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EMPOWER THE INFORMAL CAREGIVER ALONG HIS COURSE OF HOME PROVIDING CARE

CAPACITAR O CUIDADOR INFORMAL NO DECORRER DA PRESTAÇÃO DE CUIDADOS NO DOMICÍLIO

POTENCIAR EL CUIDADOR INFORMAL EN EL TRANSCURSO DE LA PRESTACIÓN DE CUIDADOS EN EL HOGAR

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ABSTRACT

Portugal is one of the most aged countries in Europe and in the world, where elderly people have a very high level of disease and dependence. Needing an Informal Caregiver, who are mostly relatives not prepared to this kind of care. The Informal Caregiver comfort themselves with the reality of their good performance, which is a complex process that carries changes in their daily routines and their own health, that can lead to overload of work and exhaustion.

Objectives: To reduce the Informal Caregiver overload and to give them skills to provide suitable care to the elderly people, who are targets to the Integrated Continued Care Team of a Central Alentejo Care Community.

Methods: Health Planning Methodology. 11 stages and characterisation questionnaires of the Informal Caregiver were applied and analysed with Software Microsoft Excel support. All the procedures are in accordance with the ethic-legal component of research with human beings.

Results: The Informal Caregivers have an intense overload of 27% and light overload of 54% but some Informal Caregiver were found without any at all, 18,2%. The most important learning needs of the Informal Caregiver are fall prevention and uprising/transferring and ulcers caused by pressure prevention.

Conclusion: It turns out that the Informal Caregiver have high overload work and need the help of health care professionals, in particular because they show knowledge deficits and practical skills that can provide the needs of the dependent person.

Keywords: Burden Caregiver; Caregiver; Elderly Person.

RESUMO

Portugal é um dos países mais envelhecidos da Europa e do Mundo, em que as pessoas idosas, apresentam elevada carga de doença e dependência. Necessitando de apoio de um Cuidador Informal, sendo na sua globalidade familiares, que não estão preparados para prestarem este tipo de cuidados. O Cuidador Informal confronta-se com a realidade do desempenho do papel, sendo um processo complexo que acarreta mudanças no quotidiano e na saúde do mesmo, que pode originar sobrecarga e exaustão.

Objetivos: Diminuir a sobrecarga do Cuidador Informal e capacitá-lo para prestar cuidados adequados às pessoas idosas, que são admitidos na Equipa de Cuidados Continuados Integrados de uma Unidade de Cuidados na Comunidade no Alentejo Central.

Métodos: Metodologia do Planeamento em Saúde. Foram aplicadas 11 escalas e questionários de caracterização do Cuidador Informal e analisados com recurso ao Software Microsoft Excel. Todos os procedimentos, estão de acordo com a componente ético-legal da pesquisa com seres humanos.

Resultados: Os Cuidadores Informais apresentam sobrecarga intensa 27,3% e sobrecarga ligeira 54,5%, mas também foram encontrados Cuidadores sem sobrecarga 18,2%. As principais necessidades de aprendizagem dos Cuidadores Informais são primeiramente a prevenção de quedas, e igualmente o levante/transferências e prevenção de úlceras por pressão.

Conclusão: Verifica-se que os Cuidadores Informais têm sobrecarga elevada e necessitam dos profissionais de saúde, nomeadamente por apresentarem défices de conhecimento e competências práticas que lhe permita satisfazer as necessidades da pessoa dependente.

Palavras-chave: Cuidador; Pessoa idosa; Sobrecarga do Cuidador.

RESUMEN

Portugal es uno de los países, mas envejecidos de Europa y del Mundo, las personas mayores tienen una alta carga de enfermedad y dependencia. Necesitando del apoyo de un Cuidador Informal, son generalmente familiares, non preparados para proporcionar este tipo de cuidados. El Cuidador Informal se reconforta en el desempeño de ese papel, siendo un proceso complejo que provoca câmbios en vida cotidiana y en salud, que puede llevar a la sobrecarga y al agotamiento.

Objetivos: Reducir la sobrecarga del Cuidador Informal y potenciarlos para proporcionar cuidados adecuados a las personas mayores, a las que se dirijen los cuidados en el Equipo de Cuidados Continuados Integrados de una Unidad de Cuidados en la Comunidad del Alentejo Central.

Métodos: Metodología de Planificación en la Salud. Se han aplicado 11 escalas y cuestionarios de caracterización del Cuidador Informal y se han analizado con recursos del Software Microsoft Excel. Todos los procedimientos estan de acuerdo con la competencia ética y jurídica de la investigación con seres humanos.

Resultados: Los Cuidadores Informales presentan sobrecarga intensa 27,3% e sobrecarga ligera 54,5%, pero tambien fueron encontrados Cuidadores sin sobrecarga 18,2%. Las principales necesidades de aprendizaje son primeramente la prevención de las caídas, e igualmente el levante/transferencias y prevención de úlceras de presion.

Conclusión: Se hay verificado que los Cuidadores Informales tienen sobrecarga elevada y necesitan de los professionales de salud, especialmente porque tienen déficits de conoci-

mientos y habilidades prácticas que permiten satisfacer las necesidades de la persona dependiente.
Descriptores: Cuidador; Persona Mayor; Sobrecarga del Cuidador.

INTRODUCTION

Currently, a demographic transition is taking place, leading to an ageing population, which requires more care. The human ageing process currently has repercussions all over the world; the elderly population has increased significantly in the last decades. The aging process brings great changes in the life of the elderly person, as well as in the family routine itself, being necessary to guarantee quality to the years added to life[1].

Taking into account the technological evolution of Medicine and, in general, the improvement of socioeconomic conditions, this has allowed for an increase in the population's longevity, which is also associated with a higher prevalence of chronic diseases and dependence in daily living activities. Thus, the increase in longevity in society poses new challenges in various areas, among which the provision of care stands out[2].

Ageing brings with it greater needs for physical, psychological and social care, and a serious consequence of the situation of chronicity and longevity of the elderly person is physical and mental disability, defined as dependence on others to perform essential or personal tasks and activities[3].

Social changes have led to an increase in the number of self-care-dependent people, who, in turn, require the support of an Informal Caregiver (IC). The Informal Caregiver is comfortable with the reality of performing the role, which is a complex process that brings about changes in daily life and health, which may lead to overload and exhaustion. We are witnessing an increase in non-transmissible chronic diseases, disabilities and loss of autonomy among the elderly, leading to the need for care provision, provided by IC. On the other hand, there has been an inversion of the population pyramid, resulting in greater changes in the health and care needs of the elderly population[4]. The main caregiver is the individual from the dependent person's social network with a close relationship who cares for another person in a situation of chronic illness and who is responsible for most of the care, experiencing a greater degree of involvement than other family members, without training to provide certain types of care and without being paid for this role[5].

In our society, IC have played an important role in elderly care since the beginning of time. They play a fundamental role in the health system, as they provide long-term care to the elderly dependent person. It should be emphasised that the family is the caregiver at all stages of life[6].

The provision of care can lead to emotional and physical stress, especially when the demand for care occurs without proper guidance, resulting from inappropriate practices by the IC, damaging their own health, giving rise to an increase and/or worsening of existing pathologies, since the caregiver also has care needs that are not always considered, since the attention is totally directed to the dependent elderly person[7].

This situation can lead to overload, as the caregiver does not have a profession and, in turn, does not have time for leisure, to perform self-care, clearly impairing their quality of life and the care provided to the older person[8].

The target population was the ICs of the elderly patients integrated into the Integrated Long-term Care Team (ECCI). Data collection scales and questionnaires were applied to the ICs of the users who are cared for by the ECCI of the Long-term Care Unit (UCC) in Central Alentejo.

The purpose of this study is to: To empower the IC of older people who are cared for by an ECCI in a municipality of Central Alentejo, by the end of 2022. Thus, we intend to increase the ICs' knowledge about self-care provided to older people receiving care from the ECCI and reduce the ICs' burden of the older people receiving care from the ECCI.

The purpose of this study is to: Promote the empowerment of IC of older people who are cared for by an ECCI in the Central Alentejo, by the end of 2022, through the implementation of a community intervention project with the target population.

METHODOLOGY

Simple descriptive study, more specifically case series, with a quantitative approach.

The target population is the ICUs of the CCU that are integrated into the ECCI, as well as the patients who are the target of IC care. Its purpose is to assess the IC overload and their knowledge deficits regarding the self-care to be provided to the patients under their care. Home visits were scheduled, with the purpose of collecting data through the application of the instruments. After data analysis, an individual care plan was designed and implemented in accordance with the caregiver's needs during home visits.

The training method was carried out through the provision of support material in the different areas, skills training, execution of techniques with supervision, monitoring of the gains obtained in the provision of care and validation with the IC.

The enabling agents are the ECCI multidisciplinary team in the different care areas and the master's student.

It is a convenience sample, consisting of IC and care target users, who agreed to participate, admitted between October and December 2021, being a total of 11 users.

The exclusion criteria were the IC who did not agree to participate, did not speak Portuguese fluently, were under 18 years of age, and patients under 65 years of age. It should also be taken into account that, if the target patient does not wish to participate in the study, this will not be invalidated, but only the IC may participate.

All scales were translated and validated for Portugal and authorized by the respective authors. The questionnaire used for caregiver characterization allowed characterizing the IC, making a sociodemographic assessment of the population under study and characterizing their age, gender, education and pathologies. The scales used were the Informal Caregiver Learning Needs Scale and the Caregiver Overload Scale. The first scale allows identifying the needs that ICs have in providing self-care to the dependent person. The second scale is an assessment tool which allows assessing the objective and subjective burden of the IC and, on the other hand, obtaining information on the IC health status, social and personal context, as well as the financial situation, emotional status and the relationship between the IC and the person receiving care[9].

The data collection instruments, were applied in the initial assessment and replicated in the final assessment.

After data collection, obtained through the scales and questionnaire, the respective organisation and statistical analysis was performed using Microsoft Excel version 2022 software.

Ethical procedures (informed consent, confidentiality and anonymity), are in accordance with the Declaration of Helsinki on Human Research Ethics[10].

The participants in the study were the IC and the patients receiving care, whose rights and possible harm to both were safeguarded. In this way, the project in question is part of the study of the University of Évora, "Diagnosis of Informal Caregivers", which I was invited to participate in. In this sense, the study in question was submitted to the Ethics Committee of the Regional Health Administration of Alentejo, having obtained a favourable opinion.

A prior telephone contact was made to inform about the project and clarify any doubts about it. The ICs and care users who agreed and accepted to participate read and signed it, and, if they were unable to read and/or sign, their fingerprints were taken and it was read by the researcher and the Informed Consent was given again, together with the completed data collection instruments, in a scheduled home visit.

It was ensured that, if the patient and/or IC were tired or changed their mind about participating in the study, or if they did not wish to continue participating, they could do so at any time or resume the study whenever they saw fit. In addition, data confidentiality, anonymity and data will be used exclusively within the scope of the research.

The information collected will be destroyed one year after the completion of the study.

RESULTS

It was found that the IC are predominantly male, aged between 40 and 70 years. The caregiver is married to and lives with the person being cared for. As regards their level of education, they are mainly between the 9th and 12th grade and have several pathologies 63.6%. Most of the ICs reported one or more pathologies, predominantly diseases of the circulatory system (36.4%) and also endocrine, nutritional and metabolic diseases (27.2%), representing a total of 63.6% of IC with pathologies and 36.4% without pathologies. With regard to their employment situation, 45.5% of the caregivers are retired, 36.3% are active and 18.2% are unemployed. They spend an average of 19.7 hours a day caring for the elderly dependent person.

The average elderly dependent person is 78.8 years old, 54.5% female and 45.5% male. The most relevant pathologies are, in decreasing order, diseases of the circulatory system (72.7%); endocrine, nutritional and metabolic diseases (63.6%); and diseases of the musculoskeletal system (54.5%). In terms of functionality, around 81% of the older people presented moderate to severe impairment (self-care walking, hygiene, dressing and elimination) Chart 1↗.

The age range of the ICs, on average is 68.1 years, it can be seen that the caregivers intended to care, are elderly people who care for the elderly.

The caregiver is a relative, namely the spouse 82%, being united by the ties of marriage.

It was identified that 81% of the elderly people, have moderate to severe impairment at the level of their functionality.

With regard to schooling 63.6% do not have compulsory education, having a low level of schooling, however 81.9% have attended school.

The IC, as mentioned above has a close family relationship and cohabits 72.8% with the dependent person.

As can be seen from Chart 2↗, on moderate to severe learning needs education is constituted primarily by the prevention of falls (63.63%), and identically lifting/transfers (27.27%) and prevention of pressure ulcers (27.27%).

Therefore, there were health gains, since the proposed objectives were achieved and are shown in Chart 3↗, if previously there were mostly knowledge deficits in terms of fall prevention and lifting/transferring, these have been overcome. However, there are still deficits of knowledge regarding nutrition and prevention of pressure ulcers.

Chart 4↗, shows that the IC studied have mostly light overload 54.5%; followed by 27.3% heavy overload and 18.2% no overload.

We have seen a decrease in the overload, as in Chart 5↗, we can see that the slight overload drops to 9% and 91% is without overload.

DISCUSSION

As shown in Chart 1↗, and contrary to what several studies have reported, 54.5% of the elderly caregivers are men, when comparing the reality analysed by the Preliminary Data Study (PDS) on the characterisation of the Profile of Informal Caregivers[11], it can be seen that 26.5% are men who provide care, thus sustaining that it is mostly women who take on this role. Traditionally, there are differences between the male and female genders, with women being the main caregivers and being attributed this role, as it is a regular part of the lives of some family members, especially females and older people[2]. There is a noticeable increase in the proportion of men who exercise the role of IC. Despite the fact that women are part of the labour market and men are not responsible for care to the same extent, we are witnessing a global change in the gender profile of caregivers. This is motivated by affection, commitment and family obligation, emphasising that gender is not important when it comes to children and spouse. The family bond of IC is one of the determinants of the motivation of social and moral obligation in care provision[12].

The caregiver assigned to care for the older person is a family member, in particular, the wife/wife who is also an older person, which also happens in PSD, but with less expressiveness 54.3%, the caregiver assigned to care for the older person is a family member, the wife[1]. These caregivers often forget to take care of themselves, and often neglect their own health in view of the health care to be provided to the dependent person[1]. Becoming a caregiver in old age, or growing old while providing care, may mean facing more challenges and being exposed to more stressors, this is, unavoidable situations that occur in the course of care provision, minor everyday events or circumstances that may cause great pressure for a long period of time. Therefore, for these ICs to cope with everyday caregiving requires adding more resources, which may be scarce or insufficient in old age, hindering appropriate adapted responses. These caregivers, in general, care for someone in their age group, which predisposes them to deal with the progressive dependence of the caregiver at the same time, and often have to invest a lot of physical effort in exhausting tasks for a body that is also undergoing an ageing process, thus increasing the risk of becoming ill[13].

On the other hand, when analysing the PSD, it shows a mean age of the caregivers of 54.5 years, which is different from that found in the abovementioned study, as it was conducted in rural areas, where there is still a wider support network, as they have greater responsibility for the elderly, such as children, nephews and other relatives, who are in charge of care, and as life expectancy in urban areas is underlying more resources[11].

Spousal care, it is thought, will become increasingly important given trends including increasing life expectancy, decreasing supportive relationships in old age, decreasing parent-child co-residence, women working outside the home, decreasing numbers of children, and improving male health[13].

In the PSD, 77.8% attended school but not higher education, which is in line with the data analysed. It is important to emphasize that the elderly population had little access to education, as it was not a priority, thus negatively influencing care delivery and some studies show that the lower the level of education, the greater the difficulty to provide care. They have little knowledge, motivation and low skills, having difficulty in accessing and understanding health information, and are conditioned to make decisions about health care in their daily lives[14-8].

Usually the IC lives with the older person, but it can also happen that the IC lives separately from the person receiving care[6]. Thus, it can be stated that the IC is the person in the social network of the older person with a significant relationship who takes care of another person in a situation of chronic illness, causing dependence and assumes the responsibility for care, having a greater degree of involvement than the other family members[5].

The number of hours spent caring means that the ICs have little time to care for themselves and may increase their overload. When considering the hours spent caring, which are mostly 24 hours a day, only 8 hours are left for sleep, thus preventing the caregiver from resting[5].

The pathologies presented by the elderly refer to the need for differentiated technicians to respond to their specificities, as only a multidisciplinary team is able to provide integral care to the person in a situation of transitory or prolonged functional dependence, who cannot move independently, presenting a severe illness, in an advanced or terminal phase, throughout life, who have conditions at home that make the provision of care possible[15].

When analysing functionality, it is verified that the PSD shows us that more than 50% have moderate to severe functionality impairment, however, in this study, 81% of the individuals present moderate to severe impairment, as we are analysing an elderly population, encompassing all that was previously mentioned at the level of socio-demographic characterisation.

The PSD highlights moderate therapeutic exercise needs, corroborating with fall prevention and pressure ulcer prevention in this study.

Stressing the issue of risk of falling, it is a strong determinant for the elderly population, as it can lead to overload[16].

Nurses are health professionals qualified to help and assist ICs in the performance of their role and naturally promote better care to the dependent person. Thus, these professionals should have a prudent look at ICs with interventions adapted to their needs, seeking to avoid compromises in their well-being and quality of life related to the demands of caring. The more dependent older people require more complex care. The care to be provided are interventions within the scope of replacing or assisting: in hygiene, feeding, assisting in walking/transfers, positioning, accompanying the dependent person to consultations, exams, promoting or maintaining conditions for sleep and rest, providing specific care under the guidance of the health team, in simple care, in managing the therapeutic regimen, and monitoring particular situations[17].

Health promotion and disease prevention are the responsibility of health professionals, especially nurses, as the lack of knowledge is a risk for care provision, since providing care to someone is to take responsibility for that person, and in addition, it is necessary that the person designated to care is healthy and well with himself/herself[1].

As previously mentioned, by optimizing self-care in relation to the activities of daily living: mobilization of the different body segments; gait/ walking aids; balance and fall prevention; reduction of dependence and symptomatic control, and facilitation of access to community resources, the role of the IC is optimized and motivation is improved, thus allowing for a reduction in the caregiver's overload. The implementation of the individual caregiver's plan is essential to invest in the IC empowerment, in a logic of continuity of care, and is a very beneficial resource for families, the community and society in general, given the increase in the number of self-care dependent people. Health gains are effective for dependent people, as well as for the ICs' health, both at the physical, psychological and social well-being levels, and also in terms of satisfaction with care[18].

When analysing the intervention carried out with the IC, the gains in health are evident as the proposed objectives were achieved.

However, there are still deficits of knowledge regarding nutrition and prevention of pressure ulcers, which are due to several factors, such as the IC predisposition and motivation to "learn" and "seize" the knowledge and change their beliefs that were quite deep--rooted. These ICs should continue to be followed-up in other ways, namely through projects providing support and information, thus allowing for the continuity of the work developed.

The conclusions that we can draw are: the IC living in urban areas have more access to community resources in terms of home services support, focusing on hygiene support, food supply and also have the possibility to integrate other responses, allowing the caregiver's rest, leisure time and job maintenance. The multidisciplinary team, with different technicians, collaborates with the ICs in their empowerment and ensures that the elderly people achieve better levels of functionality. It should also be added that being female is one of the predisposing factors for caregivers' overload, being related to the negligence of self-care in favour of caring for the elderly person, according to the social role expected by women[12].

The ICs under analysis presented mostly a light overload, 54.5%, which corroborates the literature. Compared to the PSD, we realised that 55.5% did not have overload, 31.5% had intense overload and 13% had light overload.

Thus, we can state that the overload produced by the act of caring is related to physical and emotional wear, family breakdown, social isolation and loss of identity of the caregiver, making it essential to assess the overload to plan care and offer adequate support to the dependent older person and the IC[8]. Studies show that the greater the dependence of the older person, the greater the IC's overload[8], although we found functionality values

of 81%, the burden is no more than slight, since the social support network is essential for the IC, as well as what was previously mentioned.

It is necessary to pay attention to social isolation, due to the demand for activities developed by elderly caregivers, because when they provide care without the support of other family members, without sharing responsibility, with care being centralized in a single person, it immediately causes overload and social, physical and psychological repercussions, which make caring a negative and uninterrupted task[1]. Observing the sociodemographic characteristics, we found that there is a greater overload for spouses, since marriage may be associated with a relationship of obligation to provide care, because there is a common life project, manifested by marriage and the commitment to be together in health and in illness. Despite being satisfied with the performance of the role, they are subject to several sources of stress, resulting from the definition of tasks for which they are often not properly prepared, bringing repercussions to their daily life. The age of the IC, is related to the domains of effectiveness and control and satisfaction with the role and family, this means that the older the caregiver, the greater the overload[19].

Therefore, by empowering the IC, according to their needs and abilities, we promote the reduction of the overload, since, in Chart 5↗, we can see that the slight overload falls to 9% and 91% are not overloaded, demonstrating the fundamental need for support of these caregivers, so that they feel more motivated, maximizing their abilities.

These show greater control over the situation, since training allows for the provision of quality care. And consequently, greater safety in the performance of the role can prevent possible accidents during care provision, with health professionals, especially nurses, being a facilitator in the acquisition of skills[17].

Highlighting the importance of a multidisciplinary team, in supporting the entire care home, therefore, receiving information of necessary interventions on the disease and on how to care for the elderly person is fundamental to decrease the levels of overload, mainly in the domain of self-care clothing, food, sanitary, transfers and management of the therapeutic regime[5].

CONCLUSION

Elderly people are predominantly female, aged around 80 years, with a functionality level of 81%. The most relevant pathologies are circulatory system, endocrine, nutritional and metabolic diseases and musculoskeletal system diseases. As for the ICs, most of them are male, have attended school, but do not have compulsory education, are married, have a spouse and children and live with the elderly person. A significant relationship was found between the overload perceived by the IC and the IC socio-demographic characteristics.

As a health strategy, the family should be an integral part of the nurses' care, achieving the formation and strengthening of the bond, from the point of view of monitoring and guiding the best way to care for the elderly person, providing coherent information, informing about available resources, regular consultations and, among other practices for the promotion and fullness of care for both the dependent elderly person and the respective caregiver.

This study allows alerting nurses to the need for access to information and training, as well as support to be provided to IC and older people so as to prevent their overload and improve the quality of care. The identification of ICs with high levels of overload, as well as the factors associated with it, is essential for the practice of care, so that interventions are adequate and personalized.

The health gains resulting from empowerment and reduced overload are satisfaction in care provision, improved health and well-being of the IC and the older person, and consequently better management and control of disease symptoms, which is extremely important and valued because this dyad can delay the decision to institutionalise the older person.

The lack of scientific production on the subject, when considering the practice of care in the dimensions of the elderly person, does not allow for a more consistent basis in the literature, which focuses on the dyad IC elderly and elderly caregiver. Therefore, further research is needed to understand the transition between the levels of frailty during care provision.

Authors' contributions

MM: Study coordination, study design, collection, storage and analysis review and discussion of the results.
EC: Study design, data analysis, review and discussion of results.
SS: Study design, data analysis, review and discussion of results.
All authors read and agreed with the published version of the manuscript.

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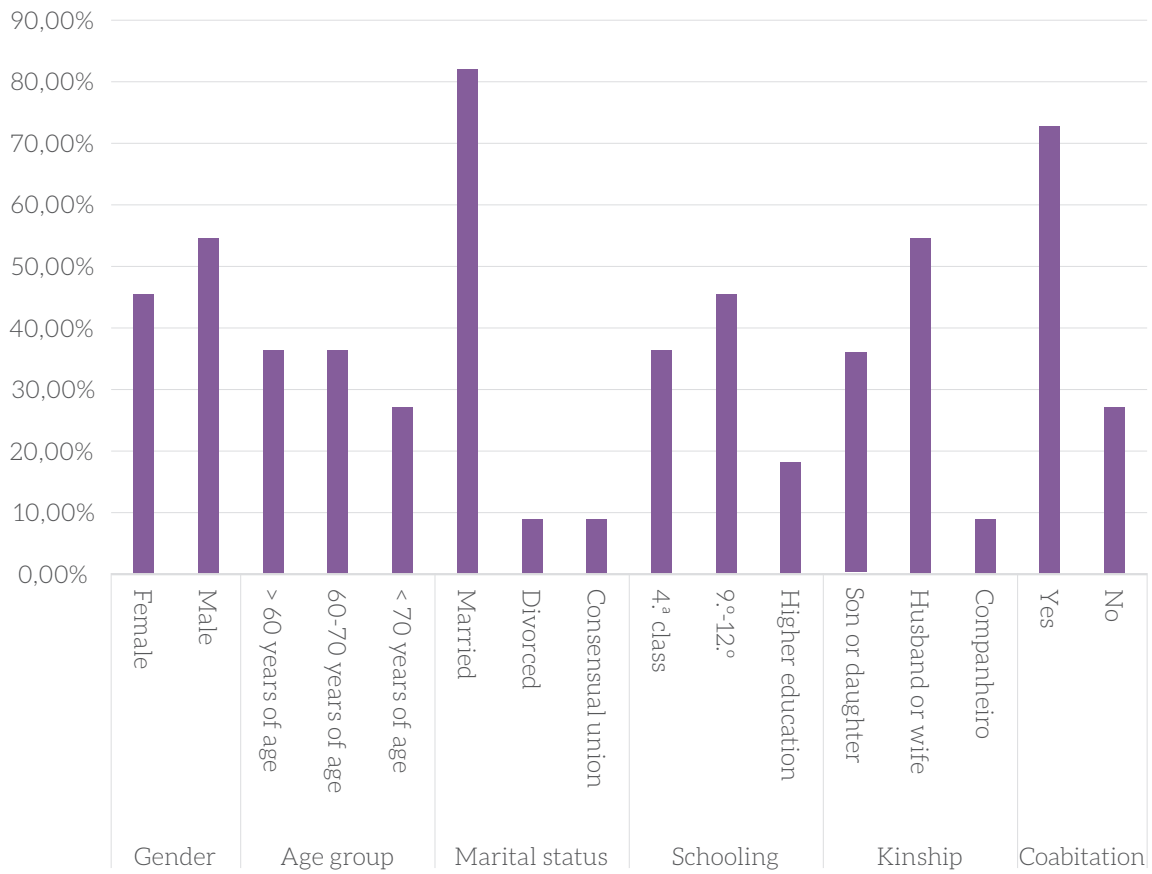

Chart 1 – Socio-demographic characterisation of the Informal Carers.

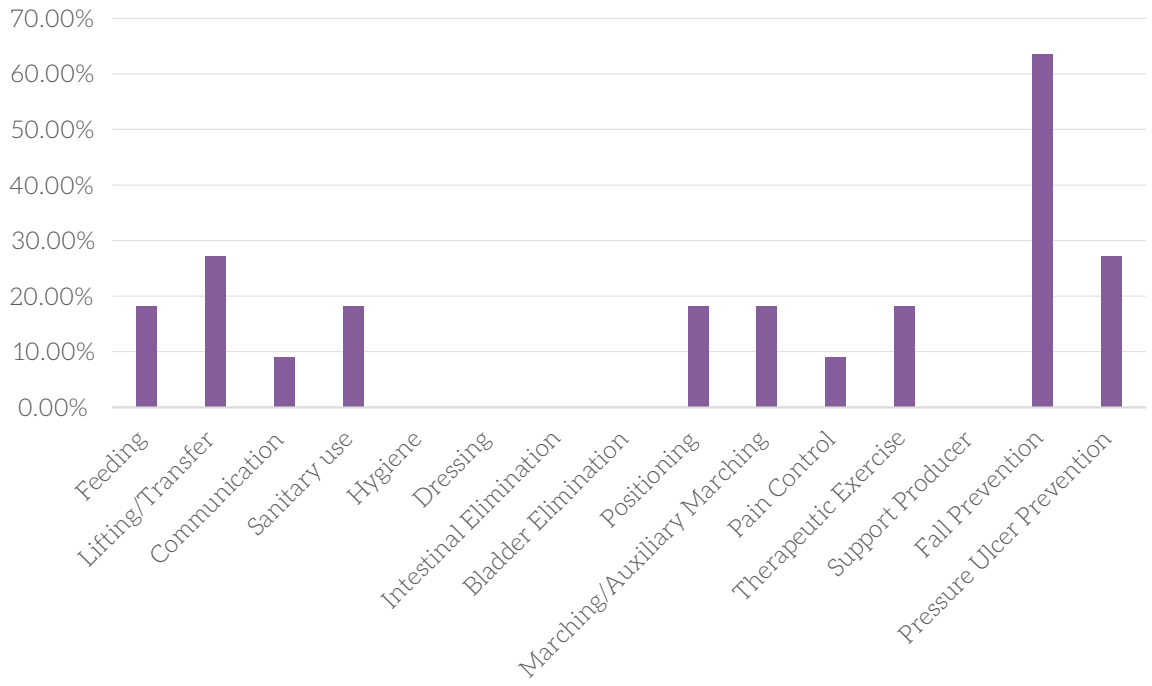

Chart 2 – Informal caregivers' learning needs, initial assessment.↖

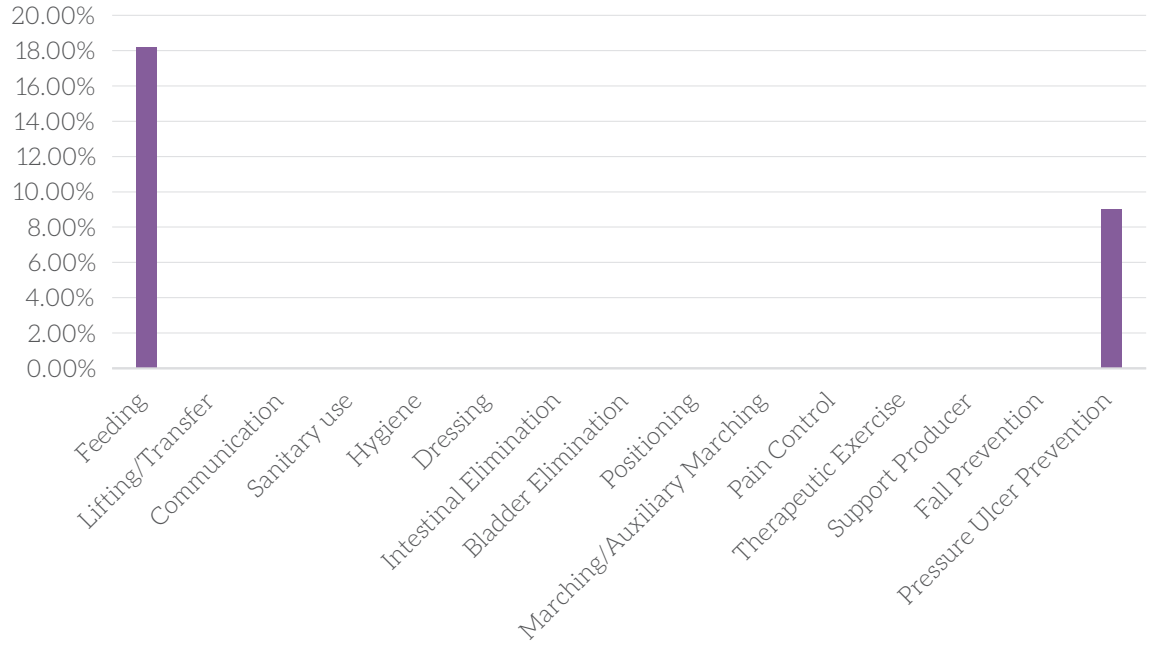

Chart 3 – Informal caregivers' learning needs, final evaluation.↖

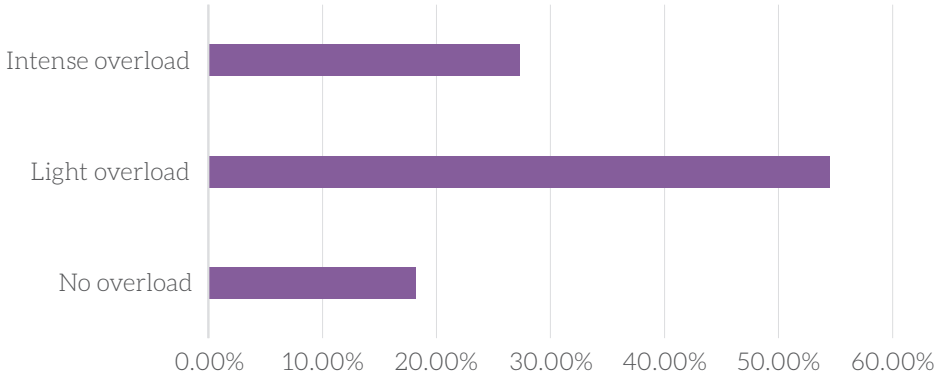

Chart 4 – Informal Caregiver Overload, initial assessment.[↖]

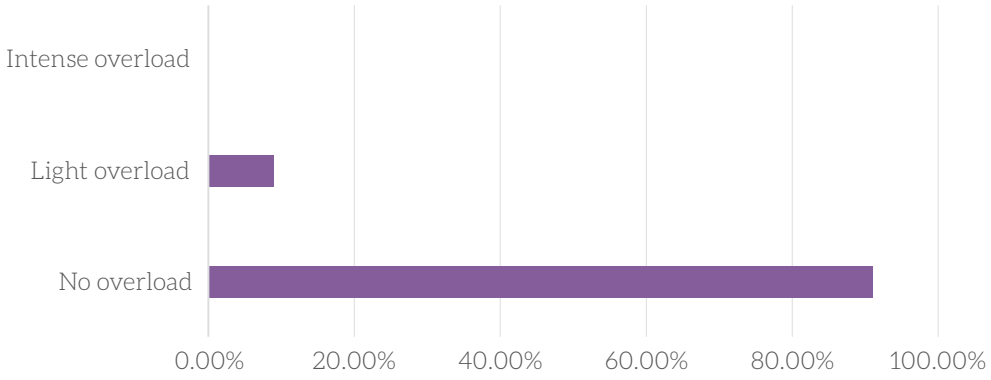

Chart 5 – Caregiver's Overload, final assessment.[↖↖]