ORIGINAL ARTICLE

Family burden, social support and community health in caregivers of people with serious mental disorder*

Sobrecarga familiar, apoyo social y salud comunitaria en cuidadores de personas con trastorno mental grave

Sobrecarga familiar, apoio social e saúde comunitária em cuidadores de pessoas com transtorno mental grave

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ABSTRACT

Objective: To identify caregivers' level of burden and analyze the factors associated with family care in mental health. **Method:** A cross-sectional descriptive study was conducted between January and July 2016. A sample of caregivers from seven public institutions and an association of relatives and patients was evaluated by identifying their burden and the contributing factors for reduction of these levels through the Zarit Burden Inventory instrument. The study was conducted according to recommendations of the ethics committees of the participating institutions. **Results:** Participation of 107 caregivers. The main contributions refer that caregivers' active participation in associative dynamics, their attendance at psychoeducational activities and territorial connection to metropolitan areas with community resources decrease their level of burden. **Conclusion:** Community nursing is highly important and responsible for preventing levels of burden and increasing health levels. In addition, many proposals are formulated in order to favor social support networks by combining treatments and increasing public health programs in contact with the community.

DESCRIPTORS

Mental Disorders; Caregivers; Family; Social Support; Community Health Nursing.

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INTRODUCTION

Serious mental disorders (SMD) involve several psychiatric diagnoses of prolonged duration, which result in a high degree of physical, mental and social disability that reduces the quality of life of affected individuals and their family[1]. Authors[2] describe this type of illness as one of the predictors of risk of dependency, because it causes significant loss of autonomy and demands constant attention and assistance from another person for performing basic and instrumental activities of daily life. In many cases, this is the reason for the constant need for attention and support required by this group of people, since the illness causes disability. Together with the lack of resources, that fact means the care of people with a serious mental disorder falls fundamentally in the hands of relatives, who place themselves as caregivers and responsible for the well-being of family members[3]. In general, this care becomes responsibility of a single member of the family who, almost exclusively, is a woman.

Family caregivers' main function is helping to meet the dependent person's basic and instrumental needs of daily life[4]. The main caregivers are exposed to various challenges and stressors on a daily basis, which make them feel loss of personal control, resulting in physical and emotional alterations that can lead to the 'Caregiver syndrome'[5], and confrontation of a wide variety of risk factors that undermine their well-being. In addition, this pathology integrates a series of negative personal and work factors affecting informal caregivers' well-being, and giving rise to feelings of emotional exhaustion, depersonalization and even lack of personal fulfillment outside family care. This can be motivated by the loss of work and job opportunities experienced by people devoting most of their time to the care of a family member, which worsens the economic situation because of direct costs and decreased family productivity[6]. The consequences of caregivers' great investment of time are less leisure and social relations, the projection of frailties around them, and vulnerability in situations of isolation and social exclusion[7].

The care of people diagnosed with a serious mental disorder presupposes significant economic, mental and personal exhaustion of those responsible for their daily care[8]. The scientific literature emphasizes that caring for people with serious mental disorders is a heavier burden than caring for people with other types of diseases[9]. Some factors influencing this deterioration are the burden of caring for a sick person, lack of specific training for the provision of adequate care, and the preparation to face the intrinsic situations to that same care[10]. All these aspects together with the stigma and social rejection of the illness itself and its association with violence, support the false social belief that people suffering from SMD are aggressive because of the disease nature, hence this is considered a risk factor for the care. This issue is aggravated by the way it affects interpersonal relationships, the lack of balance between the illness cost and the belief that violent behaviors arise as a demonstration of disappointment, stigma and rejection towards the disorder itself[11].

Different authors have tried to evaluate the impact of sociodemographic and clinical variables both of people with serious mental disorders and their caregivers, and of the burden. The results of these studies associate a higher level of burden based on variables such as sex, kinship, having a paid job, the type of mental disorder, etc. On the other hand, these authors correlate positively the caregiver's age, years of disease evolution, number of hospital admissions and the degree of disability and dependency as variables associated with the main caregiver's burden[12-13]. Likewise, social support is a protective factor to face care situations because it positively affects caregivers' psychological well-being and quality of life. According to these studies, caregivers experience greater burden when the perceived social support is lower[14-16].

The models of care for dependent individuals have changed over time in order to adapt to the needs and respond to this group's psychic and psychosocial problems. In Spain, the social care model for dependent individuals has favored their maintenance in the family and social context, which makes families the main support and care axis. Nursing is an area responsible for providing health education and care in the best possible conditions, not only to sick people, but also to their caregivers by assessing the possible effects of this work on them[17]. In this sense, community nursing is key in the process of psychophysical rehabilitation, support and social integration of people with illnesses and their caregivers[18].

Thus, the need to investigate the situation of people who dedicate their lives to the care of another person[19-20]. Therefore, the objective of the present study has two aspects; on the one hand, to identify caregivers' level of burden, and on the other, to analyze the factors associated with family care in mental health.

METHOD

TYPE OF STUDY

A cross-sectional descriptive study was performed by using the survey data collection technique. The study period was between the months of January and July 2016 in seven mental health care institutions in the province of Valencia and in an association of relatives and patients.

PARTICIPANTS

The sample included 107 caregivers who met the following inclusion criteria: caregivers of people with SMD included in the public system of Mental Health care in the Valencian Community; residence in the province of Valencia; presence of kinship ties with the sick person; age over 18 years old; performance of the primary caregiver role by adopting functions of care and supervision in basic and/or instrumental activities of daily life of the person with mental health problems; absence of remuneration for the work they do; performance of care for more than six months.

Exclusion criteria were to reject participation in the study, caregivers of people with diagnoses not classified as serious mental disorders (intellectual disability, behavioral or psychomotor development alterations) or for not being correctly completed.

INSTRUMENTS

The chosen scale[21], the Zarit Burden Inventory/Zarit Test[22-23] was selected as the data collection instrument given the extensive scientific literature demonstrating its use and validity. The aim of this instrument is the assessment of the level of burden experienced by caregivers of people with dementia. However, it has also been used for caregivers of people with mental illness because of the similar chronicity of both groups[24-25]. The present study obtained a Cronbach's alpha coefficient of 0.92 for the scale.

In order to analyze the sociodemographic characteristics of caregivers and identify their relationship with the level of burden, the most present sociodemographic and clinical variables in the scientific literature and that according to authors were collected, which are related to the Caregiver syndrome, namely: 1) Variables describing the caregiver: age, sex, marital status, kinship with the sick person, having paid work, presence of chronic illness, active associationism, attendance at family psychoeducational talks and workshops, geographical environment and type of care received; and 2) Variables describing the person with SMD: age, sex, diagnosed illness, years of evolution of the disease, recognized degree of disability, and Mental Health care service they use.

PROCEDURE

Considering the Spanish Mental Health care system does not attend caregivers directly, data collection was performed in seven institutions of the public Mental Health care system in the Valencian Community, province of Valencia, and in an association of relatives and patients. The community nurses used the appointments attended by users with a family member for identifying, from their professional judgment, those who performed the role of main caregiver of the person served.

An individualized interview was arranged with each study participant. Assessments were performed by community nurses with training in application of instruments. When a high level of burden was detected, the interviewee was informed about the existence of psychoeducational programs for relatives.

This study was conducted in accordance with recommendations of the ethics committees of participating institutions and met the national (Law 14/2007, of July 3 of biomedical research) and international standards of ethics in research. The results of the present study are taken from a broader study approved by the Commission of Ethics and Experimental Research of the Faculty of Social Sciences of the Universidad de Valencia under reference number 000217/UV-Soc/2016. Subjects who met the inclusion criteria for this study received prior information and gave their written consent for voluntary participation according to the Declaration of Helsinki (2013). Participants were explained about the possibility of interrupting or withdrawing their participation at any time.

DATA ANALYSIS

For the quantitative analysis, firstly, was performed a descriptive study of data for identifying the characteristics of the caregiver and the person cared for based on sociodemographic and clinical variables. Then, it was identified the relationship between the variables defining the caregiver and the person cared for, and the burden. Contingency tables and chi-square tests were used to verify statistically significant differences between the burden and nominal variables. A correlation analysis was performed in order to demonstrate the existence of a linear relationship between the level of burden and quantitative variables. Finally, a linear regression with the variables that had a significant relationship with the level of burden in previous analyzes was performed in order to define a predictive model of burden. Nominal variables were recoded as Dummy variables (fictitious) so they could be incorporated into the regression model. The data analysis process was performed with use of the IBM SPSS Statistics 25 software. For all tests, $p<0.5$ was considered as the level of statistical significance.

RESULTS

CAREGIVERS' CHARACTERISTICS

The total sample of the study included 107 family caregivers of people with Serious Mental Disorder treated in seven public mental health care services and an association of relatives and patients (Table 1). Women represented 71% of the sample, and 29% were men, age was between 16 and 89 years old (M=60.67; SD=13.83). Regarding marital status, 51.4% were married, 15% were divorced, 21.5% were widowed and 12.1% were single. Among interviewees, 41.1% had a paid job, and the same percentage claimed to have a chronic disease. Most caregivers were fathers/mothers of the person with SMD (78.5%), 12.1% were siblings, 4.5% were children, 3.7% were spouses and 0.9% were uncles/aunts. Of caregivers participating in the study, 48.6% had previously assumed the care of another person. This same percentage had attended psychoeducational talks for relatives in Mental Health services and 15% participated in associative activities for relatives and people with SMD.

The subjects diagnosed with chronic mental disorders were mostly male (72.4%), aged 38.64 years (SD=12.63) on average (ranging between 16 and 80 years). All were diagnosed with some Serious Mental Disorder, and the following stood out: schizophrenia (63.6%), bipolar disorder (15.9%), personality disorders (10.3%), dysthymia and chronic depression (4.7%). Obsessive compulsive disorder and schizophrenia, dual pathology and schizoaffective disorder appeared in lower percentages with 1.9% each. Of these people, 50.5% had a Recognition of the Degree of Disability of 65% or higher, while 19.6% did not have it recognized or had not requested it. The mean number of years of evolution of the disease was 17.28 (SD=13.18) and ranged between three months and 56 years.

Table 1 – Sociodemographic characteristics of the caregiver and the person cared for –Valencia, Spain, 2016.

Caregivers' characteristics		Characteristics of the person cared for	
Age (years)	60.67±13.83	**Age (years)**	38.67±12.63
Sex (female)	71%	**Sex (Male)**	72%
Marital status			
Married	51.4%	**Diagnosis**	
Divorced	15.0%	Schizophrenia	63.6%
Widowed	21.5%	Bipolar disorder	15.9%
Single	12.1%	Depression	4.7%
Paid work (yes)	41.1%	OCD and Schizophrenia	1.9%
Chronic disease (yes)	41.1%	Personality disorder	10.3%
Relationship with the person		Dual pathology	1.9%
Spouse	3.7%	Schizoaffective disorder	1.9%
Brother/Sister	12.1%		
Father/Mother	78.5%	**R. of Degree of Disability**	
Son/Daughter	4.7%	Unrecognized	19.6%
Uncle/Aunt	0.9%	Less than 65%	29.9%
Active associationism (yes)	15%	65% or more	50.5%
Previous care of another family member (yes)	48.6%	Years of disease evolution	17.28±13.18
Psychoeducational (yes)	48.6%		

CAREGIVERS' BURDEN

After applying the Zarit scale, scores demonstrated that 73.8% of interviewed people obtained severe level of burden, 9.3% mild burden and 16.4% did not show levels of burden.

RELATIONSHIP BETWEEN THE LEVEL OF BURDEN AND SOCIODEMOGRAPHIC AND CLINICAL VARIABLES

The performance of chi-square tests resulted in factors in which there was no significant relationship of $p < 0.05$ with the level of burden, such as the caregiver's sociodemographic variables of sex, age, kinship, marital status, prior care; as well as sex, age, diagnosis, recognition of the Degree of Disability and years of evolution of the person cared for. Significant relationships were found between the level of burden and variables of family intervention type (p=.000), associationism (p=.000), psychoeducational activities (p=.000), and geographical environment (p=.021). Thus, caregivers who received continuous care in a mental health care service, actively participated in some association, who had attended psychoeducational talks for relatives or who lived in metropolitan areas, had a lower level of burden than the rest of participants. In the Pearson correlation analysis, no relationship was found between quantitative variables and the caregiver's level of burden.

LINEAR REGRESSION MODEL

When using variables that had a significant relationship with the caregiver's level of burden (type of care, associationism, psychoeducational and geographic environment), the linear regression analysis created two predictive models of burden (Tables 2-4):

The first model obtained significance p=.000, which explains non-attendance at psychoeducational talks as predictors of burden. Therefore, people who attended these activities had 19.4 less points of burden than those who never attended.

In the second model, active associationism and attendance at psychoeducational talks and activities were predictors of lower burden. Caregivers who had attended these programs (p=.00) had 15 less points of burden than those who never did. Likewise, caregivers who participated actively in an association (p=.001) had 14.4 less points of burden than those who never participated.

Table 2 – Summary of the regression model of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

Model	R	R squared	Adjusted R squared	Typical error of estimate
1	.558[a]	.312	.305	14.562
2	.619[b]	.383	.371	13.853

[a] Predictors: (Constant), Psychoeducational

[b] Predictors: (Constant), Psychoeducational, Associationism

Table 3 – Summary of the ANOVA of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

Modelo		Sum of squares	Df	Half quadratic	F	Sig.
1	Regression	10076.766	1	10076.766	47.520	.000[b]
	Residue	22265.440	105	212.052		
	Total	32342.206	106			
2	Regression	12383.435	2	6191.717	32.263	.000[c]
	Residue	19958.771	104	191.911		
	Total	32342.206	106			

[a] Dependent variable: Caregivers' burden

[b] Predictors: (Constant), Psychoeducational

[c] Predictors: (Constant), Psychoeducational, Associationism

Table 4 – Regression coefficients of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

Modelo	Unstandardized coefficients		Standardized coefficients	t	Sig.
	B	Typ. error	Beta	B	Typ. error
1 (Constant)	75,782	1,964		38,594	,000
Psychoeducational	-19,416	2,817	-,558	-6,893	,000
2 (Constant)	75,782	1,868		40,569	,000
Psychoeducational	-14,976	2,970	-,431	-5,043	,000
Associationism	-14,431	4,162	-,296	-3,467	,001

ª Dependent variable: Caregivers' burden

In accordance with the second model obtained in the linear regression, the burden of the caregiver of a person with Serious Mental Disorder would be represented by the following:

$$Y^1 = B_0 + B_1 X1 + B_2 X_2$$

BURDEN = 75.78 + (-14.976) Psychoeducational + (-14.431) Associationism

DISCUSSION

Serious mental disorders cause effects on biological, psychological and social spheres of people affected by these illnesses, which makes them a susceptible population for receiving long-term care and assistance[1-2]. Studies refer that people who care for another with a serious mental disorder have high levels of burden, which leads to a series of psychological, physical, economic and social factors that negatively affect the caregiver[8]. The present study identified variables associated with the burden perception of family caregivers of people with serious mental disorders.

The predominant profile is that of a woman, average age of 60 years, married, usually the mother of the person with mental disorder and who does not have a paid job. The present study shows the high feminization as one of the main characteristics defining formal and informal care, since 71% of people performing the care were women, which is in line with authors[2,19], and demonstrates how evident and necessary is an approach from the gender perspective in informal care.

The scientific literature defends the relationship between the sociodemographic variables of the caregiver and the person cared for and the illness characteristics with the level of burden and risk factors. The most prominent variables in the studies were the following: age, sex, professional occupation and educational level of the caregiver; as well as kinship, age, years of evolution of the illness and severity of symptoms of the person cared for[12-13]. However, given the high levels of burden found in most subjects under study, the statistical tests performed for quantitative data analysis indicate that in this sample, the burden had no significant relationship with any of these variables, as it depends on the social support (formal and informal) received by the caregiver.

Different studies[14-16] emphasize the importance of social support as a variable that moderates the negative impact of performing the caregiver's role, as a stress shock absorber. In the present study, professionals' access to continuous care, active associationism and attendance at psychoeducational talks and workshops for relatives determined caregivers' levels of burden. Likewise, and coinciding with those authors, these last two variables enabled the definition of a predictive model of burden in which people with higher social support showed lower levels of burden due to the care they perform.

Recent studies emphasized the high impact of the family as a channel of access to socialization[26]. This dimension favors the coping of members of the family nucleus[27] by highlighting among these, the social support provided by parents and the potential generated from the network of relationships. Our results address this issue, as social support possibilities were built from the immersion of both relatives and patients in community activities. We agree with other analyses[28] that confirm the importance of a stable affectivity in everyday family relationships as a key factor for social adjustment and reduction of emotional burden.

Studies[29] state that the lack of social support in stressful situations affects the stability of people in need of help and consequently, of those around them or with whom they live, and related the parents' commitment to psychoeducational activities with lower levels of stress. These data are in line with our results, since relatives who attended support activities for the illness, felt less burden.

In parallel, metropolitan areas have greater and better possibilities of integration for people with SMD and their relatives given the wider and diversified offer. Our results were close to those of other authors, because in rural areas or those with less supply, the level of burden and even mortality was higher compared to large cities or those with greater prosocial leisure opportunities, diversified offer or recreational areas. The community is highly important for the collective development and welfare, therefore, the creation of social support networks improves the quality of life and mental health of its members[30].

Nursing faces the challenge and opportunity of making care significant and a priority for mental health by ensuring continuity of care and formal support that can answer sensitively and effectively to the needs of subjects and their caregivers[17-18].

CONCLUSION

Serious mental disorders are considered a public health problem worldwide that mainly affects the quality of life of people who suffer from it and their families. People with serious mental disorders sometimes require assistance and support for the performance of daily tasks. The person who assumes the caregiver role has a number of risk factors associated with the burden arising from this work. For this reason, informal caregivers are a group at risk, because they find themselves in situations of vulnerability, isolation and, in certain cases, exclusion.

In the present study, were found limitations in relation to procedures of participant selection and final sampling. Community Nursing professionals were chosen because they are in regular contact with patients and their caregivers, objects of empirical study. Sampling was based on three filters, namely: companions of people attended at institutions that fulfilled the aforementioned inclusion criteria, who performed (according to professional judgment) the caregiver role, and agreed voluntarily to participate in the study. Two problems emerged from this selection: 1) the sample of caregivers was selected subjectively and based on discretion of the professional who provided the questionnaires, y 2) questionnaires were provided only for those who accompanied the diagnosed person to the institution, which prevented access to a larger sample.

However, the findings of this study highlight the benefits of creating associative spaces of community interaction and mutual support, and the importance of psychoeducational workshops in order to understand the illness processes, develop coping strategies and empower caregivers and the people cared for.

Therefore, public health authorities should focus their efforts on the social welfare of the population they serve. In this sense, it would be advisable to support the following proposals: Encourage coordinated support networks between the areas of health education, nursing and community services, and increase mental health programs in the community by jointly favoring combined treatments for the recovery and stability of people with SMD hence, releasing the burden of caregivers. The present study mentions the need to promote community-based day hospitals where users can go in order to receive health treatment and expand their social circuit; collaborate from the health administration in the creation of associations of relatives of people with SMD, of users, or mixed associations in order to boost the support networks available and generate new ones, and implement complementary programs to those articulated with public health; and connect rural areas or those of scarce resources with metropolitan geographic areas for the reduction of family burden levels of caregivers and for the recovery and psychiatric stabilization of people with illnesses.

Ultimately, the associationism, social support programs in the community and rehabilitative socio-health activities are protective factors, and the lack of structure for their development can generate risk practices for both caregivers and people with illnesses, and have impact on community deterioration.

RESUMEN

Objetivo: Identificar el nivel de sobrecarga de los cuidadores y analizar los factores asociados con el cuidado familiar en salud mental. **Método:** Se realizó un estudio descriptivo transversal realizado entre los meses de enero y julio del año 2016, en el que se evalúa una muestra de cuidadores de siete dispositivos públicos y una asociación de familiares y pacientes identificando la sobrecarga de los mismos y los factores que contribuyen a reducir estos niveles, a través del instrumento *Zarit Burden Inventory*. El estudio se llevó a cabo de acuerdo a las recomendaciones de los comités de ética de las instituciones participantes. **Resultados:** Participaron 107 cuidadores. Las principales aportaciones refieren que la participación activa del cuidador en dinámicas asociativas, la asistencia a actividades psicoeducativas y la vinculación territorial a áreas metropolitanas con recursos comunitarios, disminuyen el nivel de sobrecarga del cuidador. **Conclusión:** Finalmente, destaca la importancia y responsabilidad de la enfermería comunitaria a efectos de prevenir los niveles de sobrecarga e incrementar los de salud; además, se realizan una serie de propuestas en la línea de favorecer redes de apoyo social, combinar tratamientos e incrementar los programas de salud pública en contacto con la comunidad.

DESCRIPTORES

Trastornos Mentales; Cuidadores; Familia, Apoyo Social; Enfermería en Salud Comunitaria.

RESUMO

Objetivo: Identificar o nível de sobrecarga dos cuidadores e analisar os fatores associados ao cuidado familiar em saúde mental. **Método:** Foi realizado um estudo descritivo transversal entre os meses de janeiro e julho do ano 2016, no qual foi avaliada uma amostra de cuidadores de sete dispositivos públicos e uma associação de familiares e pacientes identificando a sobrecarga dos mesmos e os fatores que contribuem para reduzir esses níveis, por meio do instrumento *Zarit Burden Inventory*. O estudo foi realizado de acordo com as recomendações dos comitês de ética das instituições participantes. **Resultados:** Participaram 107 cuidadores. As principais contribuições relatam que a participação ativa do cuidador em dinâmicas associativas, o comparecimento a atividades psicoeducacionais e o vínculo territorial a áreas metropolitanas com recursos comunitários diminuem o nível de sobrecarga do cuidador. **Conclusão:** Finalmente, destaca a importância e responsabilidade da enfermagem comunitária com o objetivo de prevenir os níveis de sobrecarga e aumentar os de saúde; além disso, é realizada uma série de propostas no sentido de favorecer as redes de apoio social, combinar tratamentos e aumentar os programas de saúde pública em contato com a comunidade.

DESCRITORES

Transtornos Mentais; Cuidadores; Família; Apoio Social; Enfermagem em Saúde Comunitária.

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