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Functional social support in family caregivers of elderly adults with severe dependence

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Functional social support in family caregivers of elderly adults with severe dependence

Objective. This work sought to determine functional social support in family caregivers of severely dependent elderly adults and its relationship with sociodemographic characteristics. **Methods.** This was a cross-sectional study. The Duke-UNC-11 Functional Social Support questionnaire was applied to 67 family caregivers from Family Healthcare Centers in Valdivia (Chile) in 2012. **Results.** Family caregivers perceived low levels of affective social support (49.3%) and of trust (98.5%); considering insufficient the information and advice they receive related, principally, to the scarce number of people who help, they need to establish communication to share their feelings and problems derived from the task of caring. These caregivers recognize the support from community healthcare centers. Functional social support is correlated to the following variables: number of people who live in the home, years of study, age of the caregiver, and number of people who help; with this last variable predicting the level of social support in its two dimensions. **Conclusion.** Family caregivers of severely dependent elderly adults perceive a level of

functional social support, especially in the dimension of trust. Community nurses must increase the number of home visits, evaluate the needs for social support perceived in caregivers, and teach coping strategies to mitigate problems that emerge in this work.

Key words: social support; frail elderly, caregivers; community health nursing.

Apoyo social funcional, en cuidadores familiares de adultos mayores con dependencia severa

Objetivo. Determinar el apoyo social funcional en cuidadores familiares de adultos mayores dependientes severos y su relación con características sociodemográficas. **Métodos.** Estudio transversal. Se aplicó el cuestionario de Apoyo Social Funcional Duke-UNC-11 a 67 cuidadores familiares de Centros Salud Familiar de Valdivia (Chile) en 2012. **Resultados.** Los cuidadores familiares perciben un bajo nivel de apoyo social afectivo (49.3%) y de confianza (98.5%), considerando insuficiente la información y consejo que reciben, relacionado principalmente con el escaso

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número de personas que ayudan, necesitan establecer comunicación para compartir sus sentimientos y problemas derivados de la labor de cuidar. Reconocen el apoyo de centros de salud comunitarios. El apoyo social funcional se correlaciona con las variables: número personas que viven en hogar, años de estudio, edad del cuidador y con número personas que ayudan; siendo esta última variable la que predice el nivel de apoyo social en sus dos dimensiones. **Conclusión.** Los cuidadores familiares de adultos mayores dependientes severos perciben un nivel de apoyo social funcional, especialmente en la dimensión de confianza. La enfermera comunitaria debe aumentar el número de visitas domiciliarias, evaluar las necesidades de apoyo social percibido en los cuidadores y enseñar estrategias de afrontamiento para mitigar los problemas que surjan en esta labor.

Palabras clave: apoyo social; anciano frágil; cuidadores; enfermería en salud comunitaria.

Apoio social funcional, em cuidadores familiares de adultos maiores com dependência severa

Objetivo. Determinar o apoio social funcional em cuidadores familiares de adultos maiores dependentes

severos e sua relação com características sócio-demográficas. **Métodos.** Estudo transversal. Se aplicou o questionário de Apoio Social Funcional Duke-UNC-11 a 67 cuidadores familiares de Centros Saúde Familiar de Valdivia (Chile) em 2012. **Resultados.** Os cuidadores familiares percebem um baixo nível de apoio social afetivo (49.3%) e de confiança (98.5%), considerando insuficiente a informação e conselho que recebem, relacionado principalmente com o escasso número de pessoas que ajudam, necessitam estabelecer comunicação para compartilhar seus sentimentos e problemas derivados do trabalho de cuidar. Reconhecem o apoio de centros de saúde comunitários. O apoio social funcional se correlaciona com as variáveis: número pessoas que vivem no lar, anos de estudo, idade do cuidador e com número pessoas que ajudam; sendo esta última variável a que prediz o nível de apoio social nas suas duas dimensões. **Conclusão.** Os cuidadores familiares de adultos maiores dependentes severos percebem um nível de apoio social funcional, especialmente na dimensão de confiança. A enfermeira comunitária deve aumentar o número de visitas domiciliárias, avaliar as necessidades de apoio social percebido nos cuidadores e ensinar estratégias de afrontamento para mitigar os problemas que surjam neste trabalho.

Palavras chave: apoio social; idoso fragilizado; cuidadores; enfermagem em saúde comunitária.

Introduction

Social support plays an important role in the health of people because it is a stress buffer, attenuating its assessment and diminishing the intensity of the response, thereby, individuals under vital stressing conditions who have social support will cope better, with healthcare acquiring much importance.¹ It is one of the fundamental resources to handle the stress process derived from caring for the elderly.² Elderly adults are mostly cared for in their homes, a task generally undertaken by relatives, who assume the responsibility of caring for their loved ones, support them in carrying out daily activities to compensate the existing dysfunction, and participate in decision making.³ Correlation has been shown between stress levels and the social support perceived by family caregivers of elderly adults with severe

dependence, becoming a prediction factor of the caregiver's overload.^{4,5} Relatives and caregivers of individuals with severe dependence belong to high-risk groups due to the high demand of the role and situations of stress they must endure, which have negative effects on their physical and psychological health and – principally – upon their social interaction. With the likelihood of producing weariness in the caregiver's role, it is important to have family support networks, friends, or resources from society.⁶

Social support is a diverse, multidimensional, and complex concept, which has been defined by many authors. That indicated by House¹ in 1981 becomes relevant by defining it as an interpersonal transaction that includes four support categories: emotional, related to tokens of love, trust, and

empathy; instrumental, concerning behaviors aimed at solving the problem of the receptor individual; informative, referring to gathering valid information to address the problem; evaluative, corresponding to relevant information for self-assessment, self-image, and social comparisons. Broadhead⁷ assigns greater importance to the quality of social support, calling it functional social support and identifying two factors; confidential or trust, through which people receive advice, guidance, and information, and affective support, which corresponds to belonging to groups, displays of affection, love, esteem, and empathy and sympathy; evaluating social support is as difficult as defining it, the author elaborated an instrument to measure it: "the Duke-UNC functional social support questionnaire", validated in 1988.

It has been demonstrated that emotional needs are perceived as having greater importance; caregivers must maintain relationships of trust to express and validate the motives of their emotional distress, need the family to recognize and appreciate their role as caregivers and to collaborate in care actions.⁸ They also require tangible help; the economic demands of prostrate elderly adults (PEA) are high (food, health, and housing) and economic resources to cover them are not always available. In relation to needs for instrumental-informative support, they consider that to diminish the burden a more equitable distribution should be made of the care activities, along with greater commitment and reciprocity among the members of the family; caregivers require information and guidance regarding basic needs, like feeding, prevention measures, and treatment.⁸

Studies conducted with informal caregivers determined that the social support perceived can best predict the caregiver's burden.^{4,9,10} In Chile, caregivers with slight levels of overburden showed low perceived social support, and were characterized for not receiving help from others and having incomplete basic schooling.⁹ In Taiwan, it was shown that the role of perceived social support and family functionality on caregiver burden is higher with lower levels of social

support.¹⁰ This study also revealed that informal social support is the most used by the caregivers who have difficulties using formal social support, given that they do not have time available to attend help groups or healthcare centers.^{9,11} According to the assessment of social support, caregivers may require different interventions to satisfy their individual needs.

Policies in favor of dependent elderly adults and of their caregivers, contained in the support plan for caregivers of people with severe dependence in Chile, establish potentiating social support and training, undoubtedly require designing and incorporating social and healthcare support.¹² Thus, the need emerges to dimension the perception of functional social support in family caregivers of severely dependent elderly adults and establish the relationship with sociodemographic characteristics, which contributes to satisfying their needs. Community nursing plays an important role in caring for the family caregiver, tending to increase wellbeing and avoid caregiver stress, evaluating the perception of social support, establishing support strategies, improving how to cope with problems, and increasing the number of visits to the home, among other measures.

Methods

This was a cross-sectional, correlational, and predictive research. The study population corresponded to the totality of family caregivers of 67 elderly adults with severe dependence, ascribed to the Prostrate Program of Community Healthcare Centers in the city of Valdivia, Chile. The study included family caregivers who had been performing the role of caregiver for more than three months, who accepted to participate, and who signed the informed consent. Data was gathered through a Sociodemographic Profile Survey and the Duke-UNC-11 Functional Social Support questionnaire, an instrument validated in Spain by Cuéllar and Dresch² with caregivers in 2012, evidencing acceptable internal consistency with strong correlations per item; reliability was good with a Cronbach's alpha of 0.87 for the Trust

Support Scale, 0.74 for the Affective Support Scale, and 0.89 in the general scale. It permits investigating social support in two dimensions: affective (displays of love, fondness, and empathy) and confidential (possibility of having people to communicate with). The scale has 11 items, the subscale of affective social support (questions 1, 3, 4, and 5) and of confidential social support or trust (questions 2, 6, 7, 8, 9, 10, and 11). Affective social support is considered high if at least 18 points are obtained and it is considered that at least 15 points are necessary for high confidential social support or trust; high global social support corresponds to a score above 32, bearing in mind the cutoff point indicated by Remor *et al.*¹³

Data was gathered by the research team through home visits to 100% of caregivers of elderly adults with severe dependence. The visit lasted one hour and the collection period comprised the months of August and September of 2012. Data analysis used descriptive, parametric and non-parametric statistics like the Fischer exact test for categorical correlation variables to analyze the relationships between continuous variables and simple linear regression to predict social support, bearing in mind independent sociodemographic variables. Only one prediction model was established with the independent variable of logarithm of number of people who help, given that it was the only variable presenting correlation with the global social, affective, and trust support. Linear regression assumptions of normality, specificity, influential data, and errors were proven. Most of the continuous variables were normally distributed (N° of people who live in the home, affective social support and trust, years of study, time in the role, and hours dedicated to caring), except for the variable of number of people who help in the caregiver role, which was normalized by applying the natural logarithm.

The analysis was supported in the Windows SPSS program, version 11.5. The variables used were: gender, age, relationship with the elderly adult, marital status, family income, supporting institutions or organizations, time in the caregiver role, hours per day dedicated to caring, number of

people who help in the caregiver role, number of years of study, level of caregiver overburden.

Regarding ethical implications, with the purpose of safeguarding the rights of those who participated, the study was subjected to the evaluation of the Ethics Committee for the Valdivia Healthcare Service, followed by a process of informed signed consent to respect the participant's decision capacity, thus, obtaining signed authorization from each of the caregivers.

Results

It was observed that family caregivers mostly corresponded to female gender (91%), daughters/sons (49.3%), mean age of 58.6 years, married (50.7%), with low income, dedicating 21 to 24 hours per day to care (46.3%) and 43.3% stated having spent from 1 to 5 years performing the role of caregiver. Few have people who help them (22%) and 29% have only one or two people helping them. It is worth mentioning that 92.5% reports support from healthcare institutions.

The average score of global social support was 34.0 ± 11.2 , with a minimum of 11 and a maximum of 55. The proportion of family caregivers who perceived high affective social support was 50.7%. Nevertheless, perception of trust social support presented a big difference with the prior, showing that practically all (66 caregivers) perceived it as low (98.5%).

The hypothesis of a difference between high affective social support (2.03 ± 1.82) and low affective social support (0.88 ± 1.08) in relation to the number of people helping in the care, resulted significant (Student's $t = 3.391$; $p = 0.002$), hence, it may be stated that people who are not helped in the caregiver role or are only helped by one person present low affective social support; for social support to be perceived as high, they need to receive help from at least two people. To study the correlation of the social support numerical variable with the variables of number of people who help and who live in the home, years of study and age of the caregiver, Pearson correlations

were carried out, which concluded the existence of a statistically significant correlation between global social support and number of people ($r: 0.51; p < 0.001$).

Upon entering the variable of number of people who help onto the first linear regression model, it explained 17.2% of the variability of the affective global social support (variance); when increasing the logarithm of number of people by 1%, it increases the score of affective social support by 0.05436 points (Table 1). In the second

model, the variable of number of people who help explains 27.6% of the variance of the variable of global social support of trust; upon increasing the logarithm of number of people by 1%, it increases the score of social support of trust by 0.05034 points (Table 2). Finally, the number of people explains by 25.5% the variability of the global social support scale, finding that if the logarithm of number of people is increased by 1%, it increases the global score in the Duke-UNC 11 scale by 0.1047 points (Table 3).

Table 1. Linear regression model: number of people who help and affective social support perceived

Model 1	Non-standardized coefficients		Standardized coefficients	t	Sig.
	B	Std. error	Beta	B	Std. error
(Constant)	16.333	0.969		16.856	<0.0001
logn°per	5.436	1.418	0.429	3.833	<0.0001

Predictor variables: (Constant), logn°per (Logarithm of the number of people); dependent variable: affective global social support

Table 2. Linear regression model: number of people who help and trust social support perceived

Model 2	Non-standardized coefficients		Standardized coefficients	t	Sig.
	B	Std. error	Beta	B	Std. error
(Constant)	13.495	0.672		20.077	<0.0001
logn°per	5.034	0.984	0.536	5.116	<0.0001

Predictor variables: (Constant), logn°per (Logarithm of the number of people); Dependent variable: social support of global trust

Table 3. Number of people who help and social support perceived

Model 3	Non-standardized coefficients		Standardized coefficients	t	Sig.
	B	Std. error	Beta	B	Std. error
(Constant)	29.828	1.472		20.257	<0.0001
logn°per	10.470	2.156	0.516	4.857	<0.0001

Predictor variables: (Constant), logn°per logn°per (Logarithm of the number of people); Dependent variable: Global social support

Discussion

Most of the people who collaborated in care work were members of the same family; this agrees with that stated by Chiu *et al.*,¹⁰ and

Zarit,³ given that the principal source of aid in caring for the elderly and individuals with some degree of dependence is informal and provided by the family. With respect to the help offered formally by institutions, these recognized the

Primary Healthcare Center as health services provider entity (92.5%), although they state that the frequency of visits is still far from being the necessary and half the caregivers (51%) indicated having few individuals (0-2) who collaborate with them in the work of caring. Chiu *et al.*,¹⁰ found that the use of formal support is generally low and that less than two thirds of the participants had an aide as an alternative. In light of this situation, caregivers tend to look for more help from the formal system,¹⁰ with the support provided by the staff in community healthcare centers gaining relevance and especially by nursing professionals, who are the most appropriate professionals in the healthcare system to offer support to caregivers,¹⁴ with care being the center of their work, through an interpersonal process that occurs during the help relationship established between nurses and individuals cared for. The development of the relationship and achievement of results depend upon the skills professionals have.¹⁵

The study showed that caregivers perceive global social support as high, as did the study by Pabón *et al.*,¹⁶ and Puerto¹⁷ in Colombian caregivers; however, Espinoza and Jofré⁹ reported low perception of social support in Chilean caregivers. Regarding their affective and trust dimensions, although affective social support is equitably distributed as high and low, confidential or trust social support presented a big difference; it was noted that practically all perceived it as low, that is, the family caregivers of elderly adults with severe dependence studied perceive that they have few individuals with whom they share their problems, that they receive little information, advice, and guidance in their work of caring, but – in turn – the quality of these scarce social relationships is good, that they value displays of affection, love, esteem, empathy, sympathy, and belonging to groups.² The results agree with that expressed by Pabón *et al.*,¹⁵ although the same scale was not used, and with Domínguez *et al.*,⁴ who mention that caregivers must maintain relationships of trust to express and validate the motives of their emotional distress, that they need for the family recognize and appreciate their role of caregivers and collaborate in care actions; there should be a more equitable distribution of the care activities, along with greater commitment and reciprocity

among family members; additionally, caregivers require information and guidance in relationship to basic needs, like feeding, prevention measures, and treatment.

A correlation was shown between social support and the variables of number of people who help, number of people who live in the home, years of study, and age of the caregiver; the correlation with the last two variables agrees with that found by Cuéllar and Dresch.² The linear regression analysis revealed that only the number of people who help in caring predicted significantly the level of social support in its two dimensions. That is, caregivers need to share the work, concerns, and care responsibilities with other family members and, thus, feel more supported. Correlation exists between affective social support and years of study of the caregivers,² so that people with less years of study perceive low affective social support, with these probably being the ones who require greater displays of affection and companionship from the healthcare staff, to establish an empathic relationship during home visits, and deliver recommendations and guidance to carry out their caregiver role safely and with quality.

The study concludes that family caregivers of severely dependent elderly adults perceive levels of functional social support under its dimension of trust. In other words, they consider as insufficient the information and advice they receive, which is principally correlated to the number of people who help, that is, they do not have enough people with whom they can communicate and share their feelings and problems derived from their work of caring. Family caregivers in Chile require having social support to better confront the role of caregiver and of effective intervention projects.¹¹ This experience of caring for a person at home may be simple and routine or extremely complex, especially when adequate support and guidance is not available, and it may have direct consequences on the health of the caregiver, leading to the so-called “burnout” or “caregiver syndrome”.¹² Caring for elderly individuals should not lie solely upon the families, it must be shared because the burden it provokes and the costs are quite high;³ more community and governmental institutions are needed to provide support to

these people and to the emergence of initiatives and projects of social development that increase community support networks.

Community nursing is confirmed as social support; it is necessary to increase the number of home visits, the needs for social support perceived in caregivers should be evaluated to generate actions aimed at delivering greater information, training, and teaching coping strategies to mitigate problems that emerge from the task of caring. The research contributes to visualizing a hardly studied aspect of family caregivers, which allows better confronting problems derived from the work of caring. It also views the importance of community nursing and proposes new challenges to the nursing discipline, given that models need to be formulated to emphasize on the environment, family group, community organizations, and social determinants of the health of caregivers. It is also important to delve into the needs and type of specific care required by family caregivers.

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