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Association between social support and the profiles of family caregivers of patients with disability and dependence*

ASSOCIAÇÃO ENTRE O APOIO SOCIAL E O PERFIL DE CUIDADORES FAMILIARES DE PACIENTES COM INCAPACIDADES E DEPENDÊNCIA

ASOCIACIÓN ENTRE EL APOYO SOCIAL Y EL PERFIL DE LOS CUIDADORES FAMILIARES DE PACIENTES CON DISCAPACIDAD Y DEPENDENCIA

Cintia Hitomi Yamashita¹, Fernanda Amendola², Jaqueline Correia Gaspar³, Márcia Regina Martins Alvarenga⁴, Maria Amélia de Campos Oliveira⁵

ABSTRACT

This is a descriptive cross-sectional study that analyzes the association between dimensions of social support and the profiles of family caregivers. The following instruments were used to interview 110 caregivers: a socio-demographic questionnaire, the Social Network Index, the Medical Outcomes Study, and the Barthel Index. The Mann-Whitney and Kruskal-Wallis tests were used to compare dimensions of social support and the qualitative variables as well as to determine the Spearman correlation for the quantitative variables. Caregivers who could not read or had never studied showed better perception of social support in all dimensions except the affective. In the positive interaction dimension, groups who had a partner and denied being overloaded showed a higher average than others. In addition, the number of family members and friends correlated with all dimensions of social support. Thus, the results indicate that one's social network is important for the perception of support.

DESCRIPTORS

Family
Caregivers
Social support
Home nursing

RESUMO

Estudo descritivo, transversal, cujo objetivo foi analisar a associação entre as dimensões de apoio social e o perfil de cuidadores familiares de pacientes com dependência. Entrevistaram-se 110 cuidadores, utilizando os seguintes instrumentos: questionário de caracterização sociodemográfica, *Social Network Index*, *Medical Outcomes Study* e Índice de Barthel. Os testes U de Mann-Whitney e Kruskal-Wallis foram usados para comparar as dimensões de apoio social e as variáveis qualitativas, e a correlação de Spearman para as variáveis quantitativas. Cuidadores que não sabiam ler nunca haviam estudado apresentaram melhor percepção de apoio social em todas as dimensões, exceto na afetiva. Na dimensão interação positiva, aqueles que possuíam companheiro e negaram sobrecarga apresentaram média superior a dos demais grupos. O número de familiares e amigos apresentou correlação com todas as dimensões de apoio social. Os resultados indicam que a rede social é importante para a percepção de apoio.

DESCRITORES

Família
Cuidadores
Apoio social
Assistência domiciliar

RESUMEN

Estudio descriptivo, transversal, cuyo objetivo fue analizar la asociación entre las dimensiones de apoyo social y el perfil de los cuidadores familiares de pacientes con dependencia. Se entrevistaron a 110 cuidadores utilizando los siguientes instrumentos: cuestionario de caracterización sociodemográfica, *Social Network Index*, *Medical Outcomes Study* y el Índice de Barthel. Se utilizaron los test de Mann-Whitney y Kruskal-Wallis para comparar las dimensiones del apoyo social con las variables cualitativas y la correlación de Spearman, para las variables cuantitativas. Los cuidadores que no sabían leer y nunca habían estudiado mostraron una mejor percepción del apoyo social en todas las dimensiones, excepto la afectiva. En la dimensión de interacción positiva, aquellos que tenían pareja y negaron tener sobrecarga mostraron un promedio más alto que los otros grupos y el número de familiares y amigos se correlacionó con todas las dimensiones de apoyo social. Los resultados mostraron que la red social es importante para la percepción de apoyo.

DESCRIPTORES

Familia
Cuidadores
Apoio social
Atención domiciliar de salud

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INTRODUCTION

As a result of demographic and epidemiological transitions of the population, there has been a tangible increase in the number of people with disabilities and dependency in Brazil. External causes, among which traffic accidents are at the forefront, are the major cause of disability among young adults, whereas falling is the most significant cause among the elderly⁽¹⁾. In many cases, the individual becomes incapable of performing regular activities of daily living (ADLs) without assistance, needing a caregiver to provide assistance at home⁽²⁾.

Law no. 10.424, issued on April 15, 2002, established home care as a form of care within the National Health System (SUS – *Sistema Único de Saúde*)⁽³⁾. In November 2011, the program Better at Home (*Melhor em Casa*) was launched to increase the range of home care, improve the quality of assistance, and enhance the management of the public health system⁽³⁾.

Home care has become an alternative to hospitalization, as it enables a reduction of both the inpatient time and the demand for hospital assistance, thus reducing the cost of care. Furthermore, it enables the healthcare team to become acquainted with the actual social situation of the patients and their families, taking into account all aspects which can influence patients' recovery in order to implement interventions based on families' health needs⁽³⁾.

In this form of care, the caregiver is central, serving as the person of reference for the healthcare team and as the person in charge of following the treatment plan⁽⁴⁾. Tending to an individual in a household can lead to changes in the family's routine and have significant impacts on a caregiver's life, such as social isolation, overload, and health problems. Full-time care, in many cases without the possibility of replacement or assistance, results in caregivers distancing themselves from affective and professional relationships as well as in diminishing their social network and opportunities for socialization and leisure⁽⁵⁾.

Studies have indicated the influence of social networks in people's lives: mortality rates are higher in groups with minimal social networks, whereas in groups with medium and large social networks, there are no statistically significant influences⁽⁶⁻⁷⁾. In addition, social relationships contribute to attributing a meaning to life and increasing the sense of security for the caregiver and the patient. Social support generates positive effects not only for those who receive it but also for those who provide it⁽⁸⁻⁹⁾.

Despite being synonymous in many cases, the terms *social network* and *social support* have distinct albeit interrelated meanings. Social network is defined as a group of people with whom an individual maintains contact or a social connection⁽¹⁰⁾. Social support, however, refers to the

qualitative aspect of the social network and relates to an individual's level of satisfaction with his/her relationships. It involves five dimensions: material support (financial assistance, provision of resources), emotional support (in the form of love, affection, respect, and empathy), affective support (physical demonstrations of love and affection), positive interaction support (availability of people with whom to have fun and relax), and information support (guidance, advice, and information)⁽¹¹⁾.

This study identified the social network and social support of caregivers who provide public home care. Moreover, it observed the existing associations among dimensions of social support and between family members' social and demographic characteristics as well as examined the caregiver's health.

METHOD

This was a cross-sectional study conducted using a quantitative approach at a Home Care Service (SAD – *Serviço de Assistência Domiciliária*) in the subprefecture of Cidade Ademar in São Paulo.

At the SAD in Cidade Ademar, patients are referred by the Basic Health Units (UBS – *Unidades Básicas de Saúde*) and included in the service program following an assessment by the healthcare team. To be eligible for treatment, patients must reside within the area covered by the SAD. In addition, they must be totally dependent on others for ADLs and/or require specialized care such as treatment of pressure ulcers, oxygen therapy, and use of probes.

The group comprised male and female caregivers of patients being treated by the service. Non-probability sampling was adopted for convenience. The criteria for

inclusion in the sampling consisted of having performed the role of caregiver for more than three months without financial compensation for the rendered services. Families in which care was equally shared among family members such that the primary caregiver could not be identified were excluded.

Data were collected from March to November 2011, a prolonged time frame due to a condition stipulated by the SAD, which required visiting the patient with a health professional before data collection to introduce the study to the caregiver. Following this presentation, scheduled interviews during which the public service professionals were not present were held with caregivers at their homes.

In June 2011, there were 229 patients and 218 caregivers registered with the SAD. From the total registered caregivers, 132 were visited, and 22 (16.7%) of these were excluded: ten who were professionals hired by the family; three who were no longer caregivers due to the patient having passed away; one who was a friend of the family;

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and one who, following three attempts, was not found. In addition, an assessment of patients by means of the Barthel Index indicated that four were completely independent with regard to ADLs, leading to the exclusion of their caregivers, thus resulting in a total sampling group of 110 family caregivers. From this sample, seven caregivers rendered services to more than one family member: six cared for two family members and one cared for three family members. This presented a total of 118 patients.

A questionnaire was used to determine socio-demographic characteristics; it included variables related to the patient (*gender, age, diagnosed health problems, and level of dependency*) and to the caregiver (*gender, age, marital status, relationship with the patient, average amount of time spent caring, academic background, total family income and per capita income, health problems, physical pain; overload in terms of care, social network, and social support*).

To assess the patient's level of dependency, the Barthel Index was used, an instrument which was validated in Brazil in 2010 and indicated excellent reliability and good results for converging and discriminating criteria validation⁽¹²⁾. It is composed of ten items and scores in accordance with the patient's performance of ADLs. Scores from 0 to 20 indicate total dependency, 21 to 60 severe dependency, 61 to 90 moderate dependency, 91 to 99 low dependency, and 100 independency⁽¹³⁾.

To assess the social network, the Social Network Index [Remark 1] was used, which was validated in Brazil in 2003 and comprises five issues for which caregivers must report the number of family members and friends they trust and with whom they can discuss almost anything. Furthermore, they must report their participation in activities outside the household (leisure activities, activities in associations, and voluntary work)⁽¹⁴⁾.

The perception of social support was assessed by means of the Medical Outcomes Study, validated in Brazil in 2005. Comprising 19 items, the study encompasses the five dimensions of social support (material, emotional, affective, positive interaction, and information). The scale for answers ranges from one (never) to five (always), and the score is obtained using the following calculation: [(total amount of points obtained in the dimension / maximum points for the dimension) × 100]⁽¹⁵⁾. The total score varies between 20 and 100 and is divided into terciles for a social support analysis⁽¹⁶⁾. The first tercile comprises the lowest scores, with values ranging from 20 to 46; the second tercile encompasses scores between 47 and 73, which indicate intermediate scores of social support; and the third tercile reflects the high scores, which range from 74 to 100.

Upon performing the Kolmogorov-Smirnov test, it was observed that the dimensions did not present a normal distribution; therefore, non-parametric tests were used. To compare the average scores of each dimension as well as the qualitative variables, the Mann-Whitney U-Test was

used for variables with two categories. For variables with three or more categories, the Kruskal-Wallis test was used, and if a significant statistical difference emerged, multiple comparisons were calculated by means of the Tukey test. The Spearman correlation coefficient was calculated for quantitative variables. Results were considered statistically significant when $p \leq 0.05$.

The study was approved by the Ethics Committee in Research of the School of Nursing of the *Universidade de São Paulo* (Case 934/2010) and by the Municipal Health Secretary of São Paulo (Instruction 454/10). Caregivers were informed about the objectives of the study and the confidentiality of data. The interviews were conducted only following the reading and signing of a consent form.

RESULTS

The majority of patients were female (56.8%), between 3 and 100 years of age and with an average age of 67.2 (SD=23.3). In addition, diseases of the circulatory system were predominant (55.1%). The level of dependency, assessed by the Barthel Index, showed that the majority (66.1%) were totally dependent on others for ADLs, followed by those classified within the severe dependency (20.3%), moderate dependency (11.0%), and low dependency (2.6%) ranges.

The majority of caregivers were female (90.0%), with an average age of 52.3 (SD=14.0), married (60.0%), and daughters of the dependent family member (42.7%). Most of them were capable of reading (90.0%) and writing (85.4%); however, 36.6% of them had not completed middle school. These results are displayed in Table 1.

The majority (69.1%) demonstrated some type of health problems, some physical pain (66.4%), and a feeling of overload (69.1%) due to the care they provided. The average amount of time spent caring was 7.7 years (SD=8.8); the minimum was three months and the maximum was 52 years. The average total family income of caregivers was R\$ 1,348.70 (SD=863.10; median=1,120.00), equivalent to 2.5 minimum-wage salaries (the minimum-wage salary at the time of data collection was R\$ 545.00). The per capita income of the families was R\$ 391.50 (SD=276.10; median=333.30), corresponding to 0.7 minimum-wage salaries.

With regard to the social network, the number of family members on whom the caregivers could depend and with whom they could discuss almost anything varied from 0 to 50, with an average of 4.4 people (SD=6.1; median=2.5). The number of friends varied from 0 to 100, with the average being 3.6 (SD=10.2; median=1.0). A minority indicated that they participated in activities outside the household: 13 (11.8%) reported that they participated in sports or artistic activities in groups; 5 (4.5%) participated in meetings of associations of residents, unions, or political parties; and 8 (7.3%) performed unpaid volunteer work at non-governmental organizations for charity or otherwise.

Table 1 – Socio-demographic distribution of family caregivers of patients treated by the Home Care Service – São Paulo, SP, 2011.

Variable	N	%
Gender		
Female	99	90.0
Male	11	10.0
Marital status		
Married/Consensual union	66	60.0
Single	25	22.7
Widower	10	9.1
Separated/Divorced	9	8.2
Relationship with patient*		
Daughter/Son	47	42.7
Wife/Husband	27	24.5
Mother/Father	14	12.7
Sister/Brother	7	6.4
Granddaughter/Grandson	5	4.5
Other	17	15.4
Knows how to read		
Yes	99	90.0
No	11	10.0
Knows how to write		
Yes	94	85.5
No	13	11.8
Only their name	3	2.7
Educational background		
Incomplete lower/middle school	41	37.3
Complete middle school	18	16.3
Incomplete high school	8	7.3
Complete high school	29	26.4
Other	8	7.3
Never studied	6	5.4

*Some caregivers cared for two or more family members. Percentage was calculated with regard to the 110 family caregivers.

The reliability of the Medical Outcomes Study was analyzed through Cronbach's alpha, indicating an α of 0.90. The average score of the total social support was 77.5 (SD=19.9), with a predominance of high social support (59.1%). Caregivers indicated a greater perception of support in the affective dimension, with an average of 84.9. A good internal consistency was observed in all dimensions, with an α superior to 0.80 (Table 2).

Upon analyzing the association between the averages of dimensions of social support and the qualitative variables related to the caregiver (*gender; presence of partner; knowledge of reading; academic background; physical pain; feeling of overload; participation in activities such as sports/artistic activities, meetings, and volunteer work*), it was noticed that gender and participation in activities outside the household did not present a significant statistical difference between the averages of each category ($p>0.05$).

The variables *knows how to read* and *academic background* presented significant statistical differences between the averages of all dimensions except the affective. The positive interaction dimension presented the greatest number of variations, with significant statistical differences between the averages of the following variables: *presence of partner, knowledge of reading, academic background, and feeling of overload*. In the affective dimension, only the variable *physical pain* presented a statically significant difference between the groups (Table 3).

An analysis of the correlation between the scores of each dimension of social support and the quantitative variables suggested that the age of caregivers showed a statistically significant correlation only to the material dimension ($r=0.26$). The variables *number of family members* and *number of friends* with whom they feel comfortable discussing almost anything, which indicate caregivers' social network, presented a statistically significant correlation with all dimensions of social support, with positive coefficients varying from $r=0.20$ to $r=0.35$ (Table 4).

Table 2 – Descriptive analysis of the scores of dimensions of social support for family caregivers of patients with disabilities and dependency treated by the Home Care Service – São Paulo, SP, 2011.

Dimension	α	Average	SD*	Median	Minimum	Maximum
Material	0.90	79.5	22.3	80.0	20.0	100.0
Emotional	0.84	76.0	22.2	77.5	20.0	100.0
Information	0.86	74.9	25.3	96.7	20.0	100.0
Affective	0.88	84.9	19.7	80.0	26.6	100.0
Positive interaction	0.88	72.0	26.7	85.0	20.0	100.0
Total Score	0.90	77.5	19.8	80.8	27.3	100.0

*SD=Standard Deviation

Table 3 – Comparison between the average scores of dimensions of social support and the variables related to the caregivers of dependent patients treated by the Home Care Service – São Paulo, SP, 2011.

Variables	Dimension									
	Material		Emotional		Affective		Positive Interaction		Information	
	AV (SD)	p	AV (SD)	p	AV (SD)	p	AV (SD)	p	AV (SD)	p
Gender		0.230		0.681		0.773		0.615		0.496
Male	71.8 (23.6)		79.5 (20.0)		86.6 (19.1)		77.7 (22.9)		81.3 (18.4)	
Female	80.4 (22.2)		75.6 (22.5)		84.8 (19.9)		71.4 (27.2)		74.2 (25.9)	
Presence of partner		0.156		0.368		0.082		0.024*		0.268
No	76.4 (22.7)		73.4 (23.7)		80.4 (22.7)		64.6 (28.4)		70.8 (27.3)	
Yes	81.7 (22.0)		77.8 (21.1)		87.9 (17.0)		76.9 (24.6)		77.6 (23.7)	
Knowledge of reading		0.030*		0.006*		0.967		0.044*		0.026*
No	92.7 (14.8)		92.3 (14.7)		92.1 (13.6)		85.9 (22.4)		88.2 (21.7)	
Yes	78.1 (22.6)		74.2 (22.2)		84.9 (19.9)		70.5 (26.8)		73.4 (25.3)	
Academic background		0.030*		0.043*		0.124		0.050*		0.050*
Never studied	90.0 (20.0)		92.5 (18.4)		94.4 (10.7)		92.5 (12.5)		90.0 (24.5)	
Incomplete middle school	86.8 (18.3)		80.7 (22.4)		88.9 (18.9)		76.9 (25.1)		79.9 (24.8)	
Complete middle school/ Incomplete high school	73.3 (25.3)		70.9 (20.3)		79.7 (22.7)		66.5 (30.5)		67.9 (25.4)	
Complete high school	76.7 (21.3)		71.9 (21.9)		82.9 (17.0)		69.1 (23.7)		72.6 (25.4)	
Higher education (in) complete	65.0 (25.8)		71.2 (26.0)		81.6 (25.9)		60.0 (35.5)		69.4 (26.2)	
Physical pain		0.922		0.212		0.046*		0.460		0.342
No	79.6 (20.9)		72.9 (21.3)		80.1 (20.8)		69.7 (26.5)		72.4 (25.3)	
Yes	79.5 (23.2)		77.6 (22.6)		87.4 (18.9)		73.2 (26.9)		76.1 (25.3)	
Feeling of overload		0.149		0.073		0.228		0.022*		0.070
No	84.1 (19.4)		81.7 (20.1)		87.6 (18.9)		80.4 (23.2)		80.8 (23.5)	
Yes	77.4 (23.4)		73.4 (22.8)		83.7 (20.2)		68.1 (27.5)		72.1 (25.8)	
Participation in sports/artistic activities		0.717		0.992		0.781		0.414		0.959
No	80.2 (21.6)		76.2 (21.9)		85.0 (20.0)		71.3 (26.9)		75.1 (24.7)	
Yes	74.6 (27.9)		75.0 (25.6)		84.6 (18.9)		77.7 (25.7)		73.4 (30.3)	
Participation in meetings		0.717		0.884		0.099		0.594		0.409
No	79.3 (22.5)		75.9 (22.3)		84.3 (20.0)		71.7 (27.0)		75.3 (25.2)	
Yes	84.0 (20.4)		78.0 (23.1)		98.6 (2.9)		78.0 (21.9)		66.0 (27.9)	
Participation in volunteer work		0.606		0.352		0.810		0.297		0.379
No	79.3 (22.2)		75.7 (21.7)		85.3 (18.5)		71.5 (26.0)		74.5 (24.8)	
Yes	81.9 (25.3)		80.6 (29.6)		79.9 (33.2)		78.1 (36.2)		79.4 (32.5)	

*Statistically significant difference (p≤0.05).

Table 4 – Analysis of the correlation between the average scores of dimensions of social support and the variables of age, amount of time spent caring, and social network of family caregivers of patients treated by Home Care Service – São Paulo, SP, 2011.

Variable	Dimension				
	Material	Emotional	Affective	Positive Interaction	Information
	r(p)	r(p)	r(p)	r(p)	r(p)
Age	0.26 (0.005)*	0.07 (0.416)	0.06 (0.503)	-0.01 (0.886)	0.09 (0.343)
Amount of time spent caring	-0.15 (0.113)	-0.03 (0.701)	-0.12 (0.193)	-0.00 (0.988)	- 0.07 (0.431)
Number of family members	0.25 (0.007)*	0.33 (<0.001)*	0.33 (<0.001)*	0.37 (<0.001)*	0.35 (<0.001)*
Number of friends	0.20 (0.029)*	0.27 (0.004)*	0.24 (0.009)*	0.26 (0.005)*	0.23 (0.015)*

*Statistically significant difference (p≤0.05).

DISCUSSION

In this study, the profile of the patients resembled that found in other studies in which the majority of patients were female with an average age between 60 and 67 years and who had diseases of the circulatory system^(5, 17). Most were totally dependent on others for ADLs, resulting in greater physical effort and attention required from the caregiver. As the level of dependency of patients increases, so do the difficulties encountered by the caregivers, because of their lack of technical knowledge and skills as well as their physical limitations⁽¹⁸⁾.

The interviewed caregivers were mostly wives and daughters of the dependent family member and had performed the task for an average of six years, with the average age being 52 years. Similar data were found in other studies^(2, 19). The predominance of female caregivers reflects a social condition associated with gender, according to which caring is a task traditionally assigned to women⁽²⁰⁾.

Caregivers' social networks primarily comprised family members, and the majority did not participate in any activity outside the household. The maximum number of family members and friends was 50 and 100, respectively. Upon being interviewed, caregivers referred to *having a large family or having many friends*, indicating an extensive social network. On the other hand, many caregivers report a lack of social network as a result of not having someone with whom they could discuss almost anything.

In a study on caregivers' social networks and satisfaction with life, conducted with family caregivers of elderly people with and without dementia, the researchers observed that in both groups, the social network comprised family members, followed by friends and neighbors. In addition, they noticed that within the group of caregivers of elderly people with dementia, interviewees with a smaller social network were less satisfied with life⁽²¹⁾.

In the present study, caregivers presented an average score of social support that was above 77.0, reflecting high social support, with the score for the affective dimension being particularly high, averaging above 80.0. This indicates a greater perception of being able to depend on someone when the need for physical demonstrations of love and affection arises. Yet, the dimensions of positive interactions and information showed a lower average score, 72.0 and 74.9, respectively, indicating a lower perception on the part of caregivers in terms of having someone to depend on, to have fun or relax with, or from whom to obtain guidance, advice, or information.

Both social network and social support are important for the physical and mental health of individuals, because they serve as protectors and promoters of health and contribute to how individuals deal with illness, stress, and social vulnerability⁽²²⁾. Support may originate not only from family and friends but also from health and social services. When this support is precarious, caregivers experience greater exhaustion, which can increase as the patient's health deteriorates⁽²³⁾.

With regard to the association between the average scores of each dimension and the profile of the caregiver, it was noted that caregivers who were unable to read and had never studied presented statistically significant differences in all dimensions except the affective.

Caregivers with a better academic background have a greater perception of the restrictions on their social life due to the care they provide that clearly interfere with their quality of life⁽²⁴⁾. A study on the subjective impact of Alzheimer's disease in the lives of caregivers of the elderly noted that those with a greater academic background had a greater perception of feeling overloaded⁽²⁵⁾.

However, academic background can also influence the way in which caregivers acknowledge their role. A low educational level, greater social resources, social participation, and adequate health conditions can all positively contribute to the rendering of care for a dependent patient⁽²⁶⁾. In many situations, the lack of a job outside the household, due to a low academic background, leads caregivers to taking care of the patient and, despite difficulties, leads to satisfaction for being able to contribute to the treatment of a sick family member.

Caregivers who reported some physical pain presented a greater perception of social support in the affective dimension, and those who denied feeling overloaded as a result of the care they provided presented a superior average score in the positive interaction dimension than those who reported feeling overloaded, indicating a lower perception of being able to depend on someone to have fun and relax with.

It was also observed that caregivers who had partners had a greater perception of support in the positive interaction dimension, even though many of them were unable to perform activities outside the household. The presence of a partner frequently provides caregivers with a perception that they will have someone to depend on when the need to relax, be distracted, or engage in fun activities emerges.

In a study on the quality of life and social support of caregivers of dependent patients, the researchers noticed an inversely proportional correlation between the feeling of overload and the domain of social relationships – a correlation which indicates an individual's satisfaction regarding his/her interpersonal relationships and the support received from friends and family members. It was observed that the greater the feeling of overload for caregivers, the lower the average score in this domain. The study also indicated that the presence of a partner contributes to caregivers having a greater perception of quality of life, indicating that a husband or wife enables caregivers to deal with their situation, representing potential to strengthen caregivers⁽⁵⁾.

Another study, which compared the overload acknowledged by informal caregivers in Korea and the United States, identified a greater perception of overload among the Koreans, especially regarding their satisfaction with relationships, which might be related to their reduced social support and to their social network being restricted to their families.

Furthermore, a statistically significant ($p \leq 0.05$) correlation between caregivers' ages and perceptions of social support was noticed. In other words, the older the caregiver, the greater his/her perception of social support⁽²⁷⁾. In the present study, the variable *age* only presented a correlation to the material dimension of the social support questionnaire.

The number of family members and friends that are part of a caregiver's social network showed a statistically significant correlation with all dimensions of social support. In other words, the more family members and friends with whom caregivers feels comfortable and can discuss almost anything, the greater their perception of social support.

Social networks are important for minimizing stress, dealing with diseases, and strengthening a caregiver's self-esteem. Moreover, it supports families in dealing with the situation they are faced with⁽²⁸⁾. The distancing of caregivers from society and friends can lead to a greater feeling of overload in addition to causing several health problems and an increase in the number of comorbidities⁽²⁵⁾.

A systematic revision of the support programs for families and caregivers of patients with schizophrenia revealed that participation in such programs gives caregivers the opportunity to share experiences, thus improving their perception of social support and decreasing the feeling of overload owing to the support being received both at a social as well as an emotional level. Therefore, it is important to encourage the creation of such groups as well as families' participation in them, which might increase an individual's capacity of dealing with his/her situation and preserve the caregiver's mental health⁽²⁹⁾.

Despite the health problems and the considerable changes to caregivers' routines, it is important to highlight that in many cases, the care provided is regarded even by the patient as a task that dignifies him/her and brings satisfaction through a feeling of *mission accomplished*. These positive aspects must be stimulated, enabling them to lead to a better quality of life and health for caregivers, thus increasing caregivers' self-esteem⁽³⁰⁾.

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CONCLUSION

In this study, it was noted that the interviewed caregivers' social networks comprised primarily family members and that the majority of caregivers did not participate in any activity outside the household. The dimensions of social support reflected good rates of internal consistency and the average score of total social support was adequate, with an average above 77.0. All dimensions presented an average score above 74.0, reflecting high social support; the exception to this was the positive interaction dimension, which presented an average score of 72.0. Furthermore, it was noted that the greater the social network of caregivers, the greater their perception of social support in all dimensions. Caregivers who could not read or who had never studied presented a greater perception of social support, except for when they required physical demonstrations of love and affection.

Paying attention to the health of the family caregiver is very important to guarantee the proper care of the patient. The assistance planning provided by healthcare teams should consider the needs of caregivers to ensure that they do not fall ill themselves with numerous morbidities that might lead to them becoming disabled or dependent and in need of care.

In spite of many caregivers having presented a high perception of social support, they do not always require additional attention and assistance. The perception of the support they receive might be influenced by individual characteristics; each caregiver's level of resilience; and the objective conditions he/she is dealing with, such as the level of dependency of the patient and the amount of time spent caring for the patient. It is also important to consider the culture, values, and caregiver-patient relationship when interpreting the results and planning proper care for the patient and proper assistance for the caregiver.

Notwithstanding the limitations of the study, such as that it was conducted with a convenience sample and limited to the period of data collection because of the prolonged time spent on this stage, the proposed objectives were considered to have been achieved.

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