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Desempeño ocupacional y satisfacción de los cuidadores primarios informales de pacientes con limitación en la actividad

Occupational Performance and Satisfaction of the Informal Primary Caregivers of Patients with Activity Limitations

Desempenho profissional e satisfação de cuidadores primários informais de pacientes com atividade limitada

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Resumen

Los cuidadores primarios informales familiares tienen un rol de suma importancia para las personas que requieren de sus cuidados. Cuando una persona no puede realizar alguna o varias actividades de autocuidado, esparcimiento y productividad, ya sea por una lesión, enfermedad o discapacidad, es necesario el apoyo de otra persona que les ayude a completar o realizar sus actividades. Por esta razón, quien cumple el rol de cuidador primario informal familiar puede presentar problemáticas en su desempeño y en la satisfacción ocupacional que obtiene durante las labores de cuidado comprometiendo su bienestar y salud. El objetivo principal de la presente investigación fue determinar la relación existente entre el desempeño y la satisfacción ocupacional de los cuidadores primarios informales familiares y el grado de limitación en la actividad de los pacientes a su cargo. Para ello, se les tomó variables sociodemográficas a 18 cuidadores primarios informales que acudieron a la Unidad Universitaria de Rehabilitación de la Universidad Autónoma de Yucatán y se les aplicó la Medida Canadiense del Desempeño Ocupacional (MCDO) para conocer su desempeño y satisfacción ocupacional. Mientras que a sus respectivos pacientes se les aplicó la Lista de Cotejo de la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud (CIF), con el fin de conocer el grado en la limitación en sus actividades.

Los resultados mostraron que el 83.3% de los cuidadores estudiados fueron mujeres, con una edad media de 46.6 ± 13.4 años, siendo en su mayoría madres de los pacientes, amas de casa, casadas y con una escolaridad de nivel licenciatura (50%). En promedio, los cuidadores primarios mostraron afectaciones moderadas en el desempeño (5.46±1.85) y satisfacción ocupacional (5.43±1.91). Por otra parte, el 27.7% de los pacientes obtuvo una limitación en la actividad moderada y el 27.7% presento una limitación en la actividad grave. Se encontró una correlación negativa (r = -0.582, p = 0.0114, coeficiente de correlación de Spearman) entre el nivel de satisfacción de los cuidadores y la limitación en la actividad de los pacientes a su cargo. De igual forma, se encontró una correlación negativa entre el desempeño ocupacional del cuidador y la limitación en la actividad de los pacientes a su cargo (r = -0.553, p = 0.0173, coeficiente de correlación de Spearman). De acuerdo a los resultados obtenidos, se encontró que a mayor limitación en la actividad de los pacientes,

mayor es la afectación en el nivel de desempeño y satisfacción ocupacional de los cuidadores primarios informales familiares.

Palabras clave: cuidador primario informal, desempeño ocupacional, limitación en la actividad.

Abstract

The primary family caregivers have a significant role for the people who require their care. When a person cannot perform any or several activities of self-care, recreation, and productivity, whether due to an injury, illness or disability, the support of another person is needed to help them complete or carry out their activities. For this reason, who fulfills the role of primary informal family caregiver can present problems in their performance and in the occupational satisfaction that they obtain during the work of care, compromising their well-being and health. The present investigation aimed to determine the relationship between performance and occupational satisfaction of primary family caregivers and the degree of limitation in the activity of the patients in their care. To 18 informal primary caregivers were taken sociodemographic variables and then the Canadian Occupational Performance Measure was applied to know their performance and occupational satisfaction. While the instrument known as Checklist of the International Classification of Functioning, Disability, and Health, was used to their respective patients to know the degree of limitation in their activities.

The results showed that 83.3% of the caregivers studied were women, with an average age of 46.6 ± 13.4 years, most of them being mothers of the patients, housewives, married and with a superior level of education (50%). On average, primary caregivers showed moderate impairments in performance (5.46 ± 1.85) and occupational satisfaction (5.43 ± 1.91). On the other hand, 27.7% of the patients obtained a moderate limitation in the activity, and 27.7% presented a severe limitation in the activity. We found a negative correlation ($r = -0.582$, $p = 0.0114$, Spearman's correlation coefficient) between the level of satisfaction of the caregivers and the limitation in the activity of the patients under their care. Likewise, a

negative correlation was found between the occupational performance of the caregiver and the limitation in the activity of the patients under their supervision (r = -0.553, p = 0.0173, Spearman's correlation coefficient). According to the results obtained, it was found that the higher the limitation in the activity of the patients who attended the University Rehabilitation Unit, the higher the impact on the level of performance and occupational satisfaction of the primary informal family caregivers.

Keywords: informal primary caregivers, occupational performance , activity limitation.

Resumo

Os cuidadores primários da família informal têm um papel muito importante para as pessoas que precisam de seus cuidados. Quando uma pessoa não pode realizar nenhuma ou várias atividades de autocuidado, recreação e produtividade, seja devido a uma lesão, doença ou deficiência, o apoio de outra pessoa é necessário para ajudá-los a completar ou realizar suas atividades. Por esse motivo, quem cumpre o papel de cuidador familiar primário familiar pode apresentar problemas em seu desempenho e na satisfação profissional que eles obtêm durante o trabalho de cuidado, comprometendo seu bem-estar e saúde. O principal objetivo da presente investigação foi determinar a relação entre desempenho e satisfação profissional dos cuidadores primários da família informal e o grau de limitação na atividade dos pacientes sob seus cuidados. Para esse fim, foram tomados 18 cuidadores primários informais para variáveis sociodemográficas e a Medida de Desempenho no Trabalho Canadense (MCDO) foi aplicada ao desempenho e satisfação profissional. Enquanto seus respectivos pacientes foram aplicados na lista de verificação da Classificação Internacional de Funcionamento, Incapacidade e Saúde (CIF), a fim de conhecer o grau de limitação em suas atividades.

Os resultados mostraram que 83,3% dos cuidadores estudados eram mulheres, com idade média de 46,6 ± 13,4 anos, sendo a maioria mãe de pacientes, donas de casa, casados e com nível de bacharelado (50%). Em média, os cuidadores primários apresentaram comprometimento moderado no desempenho (5,46 ± 1,85) e satisfação ocupacional (5,43 ± 1,91). Por outro lado, 27,7% dos pacientes obtiveram uma limitação na atividade moderada e 27,7% apresentaram uma limitação na atividade séria. Uma correlação negativa foi

encontrada (r = -0.582, p = 0,0114, coeficiente de correlação de Spearman) entre o nível de satisfação dos cuidadores e a limitação na atividade dos pacientes sob seus cuidados. Da mesma forma, encontrou-se uma correlação negativa entre o desempenho ocupacional do cuidador e a limitação na atividade dos pacientes sob seus cuidados (r = -0,553, p = 0,0173, coeficiente de correlação de Spearman). De acordo com os resultados obtidos, verificou-se que quanto maior a limitação na atividade dos pacientes, maior a afetação no nível de desempenho e satisfação profissional dos principais cuidadores familiares informais.

Palavras-chave: cuidador primário informal, desempenho ocupacional, limitação de atividade.

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Introduction

Disability is a problem that affects 15% of the world population and it is expected that in future years it will be a cause of even greater concern, since its prevalence is increasing (World Health Organization [WHO], 2011). In Mexico, according to the data reported by the National Survey of Demographic Dynamics [Enadid] (2014), it was shown that 6% of the total population of the country has some disability, that is, 7.1 million people. At the state level, in Yucatan, 1.9% of the total number of people with disabilities reside, that is, for every 1000 inhabitants 65 present it, this rate is higher than the one calculated nationally and makes Yucatán one of the states of the country with the highest prevalence of disability. The most frequent disability is that corresponding to motor disability, with a prevalence of 68.1% (National Institute of Statistics and Geography [Inegi], 2014).

Disability is the expression of a sensory, functional, emotional or cognitive limitation in a given context; it is the existing gap between the capacities of the person (conditioned in part by his health) and the demands of the environment (physical, social, work). For this study we talk about motor disability referring to when there are functional alterations in the muscles, bones, spinal cord or in the central nervous system affecting the mobility of the person. The difficulties presented by people with neuromusculoskeletal diseases are varied and depend on the degree of limitation in the activity they cause, as well as the existence of other conditions or associated disabilities. These limitations in the activity are defined as difficulties to execute actions or tasks and are cataloged by the Checklist of the International Classification of Functioning, Disability and Health (CIF) as light, moderate, serious and complete (WHO, 2011).

These difficulties oblige the person with a disability to use devices or, if necessary, request help from another person to carry out daily activities, creating a dependency, which may vary in relation to the degree of limitation that it has (Puga, 2005). Therefore, that family in which some of its members have some disability or limitation in the activity faces new challenges and adjustments to cover the needs of the member who needs help; so that they adapt the family dynamics to the new demands (Kielhofner et al., 2008, Ortega et al., 2012). In this sense, the person who takes charge and provides help or care to the patient, outside the professional field, is called informal primary caregiver, which in most cases is a family member. The latter, by adopting the role of carer, acquires a series of responsibilities and activities in addition to those that he already has as a participant in a community. (Martínez-González *et al.*, 2008).

In such a way that the person or relative who plays the role of informal primary caregiver can be immersed in a process of occupational imbalance that modifies their performance and corresponding satisfaction and can affect their health and well-being. Among the activities carried out by informal primary caregivers in the care of their dependents are health care, support in carrying out activities of daily living and psychosocial care of the patient (Vargas-Escobar and Pinto- Afanador, 2010, Vargas-Escobar, 2012).

Seen from the perspective of occupational therapy, caring for others can create problems to play a role. Recent studies show that care and patient care modify the time the caregiver devotes to their leisure activities, work activities, social relations and in their intimate life: all this exerts a social pressure and causes problems in the emotional health of the patient. informal primary caregiver (Kielhofner et al., 2008). In addition, there are negative effects that can occur in informal primary caregivers due to care work, including feelings of helplessness and resignation, sleep disturbances, overload and high levels of stress (McCurry et al., 2007; Paleo and Rodríguez, 2005, Sanders et al., 2008, Seidmann et al., 2004, Simonelli et al., 2008). In addition, Buenfil et al. (2016) reported that the level of limitation in patient activity is related to a higher index of depression in the informal primary caregiver. All of this can have an impact on the areas of occupational and functional performance of the informal primary caregiver, causing imbalances in the areas of self-care, work and recreation, which, in turn, can have an impact on the quality of care that can be provided to the patient (Flórez et al., 2012).

Some studies have used the Canadian Occupational Performance Measure (MCDO) (Law et al., 1990) to obtain information regarding the occupational performance of patients with some health condition, identifying difficulties in performance in the areas of self-care, productivity and recreation. (Padankatti et al., 2011; Jacobsen et al., 2015; Oestergaard et al., 2012). On the other hand, several studies have indicated that leisure and social relationships are the most affected activities in informal primary caregivers of subjects with some type of disability. (López-Márquez, 2014; Dueñas *et al.*, 2006).

With respect to this and according to our search, in Yucatan there are no studies that focus on the analysis of the satisfaction and occupational performance of the person who serves as the primary caregiver of a person with limited activity. Only one study reported on how the primary caregiver deals with patient care (Canche-May et al., 2015). Most investigations analyze the consequences of care by the caregiver and refer to stress and to a greater extent depressive illness as its consequence; there are few studies that focus on the needs of the informal primary caregiver (Buenfil et al., 2016). For this reason, the objective of this study was to determine the relationship between the degree of limitation in the patient's

activity and the occupational performance and level of satisfaction of the informal primary caregiver.

The importance of this study lies in the fact that it will allow us to know the problem of the role of caregiver from a perspective centered on the caregiver and not the patient subject of care. Based on this, it will be possible to make intervention proposals that contribute to prevent the primary caregivers of patients with neuromusculoskeletal diseases from presenting problems in their occupational performance and develop negative changes that may affect their health, well-being and patient care; that is, proposals for comprehensive care for the patient and their caregiver.

Material and methods

Ethical considerations

The present study was authorized and registered by the Evaluation and Bioethics Committees of the Autonomous University of Yucatan (UADY) (SISTPROY FMED- 2016-0001) and the Institute of Occupational Therapy (ITO) of Mexico City. The research was based on the Ethical Codes established in the Declaration of Helsinki (2003) and in compliance with the General Regulations of the General Health Law on Health Research in Mexico (RLGS, 1987).

Primary caregivers of patients with limited activity were given an informed consent letter, which specified what the study consisted of (objective, benefits, procedures, risks and clarifications), as well as the possibility of deciding to participate in the studio or not. Each participant was given a detailed letter with accessible language, which emphasized the absolute confidentiality of their data, which were exclusively for study purposes; his anonymity was guaranteed at all times.

Participants

The present study was of exploratory type, with a transversal, prospective and analytical design. Candidate participants were selected according to the inclusion criteria, with prior authorization from the Research and Bioethics Committee of the Faculty of Medicine of the UADY and the ITO of Mexico City. The study population consisted of 18 of a total of 32 informal primary caregivers, family members of patients who presented a neuromusculoskeletal disability and who attended the University Unit of Rehabilitation of the UADY in the period from January to June 2016.

Fourteen of the informal primary caregivers were excluded from the study because they were caring for two or more family members. It was also used as an exclusion criterion to have suffered a stressful life event in the last year: separation or divorce, death of a family member or being diagnosed with a serious illness. Likewise, those primary caregivers of patients who did not meet the diagnostic criteria for a neuromusculoskeletal disability or those who did not accept being part of the study were excluded from the study.

Process

The initial contact with the informal primary caregivers of the patients of the University Unit of Rehabilitation of the UADY was done through an interview during which they were invited to participate in the study, those who accepted the process were explained and they were delivered the informed consent letter for authorization. Subsequently, the Sociodemographic Questionnaire for Informal Primary Family Caregivers was applied, through which the family member who exercised the role of primary informal family caregiver was identified, and the MCDO was also applied to identify the main problems in occupational performance. your degree of satisfaction Finally, the CIF was applied to patients, in order to identify the level of limitation in the activity; In cases in which the patient could not answer the questions, they went to the caregiver to answer instead of the patients, as it was in the case of pediatric patients.

Instruments

Sociodemographic Questionnaire for Informal Primary Family Caregivers: integrated by 12 items designed to collect sociodemographic information. The scale offers information about the informal primary caregiver: sex, age, religion, marital status, maximum level of studies, economic income, time spent taking care of the family member, etcetera. As well as 13 items from which data were obtained from patients with some limitation in the activity, such as their age, sex, and so on.

CIF in its version 2.1a: formed by a selection of 125 questions that allows obtaining a profile of the patient's functioning in the most relevant areas of life. For this research, part two was used: "Limitations of activity and participation restrictions" (WHO, 2011, Ayuso et al., 2006, Vázquez-Barquero et al., 2006). This instrument allows quantifying the degree of limitation or restriction that a person possesses based on the magnitude of problems that may have in their ability to perform in various activities and tasks, so it is defined as follows: from 0% to 4 % when there is no limitation on the activity; from 5% to 24% constitutes a limitation in light activity; from 25% to 49% represents a limitation in moderate activity; from 50% to 95% a limitation in the serious activity, and from 96% to 100% a limitation in the complete activity.

MCDO: it is a standardized instrument in the sense that there are specific instructions and methods to administer and qualify the test. Based on a semi-structured interview of open questions, organized into three sections or sections (self-care, productivity and leisure), it is used to assess problems in occupational performance and satisfaction. First, the interviewee identifies the activities where there is a problem in their performance, then prioritizes these activities based on the importance that he gives them, then selects five of them that will reprioritize and finally determines their level of performance and their degree of satisfaction. , this according to a scale of one to 10, where one represents the worst performance and the lowest satisfaction and 10 the best performance and the highest satisfaction (Law et al., 1990).

Several studies indicate that the MCDO has a wide external validity, confirming its application in various sample sizes and study designs, and suggesting that this instrument is

an applicable clinical measure able to detect changes in performance and occupational satisfaction in various clinical environments (Carpenter *et al.*, 2001; Costa *et al.*, 2014; Parker, 2012; Sewell y Singh, 2001).

Statistic analysis

A descriptive and relationship analysis of the obtained data was carried out. For the Sociodemographic Questionnaire for Informal Primary Family Caregivers, the age of the caregiver and the time of care provided to the patient was reported by means of the arithmetic mean and the standard error. All other data obtained are reported as a percentage, taking as 100% the 18 primary caregivers included in this study. To determine the relationship between the limitation in the patient's activity (results obtained by the CIF) and the degree of performance and occupational satisfaction of their informal primary caregivers (results obtained by the MCDO), a Spearman correlation analysis was performed, to the size of the sample and the measurement scales used, which did not allow adjusting the homogeneity and homoscedasticity parameters. A confidence level of 95% and a significance of p were used. < 0.05.

Results

Within the sociodemographic characteristics of the population interviewed with the instrument Sociodemographic Questionnaire for Informal Primary Family Caregivers, it was found that the majority were women (83.3%), their ages ranged between 30 and 70 years of age, with an average of 46.6 ± 13.4 years and professed the Catholic religion (66.66%). However, other religions were registered as Christian (11.11%), as well as caregivers who reported not professing any religion (11.11%). Regarding the kinship of the informal primary caregiver with the patient, the majority are fathers and mothers of these (50%). The majority of the population studied was married (77.78%) and they were mainly engaged in housework (33.33%), followed by retired or retired people (27.78%). Their level of education was mostly undergraduate (50%) and their monthly family income ranged between 2,700 and 6799

Mexican pesos (33.33%), followed by income between 6800 and 11 599 Mexican pesos (27.8%).

50% of the participants stated that they had been working as informal family primary caregivers for more than five years. They reported dedicating themselves to caring activities five to seven days a week, with an average of 6.83 ± 0.51 days; the time periods of care ranged from 7 to 24 hours a day, with an average of 19.22 ± 5.36 hours. Eight of the informal primary caregivers reported providing care 24 hours a day (Table 1). As can be seen, in the present study, the caregivers who had less than six months dedicated to patient care were the minority. However, there is a progressive increase in caregivers who have more than two years dedicated to patient care.

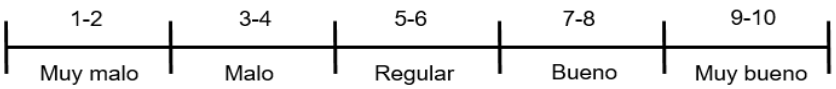
Tabla 1. Caracterización de las actividades de cuidado.

Variables	Ítems	Frecuencia en %
Tiempo total de cuidado	Menos de 6 meses	5.56
	Entre 1 y 2 años	11.11
	Entre 2 y 5 años	33.33
	Más de 5 años	50
Días a la semana dedicados al cuidado (7/7)	5/7	5.56
	6/7	5.56
	7/7	88.88
Horas dedicadas al cuidado (24/24)	7	5.56
	12	11.11
	15	5.56
	16	11.11
	17	5.56
	18	5.56
	19	5.56
	22	5.56
	24	44.44

Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

Regarding the performance and occupational satisfaction of the informal primary caregiver, data was obtained from the MCDO instrument starting from a scale of one to 10, one being a bad performance or satisfaction and 10 a very good performance or satisfaction (Figure 1).

Figura 1. Escala de puntuación para el desempeño ocupacional y la satisfacción del cuidador primario informal.



Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

In general, the results indicate that the performance and the occupational satisfaction of the informal primary caregiver present moderate affectations. For their performance, the informal primary caregivers assigned an average value of 5.46 ± 1.85 and for the satisfaction of 5.43 ± 1.91. Table 2 shows the average scores obtained for the performance and occupational satisfaction of each subject. It is important to note that several caregivers obtained low scores (2.2), which suggest that the caregiver's performance and satisfaction is considerably affected by the activities and tasks involved in the role of caregiver.

Occupational satisfaction and performance of the informal primary caregiver

The MCDO is organized into three main areas: self-care, productivity and recreation, and allows to determine the problems in performance and satisfaction in each of them.

Tabla 2. Calificación promedio de desempeño y satisfacción por individuo.

Cuidador Primario Informal	Calificación de Desempeño	Calificación de Satisfacción
1	2.2	4.2
2	6.4	5
3	2.2	2.2
4	8.4	7.8
5	7.6	9.6
6	6.2	7.4
7	6.6	6
8	6.2	6.4
9	5.4	4.4
10	5.3	6
11	5.6	5.2
12	6	5.4
13	5	4
14	8.4	8
15	4.8	4.8
16	5	5
17	4.8	4
18	2.2	2.4
Media ± DS	5.46 ± 1.85	5.43 ± 1.91

Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

Based on this, it was obtained that for self-care (which involves activities such as bathing, dressing, personal grooming, taking care of their own health), informal primary caregivers present moderate affectations (Table 3), with the most affected activities being dressing with a grade of 3.5 ± 0.7 and the transportation section with a grade of 4.66 ± 2.33. While for the area of productivity, the main activities that were affected were the ability to obtain a paid job with a grade of 4.14 ± 3.18 and continue studying with a grade of 5 ± 0.76. In addition, and as the most relevant data, it was found that the relaxation of the informal primary caregivers presented serious affectations. The informal primary caregivers reported that going on a trip was the item that presented the most problems with a rating of 3.5 ± 2.58, followed by the departure with their partner with a 3.6 ± 2.07. In addition, caregivers reported presenting impairments in activities such as exercise (4.5 ± 2.6) and dating (4.5 ± 2.36) (Table 3).

Tabla 3. Calificación promedio de desempeño y satisfacción del cuidador primario informal por actividad y área ocupacional.

ÁREA OCUPACIONAL	ACTIVIDAD	CALIFICACIÓN PROMEDIO DESEMPEÑO (1-10)	CALIFICACIÓN PROMEDIO SATISFACCIÓN (1-10)
AUTOCUIDADO	Bañarse	6.57 ± 1.51	6.42 ± 1.71
	Transportación	5.33 ± 2.65	4.66 ± 2.33
	Arreglo Personal	6.71 ± 1.79	6.28 ± 1.79
	Vestirse	5.5 ± 0.70	3.5 ± 0.70
	Alimentación	6.8 ± 1.72	7 ± 2.09
	Cuidado de la propia salud	6 ± 2.82	7 ± 4.24
PRODUCTIVIDAD	Continuar estudios	5 ± 0.76	5.5 ± 0.70
	Preparar alimentos/cocinar	6.83 ± 2.13	6.66 ± 2.33
	Limpieza del hogar	6.83 ± 1.47	8 ± 2.09
	Trabajo remunerado	4.14 ± 3.28	4.14 ± 3.18
ESPARCIMIENTO	Leer	8 ± 2.82	6.5 ± 2.12
	Ejercicio	4.5 ± 2.96	4.5 ± 2.60
	Viajes	4 ± 2.36	3.5 ± 2.58
	Salir con amigas	4.5 ± 3.10	4 ± 4.08
	Salida en pareja	3.6 ± 2.07	5 ± 3
	Actividad de ocio relacionada a un pasatiempo	5.5 ± 6.36	5.5 ± 6.36

Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

Limitation in patient activity

According to the data obtained through the CIF instrument, it was found that the majority of patients (44.44%) had a limitation in light activity, 27.78% had a limitation in moderate activity and another 27.78% had a limitation in the activity. serious or intense activity. We did not find patients with a complete limitation (Table 4).

Tabla 4. Distribución medida en porcentaje de los pacientes con limitación en la actividad, de acuerdo a la CIF.

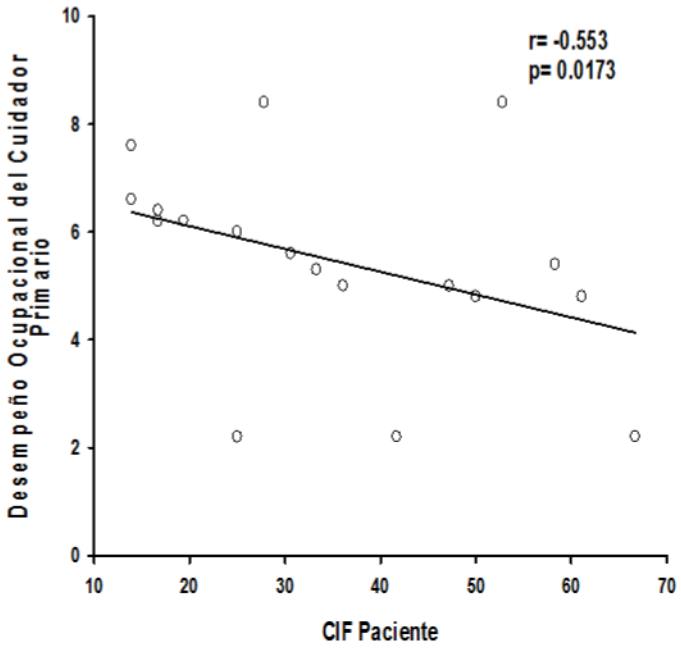
Nivel de Limitación en la Actividad del Paciente	N	Frecuencia en %
Limitación ligera	8	44.44
Limitación moderada	5	27.78
Limitación grave o intensa	5	27.78
Limitación completa	0	0

Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

Relationship between occupational performance and informal primary caregiver satisfaction and limitation in patient activity

To determine the relationship between limitation in patient activity and performance impairments and occupational satisfaction of informal primary caregivers, the Spearman correlation coefficient was used. Figure 2 shows the correlation of the occupational performance of the informal primary caregiver and the limitation in the activity of the patients, finding a significant correlation of $r = -0.553$ ($p = 0.0173$, Spearman's correlation coefficient). These results suggest that a greater limitation in the activity of the patient presents a greater affectation in the occupational performance of the informal primary caregivers.

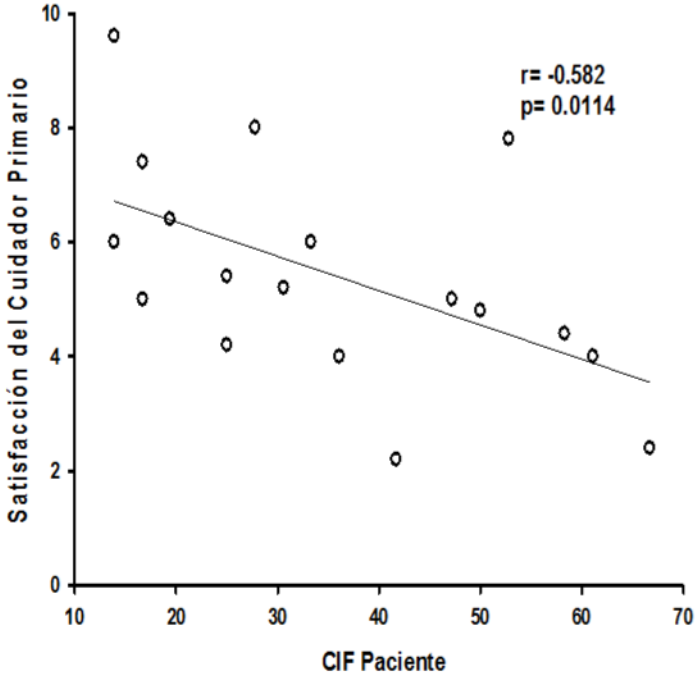
Figura 2. El grado de limitación en la actividad de los pacientes afecta la autopercepción del desempeño ocupacional de sus cuidadores primarios informales.



Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY.

Figure 3 shows the correlation between the occupational satisfaction of the informal primary caregiver and the limitation in the activity of the patients, finding a significant correlation of r = -0.582 (p = 0.0114, Spearman's correlation coefficient). These results suggest that a greater limitation in the patient's activity presents a greater affectation in the occupational satisfaction of the informal primary caregivers, that is, a lower satisfaction with their performance.

Figura 3. El grado de limitación en la actividad de los pacientes afecta la autopercepción de la satisfacción ocupacional de sus cuidadores primarios informales.



Fuente: Base de datos estudio índice de sobrecarga en cuidadores primarios. UUR, Facultad de Medicina, UADY

Discussion

The sample studied is representative of the informal primary caregivers that were presented in the primary care program of the University Unit of Rehabilitation of the Faculty of Medicine of the UADY, for which the results of this study can only be generalized to populations with similar characteristics . The present study made it possible to obtain an approximation of the sociodemographic characteristics of the primary informal family caregiver who is in charge of a person with some degree of limitation in the activity due to a neuromusculoskeletal disease, in addition to allowing to assess the impact of the care

activities of a person with limited activity and that falls on the occupational performance and satisfaction of the primary caregiver.

Regarding the data obtained in our research, the profile of the primary informal family caregiver corresponds to that of a middle-aged woman (46 years old), a housewife, a mother or a first-degree descendant of the person being cared for (mainly a daughter), and several years in the role of caregiver; a profile that is similar to that reported for other countries (Hong-Jer, 2009, López et al., 2009, Ribas et al., 2000). In addition, these results do not vary from what was found for Mexico by Islas et al. in 2006, in his study conducted with 46 informal primary caregivers of patients with chronic obstructive pulmonary disease. In all of them, it is women caregivers in adult stage between 40 and 65 years of age (Op. Cit.). Historically, women have been assigned the role of caregiver, citing their feminine nature as a condition that prepares them to care for and to be more selfless, as mentioned by Montalvo and Flórez (2008). On the other hand, Barrera (2000) points out that among the main reasons that the caregiver is a woman is due to social expectations, as well as to a moral duty assigned to the female sex. This dynamic in care work, in which it is women who assume primarily the role of the informal primary caregiver, leads to the cost that women assume in their lives is high in terms of quality of life, professional development, repercussions economic, work, social relations, leisure and recreation, and their health in general.

In relation to the education of the informal primary caregivers of this study, the bachelor's degree predominated (50%). In this case, our results differ from those reported in the literature, where the level of education on the part of the caregivers is of primary, primary and secondary schooling, mainly (Martínez-González et al., 2008; Ramos del Río and Jarillo , 2014). One possible explanation is that the study was conducted in a University Clinical Unit. This fact could be considered as favoring for the informal primary caregiver, since, as mentioned by Rivera-Mora et al. (2011), in their study carried out in the Family Medicine Clinic of the State of Mexico, "to greater studies less burden of the caregiver", suggesting a lower impact on the health and well-being of the informal primary caregiver.

On the other hand, the majority of informal family primary caregivers reported having received support with respect to the patient's care at least 10% of the time, with physical

assistance by the grandparents of the patient or the caregiver's spouse predominating, similar data to the one reported by Mateo et al. (2000), who found that 36% of caregivers of patients with neurodegenerative diseases receive some type of support from another relative, as well as Islas et al. (2006), who reported that 54.35% of caregivers received support, mainly in decision-making; which possibly influences in a positive way the perception of the overload and performance of the informal primary caregiver. Similarly, results of other research suggest that support is a protective factor for caregivers, since "the greater the social support, the better the quality of life of the caregiver" (Pérez, 2006).

In this study, it was found that the main activities that the caregivers carried out were mostly the so-called self-care activities, such as medication management and health care, mobility and patient assistance during bathing. These results are similar to that reported by Mateo et al. (2000), in their study performed with caregivers of patients with neurodegenerative diseases, indicating that medical care (medical consultations and pharmaceutical expenses), besides being primary activities in patient care, represent a factor that negatively affects the caregiver , because it supposes important economic expenses for the caregiver. In turn, Pérez (2006) points out that the activity of caring for a patient makes it difficult for caregivers to develop in the professional field.

In addition to the impact that informal primary caregivers have on paid work, caregivers also reported other activities with problems in both occupational performance and satisfaction, including dating, dating, travel, and exercise. they are contemplated in the same recreational occupational area. Several investigations report similar findings, suggesting that recreation and related activities are the most affected in informal family primary caregivers of people with some type of disability (López, 2014; Dueñas et al., 2006). In this sense, Crespo and López (2007) report the presence of affectations in the primary caregiver, which include symptoms of low self-esteem, tension, anger and feeling of social burden when feeling judged by others, in addition to presenting stress when attending the patient in the basic tasks of cleanliness and dress and even when trying to adapt to the behavioral changes experienced by the patient. Added to this, they also suggest that the decrease in economic

resources, the lack of free time, intimacy with the couple and the deterioration of social life are the most affected factors reported by informal primary caregivers.

The fact that the informal primary caregivers of our study presented an occupational performance and satisfaction with low scores in leisure activities suggests that their quality of life is affected negatively. In fact, Dueñas et al. (2006), in their study carried out with caregivers of children with disabilities, in the Teletón Children's Rehabilitation Center (CRIT) of Chihuahua, Mexico, mention that "recreation or personal recreation is an important factor to minimize the deterioration of the quality of caregiver's life ", so that, if the time of recreation or the performance in it is low, the quality of life of the caregivers decreases. This argument is reinforced from another perspective by López-Márquez (2014), who mentions that caregivers who have time for recreation and recreation have low levels of overload.

In the present study, it was found that informal family primary caregivers obtained low grades, both in occupational performance and in satisfaction. It was also found that both variables are negatively related to the degree of limitation in the activity of the patients, obtaining that, the higher the level of limitation in the patient's activity, the lower the performance and the occupational satisfaction of the informal family primary caregivers. It is important to consider that, when there is an occupational imbalance and little satisfaction, the primary informal family caregiver may find himself in a state of stress that does not allow him to continue satisfactorily performing his activities. All of which results in an affectation or loss of the occupational balance and therefore their health and well-being are affected (Buenfil-Díaz et al., 2016).

Finally, a limitation of our study is the reduced sample size. In addition, the MCDO is a widely used instrument at the international level; however, previous studies at the national level where this instrument has been used and validated in informal family primary caregivers are unknown or have not been reported. Despite these limitations, it is proposed to replicate the study carried out by means of a longitudinal design, which allows a follow-up on the evolution of the variables studied to validate the conclusions.

Finally, this is the first research work on the occupational performance and satisfaction of informal primary caregivers of patients with limited activity in the University

Unit of Rehabilitation of the Faculty of Medicine of the UADY, and the results are a contribution to scientific knowledge for the multidisciplinary team in the rehabilitation area that serves the patient and their families; In short, it will contribute to the commitment to provide not only comprehensive attention to the needs of people with disabilities, but also to their families that are decisive for the achievement of comprehensive care and rehabilitation to the fullest extent of the word. In this sense, actions aimed at the creation and implementation of occupational therapy programs focused on prevention and care in the areas of health, well-being and quality of life could improve the attention of families and counteract the enormous impact of the task of caregiver in the well-being and quality of life of the informal primary caregivers, which in turn can impact on the health and well-being of the person with disability; all this according to a perspective focused on the client that allows the integral attention of the patient and his caregiver. This can be achieved through strategies whose purpose is to provide tools that help in the difficult task of the caregiver and in the management of stressful situations that derive from the care of patients with limited activity. (Molina *et al.*, 2005; Nigenda *et al.*, 2007).

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