality of life⁸. However, when these aspects are lacking, this can negatively impact older caregivers, leading to depressive symptoms, lack of social interaction and difficulty performing self-care⁹. Thus, studies investigating this subject are imperative.

Evidence in the literature suggests that social support can optimize quality of life, promoting a reduction in negative feelings and loneliness¹⁰ and improvements in cognitive performance^{11,12}, with greater effects when this support is derived from family as opposed to friends or others¹³.

Corroborating these findings, both national and international literature show that social support is associated with positive perceived quality of life among older people. However, no studies

investigating social support and quality of life in the older caregiver-care recipient dyad were found in the literature, prompting the present study.

Thus, understanding the interaction of these variables in this population group is pertinent, especially amid situations of high social vulnerability, where lack of resources may negatively impact quality of life and social support of those involved¹⁴. The objective of this study was to compare the quality of life and social support of older caregivers and care recipients.

The initial hypothesis holds that older caregivers have lower perceived social support and better perceived quality of life compared to care recipients.

METHOD

A cross-sectional, observational, quantitative study drawing on data from the investigation “Factors associated with poor sleep quality in older caregivers” was conducted. The study project was approved by the Research Ethics Committee of the Federal University of São Carlos (permit no. 3.275.704, 22/04/2019) and complied with Resolution no. 466/2012. Participation was voluntary and all participants of the study read and signed the Free and Informed Consent Form in duplicate.

The study was carried out between July 2019 and March 2020 and involved older adults enrolled at 5 Family Health Units (USFs) situated in areas of high social vulnerability, according to the Paulista Social Vulnerability Index (IPVS) of a city in the interior of São Paulo state.

The IPVS reflects demographic and socioeconomic aspects of people living in São Paulo State and is categorized into 7 levels of vulnerability: Group 1 (extremely low vulnerability), Group 2 (very low vulnerability), Group 3 (low vulnerability), Group 4 (moderate vulnerability), Group 5 (high vulnerability – urban sectors), Group 6 (very high vulnerability) and Group 7 (high vulnerability – rural sectors)¹⁵. In 2019, the city of São Carlos had 9 USFs located in areas of high social vulnerability (IPVS= 5), of which, 5 agreed to take part in the study.

The sample comprised all individuals that met the following inclusion criteria: age ≥ 60 years; living with another older adult in the same household; located by the researchers at the household within 3 attempts on different days and times; and living within the catchment area of the USF, according to the address provided by the professionals of the USF. Criteria for inclusion in the caregiver group were: being the primary caregiver of the care recipient; performing the role of caring on an informal basis; being a relative of the care recipient, who was dependent for at least one basic activity of daily living (BADL), as measured by the Katz Index^{16,17} or instrumental activity of daily living (IADL), as measured by the Lawton & Brody scale^{18,19}. The exclusion criteria adopted were: severe speech and/or hearing deficit perceived at time of data collection potentially hampering or preventing communication during application of the scales; and incomplete data on the variables of interest.

The sample was selected from a total of 168 households listed by professionals of the 5 USFs, each with a dyad of older residents. All households were visited. Of the overall sample, 49 refused to take part in the study, 32 were not found by the researchers after 3 attempts on different days and times, 18 were no longer residing at the address given, 3 had died and, for 1 of the households, the older residents were independent for BADLs and IADLs. Data collection included the dyads of older people from the 65 households visited. However, after analysis of the database, 9 dyads were later excluded for not having all data on the variables of interest. Therefore, the final study sample included 56 older caregivers and 56 care recipients.

Interviews took place at the participants' homes and were conducted individually during a single session averaging 2 hours duration, in a room made available by the residents. Data collection was performed by 8 previously trained graduate and postgraduate students.

The variables of interest were investigated for the following parameters:

- Sociodemographic and health characteristics of participants: sex (female or male), age (years),

marital status (with or without partner), education (years), race (brown, white, black, yellow or indigenous), family and individual income (BRI), retirement (yes or no), currently working (yes or no), deem income sufficient (yes or no), private health plan (yes or no), multimorbidities (yes or no), number of medications in use, falls and hospital admissions in last year (yes or no), alcohol use (yes or no), and tobacco use (yes or no).

- Care context characteristics: degree of kinship with older person cared for (spouse, father/mother, mother/father-in-law, brother/sister or other), time in role as carer (years), number of hours and days per week dedicated to caregiving, undertaken preparatory course for caring for older person (yes or no), and help received for the task of caring (yes or no).
- Functional capacity for BADLs: determined using the Katz Index^{16,17} which measures the capacity to perform basic activities such as bathing, dressing, toileting, transferring, continence and feeding. Upon completion, the interviewer checks for how many activities the individual displays independence and dependence. One point is given for each item the individual reports independence, and zero points for dependence. The final score ranged from 0-6 points. For the purposes of analysis, 6 points indicated independent and ≤ 5 points dependent.
- Functional capacity for IADLs: determined using the Lawton Brody Instrumental Activities of Daily Living Scale^{18,19}, which measures the degree of dependence for performing instrumental activities such as housekeeping, handling finances, using telephone, managing medications, using transportation, shopping, and preparing food. Upon completion, the score is summed to give a total of between 7 and 21 points. For the purposes of analysis, a score of 21 points indicated independence and 7-10 points dependence.
- Social support, assessed using the Social Support Scale of the Medical Outcomes Study, which comprises 19 items covering 5 functional dimensions of social support: tangible,

affectionate; emotional; positive social interaction and informational. For each item, the participants indicate how often they consider each type of support is available on a frequency scale of options (“never” to “always”). The values are standardized on a scale ranging from 20-100 points, where higher scores indicate better level of social support²⁰.

- Quality of life (QoL): assessed using questionnaires devised by the World Health Questionnaires – WHOQOL-*bref*²¹ and WHOQOL-*old*. The WHOQOL-*bref*²² comprises 26 questions, of which 2 are general domain and the others represent each of the 24 facets making up the original QoL scale. The domains assessed (Physical health, Environmental health, Social relationships and Psychological health) comprise questions scored from 1 to 5 on a response scale. Final scores on each domain are calculated by syntax, which quantifies the global quality of life and the quality of life domains on scales with scores ranging from 0 to 100, where 100 implies higher QoL. The WHOQOL-*old* questionnaire comprised 24 questions divided into 6 domains: sensory abilities; autonomy; past, present and future activities; social participation; death and dying; and intimacy. This questionnaire is also scored according to the syntax defined by the WHOQOL group^{21,22}. Quality of life was considered the dependent variable of this study.

For the descriptive analysis of data, distributions of frequency, medians, means and standard-deviation were estimated for numeric variables. Proportions were estimated for categorical variables. The Kolmogorov-Smirnov test was used to test for normality of variables and a non-parametric distribution was confirmed. Differences between groups were estimated using Pearson’s chi-square and Mann-Whitney tests. Analysis of correlation between QoL score and social support was carried out using Spearman’s correlation test. The magnitude of correlation was classified as weak (<0.30); moderate ($0.30-0.59$); strong ($0.60-0.99$) and perfect (1.0)²³. A significance level of 5% was adopted.

RESULTS

The study sample comprised 56 older caregivers and 56 care recipients. The sociodemographic characteristics of participants are given in Table 1. The sample consisted predominantly of individuals who were female, aged 60-74 years, with low educational level and living with partner.

Information on the health situation of the participants is given in Table 2.

Regarding care context, 91.1% of caregivers were spouses of the care recipient and time in role of caregiver averaged 11.8 ± 13.41 years. Time dedicated to care averaged 17.4 ± 8.5 hours a day, 4.9 ± 0.5 days a week. Most caregivers had no previous training (98.2%) and received no help with the task of caring (58.9%).

Regarding social support network, caregivers had a mean of 10.0 ± 14.1 and median of 5.5 people in their network. Care recipients had a mean of 16.4 ± 34.0 and median of 5.0 people in their social support network. There was no statistically significant group difference in number of people comprising the respective social support networks ($p=0.905$).

A comparison of social support of caregiver versus care recipients is shown in Table 3.

Caregivers scored lower for tangible support compared to care recipients ($p=0.004$).

Differences in perceived QoL of caregivers and care recipients are presented in Table 4.

A statistically significant relationship was found between the Physical health domain of the QoL scale among participants, where caregivers had better perceived physical health than care recipients ($p=0.002$).

The correlation between QoL and social support of caregivers is presented in Table 5.

A moderate direct correlation was found between social support and QoL of caregivers, i.e. high score on social support scale was associated with high score on QoL scale.

Table 1. Distribution of participants according to demographic aspects (N=112). São Carlos, São Paulo state, 2019-2020.

Variables	Caregiver	Care recipient	<i>p-value</i>
	n (%)	n (%)	
Age			0.257#
60-74 years	46 (82.1)	41 (73.2)	
≥ 75 years	10 (17.9)	15 (26.8)	
Sex			0.705#
Female	31 (55.4)	29 (51.8)	
Male	25 (44.6)	27 (48.2)	
Education			0.622#
0-4 years	45 (80.4)	47 (83.9)	
≥ 5 years	11 (19.6)	9 (16.1)	
Marital status			0.499#
With partner	53 (94.6)	51 (91.1)	
Without partner	3 (5.4)	5 (8.9)	
Race			0.535#
Brown	28 (50.0)	24 (42.9)	
White	19 (33.9)	20 (35.7)	
Black	6 (10.7)	11 (19.6)	
Yellow	2 (3.6)	1 (1.8)	
Indigenous	1 (1.8)	0 (0.0)	
Currently working			0.001#
No	42 (75.0)	54 (96.4)	
Yes	14 (25.0)	2 (3.6)	
Retired			0.065#
No	16 (28.6)	8 (14.3)	
Yes	40 (71.4)	48 (85.7)	
Personal income*			0.847#
0-1 minimum wage	27 (50.0)	28 (51.9)	
>1 minimum wage	27 (50.0)	26 (48.1)	
Family income*			0.801#
0-1 minimum wage	6 (11.1)	5 (9.6)	
>1 minimum wage	48 (88.9)	47 (90.4)	
Sufficient income			0.848#
No	33 (58.9)	32 (57.1)	
Yes	23 (41.1)	24 (42.9)	

Source: Data from Study, 2020. SD = Standard Deviation; #Chi-square; *Some participants gave no answer.

Table 2. Distribution of participants according to health aspects (N=112). São Carlos, São Paulo state, 2019-2020.

Variables	Caregiver		Care recipient		<i>p-value</i>
	n (%)	n (%)	n (%)	n (%)	
Polypharmacy	38 (67.9)	28 (50.9)	28 (50.9)	27 (49.1)	0.069#
No (0-4 medications)	18 (32.1)		27 (49.1)		
Yes (≥ 5 medications)					
Health plan					0.768#
No	49 (87.5)		50 (89.3)		
Yes	07 (12.5)		6 (10.7)		
Multimorbidity					0.558#
No	2 (3.6)		1 (1.8)		
Yes	54 (96.4)		55 (98.2)		
Functional capacity for BADLs					0.031#
Independent	41 (73.2)		30 (53.6)		
Dependent	15 (26.8)		26 (46.4)		
Functional capacity for IADLs					<0.001#
Independent	21 (37.5)		1 (1.8)		
Dependent	35 (62.5)		55 (98.2)		
Falls in last year					0.425#
No	35 (62.5)		39 (69.6)		
Yes	21 (37.5)		17 (30.4)		
Hospital admission in last year					1.000#
No	46 (82.1)		46 (82.1)		
Yes	10 (17.9)		10 (17.9)		
Engagement in physical activity					0.403#
No	42 (75.0)		38 (67.9)		
Yes	14 (25.0)		18 (32.1)		
Alcohol use					0.607#
No	46 (82.1)		48 (85.7)		
Yes	10 (17.9)		8 (14.3)		
Tobacco use					0.450#
No	45 (80.4)		48 (85.7)		
Yes	11 (19.6)		8 (14.3)		

Source: Data from Study, 2020. SD = Standard Deviation; #Chi-square.

Table 3. Comparative analysis of social support of participants (N=112). São Carlos, São Paulo state, 2019-2020.

Dimension of social support	Caregiver		Care recipient		<i>p-value*</i>
	Mean (SD)	Median	Mean (SD)	Median	
Tangible support	82.95 (18.31)	90.00	91.70 (13.29)	100.00	0.004
Affectionate support	89.29 (17.46)	100.00	89.52 (17.75)	100.00	0.974
Emotional support	77.95 (22.84)	85.00	80.45 (21.03)	87.50	0.564
Informational support	80.27 (20.81)	85.00	79.38 (21.74)	85.00	0.960
Positive social interaction	77.77 (20.40)	82.50	76.71 (22.02)	80.00	0.962
Total score	81.64 (17.09)	85.67	83.53 (16.18)	86.83	0.501

Source: Data from Study, 2020. SD = Standard Deviation; *Mann-Whitney

Table 4. Comparative analysis of quality of life of participants (N=112). São Carlos, São Paulo state, 2019-2020.

Domains of WHOQOL-bref	Caregiver		Care recipient		p-value*
	Mean (SD)	Median	Mean (SD)	Median	
Physical health	64.16 (13.97)	64.29	54.97 (16.66)	53.57	0.002
Environmental health	55.02 (14.31)	56.25	55.58 (13.29)	56.25	0.581
Social relationships	66.07 (17.56)	70.83	64.66 (17.21)	66.67	0.577
Psychological health	61.90 (15.06)	62.50	67.71 (18.47)	70.84	0.075
Total score	61.79 (11.37)	62.75	60.73 (12.31)	60.75	0.434

Domains of WHOQOL-old	Caregiver		Care recipient		p-value*
	Mean (SD)	Median	Mean (SD)	Median	
Sensory abilities	69.20 (25.36)	75.00	67.08 (23.88)	75.00	0.538
Autonomy	58.26 (20.92)	59.38	55.92 (17.61)	56.25	0.391
Past, present and future activities	61.72 (18.19)	62.50	61.38 (15.41)	62.50	0.701
Social participation	64.17 (17.13)	68.75	61.05 (16.47)	62.50	0.243
Death and dying	67.97 (24.34)	75.00	64.06 (26.28)	75.00	0.418
Intimacy	66.63 (19.95)	68.75	68.42 (21.23)	75.00	0.393
Total score	71.73 (11.86)	73.75	70.39 (10.07)	69.17	0.303

Source: Data from Study, 2020. SD = Standard Deviation; *Mann-Whitney

Table 5. Analysis of correlation between QoL and social support in caregivers (N=56). São Carlos, São Paulo state, 2019-2020.

QoL domains	Tangible support		Affectionate support		Emotional support		Positive Social Interaction		Informational support		Total social support score	
	Rho	p*	Rho	p*	Rho	p*	Rho	p*	Rho	p*	Rho	p*
Physical health	0.207	0.125	0.026	0.850	0.050	0.716	0.147	0.278	0.085	0.532	0.130	0.340
Environmental health	0.324	0.015	0.250	0.063	0.298	0.026	0.282	0.035	0.389	0.003	0.366	0.005
Social relationships	0.341	0.010	0.268	0.046	0.251	0.062	0.389	0.003	0.182	0.180	0.388	0.011
Psychological health	0.287	0.032	0.313	0.019	0.232	0.085	0.423	0.001	0.236	0.080	0.370	0.005
Total QOL(bref)	0.141	0.137	0.261	0.050	0.252	0.007	0.317	0.001	0.294	0.002	0.340	<0.001
Sensory abilities	0.444	0.001	0.456	<0.001	0.425	0.001	0.343	0.010	0.247	0.066	0.428	0.001
Autonomy	0.306	0.022	0.194	0.152	0.265	0.048	0.135	0.321	0.292	0.029	0.298	0.026
Past, present and future activities	0.255	0.057	0.256	0.057	0.390	0.003	0.224	0.098	0.248	0.065	0.344	0.009
Social participation	0.238	0.078	0.196	0.148	0.100	0.462	0.100	0.465	0.201	0.138	0.176	0.195
Death and dying	-0.061	0.656	0.024	0.863	0.106	0.438	0.169	0.214	0.013	0.924	0.070	0.607
Intimacy	0.327	0.014	0.336	0.011	0.324	0.015	0.245	0.069	0.233	0.083	0.342	0.010
Tot QOL (Old)	0.348	0.009	0.323	0.015	0.407	0.002	0.321	0.016	0.267	0.046	0.402	0.002

Source: Data from study, 2020.

QoL = Quality of life; Total QoL (Old) = Total quality of life score on WHOQOL-OLD. *Spearman Correlation Coefficient..

DISCUSSION

This study compared the quality of life and social support of older caregivers versus care recipients. Caregivers scored lower for tangible support and had better perceived physical health on the QoL scale compared to care recipients.

With regard to social support networks of the dyads, caregivers had a mean of 10 people in their network, while care recipients had 16. In a previous Brazilian study of 85 caregivers and 84 non-caregivers seen at Family Health Clinics (USF) of a city situated in the interior of São Paulo state found that mean number of individuals in the social support network was higher in the non-caregivers²⁴.

Social support is a determinant of health aging²⁵, where informal support networks consolidate social relationships, interaction and affectionate, instrumental and tangible support, helping to promote the health and quality of life of older people. Among individuals with less financial means and in situations of social vulnerability, this type of help is even more important. Under circumstances of illness and problems accessing medication and treatment, this group may become more dependent on an informal support network²⁶, where people tend to help each other cope with the many everyday struggles²⁴.

In the present study, older caregivers had lower score for tangible support compared to care recipients. A cross-sectional study of 962 community-dwelling older adults in Minas Gerais also found that the highest score for social support was for the tangible support dimension²⁷. Tangible support encompasses physical support for practical services and material resources, such as performing activities of daily living (ADLs). The fact that care recipients received more tangible support than caregivers should be interpreted from a demand perspective. Older people who need care generally have functional limitations, rendering this age group more dependent on others, having greater demands. Thus, it follows that these individuals receive more tangible support because they have greater needs²⁸.

In this investigation, caregivers had better perceived physical health on the QoL scale compared

to care recipients. Another Brazilian study of 100 older adults aged ≥ 80 years and their family caregivers (mean age 0.63 ± 14.53 years) in a city of Rio Grande do Sul state assessed QoL of the participants. For the physical domain of QoL, results revealed that care recipients had lower mean scores on this domain (51.76) compared to caregivers (82.61)²⁹.

The physical domain of QoL is related to many facets, such as pain and discomfort; energy and fatigue; sleep and rest; mobility; activities of daily living; dependence on medicational substances and medical aids; and work capacity²¹. Given QoL involves a subjective concept and depends on the feeling of well being and level of satisfaction with life, care recipients are believed to have a negative view of the physical component because of lack of autonomy and dependence on caregivers for some daily tasks, a scenario which might produce negative feelings of stress and dissatisfaction which, in turn, lead to worse quality of life³⁰.

In the present study, a moderate direct correlation between social support and QoL of caregivers was identified. The literature shows that the importance of social support increases in late life, constituting a predictor of greater well being and QoL in caregivers³¹.

In Brazil, a study of 148 older adults who were caregivers of other older adults found that those with better perceived QoL also rated emotional support received from family members as satisfactory. The authors revealed that satisfaction with emotional support can have a positive direct influence on perceived burden of care, a variable strongly associated with QoL³².

Conversely, the literature shows that a lack of and/or insufficient social support can trigger caregiver overload and stress, culminating in a lessened capacity to respond to physical and emotional stressors, poorer self-perceived health and resultant worse quality of life^{32,33}. Another aspect which might potentially confer poor quality of life is the unpreparedness to perform the role of caring, where many caregivers report a feeling of reduced self-efficacy³³.

A decrease in social and family contacts can occur during the course of the aging process and lead to social isolation, especially in situations of high social vulnerability. The lack of social support due to “family insufficiency” (recognized geriatric syndrome which can stem from conflicting relationships over the life course) can render older adults more dependent on Primary Care professionals, placing greater demand on health services. However, a closer relationship between older individuals and health professionals can be helpful in attenuating the impact of social vulnerability to which they are exposed³⁴.

Amid the context of high social vulnerability, characterized by lack of resources of all kinds, and care delivered to older people within Primary Care, it is imperative that health professionals offer care involving assertive and individualized actions based on the actual needs of older people, centered on the individual integrated with the family and the community. Taking into account the aspects specific to the older population, adopting a humanized integrated care approach, bringing a qualified ear to bear and showing empathy, can be pivotal in the successful resolution of each case³⁴.

This study has some limitations. The dearth of similar studies investigating older caregivers and their respective care recipients hampered comparison of the present findings against the national and international literature. In addition, the small, highly specific sample limits the generalization of the study findings. Also, the composition of the sample may also represent a limitation, in that the sample comprised older participants from only a third of the total households listed by the health center professionals. The cross-sectional design precludes any inferences regarding cause and effect relationships for the variables investigated. Lastly, the data obtained may not be fully reliable because it was collected by self-report, although the literature has confirmed the potential of self-reported measures³⁵. Future longitudinal studies, including older people in different situations of social vulnerability, are warranted.

CONCLUSION

Caregivers scored lower for tangible support and had better perceived physical health on the QoL scale compared to care recipients. These findings serve as an alert to health professionals on the need to assess both social support and QoL of older people, thereby allowing individualized interventions to be offered to this group.

Identifying the key members of the social support network of caregivers is paramount, given it is these individuals who provide the necessary support in the event of unexpected situations involving care recipients. Moreover, getting these caregivers involved in health promotion activities and disease prevention, e.g. groups engaged in organized walks, stretching, manual activities, or workshops on health education and caregiving, can be helpful in increasing the number of significant relationships, with consequent improvement in QoL of all involved.

Primary Care professionals should also undergo continual training to enable delivery of optimal support to family caregivers, because this group can often have doubts regarding care management and typically lacks any specific guidance. Assertive actions to promote social support can be useful to improve the QoL of this dyad. Lastly, public policies targeting older caregivers in the Primary Health setting should be devised.

AUTHOR CONTRIBUTIONS

Mayara M. Yazawa - Writing – First Draft and Methodology; Ana C. Ottaviani - Writing – Review and Editing; Ana L.S. Silva - Writing – First draft and Methodology; Keika Inouye - Formal Analysis and Writing – Review and Editing; Tábatta R.P. Brito - Writing – Review and Editing; Ariene A. Santos-Orlandi – Administration of Project, Methodology, Securing funding and Writing - Review and Editing.

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