# Influence of social support on the quality of life of family caregivers while caring for people with dependence\*

INFLUÊNCIA DO APOIO SOCIAL NA QUALIDADE DE VIDA DO CUIDADOR FAMILIAR DE PESSOAS COM DEPENDÊNCIA'

INFLUENCIA DEL APOYO SOCIAL EN LA CALIDAD DE VIDA DEL CUIDADOR FAMILIAR DE PERSONAS CON DEPENDENCIA

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## **ABSTRACT**

The objective of this study was to evaluate the Quality of Life (QOL) of family caregivers of handicapped people attended at home by Family Health Teams and the relationship with their social support. Sixty-six family caregivers were interviewed using the WHOQOL-bref for a QOL evaluation and Zarit Burden Interview for the burden. The Social Relations domain of the WHO-QOL-bref received the second best score within the domains of the instrument. During multiple linear regressions analysis, female caregivers, with low burden scores and who had received help from someone to perform the care, obtained the highest scores. Similarly, caregivers with partners had higher mean scores in the overall global assessment for QOL and health than those without partners. The results provide evidence of the influence of social support regarding Quality of Life and the burden perceived by family caregivers.

# **DESCRIPTORS**

Quality of life Caregivers Family Social support Family nursing

#### **RESUMO**

O objetivo deste estudo foi avaliar a qualidade de vida de cuidadores familiares de pessoas dependentes atendidas por equipes de Saúde da Família e a relação com o apoio social. Foram entrevistados 66 cuidadores, utilizando o WHOQOL-bref para avaliação da qualidade de vida, e Zarit Burden Interview para a sobrecarga. O domínio Relações Sociais do WHOQOL-bref obteve o segundo melhor escore. Na análise de regressão linear múltipla, cuidadores do sexo feminino com menores escores de sobrecarga e aqueles que recebiam ajuda de alguém para realizar o cuidado alcançaram os maiores escores. Da mesma forma, cuidadoras com companheiros apresentaram maior escore médio na avaliação global da qualidade de vida e saúde do que as sem companheiros. Os resultados fornecem indícios da influência da rede de apoio social na qualidade de vida e sobrecarga dos cuidadores familiares.

# **DESCRITORES**

Qualidade de vida Cuidadores Família Apoio social Enfermagem familiar

#### **RESUMEN**

El estudio objetivó evaluar la calidad de vida de cuidadores familiares de personas dependientes atendidas por equipos de Salud de la Familia y la relación con el apoyo social. Fueron entrevistados 66 cuidadores, utilizando el WHOQOL-bref para evaluación de calidad de vida y Zarit Burden Interview para la sobre varga. El dominio Relacionas Sociales del WHOQOL-bref obtuvo el segundo mejor puntaje. En el análisis de regresión linear múltiple, cuidadores de sexo femenino con menores puntajes de sobrecarga y recibiendo ayuda de alguien para efectuar los cuidados presentaron mayores puntajes medios en la evaluación global de la calidad de vida y salud que las que no tienen compañero. Los resultados brindan indicios de la influencia de la red de apoyo social en la calidad de vida y sobrecarga de los cuidadores familiares.

# **DESCRIPTORES**

Calidad de vida Cuidadores Familia Apoyo social Enfermería de la familia

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#### INTRODUCTION

Taking care of a dependent relative at home entails different physical, psychological and social changes for caregivers. One of the most affected aspects is the social network and support, due to the lack of opportunities for leisure activities, impossibility to go out to work and changes in family routines.

The terms social network, social support and social relations are often used as synonyms. Social network, however, refers to the group of people with whom the individual keeps contact or some kind of social bond and mainly involves quantitative aspects of social contacts<sup>(1)</sup>. Therefore, it is related to that person's structural and institutional dimension.

Social support, on the other hand, is a reciprocal process, regarding any information or support offered by people or groups whom we usually have contact with and

which entails a positive effect for support receivers or also for the providers. It refers to having someone to count on in difficult situations in order to receive, for example, material, emotional or affective help and, in addition, relates to finding oneself valued in the context of the groups one is part of<sup>(2)</sup>. Thus, it considers the functional or qualitative dimension of the social network.

The role of family caregiver can affect both caregivers' social network and social support. Many studies have revealed that the caregiver's main network comprises relatives and friends. It should be highlighted that many caregivers do not receive help from anyone<sup>(3)</sup> or have few people to count on in comparison with the number they considered part of their social network<sup>(4)</sup>.

Specialists consider that the social network entails positive and negative effects for individual health, as: a) the presence of family figures mitigates the reaction of alertness (greater safety); b) social relations contribute to give meaning to members' lives and c) the network provides daily feedback, monitoring perceived health alterations<sup>(5)</sup>.

Diseases can also affect this network, due to an interpersonal aversive effect (in case of stigmatizing conditions), restrictions to the subject's mobility (reducing opportunities for social contacts and causing isolation), weakness (limiting the subject's initiatives to activate the network), impossibility to produce reciprocal behaviors, in case of caregivers, and the little gratification resulting from care delivery to patients with chronic conditions<sup>(5)</sup>.

Although these restrictions seem to be particularly evident, in case of family caregivers, the positive and negative effects deriving from home care may not be so easily visible. Many caregivers deny facing difficulties to perform care<sup>(6)</sup>,

perhaps due to a feeling of self-acknowledgement for the role played, and demonstrate that there are positive aspects attached to care, including the feeling of polyvalence for taking care of the patient and other daily life tasks. These aspects contribute to a positive subjective assessment<sup>(7)</sup>

In recent years, some studies have been accomplished to assess the influence of the social network and support on caregivers' physical and mental health<sup>(4,8-9)</sup>. Among the results, however, great disagreement exists on the extent to which the caregiver's social network influences different health aspects.

If, on the one hand, caregivers are deprived of contact with much of their network due to care delivery to the family member, on the other, the internal circle of intimate relations can be strengthened or overlap with the intermediary or external circle that is impaired. In other words, taking care of a loved one can me more significant and rewarding than the social losses the burden and confinement entail

for the caregiver. It should be highlighted that family caregivers do not always take care of a *loved* one, which undoubtedly makes the situation less pleasant and more exhausting.

In this study, we selected socio-demographic variables related to social support, understood as any information, spoken or not, and/or material help offered by groups and/or people who know each other and which result in emotional effects and/or positive behaviors<sup>(10)</sup> and assess the association between objective characteristics of the caregiver's social support and their relation with subjective quality of life. We also attempt to identify the influence of social support and the burden level on subjective assessment of the Social Relations domain in the quality of life assessment questionnaire WHOQOL-bref.

# OBJECTIVES

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To investigate objective data related to social network and support and assess their association with caregivers' subjective assessment of different aspects of their life and burden.

### **METHOD**

A descriptive and cross-sectional study was carried out, involving 66 family caregivers to dependent patients registered and attended in the Family Health Strategy (FHS) between December/2006 and March/2007. The FHS Primary Care Units are located in the South of São Paulo City and administered under the Sub-Prefecture Cidade Ademar.

Inclusion criteria to select the subjects were: family caregivers aged 16 years or older, non-remunerated and delivering care for more than two months. Families in which the main caregiver could not be identified were excluded.



Approval was obtained from the Institutional Review Boards at the University of São Paulo School of Nursing (No 488-2005) and the São Paulo Municipal Health Secretary (No 041/06). After being informed about the research aims, participants signed the Informed Consent Term. Funding for this research was obtained from the São Paulo Research Foundation (Process No 2007/00532-1).

To measure the caregivers' burden, the *Zarit Burden Interview* (ZBI)<sup>(11)</sup> was used, with 22 items that assess the caregiver-patient relation, health status, psychological wellbeing, finance and social life. The total score ranges from 0 to 88. The higher the score, the greater the burden.

The questionnaire used to assess the caregivers' QoL, the WHOQOL-bref<sup>(12)</sup>, contains 26 questions, two of which are general (general quality of life and satisfaction with health) and 24 addressing the Physical, Psychological, Social Relations and Environment domains. The two general questions are calculated jointly to produce one single score, independently of domain scores, called the Overall Quality of Life Index (OQLI).

In a similar study<sup>(13)</sup>, most correlation coefficients between socio-demographic and health characteristics and WHOQOL-bref total and domain scores exceeded 0.35. Based on this finding and assuming a 5% type I error and 80% power, it was estimated that at least 62 caregivers would be necessary. Data were treated using Statistical Package for the Social Sciences software, version 12.0.

To analyze the association between family caregivers' QoL and social support characteristics, the mean OQLI and domain scores were compared.

The Kolmogorov-Smirnov test was used to assess the variables' adherence to normal distribution, some of which did not present normal distribution. Non-parametrical tests were used, mainly due to the nature of the variables (scores).

For the qualitative variables, the Mann-Whitney test for differences in mean ranks was used for two scores and the Kruskal-Wallis test for three or more scores. In those situations, Tukey's multiple comparison test was also applied, with a view to identifying statistically significant differences between the groups.

To assess the correlation between the caregiver and patient's quantitative variables and the caregiver's QoL, Spearman's correlation coefficient was used.

Finally, a multiple linear regression model was estimated, using the Social Relations domain of the WHOQOL-bref as the dependent variable and the social support characteristics and burden score as independent variables. The Social Relations domain of the WHOQOL-bref covers three questions, related to the satisfaction level with sexual activity, personal relations and support (social support).

For the multiple modeling process, those variables with p<0.20 were chosen. The stepwise forward selection

process was used and the independent variable continued in the multiple model when p<0.05. Significance for the study was set at 5%.

#### **RESULTS**

Most caregivers were female (83.3%), with a mean age of 50.5 years (sd=14.8), generally daughters (37.9%) or wives (24.2%), married (62.2%), housewives (43.9%) and mentioning no sexual activity (60.6%). On average, they lived with 3.7 people per home, ranging from two to eight people. The most mentioned social activities were related to religion (39.0%) and visits to family members and friends (14.2%), but 35.1% indicated no social activity. The type of support they most cited was informal help from relatives (57.8%), followed by 26.8% who said they do not receive help from anyone.

Table 1 presents the mean domain scores, calculated on a scale from 0 to 100, according to WHOQOL-group orientations. The Physical and Social Relations domains showed the highest scores (66.7 and 60.9, respectively), while the Environment domain showed the lowest score (52.5).

**Table 1** - Descriptive statistics of Overall Quality of Life Index and WHOQOL-bref domains - Family Health Strategy - São Paulo - 2007

Domains	Mean (sd)	Min-max	Median	Cronbach's alpha
OQLI	54,6 (21,4)	0,0 - 87,5	62,5	0,58
Physical	66,7 (17,8)	21,4 – 96,4	67,9	0,82
Psicológico	57,8 (14,8)	25,0 - 87,5	58,3	0,74
Social Relations	60,9 (13,6)	25,0 – 100,0	58,3	0,49
Environment	52,5 (9,4)	31,3 – 75,0	53,1	0,45

Table 1 reveals that instrument reliability, assessed through Cronbach's alpha, showed a good internal consistency rate in the Physical and Psychological domains (0.82 and 0.74, respectively) and a low internal consistency rate in the Social Relations and Environment domains (0.49 and 0.45, respectively). The low alpha rates in this case seem to indicate heterogeneity among sample members, instead of the instrument's lack of coherence.

Scores on the Zarit Burden Interview ranged from 0 to 67, with a mean 32.1 (sd=14.7) and median 31.0, indicating that the caregivers under analysis did not mention high burden levels.

In the Social Relations domain, when asked whether they were satisfied with their personal relations, 75.8% of caregivers reported that they were satisfied or very dissatisfied. Only two mentioned being dissatisfied or very dissatisfied. Regarding sexual life, most answered being neither satisfied nor dissatisfied (68.2%). Among the 66 caregivers, 25 (37.9%) indicated being neither satisfied nor dissatisfied with the support they received from friends or relatives and 31 (47.0%), satisfied or very satisfied.



The mean domain and OQLI scores were compared with the caregiver's qualitative variables regarding social support: marital status, level of parenthood, religious activity, help received, sexual activity.

Among caregivers with and without partners, a statistically significant difference in mean OQLI was found. Caregivers with partners obtained a higher mean score than those without partners (p=0.037).

When comparing caregivers' mean quality of life scores according to the level of parenthood, a significant difference was observed in the Environment domain only. Caregivers who were wives, daughters or mothers showed a better QoL in the Environment domain than others with different levels of parenthood (54.3x53.5; p=0.009). No statistically significant differences were observed among wives, daughters and mothers and caregivers who were husbands, sons or fathers.

Caregivers who obtained some type of help scored worse means in the Physical Domain (73.5x64.0; p=0.050), although with a significant marginal value, and better scores in the Social Relations domain (55.3x63.1; p=0.038), with statistical significance.

Caregivers who mentioned sexual activities obtained higher mean scores, with statistical significance (p=0.017; p=0.001; p=0.006, respectively), in OQLI and Physical and Social domains. These caregivers also displayed higher scores in the Psychological domain.

Regarding the quantitative variable, the correlation was assessed between the number of people living at the caregiver's home and his/her burden score on the one hand and the caregiver's QoL on the other. In the Social Relations domain, the number of people living at the home showed a statistically significant correlation (r = 0.30; p = 0.014) and, the higher the number of people living at the home, the higher the score in that domain.

The Zarit Burden Interview also showed an inversely proportional statistically significant correlation (r = -0.26; p=0.033), that is, the higher the burden, the lower the mean *Social Relations* score.

Table 2 presents the final multiple linear regression model. The caregiver's age only continued to adjust the model.

**Table 2** - Final multiple linear regression model for the Social Relations Domain - Family health Strategy - São Paulo - 2007

Variable	β regression coefficient	P
Zarit	-0,289	0,007
Receives help from someone	+6,689	0,053
Sexual activity of female caregiver	+8,192	0,051
Patient age	-0,089	0,198

adjusted  $r^2 = 0.19$ ; p (model) < 0.001

It was observed that, for each point on the Zarit, on average, an 0.289 decrease occurred in the Social Relations

Domain. On average, caregivers who receive help from someone score 6.689 points more in this domain, while female caregivers score 8.192 points more.

#### DISCUSSION

Caregivers who indicate they receive some informal support scored better in the Social Relations domain, with statistically significant differences, and worse in the Physical domain.

In the Physical domain, there seems to be a case of reverse causality, that is, it is not because they receive help from someone that caregivers score worse in the domain. Instead, it is because they score worse in this domain that they receive help from somebody. The most mentioned help came from relatives themselves. Hence, one can infer that people with more physical problems needed more help or even more constant alternations in patient care.

In the Social Relations domain, which assesses satisfaction with interpersonal relations and support from friends and relatives, the fact that they receive help from someone indicated greater satisfaction with regard to these issues.

Informal support has been defined as

care and attention altruistically delivered to people with some level of disability or dependence, fundamentally by relatives, but also by other agents and distinct formalized care service networks<sup>(14)</sup>.

Many studies have shown that the main support network is informal<sup>(14)</sup> and that many caregivers indicate they do not receive help<sup>(7,15)</sup>, in line with the present findings (26.8%). Caregivers need help from other relatives to alternate in care as well as orientations from the health team to deal with specific aspects of the patient's illness or dependence level. Services and trained professionals to support caregivers to cope with their difficulties have shown to be quite favorable means to strengthen them and decrease the care burden. Experiences with caregiver groups appoint the use of strategies with a problematizing approach, based on experienced situations, and indicate good results, based on the planning of coping strategies shared with the group, granting caregivers motivation as well as valuation<sup>(16)</sup>.

The increased burden was associated with a decreased mean score in the Social Relations domain. In a study that involved caregivers to elderly patients with chronic illnesses, lack of support from other relatives was indicated as one of the main causes of using the emotion instead of problem-centered coping strategy. This means that caregivers prefer to face their problems not by solving them objectively, but by trying to mitigate them, mainly through religion and renunciation<sup>(17)</sup>.

Regarding sexual activities, female caregivers showed higher mean scores in the Social Relations domain than



male caregivers. As reported by different authors and proven in scientific research<sup>(6-7)</sup>, women serve as the main family caregivers for historical and cultural reasons. Men who deliver care more probably do this due to a lack of option, because they do not have close relatives or because these are distanced. That would explain their higher level of dissatisfaction with their social relations.

In a study carried out in Russia<sup>(18)</sup>, women showed lower mean scores on *satisfaction with health* (question 2) and in the Physical domain, and also showed to be significantly more stressed than male caregivers.

In a qualitative research that investigated male experience in care delivery to a relative with Alzheimer<sup>(19)</sup>, a positive view of the caregiver was found behind negative feelings, questioning the supremacy of the *burden* concept as a predominant aspect of care.

Another author<sup>(7)</sup>, after observing daily care practice at patients' homes, believes that the quality of care delivered by men is no worse than by women, as men also showed concern with good care and demonstrated being equally (or more) considerate and concerned than female caregivers.

Caregivers with partners showed higher mean OQLI scores than those without partners. The fact of having a partner seems to represent potential strengthening, indicating good relations with these partners.

The level of parenthood showed a higher mean score in the Environment domain among wives, daughters and mothers than with other relatives (except for husbands, sons and fathers). In the other domains, no differences were observed.

In the study accomplished in Russia<sup>(18)</sup>, scores in all domains except for Environment were significantly lower among daughters and wives than among other relativescaregivers.

The close parenthood relation (*nuclear family*) showed a statistically significant positive correlation with caregiver burden in a study that involved caregivers to elderly dementia patients<sup>(20)</sup>. The history of the relationship between patient and caregivers should also be taken into account, as well as personal coping resources.

When present, sexual activity increased mean OQLI and scores in the Physical and Social Relations domains.

Again, this may be a reverse causality relation, that is, it is not because they were sexually active that caregivers scored better in these domains, but because better conditions in these domains made them sexually active. One study<sup>(15)</sup> found that care affects caregivers' sexual activity. There are no detailed studies on the theme that permit discussing these data in further depth.

A positive correlation was found between the number of people living in the same home and the Social Relations domain. This variable also showed a statistically significant positive correlation in another study<sup>(21)</sup>, but with regard to the Physical domain. The number of people living in the same home also seem to entail a better support network, as there are more close people who can help and alternate in care, although that still does not guarantee that they will receive help.

#### CONCLUSION

There are some limitations to this study, as the collected data are part of an original research on caregiver QoL, in which social support was a focus secondary to primary data collection. This limited methodological depth of the social network and support concept. The data, however, evidenced important aspects for the sake of comparison with other studies, besides contributing to the production of literature on the theme, which remains scarce in our midst.

In Brazil, one of the most used instruments for social support assessment, the Medical Outcomes Study (MOS) was translated and validated<sup>(22-23)</sup> for employees from a public university in Rio de Janeiro. The use of this instrument, validated for caregivers, can be very useful to better explore the concept and accomplish future comparative studies.

It should be highlighted that, although this study did not cover all variables described as part of social support, and mainly those related to quantitative social network assessment, some related important indicators were addressed, attempting to associate them with subjective data on satisfaction with social relations, indicating that caregivers who are less satisfied with their social relations present higher perceived burden levels. Research is needed to indicate the influence of social network and support on caregiver health, so as to identify factors of exhaustion that support health promotion and prevention action planning for caregivers followed by Family Health Teams.

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