




The impact of community care: Burden and quality of life of the informal caregivers of patients with severe mental disorder

María Eugenia Estrada-Fernández¹  | Marta Gil-Lacruz²  |
Ana I. Gil-Lacruz³  | Antonio Viñas-López⁴

¹Department of Psychology, Nursing School, University of Zaragoza, Huesca, Spain

²Department of Psychology and Sociology, University of Zaragoza, Zaragoza, Spain

³Department of Management and Organisation, University of Zaragoza, Zaragoza, Spain

⁴Department of Traumatology and Orthopaedics Surgery Unit, San Jorge Hospital, Huesca, Spain

Correspondence

María Eugenia Estrada-Fernández,
Department of Psychology, Nursing School,
University of Zaragoza, Martínez de Velasco,
Ave, 36, 22004 Huesca, Spain.
Email: eugeniaestradafernandez@gmail.com

Abstract

This study analyzes the dimensions and consequences of the burden of caregivers of patients with SMD (Severe Mental Disorder) and the repercussions that this role has on their quality of life and health in the physical, psychic and social spheres. This is a descriptive cross-sectional study and inferential observational study which explores caregivers of patients with SMD admitted to Psychiatry Day Hospital (Huesca, Spain). The technique of consecutive cases was used as a technique for sampling and sample selection. An individualized interview was arranged, where sociodemographic data were collected and scales and instruments were administered. 52 caregivers met the inclusion criteria. The female sex predominates (67%), being the patient's mother (48%). The average age of caregivers is 60 years old. Almost 60% of the sample presents intense burden and alterations of general mental health, 77% reveal anxiety and depression, and 46% little social support. Burden is associated with hospitalization within the last year, anxiety, or total social support received. It is appreciated how the diagnosis of a chronic disease constitutes an important challenge for the patient and their family, due

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to the burden of the disease and the impact of the new routines imposed by the continuous treatment.

KEYWORDS

burden, caregiver, family relations, mental disorder, quality of life

1 | INTRODUCTION

Often, mental illness involves a considerable family burden. The majority of mental health unit users living with their families spend much of their time at home, in which a family member generally takes on the role of caregiver. Therefore, if the vast majority of patients have a relative in charge of their care, it could be said that the role of the caregiver and its associated burden affects a considerable part of society (Kessler et al., 2005). The diagnosis of Several Mental Disorder (SMD) has a great impact on the life of the patient and the caregiver, since a change of life and a grief of the activities before the diagnosis must be elaborated: work occupation, social relationships, frequent or occasional hospitalization. Maintaining some of these factors is decisive for the improvement directly, and indirectly to the caregiver. Therefore, some of these variables are collected in this study.

Main or Informal caregiver is understood as the person in charge of, for most of the day, assisting in the basic and instrumental needs of the patient's daily life without financial compensation (López Gil et al., 2009). They are nonprofessional people (such as a family member, friend, or paid caregiver) who provide care in a home setting for another person and who usually deliver care and supervision to people with disabilities and with health problems living in the community (Etters et al., 2008). The intense dedication and long-term care of their family members can lead them to a situation of vulnerability, since such commitment implies great material, emotional, and health costs as well as alterations in the quality of life, stress (Ashley et al., 2011), and the evolutionary process of the life cycle (Joyce et al., 2003). In prolonged conditions of burden, family dynamics can be affected and lead to hard to sustain situations that trigger the institutionalization of the patient (Gort et al., 2007; Safavi et al., 2018).

If we look at the results obtained in previous research, we can verify that practically all studies report high levels of mental upset among caregivers, from 30% to 80% of the sample depending on the study (Burns et al., 2013; Gonçalves-Pereira et al., 2013; Kate et al., 2013; Lasebikan & Ayinde, 2013; Lloyd et al., 2011; Soares & Thais Dias Ceciliano, 2014). The *burden* factor is equally influential and related to the previous (Gutiérrez-Maldonado et al., 2005; Özkan Tuncay & Kars Fertelli, 2019). One of the most commonly accepted definitions is that which refers to as "the degree to which a carer's emotional or physical health, social life or financial status had suffered as a result of caring for their relative" (Zarit et al., 1986, p. 261). The scientific literature associates an increase in burden with certain degrees of kinship at the sociodemographic level, such as being a spouse or mother (Alexander et al., 2016; Lasebikan & Ayinde, 2013). In addition, the patient's symptomatic behavior can be influential (Yildirim et al., 2018), as well as a recent hospitalization (Foldemo et al., 2005; Lloyd et al., 2011; Möller-Leimkühler, 2005), a high number of relapses (Alexander et al., 2016), financial problems (Zivin et al., 2013), infrequent social and occupational contact of the patient (Gutiérrez-Maldonado et al., 2012) or cultural aspects (Awad & Voruganti, 2008), among others. This whole set of situations can favor the tendency of the appearance of the so-called *caregiver syndrome*. If we turn to the health consequences derived from the care of a dependent relative, the evidence reports an increased risk of suffering physical, psychological, and social disorders (García-Calvente et al., 2004; Özkan Tuncay & Kars Fertelli, 2019; Vitaliano et al., 2003), thus increasing the mortality rate which that entails and affirming previous studies (Pristavec & Luth, 2020). The decrease of the quality of life could affect 46% of patients with SMD (Hansson, 2006), also influence health's caregiver (Fernández de Larrinoa et al., 2011), and in relation to the general population (Heru et al., 2004). This affectation of Quality of Life (QoL) is especially related to a subjective burden (Heru et al., 2004). Some variables are considered risk factors in the QoL's

caregiver: female sex, severity of mental illness (Awadalla et al., 2005), decreased health's status, negative evaluation of his/her role, and low social support (Haltermann et al., 2004; Li et al., 2004; Lim & Zebrack, 2004).

Empirical evidence highlights the high personal and social costs that care generates. Therefore, we should keep in mind the causes and consequences of SMD on patients and caregivers to prioritize new family intervention designs. An essential feature of community health services is that care must be continuous (Poremski et al., 2016) and focus on health policies and service delivery. However, due to the low consensus on the prioritization of which indicators to use, in practice there are difficulties in adopting clear political solutions (Boeckxstaens, 2011; Vara, 2014). The family will therefore provide a high percentage of nonprofessional care, becoming the main source of service provision, and the home, the first center of service and care.

The professional experience at the Huesca Psychiatry Day Hospital with patients with SMD (Severe Mental Disorder) and their families reflect the magnitude of this problem and the need to investigate the determinants of the health of caregivers as an area of fundamental study. This paper analyzes the dimensions and consequences of the burden of caregivers of patients with SMD and the repercussions that this role has on their quality of life and health in the physical, psychic and social spheres.

2 | METHODS

2.1 | Design

This is a descriptive cross-sectional study and inferential observational study, which explores the relationships between sociodemographic characteristics and the physical, psychological and social consequences of the burden for caregivers of patients with severe mental disorder. The study is also, quantitative and correlational.

2.2 | Universe and sample

The reference context in which the study was conducted is the Huesca Psychiatry Day Hospital (Spain): a morning resource for partial admission of patients coming from both the outpatient level and from full hospitalization units. The maximum number of patients admitted simultaneously ranges between 15 and 20 users, with a minimum age of 18 years.

We have considered the informal caregiver of a patient with Serious Mental Disorder as an object of the target population in this study and as an inclusion criterion, as those people of reference for the user, who are responsible for helping in the basic and instrumental needs of the daily life of the patient for most of the day, without receiving financial compensation for it (López Gil et al., 2009). These caregivers offered their care to patients with SMD aged 18 or older, admitted to the Huesca Psychiatry Day Hospital, from June 2016 to June 2017.

The following aspects were considered as exclusion criteria: acute state of mental illness in the user; caregiver illnesses that require other caregivers, such as organically based diseases, sensory or cognitive disorders, psychiatric disorder or substance abuse; users and family members who refuse to collaborate in the study and do not sign the informed consent; having performed the role of caregiver for less than 2 months because it is considered a limited time in the adoption of the role; or receiving financial compensation for carrying out the role.

The technique of consecutive cases was used as a technique for sampling and sample selection, as of June 2016, with the recruitment of caregivers over 1 year. Using this technique, we tried to include all accessible and available caregivers who meet inclusion criteria for a year, which makes it easier for the sample to better represent the entire population. Based on previous information (the records of 5 previous years), the usual number of admissions during the 1-year period at the Psychiatry Day Hospital, fluctuates around 50 patients (in 2010, 67 patients were admitted; in 2011, 44; in 2012 it was 51; in 2013, 64; in 2014, 48 patients entered and in 2015, 52). In turn, with few exceptions in which the disorder is

associated with social isolation, the vast majority of those admitted have the help of a primary informal caregiver. Therefore, obtaining a sample of caregivers similar to these figures was expected.

During the period of data collection of the sample, of a total of 60 caregivers, 52 met the inclusion criteria and accepted participation and informed consent. Likewise, eight subjects were excluded, since they did not meet these inclusion criteria: two cases for mental illness of the caregiver, one for receiving financial compensation for the care, one for not having spent more than 2 months in the role, and four more for not accepting the conditions of the study or signing the consent.

2.3 | Instruments/measures

Because of the small size of our sample, we wanted to guarantee that the selection of instruments was done according to previous evidence of its right translation and validity in Spanish samples. The state of burden was identified by Zarit test (Zarit et al., 1980) using a Spanish validation (Martín-Carrasco et al., 1996; Martín-Carrasco et al., 2010), whose Cronbach α was 0.91, and the cutoff range by *intense burden* if ≤ 56 points.

On the one hand, psychological well-being and to nonpsychotic psychiatric problems. has been measured with Goldberg General Health Scale (Goldberg & Williams, 1988) validated in Spain whose Cronbach α was 0.76 (Sánchez-López & Dresch, 2008), whose cutoff range of "*probable case of mental health disorder*" is ≥ 5 . On the other hand, the state of psychological well-being has been informed by the application of Anxiety and Depression Goldberg scale (Goldberg et al., 1988; Montón et al., 1993) with Cronbach α 0.86 (cutoff range (GADS): "*probable anxiety*" ≥ 4 and "*probable depression*" ≥ 2), and the Spanish version of Quality of Life Questionnaire Whoqol (Cronbach $\alpha \geq 70$; Lucas, 1998; The Whoqol Group, 1993). We have taken into account two general questions to measure quality of life. The first two quality of life general questions ("*general*" and "*satisfaction with life*"), are measured with a Likert scale depending on the intensity: 0 (*very bad*) – 5 (*very good*). The four dimensions of quality of life related to health (physical health, psychological health, interpersonal relationships, or surroundings/environment), vary between scores from 0 to 100. Finally, Duke-Unk Functional Social Support Questionnaire (Broadhead et al., 1988) validated in Spanish population (Cuéllar & Dresch, 2012) whose Cronbach α corresponded as 0.90 has measured the social status. The cutoff range is considered "*poor confidential social support*" if ≤ 18 ; "*affective support*" poor if ≤ 15 and "*total social support*" poor if ≤ 32 .

2.4 | Data collection

Before the application of the instruments, the participants received an informative document specifying the objectives of the research, the willingness to collaborate with the study, the confidentiality of the data, and the inclusion criteria. Voluntary informed written consent was requested from those caregivers and patients who agreed to participate, with the prior authorization of the patient. An individualized interview was arranged with each member included in the study, where sociodemographic data were collected and scales and instruments were administered.

All procedures performed in studies involving human participants were in accordance with the ethical standards (1964 Declaration of Helsinki) and the approval by the Regional Ethics Committee of Aragón, Spain (CEICA). Informed consent was obtained from all individual participants included in the study (patients and caregivers).

2.5 | Statistical analysis

First, a descriptive analysis of the sample data has been performed. With respect to qualitative variables, frequency and percentage data are provided, and for quantitative variables, other statistical data such as the mean and

standard deviation, and the non-parametric Kolmogorov–Smirnov normality test are also included. In the analysis between variables or bivariate model, χ^2 or Fisher has been used for qualitative variables, the TStudent for the relationship between a qualitative variable of two categories and a quantitative one, and the ANOVA test as a method of relation of qualitative variables of more than two categories and a quantitative one. The analysis of the relationship between two quantitative variables was carried out through the use of correlations. The differences have been considered statistically significant when $p \leq 0.05$.

As a multivariate model and as an analysis of the factors that are independently related to the burden, a multiple linear regression has been performed. For this, a manual procedure has been carried out backwards starting from the complete model (Stepwise technique), checking that the B coefficient is maintained and its result is not modified more than 10% (discard the variables manually). In this case, the differences will be considered statistically significant when $p \leq 0.10$, and the variables that are significant in the bivariate process and those that are considered transcendent will be selected.

Statistical processing was performed using the statistical package SPSS 22 (Statistical Package for Social Science), in addition to the Epidat 4.2 program for calculating the sample size and confidence intervals.

3 | RESULTS

3.1 | Descriptive results

The variables analyzed in the study are specified in Table 1. Regarding the analysis of sociodemographic variables, the female sex predominates in 67% of cases, which generally coincides with being the patient's mother (48%), and married (65%). The most frequent studies are primary level (40%) and half of the respondents maintain employment. Little more than 40% of the sample considers that it suffers from some illness, and also just more than half feel that they receive external help, that is, they feel that they receive support from other people, although not directly in the care work (52%). Regarding the diagnosis of the patient admitted and the object of care, more than half suffer from schizophrenia (54%). These patients usually go to the periodic reviews of mental health professionals (83%), but do not usually have a work or occupational activity (61%). Likewise, 31% of the sample required hospital admission due to imbalance in the last month, and 65% in the last year.

The average age of caregivers is 59.25 ± 13.3 years, and it is noteworthy that in the 50th percentile, the age range is 62 years. The average years of care were 9.31 ± 8.4 years, taking into account the wide range of the sample, which ranges from less than one year in charge of care, up to 30 years.

When focusing on the variables resulting from the corresponding tests or questionnaires, high scores with respect to their cutoff point stand out (see Table 2):

- General Health Questionnaire (Goldberg 12, GHQ): An average of 5.56 ± 3.22 is obtained. 58% of the sample is in a position of vulnerability in terms of their general and mental health.
- Caregiver's burden (Zarit): The burden caused by the care of the dependent relative is shown intensely in 60% of the sample, while there is no burden present in 21%. At the intermediate level, the category classified as mild burden would occur in 19% of cases. The average is 61.04 ± 15.15 points.
- Anxiety and depression (Anxiety and depression scale Goldberg): For anxiety, the average obtained is 5.50 ± 2.69 . 77% of the sample is identified as "probable anxiety." In the case of the scale that assesses depression, an average of 3.81 ± 2.58 has been obtained, being remarkable that 77% of the sample is considered within the criteria of suffering "probable depression."
- Quality of Life (Whoqol Questionnaire): This questionnaire consists of two first independent questions about perception of general quality of life and health satisfaction. In the first one, the average is 2.98 ± 0.87 , which would be between "poor quality of life" and "normal quality of life." 48% of the sample has replied that they

TABLE 1 Profile of respondents

Construct	Dimension	Variables
Social Demographic (of the caregiver)	Demographic	Age (in years) Sex (feminine/masculine) Civil status (single/with partner/married/widowed)
	Social-work	Studies (no studies/primary/secondary/vocational/university training) Employment outside the home (yes/no)
	Family	Relationship with the patient (father/mother/brother/spouse/other) Type of family at home (family of origin/own family/in-laws) Number of people living in the home
Other	Patient	Disease of the patient you care for (schizophrenia/schizoaffective/Bipolar Disorder/OCD/Severe depression/other) Work occupation of the patient (yes/no) Frequent links to mental health tracking units in the patient (at least one visit every two months to the referral center) (yes/no) Time spent playing the role of caregiver (in years) Patient hospitalization less than a month ago (yes/no) Hospitalization in the last year (yes/no) Receipt of outside help (yes/no)
State of Overload or Burden	Health/general/psychological/social	Zarit test
State of Health	General Health	Caregiver diseases (yes/no) Goldberg General Health Scale G-12
State Psychological well-being	Psychological	Anxiety and depression using the Goldberg scale Quality of Life Questionnaire: Whoqol bref
Social status	Social	Duke-Unk Functional Social Support Questionnaire

Note: Total N = 52.

perceive a normal quality of life, while almost 25% *quite good* or *very good*. However, 27% consider *poor quality of life* or *very bad*. In the second question corresponding to the perception of health satisfaction, an average of 2.87 ± 0.88 is obtained, with 50% of the sample answering *normal satisfaction* with health, 21.15% rate it as *pretty good* or *good*, and yet 3% consider they have a very low level. As for the domains measured by the scale, a lower average of quality of life is observed in the domain of interpersonal relationships. The highest average QL is given in the environmental dimension.

- Social support (Duke-UNK Functional Social Support Questionnaire): This instrument distinguishes confidential, affective, and total support. Confidential support, that is, the possibility of having people to communicate personal and intimate aspects to, has an average of 19.29 ± 6.60 . 52% of family members surveyed do not

TABLE 2 Descriptive characteristics of variables

Logistic parameter	Average	SD	95% CI	
			LL	UP
General health (GHQ)	5.56 (n = 22.9)	3.22	3.89	7.23
Caregiver burden (ZARIT)	61.04 (n = 28)	15.15	44.19	77.88
General Quality of Life (QL)	2.98 (n = 39)	0.87	2.14	3.81
Satisfaction with life	2.87 (n = 40.9)	0.88	2.03	3.70
Physical Health QL	53.85 (n = 26)	16.58	38.26	69.44
Psychological QL	48.52 (n = 26)	15.42	34.60	62.02
Interpersonal Relations QL	48.10 (n = 32.3)	15.69	34.18	62.38
Environment QL	51.46 (n = 32.2)	16.65	37.54	65.38
Anxiety (GADS)	5.50 (n = 27.5)	2.69	3.83	7.17
Depression (GADS)	3.81 (n = 31.7)	2.58	2.69	4.92
Confidential Social Support	19.29 (n = 29.2)	6.60	14.27	24.30
Affective Social Support	15.40 (n = 28)	4.94	11.22	19.57
Total Social support	34.79 (n = 27)	11.25	25.46	44.11

Note: Research data. Total N = 52; CI, confidence interval; LL, lower limit; UP, upper limit.

receive such support. Regarding the affective support, the average of the sample has been 15.40 ± 4.94 , data that suppose that 54% of the sample scored below the cutoff figure. Finally, in relation to total support, 46% of the sample would be below this figure, with an average of 34.79 ± 11.25 .

3.2 | Inferential statistical results. Bivariate burden analysis

In Tables 3 and 4, the most significant results of burden variable can be observed with the rest of the variables. It shows a significant relationship between the variable that measures the burden when feeling sick or in the absence of attention for the person being cared for, increasing the burden in both cases.

In addition, the burden shows a significant relationship with the general health state and with the quality of life, decreasing the correlation as the burden increases. It can be emphasized that the general QL offers a *B* coefficient of -10.79 (95% confidence interval [CI] = -14.6 to -6.9), in other words, at each point the QoL increases, 10.79 burden score decreases.

In addition, statistical significance is observed when the burden increases with the presence of anxiety (coefficient *B* 3.7, 95% CI = 2.5–4.99): As anxiety score increases, burden score increases 3.7 points. And also with depression (*B* 3.5 coefficient, 95% CI = 2.2–4.8). By last, social support decreases in a significant way when the burden increases.

3.3 | Multivariate burden analysis results

Multivariate analysis is used both to detect and study the structure in the relationships between a group of variables, and to reduce the number of variables in a broad set. It assumes that the correlations between variables

TABLE 3 Estimates and averages of Zarit results with qualitative variables

Zarit		<i>n</i>	Average	<i>SD</i>	<i>p</i>	<i>F</i>
Caregiver sex	Female	35	63.14	14.086	n.s.	1.384
	Male	17	56.71	16.762		
Family relationship	Mother/father	37	60.92	16.189	n.s.	0.008
	Sibling/spouse	15	61.33	12.760		
Caregiver studies	Illiterate	8	67.63	17.427	n.s.	1.243
	Primary	21	61.81	14.617		
	Secondary or more	23	58.04	14.695		
Marital status	Married/couple	41	58.68	13.852	n.s.	5.053
	Widower/single/divorced	11	69.82	17.221		
Caregiver illness	Yes	21	66.10	14.398	0.047	0.035
	No	31	57.61	14.910		
Caregiver employment	Yes	26	60.46	12.067	n.s.	9.123
	No	26	61.62	17.953		
Patient occupation	Yes	20	55.45	13.496	0.034	0.987
	No	32	64.53	15.282		
Patient hospitalization within ≤1 month	Yes	16	66.38	14.449	n.s. (0.091)	0.099
	No	36	58.67	15.048		
Hosp. Patient ≤1 year ago	Yes	34	65.62	14.883	0.002	1.996
	No	18	52.39	11.748		
Patient diagnosis	Psychotic disorder	31	62.71	15.038	n.s.	0.457
	Affective disorder	17	58.59	16.845		
	Anxiety disorder/OCD	4	58.50	7.681		

Note: Research data. Total *N* = 52. Zarit dependent variable with the rest of the variables; ns: not significant.

are not random, but are due to the underlying existence of common factors between them. Therefore, to control possibly confusing factors, the multivariate test has been designed using multiple linear regression, being burden score the dependent variable. All those variables that showed statistical significance in the bivariate tests have been introduced as possible related factors.

The multivariate analysis highlights the importance of the following independently related variables on the perception of burden: hospitalization within the last year, anxiety, or total social support received. The caregiver's age is considered a remarkable finding (close to 0.1). Despite not reaching the level of significance, it is considered a tendency to take into account, and it may be likely to be an independent factor if we increase the sample of the study and it may be indirectly proportionally related to burden (see Table 5).

Therefore, after analyzing these constructs in a multivariate way, it can be said that anxiety is directly related to burden (positive *B* coefficient): the higher the level of anxiety, the more burden (on average, two more burden score points). It is also found that having been admitted in the last year increases the burden by 6.1 burden score points more than those who had no recent admissions or have done so imminently in the last month. In relation to social support, as the social support scale score increases, the felt burden decreases 0.7 points for each point more

TABLE 4 Estimates and averages of Zarit results with qualitative variables

Zarit		Age	Years caring	GHQ	General QL	Satisfact. Health	W1 Physical QL	W2 Psychol QL
Z-no burden		59.80	11.10	2.50	3.70	3.40	63.30	65.70
Z-light burden		51.73	8.73	5.00	3.27	2.73	63.73	50.00
Z-heavy burden		61.74	8.94	6.74	2.65	2.74	47.29	42.45
Sig.		n.s.	n.s.	$p = 0.001$	$p = 0.001$	n.s.	$p = 0.001$	$p = 0.000$
		W3. Relation QL	W4. Environment QL	Anxiety	Depression	Confident social support	Affective social support	Total social support
Z-no burden		56.90	66.40	2.10	0.60	23.70	19.70	43.40
Z-light burden		49.36	54.09	4.91	3.36	25.64	19.73	45.00
Z-heavy burden		44.81	45.71	6.81	5.00	15.61	12.48	28.39
Sig.		n.s.	$p = 0.001$	$p = 0.000$	$p = 0.000$	$p = 0.000$	$p = 0.000$	$p = 0.000$

Note: Research data. Total N = 52; Zarit dependent variable with the rest of the variables; ns: not significant.

TABLE 5 Multivariate model coefficients for Zarit (multiple linear regression)

	Coefficient B	Sig.	95% CI for B	
			LL	UL
Age	-0.143	0.114	-0.322	0.036
Hospitalization a year ago	-6.155	0.018	-11.218	-1.093
Anxiety	2.209	0.000	1.270	3.147
Total Social support (Duke total)	-0.749	0.000	-0.980	-0.517

Note: Research data. Total $N = 52$; CI, confidence interval; LL, lower limit; UL, upper limit; Dependent Variable: Zarit; Test significance: $p < 0.05$.

in social support, with protective social support being the burden felt. Finally, the negative relationship is observed in the case of age (for each year more, the caregiver's burden falls 0.14 points, so that young caregivers are more heavily burdened). These latest results reflect how through multivariate analysis, confusing factors or uncontrolled variables that in a bivariate analysis can cause a different or inverse result are eliminated.

4 | DISCUSSION

With the results of the sample, it is appreciated how the diagnosis of a chronic disease constitutes an important challenge for the patient and their family, due to the burden of the disease and the impact of the new routines imposed by the continuous treatment. The adaptation to these changes is a challenge in the family environment, who must restructure their lives to cope with the disease and its consequences (Dogba et al., 2013).

The profile of the caregiver obtained in this study closely resembles the Spanish criteria and characteristics described, in which married women, with primary studies, with an average age of around 60, and who have been performing the caregiver activity for many years (Zueras et al., 2018) stand out. The sample of the present study is distributed by sex in 67% women and 33% men, being consistent with other previous studies (Burns et al., 2013; Gort et al., 2007; Joyce et al., 2003), in which the number of women is greater than that of men, even in figures higher than the present (Fernández de Larrinoa et al., 2011; Gonçalves-Pereira et al., 2013; Joyce et al., 2003; López Gil et al., 2009). The average age of the caregiver is 59 years, the decade in which similar data to other works has shown, starting in the 50 s (Burns et al., 2013; Fernández de Larrinoa et al., 2011; Joyce et al., 2003; Lasebikan & Ayinde, 2013), or increasing until 60, in others (Gonçalves-Pereira et al., 2013).

One thing to keep in mind is the tendency to increase the level of education in younger caregivers, and therefore also in women. Perhaps this fact is influenced by cultural evolution itself and by the entry of women into the world of work. The most frequent level of education achieved is primary, followed by secondary. Both maintaining a stable partner, and having reached high level of education, are associated with a better quality of life (Awadalla et al., 2005).

Imbalances or worsening of the care recipient's disease is reflected in the caregiver's status. However, the patient's admission very recently in the last month (acute state of illness), affects the caregiver less than when the relapse occurs in the last year (subacute state), which implies a costlier adaptation process. Perhaps a month is not sufficient time to accept, to assimilate, and to feel the consequences of needing a more intense level of care. Nevertheless, as months after the relapse pass, it is more probable that these interfere. In this way, the health of the caregiver will suffer when the patient finds himself in a subacute or long-term state of his symptomatology. The investigations support these results, since they indicate that for those patients who are more stable in the community (without relapses or worsening in the last year at least), the caregivers show less burden (Alexander et al., 2016; Foldemo et al., 2005; Lloyd et al., 2011; Möller-Leimkühler, 2005).

The data of this study have not only demonstrated the significance at a socio-demographic level, but also in relation to the perception of health itself and to the quality of life. The main purpose of this study focuses on the dimension of the caregiver's burden. The physical or emotional burden is related to a recent relapse that triggers the admission to partial hospitalization such as the day hospital, situations that can lead to fears about future plans or difficulties to cope with new similar situations at such an advanced age. Studies carried out in caregivers of psychiatric patients on an outpatient basis, without recent prior relapse, point to less elevated burden levels, ranging between 35% and 57% (López Gil et al., 2009). In the results of this study, it is directly related to anxiety, as in other research (Gutiérrez-Maldonado et al., 2005; Özkan Tuncay & Kars Fertelli, 2019). It has also detected an inversely proportional relationship between the burden and age or social support, the latter also considered as an influential factor in the burden for other authors (Ribé et al., 2018). The perception of increased burden has to do with the hospitalization during the last year.

The role of caring for a person with mental health problems affects the general and mental health of the caregiver. Almost 58% of the sample is considered vulnerable. The figures in the scientific literature vary markedly without defining a clear profile. Some resemble the present results (Gonçalves-Pereira et al., 2013; Montero et al., 2006), and others show worse general and mental health like Soares in the study of carers for patients at outpatient clinics in Brazil (Soares & Thais Dias Ceciliano, 2014). Other investigations with even better scores can be cited, whose study has been carried out with more temporal continuity (Burns et al., 2013), in patients with organic pathology (Özkan Tuncay & Kars Fertelli, 2019), or in culturally different countries such as India (Kate et al., 2013).

The findings related to mood states (anxiety or depression) are especially important in this and other studies (Larrañaga et al., 2008; Özkan Tuncay & Kars Fertelli, 2019; Vitaliano et al., 2003). 77% of respondents would show both a "probable anxiety" and a "probable depression." As the literature shows, in a situation of care and burden, there is an affectation of the psychic sphere. These complementary studies also detect high levels of these alterations, although to a lesser extent, fluctuating around 60% in anxiety and 40% in depression (López Gil et al., 2009). This study relates this elevated data with the subacute situation of the patient and the consequent intense emotional overflow of the relative, regardless of the prolonged time of care. Through the analysis of the data, the significant relationship of mood with higher levels of burden and lower social support has been verified.

Half of the caregivers have little support, a figure comparatively similar to other samples previously studied (López Gil et al., 2009; Pérez Peñaranda et al., 2009). Perceived anxiety and depression are associated with lower rates of social support (Casale et al., 2015; Kate et al., 2013). Analyzing the case of women, the cultural influence that offers them fewer job opportunities outside the home can be detected, an aspect that enhances their care role at home. This may also lead to fewer opportunities to develop social relationships and therefore have less social support. The sociodemographic changes experienced in recent decades, motivated by the incorporation of women into employment, force a modification of the caregiver's patterns and threaten the viability of maintaining long-term informal care (Maher et al., 2015).

Finally, we compare our results with those of other studies focused on caregivers of other nonmental organic pathologies (Manso-Martinez et al., 2013), and it is observed that the present work shows a lower average age of the caregiver (20 years less), although similar percentages between sexes and kinship. Manso-Martinez et al. (2013) highlight similarities with this trend, such as the fact that the anxiety variable is the variable that most affects burden (32% more impact), followed by perceived social support (4%). In spite of this, this study done in Huesca shows worse levels of general and mental health, less perceived social support, and greater burden, with worse results in women. Other studies aimed at the study of caregivers with Alzheimer's pathologies or cognitive impairment show lower levels of general and mental health than this study, and in turn, better social support (Larrañaga et al., 2008).

4.1 | Implications for practice

The important social involvement that caregivers do has not been sufficiently contemplated. In view of all the results shown and their severity, we can suggest the importance of policies focusing on the provision and financing of programs

that are aimed at social and occupational rehabilitation for patients, as well as the programs of accompaniment and psychosocial support to families and caregivers of patients with severe mental disorders (Han et al., 2017). From all this, an evident impact of the care work on the quality of life of the caregiver is inferred, and as such community services should not only target the patients in treatment, but should also focus on the caregivers.

5 | CONCLUSION

The data reveal a profile of caregivers for patients with severe mental disorder who is usually a woman, is married, with primary studies and with an average age of around 60 years, who takes care of their family member permanently throughout the day and does this study over many years. Elderly caregivers are those who show the lowest level of education. Other data of interest that must be taken into account in future research/interventions with this target population are the tendency for worse consequences in women, and the high burden effects in alterations of general mental health. Further, most caregivers suffer from anxiety, depression, or a decrease in quality of life and social support. By last, if the patient's work or occupational activity is maintained, family members show better general health conditions, less burden, more quality of life, and better levels of social support.

6 | LIMITATIONS AND STRONG POINTS

This study shows evidence of the risk of suffering physical, mental, and social disorders in a specific target population in psychiatry. Much of the care comes from nonprofessional caregivers who have assumed a substantial part of the burden, with or without the support of professional, economic, technical resources, among others.

As possible points of improvement for future research, in addition to an extension of the sample (the small sample size does not allow the generalization of findings), it would be necessary to conduct a study at the beginning and at the end of hospital admission. This would verify if the impact of this hospitalization is a modification factor in the variables, since this fact can reduce the burden throughout the admission by having the daily support of the professionals of the unit, thus releasing their burden. Other probable lines of research would consist in focusing the study towards the investigation of the congruence between the caregiver's perception and the family member being cared for, partly to better understand the dynamics of social support and rehabilitation. The possibility of using other measurement instruments to ensure the reliability and validation of the selected tests could also be contemplated.

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1002/jcop.22594>

DATA AVAILABILITY STATEMENT

The data of this study are available on request from the corresponding author. The dataset data set is not publicly available because it contains information that could compromise the privacy of our participants.

ORCID

María Eugenia Estrada-Fernández  <https://orcid.org/0000-0001-8893-8527>

Marta Gil-Lacruz  <https://orcid.org/0000-0001-8261-058X>

Ana I. Gil-Lacruz  <https://orcid.org/0000-0002-7994-923X>

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How to cite this article: Estrada-Fernández, M. E., Gil-Lacruz, M., Gil-Lacruz, A. I., & Viñas-López, A. (2022). The impact of community care: Burden and quality of life of the informal caregivers of patients with severe mental disorder. *J Community Psychol, 50*, 487–501. <https://doi.org/10.1002/jcop.22594>