Quality of life and social support for informal caregivers of dependent patients in Spain: A cross-sectional study

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Original

ABSTRACT

Objective: The purpose of this study is to analyze the quality of life and perception of social support among informal caregivers of dependent patients.

Methods: A cross-sectional study in the Southeast of Spain was conducted. This research employed a comprehensive questionnaire and the Multidimensional Scale of Perceived Social Support to assess caregiver variables in relation to quality of life. Ethical considerations were strictly observed, and statistical analysis utilized SPSS software, with a significance level of p<.05.-

Results: A total of 80 caregivers of dependent patients took part in the study. The **informal** caregiver was typically a **middle-aged man, who was married**, the **son of the dependent patient**, had no other work, had only completed primary education, and lived with the patient. The caregiver spends an average of 16 hours per day providing care and at least for 4.75 years. Factors such as living with the dependent person, lacking external support, and significant caregiving hours were associated with lower quality of life and perceived social support. A statistically significant negative correlation was observed between quality of life and perceived social support (r=.670; p<.001).

Conclusion: Caregivers with a stronger perception of social support reported a higher quality of life. Reinforcing social support such as institutions and networks could improve the quality of life and health outcomes perceived by caregivers, making it a necessary intervention. In conclusion, the study demonstrated the significance of promoting and strengthening the social support network to enhance the caregiver's quality of life and health status.

Keywords:

Ageing, Community health, Informal caregivers, Quality of life, Social support.

Calidad de vida y apoyo social de los cuidadores informales de pacientes dependientes en España: Estudio transversal

Resumen

Objetivo: El propósito de este estudio es analizar la calidad de vida y la percepción de apoyo social entre los cuidadores informales de pacientes dependientes.

Métodos: Se llevó a cabo un estudio transversal en el sureste de España. Esta investigación empleó un cuestionario de comprensión y la Escala Multidimensional de Percepción de Apoyo Social para evaluar variables del cuidador en relación con la calidad de vida. Se observaron estrictamente consideraciones éticas, y el análisis estadístico se realizó utilizando el software SPSS, con un nivel de significancia de $p<.05$.

Resultados: Un total de 80 cuidadores de pacientes dependientes participaron en el estudio. El cuidador informal típicamente era un hombre de mediana edad, casado, hijo del paciente dependiente, sin otro trabajo, con solo educación primaria completada, y vivía con el paciente. El cuidador dedica un promedio de 16 horas al día proporcionando cuidados y al menos durante 4.75 años. Factores como vivir con la persona dependiente, carecer de apoyo externo y un número significativo de horas de cuidado se asociaron con una menor calidad de vida y percepción de apoyo social. Se observó una correlación negativa estadísticamente significativa entre la calidad de vida y la percepción de apoyo social ($r=.670$; $p<.001$).

Conclusión: Los cuidadores con una percepción más fuerte de apoyo social informaron una mayor calidad de vida. Reforzar el apoyo social, como instituciones y redes, podría mejorar la calidad de vida y los resultados de salud percibidos por los cuidadores, convirtiéndolo en una intervención necesaria. En conclusión, el estudio demostró la importancia de promover y fortalecer la red de apoyo social para mejorar la calidad de vida y el estado de salud del cuidador.

Palabras clave:

Envejecimiento, Salud comunitaria, Cuidadores informales, Calidad de vida, Apoyo social.

Introduction

The undeniable reality of an aging population is continually expanding. According to Eurostat (1) data, individuals over 65 years old constitute 19.4% of the European population. On average, those over 65 can expect to live another 20 years, with 9 being disability-free and 11 involving some level of disability, requiring assistance and everyday care.

Presently, 29.94% of people aged 64 and above in Spain are dependent on others for their daily activities (2). The majority of care is provided by informal caregivers at home, driven by the aging population (3). Female caregivers, typically aged 55 to 60 with limited education and no paid employment, are the primary caregivers, significantly impacting their quality of life (4).

However, challenges in balancing family care and work lead to immigrant women filling the caregiving gap (5). Conversely, the recent economic crisis and high unemployment rates have resulted in increased male presence in households, a significant deviation from previous decades. The rise in demand for informal home care is associated with the aging population.

The consequences of caregiving are substantial, potentially overwhelming caregivers (6) and impacting not only their health but also that of the dependent individual (7). Support for caregivers can enhance the quality of life for both parties (8). Insufficient social support emerges as a risk factor for increased morbidity and mortality among caregivers, profoundly affecting their quality of life (9).

This study aims to analyze the quality of life of primary caregivers for dependent individuals, examining social support as an associated variable. Secondary objectives include profiling these caregivers and exploring associations with quality of life and perceived social support. The study seeks to provide valuable insights into the intricate dynamics of caregiving and its impact on both caregivers and dependents.

Methods

Study design

We conducted a cross-sectional study using both descriptive and quantitative methods. To ensure the quality of our study, we employed the STROBE checklist for cross-sectional studies.

A consecutive non-probabilistic sampling method was utilized to select caregivers of dependent patients requiring a high level of care, meeting inclusion criteria of providing care for over six months, not receiving any financial benefits, and willingly participating by signing an informed consent form. Data were collected in 2018 by two teams comprising nursing and psychology professionals working at two primary care centres in the Region of Murcia (Southeast Spain). The study included 80 participants, providing a 95% confidence level that the population mean would not deviate from the sample mean by more than 2 units. To determine the sample size, the standard deviation of the dependent variable (the quality-of-life test) was assumed to be 9 units based on data from the pilot study's 30 subjects.

Assessment tools

For this study, a health-related quality of life (QLRH) questionnaire was developed to capture information on the variables of interest. A 14-item test was specifically designed to assess health-related quality of life, serving as the primary response variable. The Likert scale employed ranged from 1 (never or none, indicating a better state) to 4 (always or a lot, signifying the opposite), thereby eliminating neutral responses and compelling respondents to choose either a positive or negative option. Scores ranged from a minimum of 14 to a maximum of 56, with a higher score indicating poorer quality of life.

The questionnaire incorporated the Multidimensional Scale of Perceived Social Support (MSPSS) developed by Zimet (10), a tool that has undergone psychometric validation in multiple studies (11). The MSPSS was utilized to assess caregivers' subjective perception of social support and its correlation with their quality of life. Comprising 12 items, the scale used a Likert response format with four options, ranging from 0 (almost never) to 3 (always or almost always). A higher score indicated a greater perception of social support.

The study introduced several independent variables to analyze their influence on caregivers' quality of life and social support, including perception, gender, age, marital status, education, years of dedication to the dependent patient, hours per day dedicated to care, health status, cohabitation with the patient, type of family relationship with the patient, and professional activity. The study received ethical approval. The participants were informed in detail about the objectives and content of the study, and signed an informed consent form before the data collection. Moreover, authorization was obtained from the health centers. To follow ethical standards, confidentiality of the information was maintained at all times.

The study was conducted in accordance with the ethical standards outlined int the Declaration of Helsinki (12). The study was approved by the Ethics Committee of UCAM University (CE032105).

Analysis of data

Statistical analysis was performed using SPSS version 21.0 software. Descriptive statistics were used to summarize the continuous quantitative variables and frequency distributions were used for the categorical variables. The quality-of-life measure scale which was developed to address health issues, was evaluated via Cronbach's alpha calculation, along with the correlation coefficient of each item and the corrected total of the scale. To confirm that the quantitative variables to be analyzed followed a normal distribution, the Kolmogorov Smirnov test was performed prior to initiating the analysis, thereby allowing us to use parametric testing. To investigate the correlation between two quantitative variables, Pearson's correlation coefficient was employed. If the analysis was conducted on a dichotomous quantitative variable, Student's t-test for independent samples was utilized. If the qualitative variable was categorical, an analysis of variance (ANOVA) was performed, preceded by verifying the homogeneity of variances of the groups using Levene's test. The accepted confidence level used was set at $p<.05$.

Results

The study involved 80 caregivers with a mean age of 56.4 ± 15.2 years. Of the participants, 56 (70%) were men and 24 (30%) were women. The 14-item scale developed to assess negative quality of life (higher score indicating lower quality of live) achieved a Cronbach's alpha coefficient of .911 in the homogeneity test, with each item having a correlation coefficient with the total corrected scale greater than .300 (Table 1). The mean total score of the scale was 35.7 ± 7.1. The Zimet scale, that measures the perceived social support of the caregivers (higher score indicating more and greater support), achieved a Cronbach's alpha coefficient of .969 and a mean value of 16.3 ± 9.7 in the homogeneity test performed to ensure study reliability.

Relationship between caregiver age daily hours of dedication, perceived social support and quality of life. The analysis of correlation between quality of life and social support based on the two scales used in the study, indicated a significant negative correlation ($r=.670$; $p<.001$). Caregivers of the dependent patients had a wide age range, with 32.5% of them being 65 years and older. Moreover, 72.5% of the caregivers had been performing their duties for 5 years of more, and half of them dedicated

Table 1. Quality of Life related with health Questionnaire

Item	Value of the response (N=80) %				M±SD	R Item with total scale
	1	2	3	4		
1. How would you define your current health?	1.3	28.8	52.5	17.5	2.86 ± .70	.686
2. In the last few months, has your health become worse?	11.3	36.3	43.8	8.8	2.50 ± .81	.673
3. In the last few months have you felt pain that impeded you from doing your daily activities?	11.3	42.5	32.5	13.8	2.49 ± .87	.692
4. In the last month, have you had difficulty going to sleep?	2.5	47.5	35.0	13.8	2.49 ± .87	.692
5. In the last three months, have you experienced changes in body weight?	28.8	42.5	28.8	0.0	2.00 ± .76	.492
6. In the last month, have you had gastrointestinal problems?	28.8	52.5	18.8	0.0	1.90 ± .68	.514
7. In the last month, how frequently have you felt unmotivated?	5.0	37.5	50.0	7.15	2.60 ± .70	.571
8. In the last month, has your emotional state negatively affected your ability to perform your daily activities?	20.0	43.8	31.3	5.0	2.21± .82	.646
9. In the last month, how frequently have you felt sad and/or depressed?	5.0	48.8	40.0	6.3	2.48 ± .69	.736
10. In the last month, how frequently have you felt anxious and/or stressed?	.0	42.5	52.5	5.0	2.63 ± .58	.545
11. In the last month, how frequently have you felt you needed help?	.0	27.5	32.5	40.0	3.13 ± .81	.614
12. Have you felt that your quality of life has become worse lately?	2.5	23.8	55.0	18.8	2.90 ± .72	.658
13. In the last few months, has your relationship with the rest of your family and/or friends decreased?	13.8	51.3	31.3	3.8	2.25 ± .73	.590
14. In the last month, have your responsibilities impeded you from doing what you truly like?	.0	21.3	42.5	36.3	3.15 ± .74	.651

M±DT - Mean ± standard deviation; R - correlation of the item with the total corrected scale; Responses 1, 2, 3, 4 - From 1 never or nothing, to 4 always and much.

Table 2. Age, years of Informal Care, hours of dedication per day and their relationship with quality of life and social support

Variables	M±SD	Quality of life		Social support
		Median	r (p)	r (p)
Age	56.4±15.2	56.5	.536 (<0.001)	-.357 (0.001)
Years of Informal Care	4.7±6.3	3	.167 (0.139)	-.101 (0.371)
Hours per day	16.3±7.8	16	.592 (<0.001)	-.475 (<0.001)

M - mean; SD - standard deviation; r - correlation coefficient; p - statistical significance.

16 or more hours per day. Of these, 46.3% dedicated themselves continuously for 24 hours each day. Table 2 shows the relationships between these variables and the quality of life as well as social support.

Table 3 shows the association of caregiver characteristics with quality of life and social support, gender, marital status, presence of any illness, living with the dependent person, support from other people, work outside home, level of studies, and type of relationship with the patient.

Table 3. Factors of study and their relationship with quality of life and social support

Factor of study		N (%)	Quality of life M ± SD	Social support M ± SD
Gender				
	Male	56 (70.0)	35.6 ± 6.4	16.5 ± 8.9
	Female	24 (30.0)	35.8 ± 8.7	15.7 ± 11.6
			p= .931	p= .740
Marital status				
	Married-widower	61 (76.2)	36.5 ± 6.9	16.2 ± 9.6
	Single-separated	19 (23.8)	33.0 ± 7.1,	16.6 ± 10.5
			p= .058	p= .866
Do you suffer from an illness?				
	Yes	35 (43.8)	39.4 ± 6.3	14.4 ± 10.0
	No	45 (56.2)	32.7 ± 6.3	17.8 ± 9.4
			p< .001	p= .128
Do you live with the dependent?				
	Yes	53 (66.3)	38.1 ± 6.5	13.6 ± 9.6
	No	27 (33.7)	31.0 ± 6.0	21.4 ± 8.1
			p= <.001	p= .001
Do you have support from others?				
	Yes	59 (73.8)	33.4 ± 6.5	20.0 ± 8.4
	No	21 (26.2)	41.9 ± 4.8	6.1 ± 4.8
			p< .001	p< .001
Do you work outside of the home?				
	Yes	31 (38.8)	32.6 ± 7.1	19.8 ± 8.7
	No	49 (61.2)	37.6 ± 6.4	14.1 ± 9.8
			p= .002	p= .010
Education of the caregiver				
	No education	16 (20.0)	39.1 ± 4.5	14.5 ± 8.1
	Primary school	42 (52.5)	36.6 ± 4.4	14.6 ± 9.3
	High school-university	22 (27.5)	31.3 ± 7.1	20.9 ±10.5
			p= .001	p= .035
Relationship with the patient				
	Spouse	16 (20.0)	40.8 ± 4.5	12.8 ± 8.1
	Son	46 (57.5)	35.0 ± 7.1	17.4 ± 10.1
	Other family member	18 (22.5)	32.8 ± 7.0	16.6 ± 9.9
			p= .002	p= .273

M - mean; SD - standard deviation; N (%) - sample size, category frequency; p - statistical significance.

Discussion

The profile of caregivers found in our study was consistent with that reported in the existing scientific literature. They are older caregivers (13), do not work outside home (14), are married (15). However, in terms of gender, and contrary to findings in the scientific literature (4), our sample of caregivers was predominantly male. According to Rodríguez del Pino et al. (16), as life expectancy increases, men begin to take on family care responsibilities apart from the gender-based inequality of rights and duties, which begins to change with the state of well-being. The state of unemployment caused by the economic crises of recent years has also had an impact leading men to become more active in these tasks. In terms of the participants' health, 43.8% admitted to suffering from some kind of illness. Previous studies like our data, have shown that these illnesses could be related to the process of caring (4). The risk of illness also increases for people living with dependent family members (17). According to Mosquera Metcalfe et al. (18), female carers have more health problems than men. However, and in relation to the overload suffered, our study showed that there were no significant differences in overload between men and women, and the notion that gender could predict it was not observed (19). It seems that when men start to have a greater overload, these gender differences in health problems disappear or are even reversed (20).

With regard to the characteristics related to the dedication to caregiving tasks, the mean value of the hours devoted per day was 16.3 hours, similar to findings in other studies (21). Among the factors related to caregiver strain, the time devoted to caregiving was found to be one of them, showing that the greater the number of hours, the greater the strain (7). Regarding the prolongation of care over time, our sample of caregivers had carried out their duties for an average of 4.75 years. These values are similar to those found in the study by Flores et al. (22), which showed that most of them had been dedicated to it for 1 to 5 years. While it is common to find only one family member providing care, our study revealed that 73.8% of participants received assistance with their caregiving duties. In more than half of these cases, the support came from another family member who did not reside in the same household.

The impact of caregiving on the quality of life and health of caregivers is significant (15,23). Our data provided evidence of worsening quality of life as a result of caring for a dependent patient. From the data obtained, it was concluded that the quality of life of caregivers was significantly influenced by the number of hours they spent caring for a dependent patient each day. Those who devoted all their time to care for these patients and had no paid work, had a lower quality of life. Finally, as a limitation of the study, it should be pointed out that the participants were selected according to the criteria of accessibility and cooperation, and therefore, the representation of the sample to the general population cannot be discussed due to the limited nature of the sample. Therefore, the generalisation of results and conclusions should be done with caution. A new health-related quality of life (QLRH) questionnaire was created, which we believe is well-adapted to the population with which it was used, overcoming the limitations found in other QLRH questionnaires, it is crucial to note that the validity of this tool was never the primary objective of the study. The questionnaire has demonstrated excellent psychometric properties, evidenced by a robust Cronbach's alpha coefficient, indicative of high internal consistency. Additionally, the instrument has shown to be highly sensitive to changes in the measured variables. Despite these promising results, a formal validation process, including measures such as face validity or evaluation by an expert panel, was not conducted. While internal reliability indicators are strong, we acknowledge the need to address questionnaire validation in future research to further enhance its utility and applicability in different contexts.

The findings highlight the need to implement multidisciplinary interventions to support caregivers, both preventive and supportive, and to advocate for effective time management to reduce stress (24). Nurses are a primary source of support for caregivers and training for better patient care (25).

In a Canadian study, almost a third of caregivers who received support said they wish they had received more; on the other hand, not receiving adequate support was a factor with a direct impact on life satisfaction and mental health (26). A European study also found greater well-being among caregivers in countries with higher levels of support for older people (27). According to Schüz et al. (28), participating in social activities and self-help groups are a resource for informal carers. Strengthening social support (institutions, social network and family-based support) could improve quality of life and benefit caregivers perceived health, making it a necessary intervention. According to Marsack-Toppolewski (29), informal social support influences the relationship between strain and quality of life, making it necessary to provide such support with social and financial assistance.

The used tools related to quality of life and perceived social support, allow for a proactive approach, and have a specific predictive character on the state of health of informal carers, a very important group of the population who take care of the elderly and are dependent on the community environment, and in line with Henderson and Denny (30), we believe that strengthening resilience in the general population would be an important health tool for both, carers and patients.

Limitations

This study is subject to certain limitations that should be taken into account when interpreting the findings. Firstly, the relatively small sample size may impact the generalizability of the results to larger populations. Additionally, it is noteworthy that data collection occurred in 2018, marking a five-year gap since the information was gathered. This temporal aspect raises considerations about the current relevance and applicability of the results, particularly in a field characterized by rapid developments. Furthermore, the potential for sampling bias exists, given that the proportion of male participants in the study exceeds expectations based on prior literature.

Consequently, caution is advised when extrapolating the findings to other populations or healthcare contexts.

Conclusion

In conclusion, this study provided valuable insights into the demographic and health characteristics of informal caregivers for dependent patients. Our findings revealed a notable presence of male caregivers, primarily sons of the dependent individuals, dedicating an average of 16 hours daily to caregiving duties, with 4-5 years of commitment and sporadic assistance from family members. The inclusion of men in informal care challenges traditional gender associations, suggesting a noteworthy shift that merits consideration in future research studies. It emphasizes the importance of viewing informal care beyond traditional gender roles.

Moreover, our study highlighted that caregivers tended to have lower educational levels and fewer employment opportunities, coupled with health issues. Notably, a higher quality of life among caregivers was linked to a perceived increase in social support. Conversely, factors such as not working outside the home, experiencing health problems, dedicating more hours to caregiving, cohabitating with the patient, and lacking support were associated with a poorer quality of life. Recognizing and addressing these determinants could contribute to enhancing caregivers' overall well-being.

The implications of our findings suggest a crucial role for psychologists and nurses in promoting self-care and strengthening the support networks for caregivers of dependent patients. Future research should continue exploring the evolving landscape of caregiving dynamics, considering the changing demographics and the diverse challenges faced by caregivers. Ultimately, fostering a comprehensive understanding of these factors will facilitate targeted interventions to improve the quality of life and health outcomes for caregivers and, by extension, the individuals they care for.

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