ORIGINAL ARTICLE

Quality of life of caregivers of persons with neurological disorder sequels

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KEYWORDS
Caregivers;
Burden;
Quality of life;
Nursing

Abstract
Introduction: People with neurological disorders require family support; therefore, they have to assume the function of taking care of them. The persons that take on the important work of caring and attending the needs of these people have to modify their life, which could be a burden and could affect their quality of life.
Aim: To determine the health related quality of life and burden in caregivers of people with neurological disorders.
Method: A descriptive correlational, cross-sectional study was conducted using an intentional sample. The information was collected using 4 different tools: sociodemographic variables, Barthel scale, Betty Ferrell, and Zarit scale.
Results: A total of 47 caregivers were included, with a mean age of the patient of 61.1 years (SD 15.36). The mean age of the caregiver was 48.21 years (SD 13.65), and were mainly women (70.2%), and the predominant relationship was wife. It was found that the spiritual and social wellness domains of the quality of life were affected. The overall score of the Zarit scale did not show overload (28.86). There was a correlation between the physical, psychological, and social dimensions of the quality of life, but not with the spiritual. There was also a correlation between burden and the physical and social dimensions.

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Conclusions: The caregivers are mainly women, with their quality of life affected in 2 dimensions, and do not show burden. Low correlations were found between the burden and the physical and social dimensions. The aim of health professionals is to offer a comprehensive approach to informal caregivers to mitigate the impact of burden on their quality of life.

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<table>
<thead>
<tr>
<th>PALABRAS CLAVE</th>
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<tbody>
<tr>
<td>Cuidadores;</td>
</tr>
<tr>
<td>Sobrecarga;</td>
</tr>
<tr>
<td>Calidad de vida;</td>
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<tr>
<td>Enfermería</td>
</tr>
</tbody>
</table>

Calidad de vida de cuidadores de personas con secuelas de trastornos neurológicos

Resumen
Introducción: Las personas con trastornos neurológicos requieren de apoyo familiar, por lo tanto, deben asumir la función de cuidado; la persona que desempeña la importante labor de cuidar y atender las necesidades de estas personas debe modificar su vida, lo cual puede llevarla a presentar sobrecarga y afectar su calidad de vida.

Objetivo: Determinar la calidad de vida relacionada con la salud y el grado de sobrecarga en cuidadores de personas con trastornos neurológicos.

Método: Estudio descriptivo, correlacional, transversal, con una muestra intencional. La información se recolectó mediante 4 instrumentos: caracterización sociodemográfica, escala de Barthel, instrumento Betty Ferrell y escala de Zarit.

Resultados: Se incluyeron 47 cuidadores; la edad promedio del paciente fue de 61,1 años (DE 15,36) y la del cuidador, de 48,21 (DE 13,65). Eran principalmente mujeres (70,2%) y la relación, de esposa. Se encontró afectación en la calidad de vida en el bienestar social y espiritual. La calificación global de la escala de Zarit no reporta sobrecarga (28,86); se encontró correlación entre las dimensiones física, psicológica y social de la calidad de vida, no hay correlación con la espiritual; existe correlación entre la sobrecarga y las dimensiones física y social.

Conclusiones: Los cuidadores son principalmente mujeres, con afectación de la calidad de vida en 2 dimensiones y no presentan sobrecarga; se encontraron correlaciones bajas entre la sobrecarga y las dimensiones física y social. La meta de los profesionales de la salud es el abordaje integral de los cuidadores informales para mitigar el impacto de la sobrecarga sobre la calidad de vida.

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Introduction
The World Health Organisation considers that the increase in life expectations and the ageing of the population worldwide will lead to an increase in the prevalence of many non-contagious, chronic and progressive conditions, such as neurological disorders. According to estimations for the year 2030, 6.77% of the population will have some type of neurological disorder. Furthermore, the increasing capacity of medicine to prevent death has increased the frequency and severity of deterioration associated with these disorders, bringing with it the need to offer an acceptable quality of life to people presenting with sequelae leading to these disorders.¹

The above leads health professionals to care for people who are victims of neurological disorders which require family support. Strategies therefore need to be devised to help resolve the caregiver’s needs and those of the person cared for. According to Roy, the caregivers play primary, secondary and tertiary roles, which makes it possible for the care experience to become a doable practice. Dependent relationships affect the desire and capacity to give to others and to receive from them all that may be offered: love, respect, values, education, knowledge, skill, responsibilities, material goods, time and talent.²

The family must satisfy the basic needs of its members and it is the essential means for conveying cultural, moral and spiritual values to new generations, together with the customs and traditions of each society.³ The way the family functions is changed by how its members face up to new situations. These may bring fear, uncertainty and discussions regarding adverse situations that affect the physical, psychological, social and spiritual well-being in the quality of life of family members (Appendix).

The role of the caregiver is undoubtedly important in the process of recovery of the patient, but it is not easy for either of them. Both must confront a series of social conditions which, when added to their emotional state and the drama derived from the illness, forces them to confront different obstacles. This is where the preparation of the caregiver plays an essential role, where trust, tranquility and the security that the ill person has temporarily lost will
Quality of life of caregivers of persons with neurological disorder sequels

be recuperated as the caregiver gradually accepts his or her role.

The main caregiver is the family member or close person who becomes the main support to the other person permanently and committedly, both physically and emotionally. The family generally offer the main support. It is usually a family member who accepts maximum responsibility and therefore the person who undertakes the greatest physical and emotional burden of care.4

That person who plays the important role of caring for and attending to the needs of people from their home and from their available resources, overloads the functions of their family and social role, adapting to new conditions to improve the health and well-being of the person they are caring for. Care thus becomes a daily battle against the disease, where monotonous and repetitive tasks are carried out with a sensation of lack of control over the result of this labour which finally exhausts the physical and mental reserves of the caregiver, leading to overburden and affecting their quality of life.

Ferrel accepts quality of life of the caregivers as a subjective evaluation of attributes, both positive and negative, which characterise their life itself. There are basically 4 areas which cover different types of well-being: physical, psychological, social and spiritual.3

The above has led to the suggestion of an objective which is: to determine the quality of life relating to health and the degree of overburden in caregivers of people with neurological disorders.

Materials and methods

A quantitative, descriptive, correlational, transversal study with an intentional sample design was conducted. The participants (n = 47), the main caregivers of people with neurological disorders (traumatic cerebral vascular injury, spinal injury, brain injury), reported in the data base of the Hospital Universitario de Neiva (Colombia), who met with the inclusion criteria: over 18 years of age, caregiver for a period of more than 3 months, caregivers of people which severe and major dependency, according to the Barthel scale classification. The study was approved by the Committee of Bioethics of the Universidad Surcolombiana, with concern for the bioethical principles: respect for human dignity, privacy, freedom of expression and feelings, confidentiality and reciprocity. Data collection was made by the researchers and 2 research assistants. Initially this was through telephone contact and an appointment was confirmed at the caregiver’s home, where research tools were implemented.

Data collection tools

Socio-democratic characterisation of caregivers (drawn up by the chronic patient Care Group and their family, the Faculty of Nursing, Universidad Nacional de Colombia, 2002), with the following variables: gender, age of caregiver, age of person receiving care, educational level, marital status, occupation, socio-economic strata, time as caregiver, hours dedicated to care, single caregiver, caregiver-patient relationship, religion, support which they may count on for caring, profession or job of the caregiver and other support sources.

The Barthel scale5,6 which seeks to give each patient a score according to their level of dependency in basic daily life activities. The scores are given as follows: autonomy 100, partial dependency 71–99, moderate dependency 51–70, serious dependency 31–50, major dependency 0–30. Quality of life of the caregiver,5,7 with 37 items, 16 formulated positively and 21 inversely; consists of 4 subscales which make up the quality of life: physical (5 items), psychological (16 items), spiritual (7 items) and social (9 items).

The group of teachers from the Nursing Faculty of the Universidad Nacional de Colombia undertook the translation into Spanish, the adaptation of the Likert scale, the semantic fine-tuning, the facial validity and the validity of content; confidence level was established with 37 items, with a base of 108 data intake and re-test. Cronbach’s alfa was 0.88, which indicated a positive correlation and satisfied stability criteria.6,7 The assessment of each item was made using a Likert scale of 1 to 4: 1, absence of any problem; 2 somewhat problematic; 3, problematic, and 4, greatly problematic.10

Scores for each area of well-being were established as follows: physical 5–20; psychological 16–64; social 9–36; spiritual 7–28. Minimum values were interpreted in the following way: physical (<12.5), social (<22.5) and spiritual (<17.5) are equivalent to a positive perception in each dimension; in psychological (<40), negative perception in the emotional area.10

Overload of the caregiver using the abbreviated Zarit scale11; this assesses several factors of influence: impact of care, interpersonal relations and expectations of self-efficacy. This tool has been used in Spanish cities, effectively adapted to primary care settings and with predictive positive levels of up to 100%. It contains 22 Likert type questions with a response range of between 0 and 4 (never, almost never, sometimes, often, always); the range under 46 indicates no overburden, from 46 to 56 slight overburden, and over 56 intense overburden.

Data analysis

A data collection matrix was prepared in drawn Microsoft Office Excel2007; the SPSS7 version 15.0. programme was used for statistical analysis. For data analysis the following statistics were applied: central tendency, frequency tables, general tables and Spearman correlation with statistical significance at a value of p < 0.05.

Results

The average patient age was 61.1 years (SD 15.36), 64% with major dependency and 36% with severe dependency (Table 1). Relevant socio-demographic traits of the caregivers (n = 4) were as follows: most were female (70.2%), over 36 years of age (82.9%), and with a mean age of 48.21 (SD 13.65), education level: did not complete high school and completed high school of 21.3% and 31.9%, respectively, married 63.9%, time dedicated to care over 7 months, hours dedicated to care over 13 h, mainly belonging to socio economic strata 2 and relationship to caregiver was spouse in 38.3% of cases.
Table 1  Patient and caregiver characteristics (No. = 47).

<table>
<thead>
<tr>
<th>Socio-demographic variables</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>33</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
</tr>
<tr>
<td>Caregiver’s age, n (%)</td>
<td></td>
</tr>
<tr>
<td>18–35</td>
<td>8</td>
</tr>
<tr>
<td>36–59</td>
<td>27</td>
</tr>
<tr>
<td>Over 60</td>
<td>12</td>
</tr>
<tr>
<td>Mean ± standard deviation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>48.21 ± 13.65</td>
</tr>
<tr>
<td>Mean</td>
<td></td>
</tr>
<tr>
<td>Patient’s age</td>
<td></td>
</tr>
<tr>
<td>Mean ± standard deviation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>61.11 ± 15.36</td>
</tr>
<tr>
<td>Mean</td>
<td></td>
</tr>
<tr>
<td>Level of dependence according to Barthel, n (%)</td>
<td></td>
</tr>
<tr>
<td>Major dependence</td>
<td>30</td>
</tr>
<tr>
<td>Severe dependence</td>
<td>17</td>
</tr>
<tr>
<td>Level of education, n (%)</td>
<td></td>
</tr>
<tr>
<td>Incomplete primary</td>
<td>12</td>
</tr>
<tr>
<td>Complete primary</td>
<td>5</td>
</tr>
<tr>
<td>Incomplete high school</td>
<td>10</td>
</tr>
<tr>
<td>Complete high school</td>
<td>15</td>
</tr>
<tr>
<td>Technical</td>
<td>4</td>
</tr>
<tr>
<td>Complete University</td>
<td>1</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
</tr>
<tr>
<td>Married</td>
<td>30</td>
</tr>
<tr>
<td>Separated</td>
<td>5</td>
</tr>
<tr>
<td>Widow/widower</td>
<td>1</td>
</tr>
<tr>
<td>Living together</td>
<td>7</td>
</tr>
<tr>
<td>Time as caregiver, n (%)</td>
<td></td>
</tr>
<tr>
<td>0–6 months</td>
<td>7</td>
</tr>
<tr>
<td>7–18 months</td>
<td>21</td>
</tr>
<tr>
<td>19–36 months</td>
<td>7</td>
</tr>
<tr>
<td>Over 37 months</td>
<td>12</td>
</tr>
<tr>
<td>Hours dedicated to caring daily, n (%)</td>
<td></td>
</tr>
<tr>
<td>7–12 h</td>
<td>10</td>
</tr>
<tr>
<td>13–23 h</td>
<td>17</td>
</tr>
<tr>
<td>24 h</td>
<td>20</td>
</tr>
<tr>
<td>Social strata of where they live, n (%)</td>
<td></td>
</tr>
<tr>
<td>Strata 1</td>
<td>13</td>
</tr>
<tr>
<td>Strata 2</td>
<td>26</td>
</tr>
<tr>
<td>Strata 3</td>
<td>5</td>
</tr>
<tr>
<td>Strata 4</td>
<td>3</td>
</tr>
<tr>
<td>Relationship with person cared for, n (%)</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>18</td>
</tr>
<tr>
<td>Mother/father</td>
<td>2</td>
</tr>
<tr>
<td>Son/daughter</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
</tr>
</tbody>
</table>

To confirm the normal distribution of variables the Shapiro–Wilk (Table 2) test was used. The total score of the dimension comprising quality of life are presented; the data reported in the physical well-being show a mean of 11.2, with positive perception in their state of health being observed, due to the condition as main caregiver. Equally, in the psychological well-being there was a score of 53.3, the data recorded were related to low influence in this dimension, with a positive perception existing in the same. In social well-being there was a mean score of 24.4; there are negative perceptions of its social relationships, which has a negative influence on quality of life as a caregiver. Lastly, there was a mean score of 20 in the spiritual dimension, a consistent value with a negative perception of spirituality (Table 2).

With regards to the overburden of the caregiver, it was found that the overall score was 28.6, a value associated with the absence of overburden (Table 2); we also found that the majority of the items were given a score of between never and almost never. It is important to emphasise the following items which received scores of between sometimes, often and almost always: item 1 with 51.1%; item 2 with 53.3%; item 7 with 87.3%; item 8 with 97.9%; item 14 with 85%; item 15 with 65.9%; item 18 with 61.8%; item 22 with 54.8%. The previously stated variables may be factors which when not appropriately controlled may lead to overburden in the main caregiver (Table 3).

According to Table 4, when contrasting physical well-being and psychological well-being a correlation was found to exist at \( r = 0.581; p = 0.00 < 0.05 \), which indicates the greater the physical well-being the higher the psychological well-being. Significant correlation was found when comparing physical well-being with social well-being \( (r = 0.336; p = 0.021 < 0.05) \), the greater the physical well-being the higher the social well-being. When physical well-being was correlated with spiritual well-being \( (r = 0.185; p = 0.212 < 0.05) \), psychological with social \( (r = 0.184; p = 0.216 < 0.05) \), psychological with spiritual \( (r = -0.073; p = 0.672 > 0.05) \) and social with spiritual \( (r = -0.163; p = 0.230 > 0.05) \) no significant associations were found.

It was observed that there were correlations between overburden and physical well-being \( (r = 0.355; p = 0.014 < 0.05) \) and overburden and social well-being \( (r = 0.380; p = 0.008 < 0.05) \). Overburden has no association with psychological well-being \( (r = -0.085; p = 0.570 > 0.05) \) or spiritual \( (r = 0.037; p = 0.803 > 0.05) \).

Discussion

The predominant socio-demographic characteristics of caregivers are: female; married; over 36 with a mean of 48.21 years of age; complete and incomplete primary educational level and to a lower extent completed technical studies (8.5%) and university education (2.1%); low socioeconomic strata level with predominance of 1 and 2; care duration of over 7 months; dedicate over 12 h to care; relationship with the cared for person: spouse. Findings are concordant with the results of investigations by: Flórez et al., 5, Kruthof et al., 6, Covarrubias and Andrade, 7 Cedano et al., 8 Romero et al., 9 Ávila-Toscano and Vergara-Mercado, 10 Vega et al., 11 Rha et al., 12 and López-Espuela et al., 13 That previously described could become a factor affecting the quality of life and therefore lead to overburden of the caregiver, associated with adverse conditions related to economic aspects...
which affect people with fewer resources, modification of
their lifestyle, which depends on the long days they have to
accept when caring for people with chronic illnesses, and
which transform their personal, working and social relation-
ships.

In practice, these traits mean that caring for the depend-
ent person becomes a negative event, leading to the fact
that the experience of caring is defined in terms of care-
giver burden, exhaustion of the caregiver or care demands.\textsuperscript{20} Moreover, Blum and Sherman\textsuperscript{21} acknowledge that caring is
regarded as a feminine quality. The caregiver is usually the
wife, mother, grandmother or another female figure of the
family.

Here, Cho\textsuperscript{22} identified that support is given through
different types of relationships, by primary groups: spouses,
children, relatives and non relatives. The spouses live
together and therefore have a face to face relationship, and
offer support over long periods of time. This is consistent
with research findings, which confirm that the main rela-
tionships with the person cared for is that of wife, daughter
or sister.

With regard to quality of life, we found that there was
greater influence in social and spiritual well-being, two
traits that are considered essential for maintaining the
caregivers’ quality of life and findings which are incon-
gruent with those of Flórez et al.,\textsuperscript{23} where the physical
and psychological dimensions were most influential, and
social and spiritual to a lesser extent. However, when com-
paring children and adults with chronic diseases, Flórez
et al.\textsuperscript{23} found that the dimension with the greatest in-
fluence was physical. Vega et al.\textsuperscript{24} results reported there was
influence in the dimensions related to physical and social
well-being and good scores in the physical and spiritual
dimensions.

At the same time, Grant and Ferrell\textsuperscript{24} identify the need
for caregivers to be aware of the demands which their
new responsibilities entail, and these include physical care,
social well-being, psychological well-being and spiritual
support. Likewise, Northouse et al.\textsuperscript{25} describe how chronic
diseases affect the quality of life of the caregivers, in all
areas, but mainly in the psychological sphere. They consider
that to reduce emotional distress it is important to assess
family needs, and generate strategies which help to reduce
them. The main objective of these is to offer effective care
while maintaining well-being and the caregiver’s health.

It is therefore important to maintain healthy conditions
and support to caregivers, so that they are able to care
efficiently and effectively to satisfy the person’s needs.
Health professionals and particularly nurses are called upon
to develop caring relationships to cover the caregiver/cared
for person duo, design strategies of intervention which serve
as support in the long-term for the caregivers and their
families. The informal care will therefore be good quality
and will reduce the health problems of the people which
chronic diseases, upholding the quality of life of both people
involved.

When qualifying overall overburden using the Zarit tool,
the caregivers gave an overall score of low overburden in
caring for their family member. This trait may be affected
by the sample size. These results differ from findings by Flo-
res et al.,\textsuperscript{26} who reported 59.7% of their sample population
as having intense overburden. Rha et al.\textsuperscript{18} equally reported
that a quarter of their sample experienced high overload,
mainly in areas related to relationships and finances. This
trait should therefore be taken into consideration as it may
have a negative impact on the caregiver’s health,\textsuperscript{19} asso-
ciated with anxiety, sadness and depression, back pain,
insomnia, deterioration of sexual life and the relationship
of partnership, leading to a deterioration in the quality of
life of the person caring for the dependent person.

Caring for a dependent person may limit the care-
giver’s ability to participate in social activities, and this
has a negative impact on their well-being. However, when
the family caregivers have good support from the commu-
nity (for example, information, emotional and instrumen-
tal resources), they may compensate for the difficulties
associated with experience.\textsuperscript{29} In contrast, according to Zarit
and Whitlatch,\textsuperscript{28} when the family lacks support and resources,
they experience an increase in physical, financial and psy-
cosocial costs, and this in the last analysis may compromise
the quality of care which they are able to provide. When
there are adverse circumstances, the caregiver experiences
an overburden from accepting the task of caring for their
loved one and this in turn affects their quality of life.

The results show a low correlation between overburden
and the physical and social dimensions of quality of life.
When comparing these findings with the study by Fernández
et al.,\textsuperscript{15} who used the Zarit scale to determine overburden
and a different tool for measuring quality of life, we see
that they differ. The before-mentioned authors found neg-
avative associations between overburden and quality of life,
which suggest that the lower the scores on quality of life, the
greater the perceived overburden in accepting the caregiver
role.

Furthermore, there is a discrepancy between the findings
from this research with those of Mar et al.,\textsuperscript{21} who employed
the Zarit scale to score on overburden and the EuroQol qual-
ity of life tool. They recognise that the higher the score

\begin{table}[ht]
\centering
\caption{Scores and normality test (Shapiro–Wilks) of quality of life
variables and caregiver overburden.}
\begin{tabular}{|l|c|c|c|c|c|c|}
\hline
Variable & Mean & CI 95\% & Median & Variance & Standard deviation & p \\
& & Lower limit & Upper limit & & & \\
\hline
Physical & 11.2 & 10.4 & 12.0 & 12.0 & 7.5 & 2.7 & 0.008 \\
Psychological & 53.3 & 51.8 & 54.9 & 54.0 & 28.3 & 5.3 & 0.000 \\
Social & 24.4 & 23.1 & 25.6 & 25.0 & 18.2 & 4.3 & 0.298 \\
Spiritual & 20.0 & 19.2 & 20.8 & 20.0 & 7.4 & 2.7 & 0.047 \\
Overburden & 28.6 & 25.0 & 32.3 & 26.0 & 157.0 & 12.5 & 0.178 \\
\hline
\end{tabular}
\end{table}
### Table 3 Percentage in Zarit tool score.

<table>
<thead>
<tr>
<th>Items</th>
<th>Never %</th>
<th>Almost never %</th>
<th>At times %</th>
<th>Quite often %</th>
<th>Almost always %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You feel your family member asks for more help than they actually need</td>
<td>34</td>
<td>14.9</td>
<td>27.7</td>
<td>12.8</td>
<td>10.6</td>
</tr>
<tr>
<td>2. You feel that because of the time you dedicate to your family member you no longer have enough time for yourself</td>
<td>19</td>
<td>27.7</td>
<td>27.7</td>
<td>12.8</td>
<td>12.8</td>
</tr>
<tr>
<td>3. You feel tense when you have to care for your family member and also carry out other responsibilities</td>
<td>46.8</td>
<td>21.3</td>
<td>23.4</td>
<td>4.3</td>
<td>4.3</td>
</tr>
<tr>
<td>4. You feel embarrassed by your family member’s behaviour</td>
<td>93.4</td>
<td>2.1</td>
<td>2.1</td>
<td>2.1</td>
<td>2.1</td>
</tr>
<tr>
<td>5. You feel angry when you are near your family member</td>
<td>83</td>
<td>8.5</td>
<td>8.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6. You believe that the current situation has a negative effect on your relationship with friends and other family members</td>
<td>80.9</td>
<td>10.6</td>
<td>4.3</td>
<td>0</td>
<td>4.3</td>
</tr>
<tr>
<td>7. You feel afraid about the future of your family member</td>
<td>12.8</td>
<td>0</td>
<td>12.8</td>
<td>27.7</td>
<td>46.8</td>
</tr>
<tr>
<td>8. You feel that your family member depends on you</td>
<td>2.1</td>
<td>0</td>
<td>8.5</td>
<td>29.8</td>
<td>59.6</td>
</tr>
<tr>
<td>9. You feel stressed when you have to be near your family member</td>
<td>72.3</td>
<td>19.1</td>
<td>6.4</td>
<td>2.1</td>
<td>0</td>
</tr>
<tr>
<td>10. You feel your health has suffered from caring for the family member</td>
<td>29.8</td>
<td>23.4</td>
<td>27.7</td>
<td>10.6</td>
<td>8.5</td>
</tr>
<tr>
<td>11. You feel you do not have the private life you would like because of your family member</td>
<td>53.2</td>
<td>21.3</td>
<td>19.1</td>
<td>0</td>
<td>6.4</td>
</tr>
<tr>
<td>12. You think your social life has been affected by having to care for the family member</td>
<td>66</td>
<td>14.9</td>
<td>12.8</td>
<td>0</td>
<td>6.4</td>
</tr>
<tr>
<td>13. You feel uncomfortable about inviting friends home, due to your family member</td>
<td>89.4</td>
<td>0</td>
<td>4.3</td>
<td>2.1</td>
<td>4.3</td>
</tr>
<tr>
<td>14. You think that your family member expects you to care for them, as if you were the only person they can count on</td>
<td>14.9</td>
<td>2.1</td>
<td>29.8</td>
<td>23.4</td>
<td>29.8</td>
</tr>
<tr>
<td>15. You feel you do not have enough money to care for your family member and pay the other expenses</td>
<td>17</td>
<td>17</td>
<td>25.5</td>
<td>17</td>
<td>23.4</td>
</tr>
<tr>
<td>16. You feel you will be incapable of caring for your family member for much longer</td>
<td>46.8</td>
<td>21.3</td>
<td>27.7</td>
<td>2.1</td>
<td>2.1</td>
</tr>
<tr>
<td>17. You feel you have lost control of your life since the illness of your family member became apparent</td>
<td>61.7</td>
<td>19.1</td>
<td>8.5</td>
<td>4.3</td>
<td>6.4</td>
</tr>
<tr>
<td>18. You would like to be able to entrust the care of your family member to other people</td>
<td>34</td>
<td>4.3</td>
<td>44.7</td>
<td>12.8</td>
<td>4.3</td>
</tr>
<tr>
<td>19. You feel unsure about what you should do with your family member</td>
<td>51.1</td>
<td>36.2</td>
<td>10.6</td>
<td>0</td>
<td>2.1</td>
</tr>
<tr>
<td>20. You feel you should do more than you do for your family member</td>
<td>34</td>
<td>21.3</td>
<td>31.9</td>
<td>2.1</td>
<td>10.6</td>
</tr>
<tr>
<td>21. You believe you could care for your family member better than how you do now</td>
<td>27.7</td>
<td>25.5</td>
<td>31.9</td>
<td>8.5</td>
<td>6.4</td>
</tr>
<tr>
<td>22. In general, you feel very overburdened by having to care for your family member</td>
<td>19.1</td>
<td>0</td>
<td>29.8</td>
<td>34</td>
<td>17</td>
</tr>
</tbody>
</table>
on the Zarit scale, the lower the quality of life, in people with acquired brain damage, in their study sample. Likewise, López-Espuela et al.\(^{19}\) reported in their study that caregivers experienced some type of overburden and this had an effect on their physical and emotional well-being, which is not in concordance with our findings.

Overburden has a direct effect on quality of life, and for this reason the actions of health groups must be geared towards preserving that of the caregivers, using strategies that contribute to creating a positive impact on the physical, psychological, social and spiritual dimensions, strengthening caregiver programmes where educational and leisure activities are promoted and fortifying social, family, advisory, financial orientation links to consolidate links between the caregiver/person cared for. This link then becomes an effective relationship when assessing the results of the care offered by the caregiver and perceived by the person being cared for.

With regards to the correlation between the dimensions of quality of life, it was found that a correlation existed between the physical, psychological and social dimensions whilst the spiritual dimensions had no correlation with the other three. These data may be consistent with the perception that the greater the psychological and social well-being the higher the appreciation of physical well-being which produces a positive impact on the quality of life of the caregivers. It may be stated that the greater the anxiety, anguish, depression, financial and social difficulties, social isolation, among other aspects, the greater the risk that the caregiver will experience physical difficulties such as backache, headaches and fatigue, which reduces the quality of care given and often leads to its abandon.

The findings from this research should serve as a resource for the continuation of the consolidation process of caregiver programmes. These aim to build spaces for these anonymous heroines who take on the care of their loved ones, regardless of their lack of preparation for this challenge by the health system. They accept the challenge of caring for those people who depend on others to carry out the great majority of activities in their daily life. According to Blum and Sherman,\(^{21}\) "the evolution of palliative care has begun to revert the “mystery of death” back to an emphasis on relief of suffering". These same authors acknowledge the appearance of the patient/caregiver duo as the centre of palliative care, and thus shine a light on the poor preparation of the caregivers in confronting the demands entailed by care.

**Conclusions**

In the majority of cases the woman takes on the role of caregiver as the spouse. Her quality of life is affected socially and spiritually. However, there is no evidence of overburden. The goal of health professionals is to provide full support to these informal caregivers to mitigate the impact of overburden on their quality of life. This may be done through caregiver programmes, which seek to preserve life, health, support groups and family and social relationships in order for the care duty to be fully successful.

**Limitations**

The study limitation is related to the sample size, given that only 47 people met the inclusion criteria, and it is therefore not possible to generalise the research results.

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**Conflict of interests**

The authors have no conflict of interests to declare.
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References