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Burden and satisfaction experienced in relatives and patients during home hospitalisation in psychiatry

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ABSTRACT

Introduction. The role of caregivers is essential during home hospitalization since they act as co-therapists, being the level of responsibility experienced by them higher than usual. The objective of this study is to evaluate the burden experienced in the main caregivers and also to determine the level of satisfaction perceived in the main caregivers and in the patients attended in our home hospitalization unit (HADMar).

Methodology. Prospective observational study. All patients admitted to HADMar between May 2020 and April 2021 have been included. Socio-demographic and clinical data have been collected from the sample. To assess the degree of burden, the Zarit scale was used at the end of admission in the main caregivers. To determine the perceived satisfaction, the CRES-4 scale was administered at the end of admission to both the caregivers and the patients attended.

Results. 182 patients have been attended. Of them, 144 main caregivers answered the Zarit scale, being the mean score 49.59 (corresponding to mild burden). 152 caregivers answered the CRES-4 scale, obtaining a mean score of 241.75 (out of a possible maximum of 300). 158 patients answered the CRES-4 scale and the mean score was 242.57.

Conclusions. Data obtained indicate that the burden perceived by the main caregivers acting as co-therapists during intensive home follow-up is mild. It can also be concluded that both patients and primary caregivers feel satisfied with the care received during follow-up at HADMar

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Keywords. *Crisis resolution team, home hospitalization, caregiver burden, satisfaction, mental health.*

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SOBRECARGA EXPERIMENTADA Y SATISFACCIÓN EN FAMILIARES Y PACIENTES DURANTE UNA HOSPITALIZACIÓN DOMICILIARIA EN PSIQUIATRÍA

RESUMEN

Introducción. El rol de los cuidadores es esencial durante la hospitalización domiciliaria ya que ejercen de coterapeutas, siendo el nivel de responsabilidad que experimentan mayor a la habitual. El objetivo de este estudio es evaluar la sobrecarga experimentada en los cuidadores principales y también determinar el nivel de satisfacción percibida en los cuidadores principales y en los pacientes atendidos en nuestra unidad de hospitalización domiciliaria (HADMar).

Metodología. Estudio prospectivo observacional. Se han incluido todos los pacientes que han ingresado en HADMar entre mayo de 2020 y abril de 2021. Se han recogido datos socio-demográficos y clínicos de la muestra. Para evaluar el grado de sobrecarga se ha utilizado la escala de Zarit al final del ingreso en los cuidadores principales. Para determinar la satisfacción percibida se ha administrado la escala CRES-4 al final del ingreso tanto a los cuidadores como a los pacientes atendidos.

Resultados. 182 pacientes han sido atendidos. Del total, 144 cuidadores principales han respondido la escala de Zarit, siendo la puntuación media de 49,59 (correspondiente a sobrecarga ligera). 152 cuidadores han respondido la escala CRES-4, obteniendo una puntuación media de 241,75 (sobre un máximo posible de 300). 158 pacientes han respondido la escala CRES-4 y la puntuación media ha sido 242,57.

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Conclusiones. Los datos obtenidos señalan que la sobrecarga percibida por los cuidadores principales ejerciendo de coterapeutas durante un seguimiento domiciliario intensivo es leve. También puede concluirse que tanto pacientes como cuidadores principales se sienten satisfechos con la atención recibida durante el seguimiento en HADMar.

Palabras clave. *Intervención en crisis, hospitalización domiciliaria, sobrecarga cuidador, satisfacción, salud mental.*

INTRODUCTION

The deinstitutionalisation of psychiatric patients in the 1970s led to a notable improvement in the quality of care provided for the mentally ill. However, this psychiatric reform has not been without its difficulties, fundamentally in relation to the lack of intermediate resources and the burden of family members who act as the main caregivers for patients[1].

Home hospitalisation for patients with psychiatric disorders is a new, emerging initiative in mental health that allows patients with acute decompensation to be provided with intensive care at home. The main objective of this type of programme is to avoid hospital admission and for it to become a viable alternative in the care of patients with acute psychiatric symptoms[2,3]. In recent years, a growing number of community care models have been developed around the world that offer home care[4–8]. Crisis Resolution and Home Treatment Teams (CRT) were implemented nationwide in the UK following the 2000 National Health Service Plan and constitute the most studied model of home hospitalisation in psychiatry[2,9–11]. Currently, there is solid evidence that supports the effectiveness of the CRT model for the clinical improvement of patients treated in these programmes[8,11,12] and also in reducing the patient hospitalisation rate[7,13–15].

In Spain, the creation of home hospitalisation (HD) services began in 1981 at the Gregorio Marañón General University Hospital in Madrid. The initial roll-out for this type of programme was irregular, being notable in the Basque Country, Galicia and the Community of Valencia. The case of this latter autonomous community is notable, as it began to implement an HD network in 1994 with 7 units, and has now expanded to 27; constituting one of the regions of Spain with the largest number of schemes and most experience in HD[16]. In 2006, HD units were included in the portfolio of services of the National Health System[17]. Since then, HD has had erratic growth nationally as a consequence of a series of factors that range from the absence of a common regulatory framework, the lack of scientific evidence and the heterogeneity of the units in significant aspects, such as the portfolio of services and resource provision[18].

The home hospitalisation unit at the Parc de Salut Mar de Barcelona (HADMar) is a programme based on the CRT model that began in January 2015. It serves patients from the reference area (the districts of Sant Martí and Ciutat Vella in the city of Barcelona) with severe decompensated mental disorders, and consists of a team of 3 psychiatrists, 3 nurses, and a nursing assistant. Opening hours are 8 am – 6 pm, Monday to Thursday and 8 am – 3 pm on Fridays. To contact the team, the patients and main caregivers are given a telephone number with a voicemail facility. If urgent care is required outside HADMar opening hours, patients are cared for by the Hospital del Mar psychiatric emergency service, which has access to the clinical history of all patients admitted to the unit. Only patients who accept the admission conditions (taking treatment and following the therapeutic indications) with a family member or caregiver acting as a co-therapist are selected. Exclusion criteria from the programme are having serious behavioural disturbances, absence of adequate support, self-destructive ideation, being under 16 years of age and concomitant substance dependence/abuse. Follow-up is intensive and continuous, with frequent home visits (up to 3 times a week) until it is possible to link to another resource in the mental health network. It is aimed at people who would require hospital admission, were it not for an intensive home monitoring programme like ours, as well as to facilitate transfer to the homes of hospitalised patients in full regime to reduce hospital stays. Recently, studies were carried out evaluating the efficacy of the HADMar programme[8,19], with positive results in terms of psychopathological improvement and functionality of the patients treated.

The role of the patients' caregivers, who act as co-therapists during the hospitalisation process, is essential in the operation of the HADMar unit since they are asked to supervise the taking of medication and report on the progress they observe in the patient. These caregivers of patients with mental disorders take on a responsibility that requires a lot of time and which can cause social, emotional and even financial problems; leading to various limitations in their personal lives[20,21]. When practising as co-therapists during home hospitalisation, the responsibility experienced by caregivers is greater than usual; and, as far as we know, there are no studies evaluating the level of burden suffered by these caregivers acting as co-therapists during the intensive follow-up period at home.

The objective of this study was to evaluate the burden experienced by the main caregivers of patients with decompensated mental disorder during follow-up in HADMar, and to determine the level of satisfaction perceived by both the main caregivers and the patients they attend to with the care provided.

METHODOLOGY

A prospective observational study was carried out on patients admitted to the HADMar unit between May 2020 and April 2021.

Socio-demographic data were collected from the sample, and the level of functioning of the patients was evaluated at the time of admission using the global assessment of functioning (GAF) scale. The severity of the patients at the time of admission was also determined using the severity subscale of the clinical global impression (CGI) scale.

To assess the degree of burden experienced by the main caregivers, the Zarit caregiver burden interview was used[22]. This scale consists of 22 statements evaluated using a Likert scale with each response ranging from 1 to 5. Adding the scores together gives a result between 22 and 110 points. No burden is considered for a score less than 47; slight burden for a score in the range 47-55 and a heavy burden for a score greater than or equal to 56. The Zarit Interview is one of the most commonly used instruments for assessing caregiver burden[23] and has shown its usefulness in assessing burden in various studies with caregivers of people suffering from different types of illness, including psychiatric pathologies[24]. Furthermore, its numerous adaptations to different languages improve its psychometric properties, allowing comparison of scores between different types of populations[23].

The CRES-4[25] scale was used to determine the level of satisfaction with the care perceived during admission to HADMar. It consists of 4 items: one for satisfaction; another to rate the degree of resolution of the main problem; one about emotional state before the follow-up; and another about the emotional state at the end of the follow-up. The 3 components taken from these questions are satisfaction, resolution of the problem and perception of emotional change. Each component has a score ranging from 0 to 100. For the perception of emotional change, a score higher than 50 indicates an improvement in the emotional status at the end of follow-up. The results of the three components are added to obtain the global CRES-4 score and will be between 0 and 300 (the higher the score, the higher the perceived satisfaction).

At the visit prior to discharge, the Zarit interview and CRES-4 scale were taken by the main caregivers and the CRES-4 scale by the patients. If they wished to participate in the study, they were asked to deliver the questionnaires in a sealed envelope at the programme discharge visit to maintain confidentiality.

The study was approved by the Parc de Salut Mar drug research ethics committee (ref no. 2020/9072) and was conducted in compliance with the World Medical Association (Declaration of Helsinki) recommendations. The data were analysed using the IBM SPSS Statistics for Windows program (version 20.0).

RESULTS

There were 182 patients treated in the HADMar programme between May 2020 and April 2021; 57.7% women, 42.3% men and the mean age of the sample was 45.91 years. The main diagnoses were psychotic disorders (44.6%), bipolar affective disorder (23.7%) and major depressive disorder (21.5%). Most referrals came from the acute hospitalisation unit (37.3%), the outpatient mental health centre (35.1%) and the psychiatric emergency service (21.4%). At the time of admission, the mean score on the GAF scale was 50.83, while the mean score for the CGI severity subscale was 4.5. The socio-demographic and clinical characteristics of the sample data are shown in Table 1.

From the total sample, 144 main caregivers took the Zarit interview, while 152 caregivers and 158 patients took the CRES-4 instrument. The mean score on the Zarit scale was

Table 1 Socio-demographic and clinical characteristics of the sample

Age, mean (SD)	45.91 (16.38)
Sex, no (%)	
Women	105 (57,7)
Men	77 (42,3)
Main diagnosis, no (%)	
Psychotic disorders	81 (44,6)
Major depressive disorder	39 (21,5)
Bipolar affective disorder	43 (23,7)
Anxiety disorders	8 (4,3)
Personality disorders	3 (1,6)
Other psychiatric disorders	8 (4,3)
Patient referred from, no (%)	
Mental health Centre	64 (35,1)
Psychiatric emergency	39 (21,4)
Acute psychiatry unit	66 (37,3)
Other mental health resource	13 (6,2)
GAF score at admission, mean (SD)	50,83 (15,06)
Severity subscale score of the CGI scale at admission, mean (SD)	4,5 (1,01)

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Table 2 Zarit interview and CRES-4 global scores for the sample

	No	Mean	SD
Zarit interview	144	49.59	16.27
CRES-4 scale: Main caregivers	152		
1. Satisfaction		82.76	20.59
2. Resolution of the problem		90.00	16.75
3. Emotional change perception		68.99	13.64
4. Overall score		241.75	39.10
CRES-4 scale: Patients	158		
1. Satisfaction		82.91	17.89
2. Resolution of the problem		88.86	15.88
3. Emotional change perception		70.80	12.82
4. Overall score		242.57	36.74

(SD = standard deviation)

49.59, corresponding to a level of slight burden. The mean CRES-4 scale global score for the caregivers was 241.75: the satisfaction component was 82.76, the resolution of the problem component 90.00 and that for emotional change 68.99. The mean glob CRES-4 scale global score for the patients was 242.57: the satisfaction component was 82.91, the resolution of the problem component 88.86 and that for emotional change 70.80 (Table 2). The Zarit and CRES-4 scale scores in each of the main diagnostic groups are shown in Table 3.

DISCUSSION

Hospital admission for patients experiencing an acute psychiatric crisis has been the only available resource for the last twenty years. The introduction of psychiatric home hospitalisation teams, based on the United Kingdom CRT model, has made it possible to provide intensive care at home, avoiding patient admission[2,8,9,11,19]. There is also evidence that outpatient crisis care reduces the stigma inherent in hospitalisation[26]. However, there are no studies evaluating the burden that this type of treatment has upon the main caregivers of patients or the level of satisfaction

Table 3 Zarit interview and CRES-4 scale scores breakdown by diagnostic groups

Disorder		Zarit interview	CRES-4 Scale: Main Caregivers				CRES-4 Scale: Patients			
			Satisfaction	Problem resolution	Perception of emotional change	Global score	Satisfac-tion	Problem resolution	Perception of emotional change	Global score
Psychotic disorders	No	62	66				69			
	Mean	48.58	86.66	92.12	67.61	246.40	82.02	87.82	71.19	241.05
	SD	16.14	16.2	10.45	14.20	30.51	17.19	17.89	13.43	36.93
Major depressive disorder	No	32	32				33			
	Mean	46.18	83.63	92.12	73.10	248.86	84.70	90.00	73.16	247.86
	SD	13.56	22.61	14.08	13.66	37.39	18.46	14.97	11.97	38.02
Bipolar affective disorder	No	35	37				38			
	Mean	50.89	76.75	85.40	69.25	231.41	83.68	90.52	68.75	242.96
	SD	17.95	22.85	22.43	13.04	44.52	18.51	12.93	11.89	35.87
Anxiety disorders	No	5	6				7			
	Mean	58.40	90.00	96.66	66.66	253.33	91.42	94.28	69.64	255.35
	SD	12.42	10.95	8.16	10.20	22.45	10.69	9.75	9.83	13.41
Personality disorders	No	3	3				3			
	Mean	63.67	53.33	60.00	62.50	175.83	73.33	80	70.83	224.16
	SD	18.82	50.33	52.91	12.50	114.84	11.54	0	19.09	12.82
Other psychiatric disorders	No	7	8				8			
	Mean	59.11	72.00	82.00	65.00	219.00	74.00	82.00	68.75	224.75
	SD	18.65	28.59	30.47	12.90	65.60	21.18	17.51	16.92	43.99

with the care received.

The patients in our study corresponded to a population of middle-aged adults, with a preponderance of women (57.7% of the sample). The main diagnosis at discharge was a psychotic disorder (including schizophrenia, delusional disorder, schizoaffective disorder, and not otherwise specified psychotic disorder), followed by bipolar affective disorder and major depressive disorder. These conditions are also the main pathologies found in a psychiatric hospitalisation unit. The patients seen had a severity of illness between moderate and markedly ill at admission, as indicated by the mean score of 4.5 on the CGI severity subscale. The patients had a serious alteration in social, work or academic activity (corresponding to a mean score on the GAF scale of 50.83) for the level of functionality at the time of admission to HADMar.

One of the main objectives of this study was to evaluate the level of burden experienced by main caregivers when acting as co-therapists during home hospitalisation. The role of the main caregivers in this type of admission is essential, since this type of clinical care could not be carried out without them in many cases. The mean Zarit interview score for the overall sample indicates a slight level of burden experienced (49.59 points). High average scores were observed in the Zarit interview for statements 7, "Are you afraid for the future of your family member?" (average score 3.38) and statement 8, "Do you think your family member depends on you?" (average score 3.25). The average score was less than 3 for the rest of the statements.

When breaking down the level of burden based on diagnosis, a slight burden was evaluated for the main caregivers of patients with psychotic disorders (mean score = 48.58), major depressive disorder (mean score = 46.18) and bipolar affective disorder (mean score = 50.89). However, the burden experienced by primary caregivers was more intense for patients diagnosed with anxiety disorder (mean score = 58.40), personality disorder (mean score = 63.67) and other diagnoses (mean score = 59.11). It should be noted that the level of burden was slight for the three main diagnostic categories (representing 89.8% of the sample). However, the main caregivers of patients with personality disorders were those displaying the highest level of burden.

The main caregivers were generally satisfied with the care received during admission to HADMar, as indicated by the mean global score of 241.75 out of a maximum of 300 points. Breaking down the scale into its 3 components, it can be determined that the main caregivers were satisfied with the care provided by the therapeutic team (mean score 82.76 out of a maximum of 100); they considered the care received had helped to resolve the main problem for which the patients were treated (mean score of 90 out of a maximum of 100); and that there was an improvement in emotional state at the end of the follow-up in HADMar (corresponding to a score greater than 50 in this section; average score was 68.99). Similar scores were obtained in the different diagnostic groups, except for personality disorders, where satisfaction with the care received was lower (mean global score of 175.83). It should be noted that the satisfaction component of main caregivers in this diagnostic category dropped to 53.33 out of a possible 100. The lower satisfaction in this specific group of patients could be related to the fact that there are treatments in the mental health network more appropriate to the needs of these patients.

The results obtained in this study also indicate that the patients treated in the HADMar programme feel satisfied with the care received, with a mean global score of 242.57 on the CRES-4 scale. Breaking down the mean scores into the 3 CRES-4 scale components: they also demonstrate that patients are satisfied with the care provided by the therapeutic team (mean score 82.91 out of a maximum of 100); they consider the care received has helped resolve the main problem for which they were being treated (mean score 88.86 out of a maximum of 100); and that there was improvement in the emotional state at the end of the follow-up (mean score of 70.80). The scores were very similar in the different diagnostic groups, with slightly lower scores found in patients with a personality disorder and for those with other psychiatric diagnoses (mean global scores 224.16 and 224.75, respectively).

The following are considered limitations of the study: it was an observational study, so no definitive conclusions could be drawn; the sample size was relatively small, especially for some of the diagnostic groups; not all eligible subjects were included in the study, with no information being gathered as to why they decided not to participate; we were not able to obtain socio-demographic data from the main caregivers; and finally the heterogeneity in the operation of the different home hospitalisation models makes it difficult to generalise about the results found.

CONCLUSIONS

Despite the aforementioned limitations, this study provides relevant data on home hospitalisation based upon the CRT model. This is the first study in our environment of the degree of burden experienced by the main caregivers of patients with mental disorders, asked to act as co-therapists during a period of intensive follow-up at home. The data obtained indicate the degree of perceived burden was slight. It was also observed that the patients and main caregivers felt satisfied with the care received during the follow-up

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in the HADMar initiative, and was considered a well valued resource. A notable improvement for both patients and main caregivers in the emotional state at the end of the follow-up was seen, compared to the beginning of admission.

Conflicts of interest

Jordi León has been a consultant for or has received honoraria from Otsuka, Janssen and Exeltis; Dr Perez has been a consultant for or received honoraria or grants from AB Biotics, AstraZeneca, Bristol-Myers-Squibb, CIBERSAM, ISCIII, Janssen Cilag, Lundbeck, Otsuka, Servier and Pfizer; Dr Pacchiarotti has received consultancy fees from ADAMED, Janssen-Cilag and Lundbeck. The rest of the authors declare no conflicts of interest.

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