

Quality of life, burden, family emotional support: a model for older adults who are caregivers

Qualidade de vida, sobrecarga, apoio emocional familiar: um modelo em idosos cuidadores

Calidad de vida, sobrecarga, apoyo emocional familiar: un modelo en ancianos cuidadores

Carola Rosas¹

ORCID: 0000-0001-7693-3278

Anita Liberalesso Neri¹

ORCID: 0000-0002-6833-7668

¹Universidade Estadual de Campinas. Campinas, São Paulo, Brazil.

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Corresponding Author:

Carola Rosas

E-mail: carolarosas@gmail.com



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ABSTRACT

Objective: To investigate associations between quality of life, sex, age, burden, and nature of emotional support available in the family in older adults who are caregivers of older relatives. **Method:** Cross-sectional and correlational study on 148 caregivers gathered in public and private healthcare services, who were subjected to psychological measures of quality of life, burden, exchange of emotional support, sex, and age. Data were analyzed using Chi-square, Fisher's exact test and path analyses ($p < 0.05$). **Results:** A total of 77% women, average age of 69.7 years. There were significant associations between exchange of support and burden due to the provided assistance, being a woman and satisfaction with the received support, satisfaction with the received support and burden, burden and quality of life, and satisfaction with the received support and feeling of burden due to the provided support. **Conclusion:** Satisfaction with the received emotional support moderate the association between sex and burden, and such moderate the association between satisfaction with emotional support and perceived quality of life.

Descriptors: Older Adults; Family Relationships; Caregivers; Quality of Life; Social Support.

RESUMO

Objetivo: Investigar relações entre qualidade de vida, sexo, idade, sobrecarga e natureza dos apoios emocionais disponíveis na família, em idosos cuidadores de parentes idosos. **Método:** Estudo transversal e correlacional com 148 cuidadores recrutados em serviços públicos e privados de saúde foram submetidos a medidas psicológicas de qualidade de vida, sobrecarga, intercâmbio de apoio emocional, sexo e idade. Os dados foram analisados através de qui-quadrado, exato de Fisher e *path* análises ($p < 0.05$). **Resultados:** 77% mulheres, idade média 69,7 anos. Resultaram associações significativas entre intercâmbio de apoios e ônus pelo apoio oferecido, ser mulher e satisfação pelo apoio recebido, satisfação pelos apoios recebidos e sobrecarga, sobrecarga e qualidade de vida, e satisfação pelos apoios recebidos e senso de ônus pelo apoio oferecido. **Conclusão:** Satisfação com apoio emocional recebido modera a relação entre sexo e sobrecarga, e esta modera a relação entre satisfação com apoio emocional e qualidade de vida percebida.

Descritores: Idoso; Relações Familiares; Cuidadores; Qualidade de Vida; Apoio Social.

RESUMEN

Objetivo: Investigar relación entre calidad de vida, sexo, edad, sobrecarga y tipos de apoyo emocional disponibles en la familia de ancianos cuidadores de parientes ancianos. **Método:** Estudio transversal y correlacional con 148 cuidadores reclutados en servicios públicos y privados de salud, fueron sometidos a medidas psicológicas de calidad de vida, sobrecarga, intercambio de apoyo emocional, sexo y edad. Los datos fueron analizados mediante test Chi-cuadrado, prueba exacta de Fisher y *path* análisis ($p < 0,05$). **Resultados:** 77% eran mujeres, con edad media de 69,7 años. Resultaron asociaciones significativas entre intercambio de apoyo y sentimiento de carga por el apoyo ofertado, ser mujer y satisfacción por el apoyo recibido, satisfacción por el apoyo recibido y sobrecarga, sobrecarga y calidad de vida, y satisfacción por el apoyo recibido con sentimiento de carga por el apoyo ofertado. **Conclusión:** Satisfacción con apoyo emocional recibido modera la relación entre sexo y sobrecarga, y esta modera la relación entre satisfacción con apoyo emocional y calidad de vida percibida.

Descriptor: Anciano; Relaciones Familiares; Cuidadores; Calidad de Vida; Apoyo Social.

INTRODUCTION

Social relationships are based on exchanges of material, informative, instrumental, and affective supports⁽¹⁻²⁾, the last one understood as exchanges of attention, emotional comfort, companionship, consolation, and personal confirmation, among other aspects that are achieved with meetings, conversations, assessments, follow-up, listening, and counselling⁽¹⁾. Long-term care of a sick and dependent senior family member follows a hierarchical model that is properly assumed or ceded, by other relatives, to wives or daughters who may also be older adults⁽³⁾. Senior caregivers, in addition to being affected by their own health problems, have to deal with concerns arising from the responsibility of care⁽⁴⁾. Care, when performed by a relative, has the potential to alter the dynamics of support in the family⁽⁵⁾.

The provision of support is more accepted among older people, if the need for support is determined by the presence of a negative event. Authors of studies on general caregivers report that when exchanges of emotional support involve people who have a special place in their life history, older people tend to value exchanges and perceive the received support as sufficient⁽⁶⁾; in addition, the perception of burden associated with provision of support by relatives tends to be related to physical and psychological stress in caregivers⁽³⁾.

Families with the presence of physically and cognitively dependent older adults tend to present more difficulties concerning functionality, usually expressed in high levels of anguish, stress⁽⁷⁾, and perceived burden for caregivers in general⁽⁸⁾. Burden is a multidimensional phenomenon and a complex construct⁽⁹⁾. Generically, we may state two classes of burden: objective and subjective. Objective burden reflects the physical and instrumental demands of the care receiver. The subjective results from the evaluation that caregivers make about the association between the demands of care and the resources they have to perform them⁽¹⁰⁾.

Caregivers with good family functionality present lower burden and better perceived quality of life⁽¹¹⁾. Women caregivers feature worse scores in perceived quality of life than men caregivers⁽¹²⁻¹³⁾; senior caregivers score lower than middle-aged ones⁽¹⁴⁾. There are several theoretical models corresponding to different ways of assessing quality of life, most of them focusing on health. The CASP-19 scale (control, autonomy, self-realization, and pleasure) is a psychological measure of quality of life proposed and tested in English studies⁽¹⁵⁾. Although it has not been specifically delineated for use with caregivers, its content reflects elements useful to the caregiver's psychological adaptation in stressful situations⁽¹⁶⁻¹⁷⁾.

Hence, we intend to verify whether the sex and age of senior caregivers are associated with an exchange of emotional support, burden of care, and quality of life; and if exchanging, giving, or receiving emotional support is associated with perception of burden of care, contributing to a better perceived quality of life.

OBJECTIVE

To investigate associations between perceived quality of life and the variables sex and age, burden perceived as a result of providing care, and the nature of the emotional support available in the family in senior caregivers of relatives who are also older adults, but sick and dependent, through the analysis of a theoretical model.

METHOD

Ethical aspects

The research was approved by the Research Ethics Committee of the Faculty of Medical Sciences (FCM) of the University of Campinas (UNICAMP), under Opinion no. 822,364 on October 6, 2014, according to Resolution no. 466/12.

Study design, location, and period

An observational and correlational research was conducted, based on data from the project *Bem-estar psicológico de idosos que cuidam de outros idosos no contexto da família* [Psychological well-being of older people who provide care for other seniors within the family context], carried out at the Faculty of Medical Sciences, UNICAMP, in the period from 2014 to 2015.

Population or sample; inclusion and exclusion criteria

A convenience sample was constituted with 148 family caregivers of sick and dependent seniors who agreed to participate in the study. The sample was estimated in the main research project through correlations of quality of life measures⁽¹⁵⁻¹⁶⁾ and perceived burden⁽¹⁸⁾ (with minimum correlations of measures of 0.40, power of test of 90%, and significance level of 1%). They were gathered through primary healthcare units of the Brazilian Healthcare System (48%), private medical offices (8.8%), geriatric physicians and other medical specialists (39.9%), and professionals from the *Programa Saúde da Família* [Family Health Program] (3.4%), belonging to four municipalities of the countryside of São Paulo state (38.5% from Jundiaí, 29.1% from Indaiatuba, 18.2% from Campinas, and 14.2% from Vinhedo). Inclusion criteria of the caregivers were aging 60 years or over and currently caring for a sick senior family member and with some degree of physical or cognitive dependence for six months or more. Exclusion criterion was the suspicion of cognitive impairment obtained through the range of scores lower than the cutoff in the *Cognitive abilities screening instrument – Short form* (CASI-S)⁽¹⁹⁾.

Study protocol

Single interview sessions with an average duration of 56 minutes were performed, from October 2014 to July 2015, in private services (25%), in the geriatrics outpatient clinic (13.5%) where seniors and their caregivers were attended, or in their homes (61.5%), in the case of senior caregivers who were unable to leave other person taking care of the dependent relative. At the beginning of the session, participants signed an informed consent form.

The following variables and instruments were used: a) Quality of life: assessed using the psychological-based scale CASP-19⁽¹⁵⁾. The psychometric study carried out on the Brazilian version of this scale resulted in two factors, with α of 0.837 and 0.670 for factors 1 and 2, respectively⁽¹⁶⁾. Factor 1 gathered items 3, 5, 7, and from 10 to 19 of the original self-realization and pleasure factors, and factor 2 gathered the items 1, 2, 4, 6, 8, and 9 of control and autonomy. The

instrument requires respondents to assess the extent to which each statement, scored from 0 to 3, describes their feelings about their own lives. The total score can range from 0 to 57, with the highest values being indicators of better quality of life. b) Care burden: evaluated by the Zarit Burden Scale⁽¹⁶⁾. We used factors resulting from a second construct validation conducted in Brazil⁽²⁰⁾: (1) Role-related conflicts; (2) Intrapsychic conflicts; (3) Negative competences and expectations of care. The scale contains 22 items and its total score can range from 0 to 88 points, being the highest ones indicators of higher perceived burden. It has good indexes of internal consistency for all factors and the total, explained 44% of the variability (Cronbach's alpha of 0.857). c) Exchange of emotional support: assessed through questions formulated by the researchers about providing or receiving emotional support based on the categories: received support, exchange of support, and provided support⁽¹⁾, with the alternatives "Yes" or "No." d) Evaluation of emotional support: performed through questions formulated by the researchers. It questions whether the support is sufficient to meet the needs, and in the case provided aid, it questions whether there was perception of burden associated with the provision of support based on the sufficiency categories of the received emotional support and perceived burden in the provided emotional support, with positive or negative responses⁽¹⁾. e) Sex: by questions with alternatives "men" or "women". f) Age: information obtained from questions about the date of birth of the caregivers.

Analysis of results and statistics

The Chi-square test and Fisher's exact test were used to compare the variables. The level of significance adopted for the tests was 95% ($p < 0.05$). To analyze the results of the quality-of-life scale (CASP-19), the sample scores were divided into tertiles. The value of each item was weighted by the load obtained from the previous confirmatory factor analysis⁽¹⁶⁾. The same was done regarding the burden scale⁽¹⁸⁾, whose gross scores were weighted by the value of the previously obtained factorial loads⁽²⁰⁾.

To study the relationship between variables, we established a theoretical model (Figure 1), tested by means of path analysis, based on structural equation modelling with fixed (zero-path coefficients) and free parameters to be estimated (coefficients of paths other than zero), by (goodness of fit statistics. We used the following statistics: Chi-square test for goodness of fit with acceptance value > 0.05 ; Chi-square ratio, which indicates good fit when < 2 ; Goodness of Fit Index (GFI) with acceptance value of ≥ 0.85 ; Goodness of Freedom Index Adjusted for Degrees of Freedom (AGFI) with acceptance value of ≥ 0.80 ; Standardized Root Mean Square Residual (SRMR) with acceptance value of ≤ 0.10 ; Root Mean Square Error of Approximation (RMSEA) with acceptance value of ≤ 0.08 ; Bentler's Comparative Fit Index (CFI) with acceptance value of ≥ 0.90 ; and Bentler & Bonett's Non-NormedFit Index (NNFI) with acceptance value of ≥ 0.90 ⁽²¹⁾.

We performed significance tests for the fit of path coefficients. Absolute values of $t > 1.96$ were accepted as significant. We used the Wald test to verify to what extent the exclusion of a path influenced the increase in the chi-square statistics of the model. By the Lagrange multiplier test, we defined the need to create a path disregarded in the initial model to improve the quality of the fit of the model.

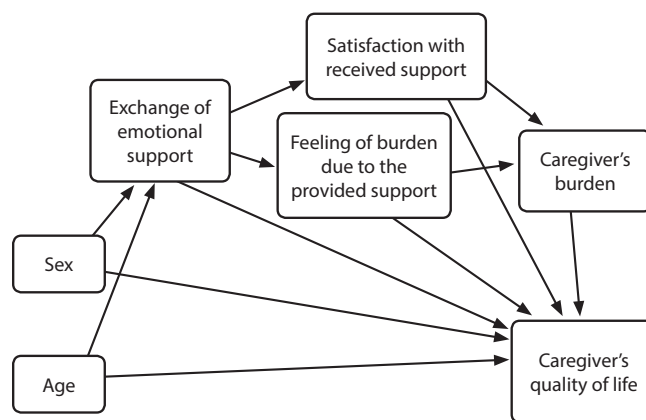


Figure 1 – Original theoretical model tested in the path analysis, Campinas, São Paulo, Brazil, 2015

RESULTS

The mean age of the caregivers was 69.7 years ($SD \pm 7.1$ years), and the mean time of care was 4.5 years ($SD \pm 7.1$ years); 77% were women; 62.1% were spouses, and 27.7% were daughters or children of care receivers. The mean score in perceived quality of life was 42.7 ± 8.8 years. The mean of the sample in the perceived burden scale was 26.1 ± 13.5 , and 45.9% scored at the moderate level (from 16 to 22) and 39.9% in the low level (≤ 15). A total of 70.5% reported they received emotional support, and 83% provided this type of support; 8.8% reported they only received it; 21.6%, only provided it; 60.8% exchanged emotional support with family members; and 8.8% reported they had neither received it nor provided it. On the other hand, 56% of the caregivers stated they were satisfied with the received emotional support; 13.1% reported dissatisfied; and 29.9% declared that they did not receive emotional support from family members. Moreover, 79.1% said they did not feel overburden for providing emotional support.

We observed a higher frequency of women (62.7%) than men (38.2%) who evaluated the received emotional support as sufficient, and more men (47.1%) than women (24.5%) who declared not to receive emotional support ($p = 0.027$). More women (31.3%) than men (15.6%) scored low in control/autonomy; however, more men (53.1%) than women (30.3%) scored at the intermediate level of this variable ($p = 0.046$). More seniors aged from 60 to 64 years (80.9%) and from 65 to 74 years (84.8%) than those aging 75 years and over (66.7%) provided emotional support with no feelings of burden ($p = 0.030$).

There were more caregivers who reported not feeling overburden than caregivers who felt overburden for providing emotional support scoring in the intermediate and high levels of quality of life. There were more caregivers with high burden who scored low level of quality of life, and more caregivers with low burden who scored high in quality of life than the inverse. More caregivers who exchanged emotional support with family members scored high and intermediate levels of quality of life. Most of them stated to provide emotional support without feeling overburden, who also scored higher in the total CASP (Table 1).

Sex was positively correlated with control/autonomy. More caregivers who exchanged emotional support with family members

scored high and intermediate levels of self-realization/pleasure and control/autonomy than those who did not exchange or receive support. Most of them stated to provide emotional support without feeling overburden, and also scored higher in self-realization/pleasure and control/autonomy. There was a negative correlation between caregivers who scored high in self-realization/pleasure and control/autonomy and those with low scores in total burden. There was a positive correlation between self-realization/pleasure and role-related conflicts, and a negative correlation between control/autonomy and role-related conflicts. Low scores in control/autonomy were negatively correlated with intrapsychic conflicts (Table 2).

Path analysis fit coefficients were obtained after three tests of the initial model (Table 3). Values of $|t| > 1.96$ were considered significant for $p < 0.05$.

In Figure 2 we show the final model. Caregivers with better perceived quality of life are those who perceive lower burden; and these are those who deemed as sufficient the emotional support received from the family; caregivers who perceive as sufficient the emotional support they receive are mostly women.

Table 1 – Caregivers according to score for the quality of life scale, considering the other variables, Campinas, São Paulo, Brazil, 2014-2015

Variáveis		Total quality of life			p value
		≤ 40 n (%)	41 - 47 n (%)	≥ 48 n (%)	
Sex	Men	8 (16)	11 (22)	15 (31.3)	0.196
	Women	42 (84)	39 (78)	33 (68.7)	
Age	60 – 64	14 (28)	12 (24)	17 (35.4)	0.110
	65 – 74	22 (44)	30 (60)	16 (33.3)	
	≥ 75	14 (28)	8 (16)	15 (31.2)	
Exchange of emotional support	Only receives	9 (18)	3 (6)	1 (2.1)	0.066
	Only provides	12 (24)	11 (22)	9 (18.7)	
	Exchange	24 (48)	34 (68)	32 (66.7)	
	Neither receives/nor provides	5 (10)	2 (4)	6 (12.5)	
Sufficiency of received emotional support	Does not receive	16 (34)	13 (26)	14 (29.8)	0.103
	Sufficient	21 (44.7)	30 (60)	31 (65.9)	
	Insufficient	10 (21.3)	7 (14)	2 (4.3)	
Burden for providing emotional support	Does not provide	13 (26.5)	5 (10.2)	7 (15.2)	0.030
	No burden	32 (65.3)	43 (87.8)	39 (84.8)	
	With burden	4 (8.2)	1 (2)	0 (0)	
Total burden	≤ 19	8 (16)	15 (30)	27 (56.2)	<0.001
	20 – 27	14 (28)	21 (42)	13 (27.1)	
	≥ 28	28 (56)	14 (28)	8 (16.7)	
Factor 1. Role-related conflicts	≤ 9	9 (18.4)	18 (39.2)	23 (51.1)	<0.001
	10 – 15	13 (26.5)	11 (23.9)	16 (35.6)	
	≥ 16	27 (55.1)	17 (36.9)	6 (13.3)	
Factor 2. Intrapsychic conflicts	≤ 1	12 (24.5)	17 (34)	23 (48.9)	0.035
	2 – 3	11 (22.5)	17 (34)	11 (23.4)	
	≥ 4	26 (53)	16 (32)	13 (27.7)	
Factor 3. Competencies and expectations	≤ 3	16 (32)	18 (37.5)	22 (46.8)	0.259
	4 – 7	10 (20)	11 (22.9)	13 (27.7)	
	≥ 8	24 (48)	19 (39.6)	12 (25.5)	

Note: Data obtained from the project Psychological well-being of older people who provide care for other seniors within the family context, 2014-2015.

DISCUSSION

In our study, the final model obtained from the path analysis demonstrates the influence of the caregiver's sex on the satisfaction with the received emotional support, which moderates the relationship between this variable and perceived burden. This, in its turn, moderates the relationship between satisfaction with the support and the quality of life perceived by the caregivers. These data correspond to the predominant trend observed in the literature on the well-being of family caregivers^(1,5,22). The exchange of emotional support appeared as a direct, positive, and robust influence on the perception of burden when providing care; in addition, satisfaction with the received support proved to be a significant, though small, influence regarding the sense of overburden. Exchange of support implies providing and receiving, and none of these actions is always and necessarily positive⁽²³⁾.

Transformations from the initial theoretical model to the final model reflect the peculiarities of senior caregivers. Both in general caregivers and in senior caregivers, improvement in quality of life⁽¹⁴⁾ is associated with a lower burden⁽⁸⁾. Moreover, we may expect that caregivers with lower burden have been those with greater satisfaction with the received support⁽⁶⁾ as well as the most satisfied ones to be women⁽¹³⁾. However, we can perceive differences between data found on general caregivers concerning exchanges of support^(3,6). In our study, senior caregivers who had higher feeling of burden due to the provided support were more satisfied with the received support. These results differ from those found in general⁽³⁾ and senior⁽²⁴⁾ caregivers.

We also showed that senior caregivers tended to provide emotional support with no burden, datum that is contrasting and, in a certain way, counterintuitive, since older people of very advanced age have more diseases than younger ones⁽³⁾, which is why they could get more tired when providing care⁽⁴⁾. Explanations can be found in mechanisms of emotional self-regulation, which are more frequent among older seniors than among younger ones^(11,22).

A study conducted with data from the *German Aging Survey* shows conflicting results⁽²⁵⁾ regarding older adults' preference for providing or receiving emotional support. In the sample of our study, there were more provisions and exchanges of emotional support. There were more seniors who found satisfaction in providing and receiving care than older people

Table 2 - Caregivers according to scores for self-realization/pleasure and control/autonomy, Campinas, São Paulo, Brazil, 2014-2015

Variables		Fator 1. Self-realization and pleasure				Fator 2. Control and autonomy			
		≤ 22 n (%)	23 - 27 n (%)	≥ 28 n (%)	p value	≤ 9 n (%)	10 - 12 n (%)	≥ 13 n (%)	p value
Sex	Men	7 (15.6)	13 (24.5)	12 (26.7)	0.402	5 (12.5)	17 (33.3)	10 (18.9)	0.046
	Women	38 (84.4)	40 (75.5)	33 (73.3)		35 (87.5)	34 (66.7)	43 (81.1)	
Age	60 - 64	14 (31.1)	10 (18.9)	18 (40)	0.123	12 (30)	13 (25.5)	18 (33.9)	0.820
	65 -74	21 (46.7)	29 (54.7)	14 (31.1)		14 (40)	25 (49)	23 (43.4)	
	≥ 75	10 (22.2)	14 (26.4)	13 (28.9)		12 (30)	13 (25.5)	12 (22.6)	
Exchange of emotional support	Only receives	7 (15.6)	4 (7.6)	1 (2.3)	0.011	9 (22.5)	3 (5.9)	1 (1.9)	0.001
	Only provides	14 (31.1)	5 (9.4)	12 (26.7)		13 (32.5)	11 (21.6)	7 (13.2)	
	Exchange	19 (42.2)	39 (73.6)	29 (64.4)		15 (37.5)	31 (60.8)	41 (77.4)	
	Neither receives/nor provides	5 (11.1)	5 (9.4)	3 (6.6)		3 (7.5)	6 (11.8)	4 (7.5)	
Sufficiency of received emotional support	Does not receive	18 (42.9)	10 (18.9)	14 (31.8)	0.001	15 (39.5)	16 (32.6)	11 (20.7)	0.069
	Sufficient	15 (35.7)	33 (62.4)	30 (68.2)		15 (39.5)	27 (55.1)	37 (69.8)	
	Insufficient	9 (21.4)	10 (18.9)	0 (0)		8 (21)	6 (12.3)	5 (9.5)	
Burden for providing emotional support	Does not provide	11 (25)	9 (17.3)	4 (9.3)	0.036	12 (30.8)	8 (16.7)	5 (9.4)	0.003
	No burden	29 (65.9)	42 (80.8)	39 (90.7)		23 (58.9)	39 (81.2)	48 (90.6)	
	With burden	4 (9.1)	1 (1.9)	0 (0)		4 (10.3)	1 (2.1)	0 (0)	
Total burden	≤ 19	6 (13.3)	20 (37.7)	21 (46.7)	<0.001	5 (12.5)	16 (31.4)	28 (52.8)	<0.001
	20 - 27	12 (26.7)	21 (39.6)	13 (28.9)		14 (35)	14 (27.4)	18 (33.9)	
	≥ 28	27 (60)	12 (22.6)	11 (24.4)		21 (52.5)	21 (41.2)	7 (13.3)	
Factor 1. Role-related conflicts	≤ 9	8 (17.8)	23 (47.9)	19 (43.2)	0.011	5 (12.8)	18 (37.5)	27 (54)	<0.001
	10 - 15	13 (28.9)	11 (22.9)	14 (31.9)		14 (35.9)	11 (22.9)	14 (28)	
	≥ 16	24 (53.3)	14 (29.2)	11 (25)		20 (51.3)	19 (39.6)	9 (18)	
Factor 2. Intrapsychic conflicts	≤ 1	10 (22.2)	19 (36.5)	22 (48.9)	0.057	11 (27.5)	12 (23.5)	28 (53.9)	<0.001
	2 - 3	11 (24.4)	15 (28.8)	11 (24.4)		6 (15)	20 (39.2)	13 (25)	
	≥ 4	24 (53.3)	18 (34.6)	12 (26.7)		23 (57.5)	19 (37.3)	11 (21.1)	
Factor 3. Competencies and expectations	≤ 3	13 (28.9)	22 (43.1)	18 (40.9)	0.324	14 (35)	18 (37.5)	23 (43.4)	0.850
	4 - 7	9 (20)	12 (23.5)	12 (27.3)		10 (25)	10 (20.8)	13 (24.5)	
	≥ 8	23 (51.1)	17 (33.3)	14 (31.8)		16 (40)	20 (41.7)	17 (32.1)	

Note: Data obtained from the project Psychological well-being of older people who provide care for other seniors within the family context, 2014-2015

Table 3 – Estimation of the coefficients of the path analysis, Campinas, São Paulo, Brazil, 2014-2015

Path from/to	Beta	t-value
Total burden/Total Quality of life	-0.430	-5.62
Sex/Satisfaction with support	0.239	2.90
Satisfaction with support/Total burden	-0.174	-2.08
Satisfaction with support/Burden in the provision of support	0.231	4.64
Support Exchange/Burden in the provision of support	0.772	15.51

Note: Data obtained from the project Psychological well-being of older people who provide care for other seniors within the family context, 2014-2015

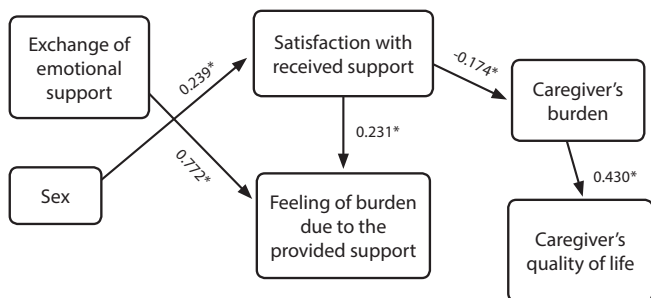


Figure 2 – Final model resulting from the path analysis, Campinas, São Paulo, Brazil, 2014-2015

who felt overburden for providing them. These data allow us to conclude that emotional support contributed to the well-being of most of them⁽²⁵⁾. In addition to soothing effects of the stress caused by aging, care, and adverse events emerging from both phenomena, providing and exchanging emotional support are better than just receiving it, because such confirms the expectations of autonomy and control of older adults about the environment and themselves^(1,13). Both those who exchange and receive have in emotional support a softener of the effects of stressful events of care, aging, and family life on subjective well-being⁽³⁻⁴⁾. However, exchanges of emotional support are not always positive and can, instead, affect the well-being of older adults⁽²³⁾.

The sample was mostly constituted by women, replicating data found in other studies on caregivers, which, in turn, reflect the influence of belonging to the female sex on the involvement with the role of caring^(8,12,22,26). More women than men assessed as sufficient the received emotional support, contradicting data from the literature according to which women report more negative experiences than men⁽¹²⁻¹³⁾. No data were collected in order to help understanding this occurrence, but we can propose the hypothesis that women are more controlled by social desirability of being seen as members of a loving and supportive family.

Data found in European caregivers demonstrated that when social support comes from relatives, most caregivers report being

satisfied with social relationships and the received social support⁽⁶⁾. The same was reported by authors of studies conducted on Australian⁽¹⁾, Afro-American, and American European⁽²⁵⁾ older adults. They also state that when support comes from people with whom they have interpersonal issues, seniors tend to show themselves dissatisfied with the received social support^(1,6,25).

The percentage of men was similar to that found in other studies, and a gradual increase is evident⁽²⁷⁻²⁸⁾. Moreover, since more men were observed than women among those who said they did not receive emotional support, such fact may be related to the practice of cultural origin that consists in the tendency of men not to get emotionally involved with the tasks of care⁽¹³⁾. Men would tend to consider care as a work and issue to be solved more than women, who, in a more or less beneficial way to their adaptation, would tend to focus more on relational aspects and involved feelings^(12,29).

The observation of more senior women than men as caregivers with low scores in control/autonomy stresses the preceding arguments⁽²⁹⁾. It is a current vision in culture that requiring emotional support means incapacity or inefficiency in facing the various situations involved in care. This is pointed out as more true for men than for women. In more individualistic than collectivist cultural contexts, this is valid for both sexes⁽²³⁾. High scores in burden of care corresponded to a more negative perception of quality of life as well as low burden scores corresponded to high scores in perceived quality of life. That is, caring submits caregivers to several stressors⁽²⁴⁾, among which the negative perception of quality of life^(3,30-31), which can compromise their physical and psychological health^(27,32).

Caregivers who provided emotional support without burden had a better score in total quality of life, self-realization/pleasure and control/autonomy than those who did not exchange or did not receive emotional support, perhaps a favorable indication of the notion that solidarity provision and without rendering can benefit the well-being of older adults^(2,33). Only providing support is an indicator of risk to the welfare of seniors, especially when they are members of dysfunctional families or very lacking in resources, in such a way that older adults represent a financial source for them⁽²³⁾. In situations of crisis, these older people are more likely to suffer from maltreatment and abandonment than those living in families more favored in socioeconomic and affective terms⁽⁶⁾.

Study limitations

Other studies may better explain the trajectories of influence between the investigated variables, incorporating the detailing

of emotional support, seeking to know how many and who are the social partners of the caregivers in the family and whether they provide or deny emotional support. The ways in which emotional support is intertwined with instrumental, informative, and material supports, and the degree of desirability of emotional support would consist in other variables that could yield good explanations which we did not address in this study. Besides sex and age, it would be interesting to study the influence of socioeconomic status and the race of caregivers. More numerous and probabilistic samples would contribute to increase the generality of data, in addition to accompanying caregivers for longer periods, which could help clarify the relationships of the phenomena in question with the progression of dependence on care receivers and the progression of caregivers' ageing.

Contributions to the field of nursing, health, or public policies

Data obtained from this research contribute to the understanding of care in older adults and the relationships of the exchange of help within the family context. It opens room for consideration of the obligations of the State regarding the protection of families who provide care. To the field of nursing, it enables an opportunity to reflect on the best ways to organize the provision and management of support to senior caregivers, considering new mechanisms that promote quality of life and provide healthcare strategies.

CONCLUSION

Senior caregivers experience a reality that makes them susceptible to losses in objective and subjective quality of life. Personal and social resources evidenced in the relationship between perceived quality of life and sex, perceived burden due to the provision of care and the nature of the emotional support available in the family may help them cope with the difficulties of care and improve their own quality of life.

Senior female caregivers present higher levels of satisfaction with family support, perceive higher burden, worse quality of life, and less sense of control and autonomy. Families which presented senior caregivers more satisfied with the received emotional support have exchanges of emotional support of better quality, which weakens the feelings of burden and strengthens the perception of quality of life of caregivers.

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