

**Title: High perceived caregiver burden for relatives of patients following hip fracture surgery.**

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**Title: High perceived caregiver burden for relatives of patients following hip fracture surgery.**

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## **Abstract**

**Purpose:** To determine the profile of the main informal caregivers, evolution of the caregiver burden and influencing factors of caregiver burden at 1-year after hip fracture surgery.

**Methods:** In this prospective cohort study, a total of 172 informal caregivers of patients were interviewed during one year following hip fracture surgery in a regional hospital. The perceived caregiver burden was assessed using the Caregiver Strain Index (CSI, 0-13 points).

**Results:** The median (Q1-Q3) age of the 172 caregivers was 54 (47-65) years, of which 133 (77%) were woman and 94 (55%) were daughters of the patient. 79 of the 172 (46%) caregivers perceived a high level of burden ( $CSI \geq 7$  points) at the hospital. The corresponding CSI-data for 1-month, 3-months and 1-Year were 87 (51%), 61 (35%) and 45 (26%). A low pre-fracture functional status, post-surgery complications, older age of patients and younger age of caregivers influence caregiver burden at 1-year.

**Conclusions:** The profile of the main caregiver of hip fracture is a woman of middle age and is the daughter of the patient. The perceived caregiver burden decreased from 1-month to 1-year. More efforts are needed to avoid post-surgical complications in order to prevent caregiver burden at 1-year.

**Key words:** Caregiver burden, hip fracture, profile of caregivers, influence factors, elderly.

## **Introduction**

Hip fracture is an important health problem due to the increase of the incidence and the high mortality showed within the last years (1). It is estimated that the number of cases of hip fracture in the world population will increase from 1,66 millions of cases in 1990 to 2,94 in 2025 and 6,26 in 2050 (1). In the Spanish population older than 65 years, the annual incidence is more than 500 cases per 100 000 inhabitants (2). The Statistics National Institute forecast presents that the population older than 65 years will increase in Spain from 18,2% at present, until 24,9% in 2029 and 38,7% in 2064 (3), meaning a continue increase of the hip fracture patients in the following years.

Most of the hip fracture patients decrease their functional level due to the loss of ability to perform activities of daily living (4–6). After hip fracture surgery, the main objective of the treatment. is to return the patient to his pre-fracture functional level (7). However, achieve this objective is not always possible (8). The functional loss after hip fracture in comparison to pre fracture level is higher to 50% at 1 month, 25% at 3 months and 12% at 1 year (9). The short length of hospital stay, extends the need of the patients to receive help and care from other persons to perform his activities of daily living (10). The main informal caregiver, who is usually a relative that provides care to the patient (11), is the less expensive alternative after patient discharge (10).

The caregivers therefore need to learn new skills to develop a proper care of the patient (12). However the hip fracture is an unexpected event, therefore, the caregiver do not have too much time to develop this skills and take the responsibility of the care (11). This abrupt responsibility causes changes in the life of caregiver as higher preoccupations, which produces an increase of the caregiver burden (12). Siddiqui et al., demonstrated that the caregivers of hip fracture patients, experience stress from the

fracture and even until 6 months thereafter (13). In the same line, Shyu et al., showed that the general health and mental health of caregivers are affected 12 months after patient discharge (10).

The main caregiver acquires an important role during the rehabilitation process, providing social, emotional and economic support (13). The caregiver-patient relationship influences the health of the patients and the health of the caregiver (14). Liu et al., indicate that the mental health of caregivers influences the recovery of patients; good mental health of the caregiver contributes to better recovery of the patients compared to patients with poorer mental health caregivers (15). Moreover, a poorer level of physical function in hip fracture patients influences the caregiver burden (16).

Despite the important role of the caregivers within the recovery of a hip fracture patient, authors indicate that the existing information regarding caregiver burden is limited (10,15), especially in the transition of back home after patient hospital discharge (12). Therefore, researchers propose to keep investigating about characteristics of caregivers (16), time evolution (12) and factors associated with caregivers' burden (15)

Considering the value of the caregivers during the recovery of a hip fracture patient, and the lack of knowledge about caregiver burden, the objectives of this study are: 1) to determine the profile of the main informal caregivers, 2) to describe the evolution of the caregiver burden, and 3) the factors that influence the caregiver burden of hip fracture patients within one year after surgery in southern Spain.

## **Materials and Methods**

A prospective cohort study of caregivers of patients with an acute hip fracture admitted at a traumatology service in southern Spain between January 2009 and January 2010 was carried out. The hospital covers a population of around 350,000 inhabitants. The

inclusion criteria were: 1) being the main caregiver of a person who had surgery after a hip fracture, was 65 years or older, 3) survived the first 24 hours after surgery and showed absence of terminal disease; 2) signing the informed consent to participate in the study. The ethics committee of the Jaen Hospital approved the study.

Sociodemographic data of the caregivers such as age, gender, kinship with the patient, paid work, support of others caregivers, number of caregivers per patient caregiver burden, main difficulties at home, and suggestions to improve the treatment of the patient were collected during the interviews with the caregivers. Clinical data of the hip fracture patients, regarding type of fracture, time from admission to surgery, type of technical surgery, health status (measured by the American Society of Anesthesiologists score) post-surgery complications (wound infection, pressure ulcer, disorientation, nosocomial infections, release, dislocation or reintervention) and length of hospital stay were taken from the patients' medical records. Socio-demographic data of the patients such as age, sex, weight and height (body mass index), level of education and residence pre and post hip fracture were recorded during the interviews with the patient and their caregivers. Information was collected through a structured face-to-face questionnaire, managed by one experienced therapist-interviewer. The medical records of the patients were usually reviewed on the day of the first interview with the caregivers and the patients. The first interview with the caregivers and the patients took place during the hospital stay after surgery, whereas the second and third interviews were done at one and three months at the hospital, coinciding with the revisions of the patients with the surgeons. The last interview was done by phone at one year.

### ***Measures***

The primary caregiver burden of each patient, our main outcome variable, was assessed using the Caregiver Strain Index (CSI). It is a questionnaire used to evaluate individuals of any age who have assumed the role of caregiver for an elderly. The CSI consist of thirteen dichotomous response items “true/false” which involve domains like employment, finance, time and physical and social readjustment. For each positive response (true), one point is awarded, considering a total score of 7 or more as a high level of burden (17, 18).

The pre-fracture functional level of the patients was assessed during the first interview using the Functional Independence Measure (FIM) (19,20). It is group into six categories with a total of 18 items. This scale assesses the level of support required for each of the categories: personal care, sphincter control, mobility, walking, communication and social knowledge. The score of each item is from 1 to 7 points where 1 indicates “totally assisted” and 7 is “completely independent”. The total score ranges are from 18 to 126 points, where higher scores indicated better functional level. This scale has been used in the follow of patients with hip fracture (9,21).

The cognitive status of the patients was assessed by the Pfeiffers’ Scale (Short Portable Mental State Questionnaire – SPMSQ). This is a clinician questionnaire composed of 10 items with a range of scoring from 0 to 10 based on the number of errors. The scale evaluates orientation, memory related to the ability for self-care, long-term memory and ability to perform complex mental operations. The cut-off point to suspect cognitive impairment is 3 or more mistakes in the case of people who are literate (can read and write), and 4 or more for those who do not (22).

## **Statistical analysis**

Continuous data are presented as means (with SD) or medians (percentiles 25 and 75), as appropriate, and categorical data are presented as numbers with percentages. The Kolmogorov-Smirnov test was used to test the normality of data and the Levene test to test the homoscedasticity.

Regarding the evolution of the caregiver's burden, comparison of the CSI score from hospital to one month, three months and one year after surgery, was done using the Friedman test for repeated measures with Bonferroni adjustments.

Respecting the CSI score, adjusted and unadjusted logistic regression were used to examine the influence of caregivers and patients predictor factors upon the caregiver's burden at one year after hip fracture surgery. The multicollinearity was checked using the Pearson correlation coefficient or Spearman rank correlation as appropriate (defined as  $r > 0.7$ ). The reference categories used in the model were; patients factors: gender (men), cognitive status (no cognitive impairment), post-surgery complications (no complications); and caregivers factors: gender (men), paid work (no paid work), support of others caregivers (yes) and kinship (daughter); whereas age of the patients and caregivers, as well as pre fracture functional status were entered as continuous variables.

The IBM SPSS statistic version 20 was used to perform all statistical analyses, and the level of significance was set at  $P < 0.05$ .

## **Results**

A total of 236 caregivers of hip fracture patients were assessed for eligibility, leaving 172 caregivers for final analysis. Figure 1 shows the study flowchart. The median age of the 172 caregivers was 54 (Q1-Q3: 47-65), of which 133 (77%) were women and 94 (55%) were daughters of the patient. Table 1 shows the rest of the caregivers



characteristics. The mean age of the patients was 80.2 years (SD: 6.6), of which 140 were women (81%) and 38 (22%) had cognitive impairment (table 2).

[Figure 1 near here]

[Table 1 near here]

[Table 2 near here]

Comparison of the CSI scores showed a decreased in the perception of the burden of care from in-hospital [median (Q1-Q3); 6 (4-8.8)] to 3-months [median (Q1-Q3); 4 (1-8)] ( $p=0.001$ ) and to 1-year [median (Q1-Q3) 2 (0-7.8)] ( $p<0.001$ ); from 1-month to the 3-months and 1-year ( $p<0.001$ ) follow up; and from 3-months to 1-year ( $p<0.001$ ). On the contrary the burden from in-hospital to 1-month (6 (3-9)) was the same. The evolution of the percentage of caregivers who showed a high burden of care within one year follow-up is expressed in the figure 2.

[Figure 2 near here]

Regarding difficulties at home, a total of 58 caregivers answer the question and 48 of them (82%) showed concern with the transfer and handling patient, 9 (16%) with self-care and 1 (2%) with other issues as problems with relatives. The main suggestions of a total of 90 caregivers who claimed some improvement of the treatment were the following; 41 (45%) indicated that it would have been necessary some training on handling patient, 18 (20%) showed the need of improve different issues such as better coordination between the hospital staff, better communication from health care providers or economic aids (Figure 3).

[Figure 3 near here]

The results obtained from the logistic regression analysis for factors influencing the 1-year caregiver burden after hip fracture are presented in Table 3. The unadjusted analysis showed that patients' factors such as age, cognitive impairment, pre-fracture functional status, post-surgery complications as well as caregiver age, gender and kinship, have a significant influence in 1-year caregiver burden. Whereas gender of patient, support of others caregivers and that the caregiver have a paid work did not. The adjusted analysis revealed that lower pre-fracture functional level, presence of post-surgery complications, older age of the patients, younger age of the caregivers and being a daughter of the patient were factors related with the increase of caregiver burden. Accord with R squared, the 53.8% of caregiver burden variability are explained by the variables includes in the model. In addition, the results of Hosmer and Lemeshow test ( $p=0.307$ ) indicates that the data are well represented by logistic model.

[Table 3 near here]

## **Discussion**

This study provides evidence that; 1) the main caregiver of a hip fracture patient is usually the daughter of the patient, 2) the evolution of the perception of burden decreases from early stage of recovery after surgery (in hospital and 1 month) until 3 months and 1 year after surgery. The main difficulties at home of the caregivers are related with the transfer and handling patient, and the principal suggestion to improve the treatment are also related to this aspect. Furthermore 3) the age of patient and caregiver, prior functional status and post-surgery complications influence the caregiver burden at one year after hip fracture surgery.

### ***Profile of the main caregivers***

Regarding the profile of caregivers, this study found a similar average age of the main caregivers in comparison with others studies: 53.2 and 53.03 years (12,15). Besides, caregivers were mostly women, and the most common relationship between the primary caregiver and the care recipient in this study was daughter. These data are similar to the results of Avila et al., who concluded that the care of person after hip fracture is mainly provided by women and patients' son or daughter (11). This profile of the caregivers could be explained because hip fracture patients are usually elderly people and they need to be cared by younger people like their daughters or sons. The spouses of the patients are elderly people too, who has comorbidities that limit the possibility of caring hip fracture patient and even the caring of themselves. The gender of the caregivers depends of cultural habits. As regards support of others caregivers, Lin et al., found that more than 70% of caregivers shared responsibility of care with others caregivers (16). These data are consistent with the present study.

### ***Evolution of caregiver burden***

The number of caregivers who showed a high burden of care in the present study, increased from hospital to 1- month and after that moment, declined until 3-months and one year. The increase from hospital to 1-month could be explained because during hospitalization of the patients, the caregivers have the support of the professionals of the hospital and the caregivers do not experiment the totally needs of the care that the patient require. At discharge, when they go home, they feel alone, with lot of doubts about handling patient, without the hospital staff to help them to resolve problems and with a patient who has a very low functional level and poor health status. Home is the place where the patients and their caregivers can realized of the difficulties and they

experiment more burden of care. Consequently, according as the patient and caregiver learn to manage the difficulties at home and the level of health and functionality of patient improve, the caregivers' burden perceived decreases. Similarly, Siddiqui et al., found statistically significant differences in the score of caregiver burden at hospital and 6 months after discharge; the burden was higher at one month than six months (13). In the same line, Shyu et al., demonstrated an improvement in the evolution of aspects related to quality of life of caregivers in the different times from hospital discharge to 12 months (10).

The caregivers of this study expressed concern about handling patients at home and they claimed for some type of training to help patients with the activities of daily living. These results are consistent with Schiller et al., who carried out a study by interviews where they observed that caregivers and patients with hip fracture were worried about the support that the patients needs during the performance of activities of daily living (23). In the same line, Nahm et al., observed that the caregivers was concern about the help that the patients need due to change of functional level, and they described too the worries of caregivers about having a good communication with the professionals (24). This information might be important to design new strategies of treatment which include the caregivers of the patients since the very early stage of the hospitalization. In this way, the training of the caregivers on the handling patients could help to improve the recovery of the functional level of the patient, and to decrease the perceived caregiver burden. Besides, could help to prevent falls and other complications for patients and their caregivers.

### ***Factors influencing caregiver burden***

The functional status after hip fracture surgery is a priority aspect. Return home with an independence functional level that let the patients perform the activities of daily living by themselves is the most important outcome (7). The results of this study indicate that adjusting for the variables included in the model, a low pre-fracture functional level is associated with a greater caregiver burden at 1-year; which is consistent with the results of the study carried out by Lin & Lu (12). This results can be explained if we consider that the pre-fracture functional status is a predictor of short and long term rehabilitation outcome in patients with hip fracture (25). Moreover, the time of the recovery is slow, and some activities of daily living continue improving until one year after hip fracture, although in some cases the previous level is not reached (9). This declining of physical functions in the elderly after hip fracture, increases their care needs and therefore the care is more difficult and the effort of caregivers is major (26).

The results of this study show an association of age of patient with the caregiver burden. The caregivers of patients with older age have a higher burden of care. In contradiction with the study of Siddiqui et al, who did not find correlation of age and caregiver burden at six months after hip fracture (13). Nevertheless, the age is an important long-term influencing factor of functional status at one year of a hip fracture (25), which is related with caregiver burden. On the other hand, as caregiver age increases, decreases the odds of burden. These could be explained because the younger caregivers are mostly a daughter or a son of the patients, and they have others preoccupations besides patient care.

Regarding post-surgery complications, the results of this paper indicate that the caregivers of patients who suffer complications after hip fracture surgery have more risk of endure burden if we compared with patients who do not suffer complications, after adjust for the others variables. This complications are an important problem due to they

produce an increased time to discharge, a negative impact in the mobility and hence in the functional independence (25). The early mobilization and weight-bearing are predictor factors of functional recovery (9,25), therefore, the effects of the delay in mobilization and weigh-bearing of the patient due to complications, influence the functional status and accordingly patients require more care.

No significant association was found in the adjusted values between caregiver burden and characteristics of patients such as gender and cognitive impairment; just as with the characteristics of caregivers as gender, paid work and support of others caregivers. These results are consistent with the study of Lin & Lu in which they found no significant relationship between the caregiver and patients characteristics and the burden of caregivers (12). However, these researchers found association between caregivers' burden and share of responsibility of care (12). This result differs from those found in the present study.

Caregivers play an important role from the start of clinical attention, providing information about the patient to professional such as medical history, previous functional ability and other information (27). This collaboration continues during the rehabilitation period of the patient, and in accordance with Liu and colleagues, the mental health of caregivers influences the recovery of care recipient. They demonstrate that patients with caregivers with good mental health have a better recovery than patients with caregivers with poor mental health (15). Future research should further investigate on how the caregivers' burden influences the functional outcomes, health of patients and recovery time. Additionally is interesting to look for new methods to improve the quality of life of caregivers and the relationships caregiver-patient. Some authors have begun research in this line (28,29), but is necessary to continue exploring the way to help to caregivers and patients who suffer a hip fracture surgery.

Nevertheless, it should go further and put into practice and serving society the scientific discoveries and check whether it is possible implement them.

### **Study limitations**

The methodological strength of this study include it's prospective design, with a long term follow-up period (1 year), more than in others studies (10,12). In this paper, a similar or larger sample size was used than the registered in other studies (13,16) in which investigated about caregivers and patients with hip fracture. Furthermore, the sample was maintained with the same number of patients and caregivers from begin to finish of follow-up. Some limitations must also be addressed, however. This design type makes it impossible to balance the frequency of some characteristics such as gender, post-surgery complications, paid work or support of others caregivers, which may influence the comparison between groups of patients who presented a characteristic with who do not. Besides, more information such as health status of the caregivers or hours to care the patients were not recorded. Another limitation is the one-year follow-up interview, which was performed by phone.

### **Conclusions**

The results of this study demonstrated that the profile of the main caregivers of hip fracture patients is a woman of middle age, who does not have a paid job, and is the daughter of the patient.

The perceived caregiver burden decreased since 1-month after hip fracture surgery until 1-year. However, more than half of the caregivers perceived the burden of care as high within the first month following surgery, and a quarter of them at one year. The main

concern of caregivers was related with the handling patients in activities of daily living. New strategies of treatment should include the training of the caregivers during hospital stay.

The low pre-fracture functional level, the presence of post-surgery complications, kinship and age of patients and caregivers influenced the caregiver burden at one year after hip fracture surgery.

We should realize that patients are not the only ones who suffer the consequences of a hip fracture. Therefore, it may be necessary to intensify the support provided to the main caregivers, especially during the period to go back home. New strategies of treatment could be carried out to reduce the caregiver burden, considering the influence factors and the suggestions of the caregivers.

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### **Declaration of interest statement**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.



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## Tables

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Table 1. Demographic characteristics of 172 caregivers

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Variables	
Age, years	54 (47-65); 25-90
Gender	
Women	133 (77)
Men	39 (23)
Kinship	
Couple	39 (23)
Son	15 (8)
Daughter	94 (55)
Others	24 (14)
Paid work	
Yes	55 (33)
No	116 (67)
Support of others caregivers	
Yes	124 (72)
No	48 (28)
Number of caregivers	
Median (Q1-Q3)	2 (1-3)

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Data are number (percentage) or median with (25-75 percentile); minimum-maximum.

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Table 2. Demographic and clinical characteristics of 172 hip fracture patients.

Variables	
Age (years), mean (SD); min-max, years	80.2 (6.6); 65-94
Gender	
Women	140 (81)
Men	32 (19)
Body mass index n=170 <sup>a</sup>	
Normal	61 (36)
Overweight	68 (40)
Obese	41 (24)
Level of education	
Non literate	51 (30)
Reading and writing	92 (53)
Primary studies	20 (12)
Secondary studies (high school)	5 (3)
College (University)	4 (2)
Residence Pre-fracture	
Own home	132 (77)
Home of relatives	40 (23)
Residence at discharge	
Own home	111 (65)
Home of relatives	55 (32)
Institution	6 (3)
Type of fracture n=170 <sup>a</sup>	
Intracapsular	83 (49)
Extracapsular	87 (51)
Type of technical surgery n=170 <sup>a</sup>	
Dynamic hip screw with plate	80 (47)
Intramedular hip screw	30 (18)
Hemiarthroplasty	60 (35)
Time from admission to surgery	
Median (Q1-Q3)in days	1 (1-6)
Post-surgery complications	
Yes	62 (36)
No	110 (64)
Length of hospital stay (days)	
Median (Q1-Q3)	11 (7-18)
Technical assistance at discharge n=170 <sup>a</sup>	
Wheel chair	51 (30)
Walker	116 (68)
Crutches	3 (2)
FIM	
Median (Q1-Q3)	117 (97-125)
Cognitive status	
Cognitive impairment	38 (22)
No cognitive impairment	134 (78)
Health status n=170 <sup>a</sup>	
High (ASA level 1-2)	75 (44)
Poor (ASA level 3-5)	95 (56)

Data are number (percentage), mean (SD); minimum-maximum, or median with (25-75 percentile). FIM; Functional Independence Measure. ASA score; American Society of Anaesthesiologists score.

<sup>a</sup> due to missing data.

Table 3. Crude and adjusted logistic regression analysis of factors influencing the 1-year caregiver burden after hip fracture

Risk Factors	Crude values			Adjusted values		
	OR	IC	p	OR	IC	p
Patients factors						
Age	1.110	1.047-1.178	0.001	1.105	1.016-1.202	0.020
Gender						
Men		Reference			Reference	
Women	1.078	0.445-2.608	0.868	0.396	0.11-1.418	0.155
Cognitive impairment at hospital (SPMSQ)						
No		Reference			Reference	
Yes	4.154	1.930-8.941	0.000	0.535	0.153-1.870	0.327
Previous functionality (FIM)	0.943	0.924-0.963	0.000	0.943	0.917-0.969	0.000
Post-surgery complications						
No		Reference			Reference	
Yes	3.459	1.707-7.010	0.001	5.129	1.878-14.008	0.001
Caregivers factors						
Age	0.965	0.939-0.993	0.013	0.943	0.896-0.993	0.027
Gender						
Men		Reference			Reference	
Women	2.925	1.066-8.024	0.037	0.198	0.032-1.227	0.082
Paid work						
No		Reference			Reference	
Yes	0.794	0.378-1.667	0.541	0.731	0.245-2.185	0.575
Support of others caregivers						
Yes		Reference			Reference	
No	1.424	0.682-2.973	0.346	2.620	0.868-7.910	0.087
Kinship						
Daughter		Reference			Reference	
Other	0.176	0.076-0.408	0.000	0.153	0.036-0.650	0.011

OR: odds ratio, IC: confidence interval 95%

## **Figures**

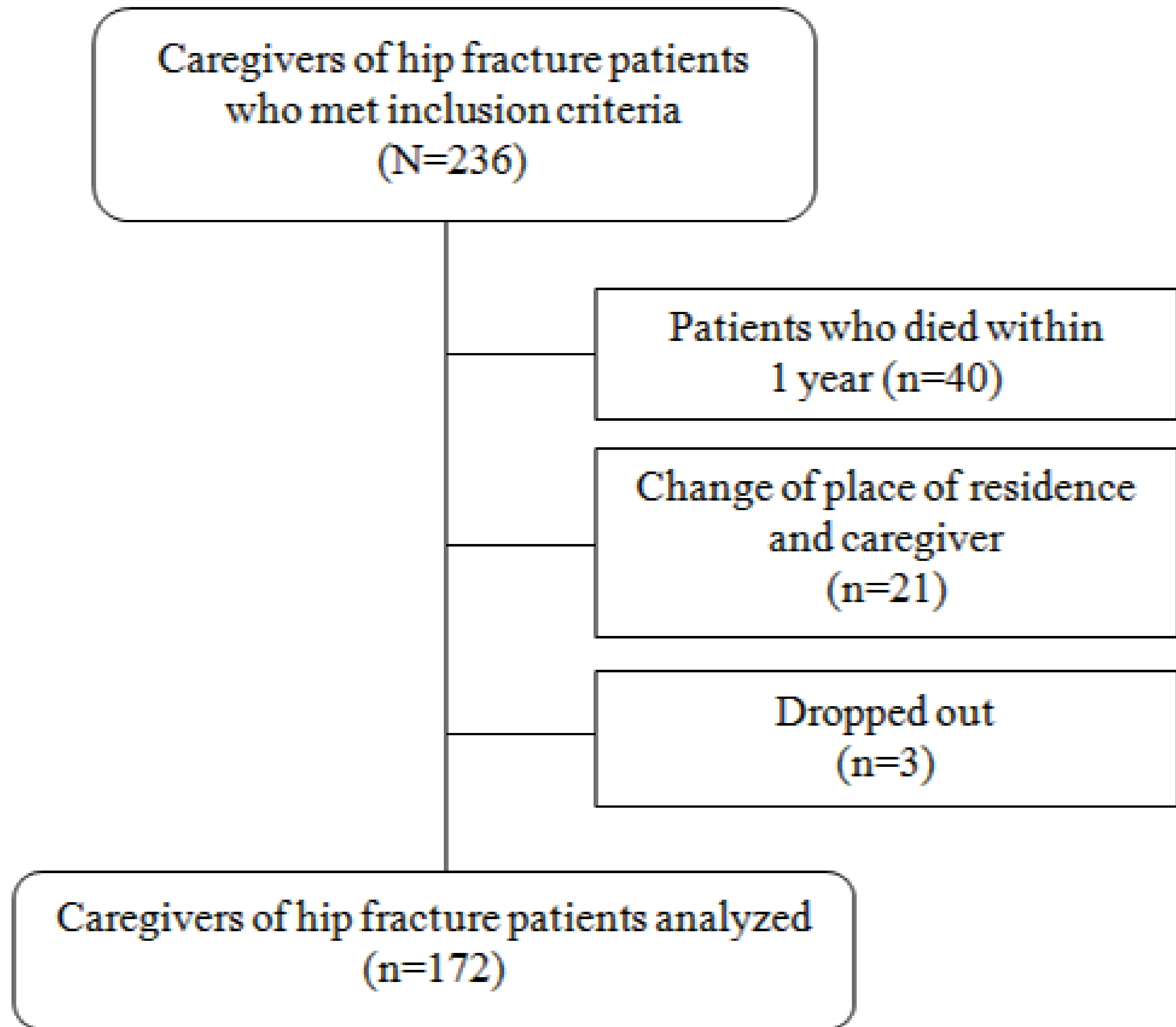
Figure 1. Flowchart of participants.

Figure 2. Caregivers burden perception at different times.

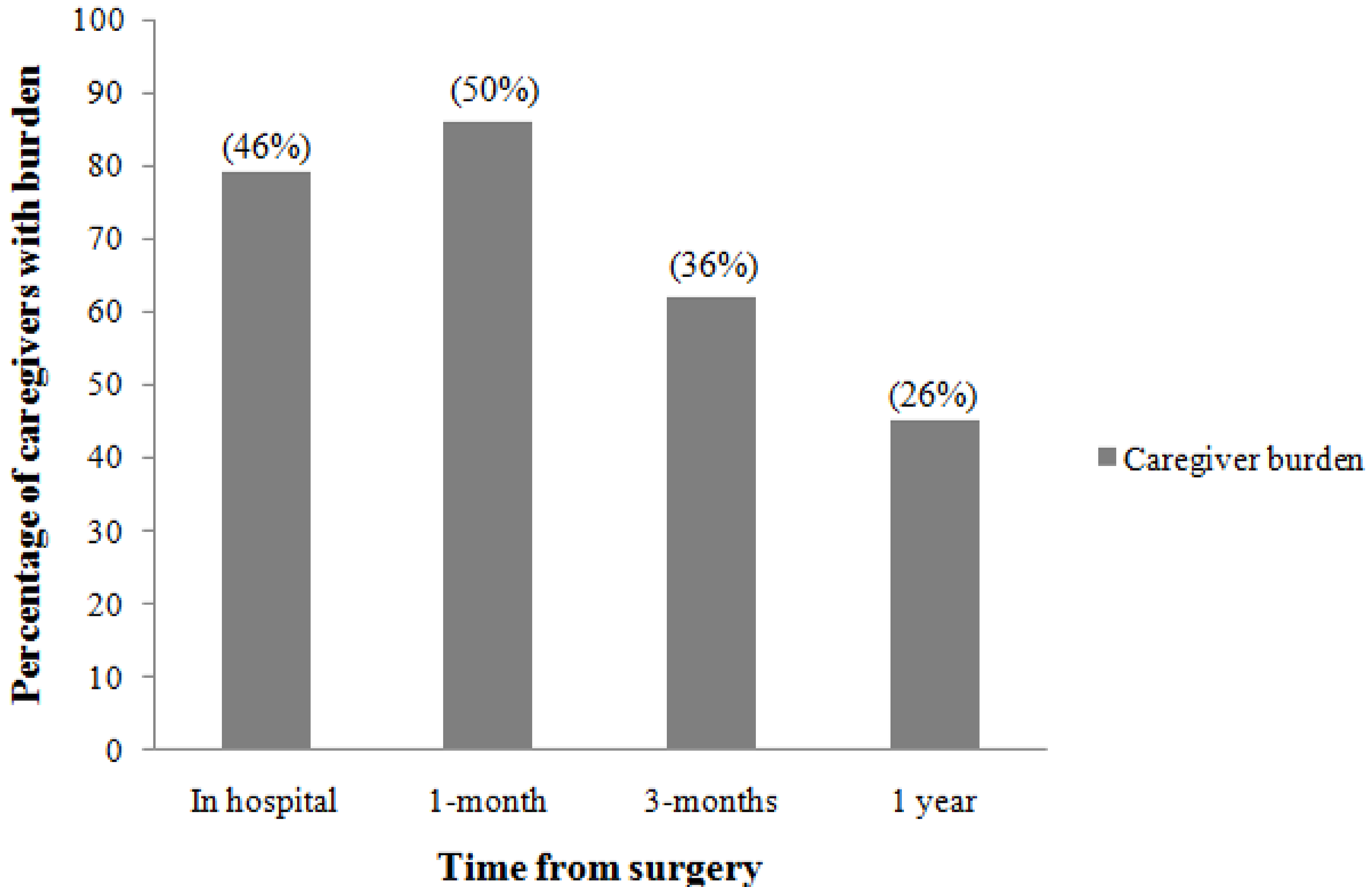
Figure 3. Suggestions of caregivers to improve the treatment.

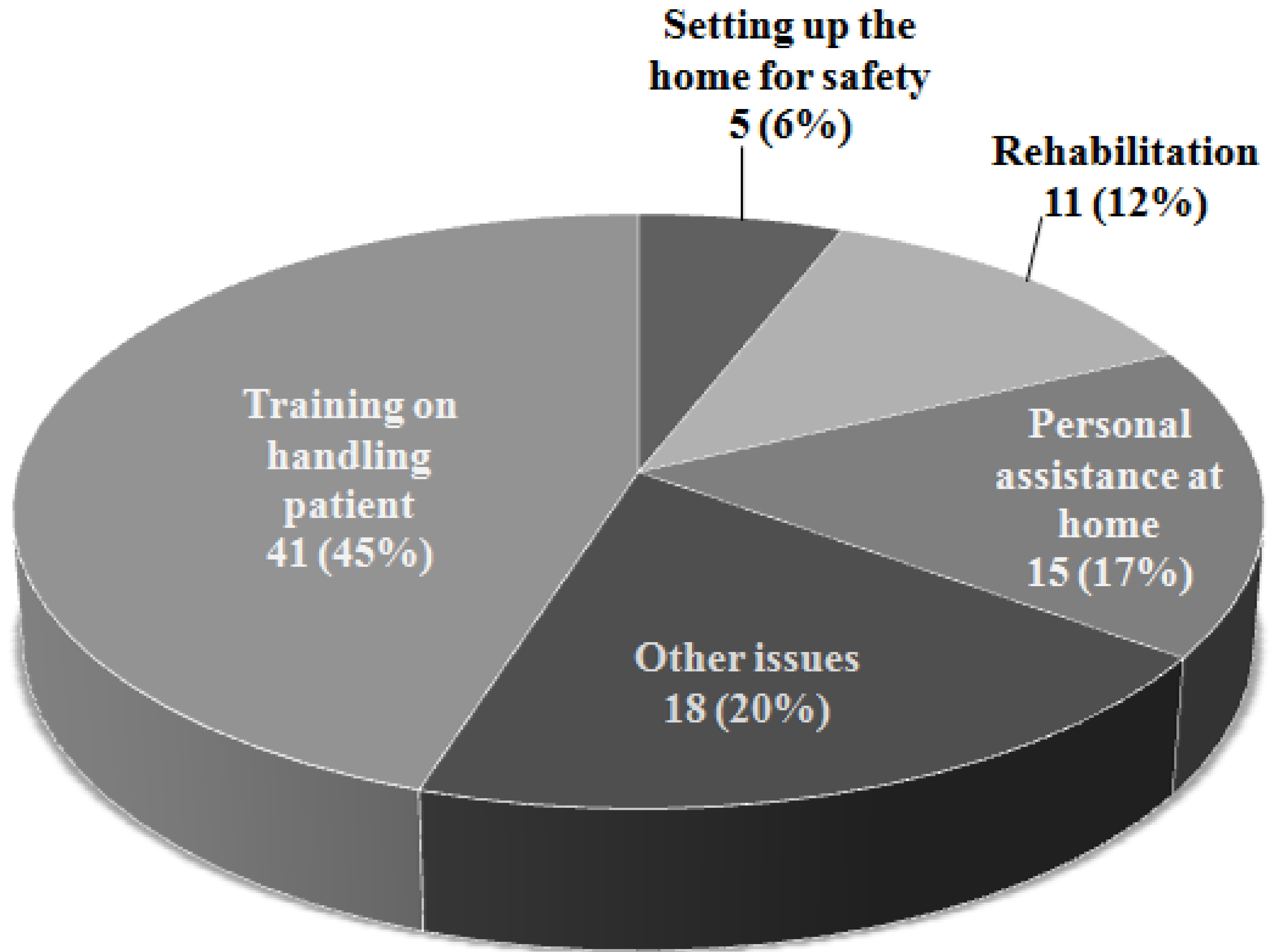


Figure 1. Flowchart of participants through follow up



**Figure 2. Caregivers burden perception af different times.  
Evaluated with CSI.**





**Figure 3. Suggestions for caregivers improve treatment. N=90**

Data are number (percentage)

## **Implications for Rehabilitation**

The main caregiver of a hip fracture patient is usually a woman who is the daughter of the patient and reducing her burden of care should be included as one of the objectives of the rehabilitation treatment.

The caregivers of hip fracture patients must be considered as part of the treatment during the recovery period of the patients, and training about handling patient should be provided to the caregivers of hip fracture patients during the hospital stay to prepare the process to go back home.

The post-surgery complications must be reduced in order to reduce the caregiver burden of hip fracture patients.