



SUPPORT STRATEGIES FOR DISEASE PREVENTION OF THE FAMILY CAREGIVER

ESTRATÉGIAS DE SUPORTE PARA PREVENÇÃO DE DOENÇA DO CUIDADOR FAMILIAR

ESTRATEGIAS DE SOPORTE PARA PREVENCIÓN DE ENFERMEDAD DEL CUIDADOR FAMILIAR

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ABSTRACT

Objective: to identify generators of illness of the family caregiver and discuss strategies to support her/him. **Method:** this is an integrative review, with data collection carried out from September to December 2011 in the databases Latin American and Caribbean Health Sciences Literature (LILACS) and Scientific Electronic Library Online (SciELO). The research question was: "What are the issues generating illness of the family caregiver indicated in the literature?". The data collection instrument contained the following items: year, database, methodology, factors related to illness, and suggested strategies. The inclusion criteria were: adherence to the aims and theme; full papers published in Portuguese; and publications from 2007 to 2011. The exclusion criteria were: repeated papers, those which didn't address the theme, those not fully available, and those whose approach doesn't contribute to Nursing knowledge. We performed a fluctuating reading of the references of 18 papers, selected by means of descriptive statistics, being 16 (89%) from the database LILACS and 2 (11%) from the database SciELO. All papers met the established criteria. **Results:** it was highlighted in 28% the overload with caring tasks; isolation occurred in 22% of the references; lack of actions aimed at the family member was identified in 17%; and lack of support and information was found in 11% of the references. **Conclusion:** the conflicts found can be mitigated through guidelines consistent with the problems presented; the elderly person's vulnerability should be understood by the family caregivers; the ongoing training of nursing professionals with regard to the singularities of nursing care; and the continuous support network for family caregivers. **Descriptors:** caregivers; elderly; nursing.

RESUMO

Objetivo: identificar geradores de adoecimento do cuidador familiar e discutir estratégias de suporte a ele. **Método:** trata-se de revisão integrativa, com coleta de dados realizada de setembro a dezembro de 2011 nas bases de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) e Scientific Electronic Library Online (SciELO). A questão de pesquisa foi: "Quais são os problemas geradores do adoecimento do cuidador familiar indicados na literatura?". O instrumento de coleta de dados continha os seguintes itens: ano, base de dados, metodologia, fatores relacionados ao adoecimento e estratégias sugeridas. Os critérios de inclusão foram: aderência aos objetivos e tema; artigos publicados em português na íntegra; e publicações com delimitação temporal de 2007 a 2011. Os critérios de exclusão foram: artigos repetidos, os que não abordavam a temática, os não disponíveis na íntegra e aqueles cuja abordagem não contribui para o conhecimento de Enfermagem. Foi realizada a leitura flutuante das referências de 18 artigos, selecionados por meio de estatística descritiva, sendo 16 (89%) da base LILACS e 2 (11%) da base SciELO. Todos os artigos atenderam os critérios estabelecidos. **Resultados:** destacou-se em 28% a sobrecarga com as tarefas de cuidar; o isolamento ocorreu em 22% das referências; ausência de ações direcionadas ao familiar foi identificada em 17%; e constatou-se a falta de suporte e informação em 11% das referências. **Conclusão:** os conflitos encontrados podem ser amenizados pelas orientações condizentes com os problemas apresentados; a vulnerabilidade do idoso deve ser compreendida pelos familiares cuidadores; a capacitação permanente dos profissionais de enfermagem em relação às singularidades dos cuidados de enfermagem; e a contínua rede de suporte aos familiares cuidadores. **Descritores:** cuidadores; idoso; enfermagem.

RESUMEN

Objetivo: identificar generadores de enfermedad del cuidador familiar y discutir estrategias de soporte a ello. **Método:** esta es una revisión integradora, con recogida de datos realizada de septiembre hasta diciembre de 2011 en las bases de datos Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS) y Scientific Electronic Library Online (SciELO). La cuestión de investigación fue: "¿Cuáles son los problemas generadores de enfermedad del cuidador familiar indicados en la literatura?". El instrumento de recogida de datos contenía los siguientes ítems: año, base de datos, metodología, factores relacionados con la enfermedad y estrategias sugeridas. Los criterios de inclusión fueron: adherencia a los objetivos y tema; artículos publicados en portugués en su totalidad; y publicaciones con delimitación temporal de 2007 hasta 2011. Los criterios de exclusión fueron: artículos repetidos, los que no abordaban la temática, los no disponibles en su totalidad y aquellos cuyo abordaje no contribuye al conocimiento de Enfermería. Fue realizada la lectura fluctuante de las referencias de 18 artículos, seleccionados por medio de estadística descriptiva, siendo 16 (89%) de la base LILACS y 2 (11%) de la base SciELO. Todos los artículos cumplieron los criterios establecidos. **Resultados:** se destacó en el 28% la sobrecarga con las tareas de cuidar; el aislamiento ocurrió en el 22% de las referencias; ausencia de acciones dirigidas al familiar fue identificada en el 17%; y se constató la falta de soporte e información en el 11% de las referencias. **Conclusión:** los conflictos encontrados pueden ser mitigados por las orientaciones en consonancia con los problemas presentados; la vulnerabilidad del anciano debe ser comprendida por los familiares cuidadores; la formación continua de los profesionales de enfermería con respecto a las singularidades de los cuidados de enfermería; y la continua red de soporte a los familiares cuidadores. **Descriptor:** cuidadores; anciano; enfermería.

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INTRODUCTION

In the care for elderly people at home, many times we witnessed situations which indicated a physical and emotional overload of family members caring for sick elderly patients, making apparent the emotional fragility they were experiencing at that moment. We live in a time of demographic transition in Brazil, due to the sharp decrease in mortality, decreased fertility, and increased life expectancy. These three factors have been increasing the number of elderly people in the country.¹

The main concern with regard to the health of the elderly population lies on the chronic diseases, which, most often, lead to disability and hinder care; moreover, they require from nursing an integral attention to the elderly person's health.² It's estimated that 85% of the elderly Brazilians have at least one chronic disease, and, out of these, 10% have some comorbidity.¹

The care is not merely an act, it's something more comprehensive which involves concern, responsibility, and emotional involvement with the person to whom we provide care. The care is rooted in the essence of man, who, without it, is no longer a human being. Thus, families faced with the installation of pathological processes or chronicity of certain diseases in one of their members experience a totally changed lifestyle. They'll necessarily need to adapt to new demands when assuming the responsibility of caring for.³

In this construction, in some families, issues such as the relationship and the history that each family had and/or have to the elderly person are taken into account, something which will signalize the choice of caregiver. There are those who take this place as soon as needed, as practiced by the family for generations, and the older ones will take care of those who fall ill. Spouses, in turn, who committed to take care of each other at the wedding, generally feel obliged to do so.

There're also those who are merely elected by their own relatives, among other reasons leading to the choice of the elderly person's caregiver.

Generally, in Brazil, the care is provided by the family; besides, in most cases, it's a woman who takes on the responsibilities of caring for.⁴ The care is socially regarded as something natural for a woman, it's one more assignment assumed by the female figure within the family environment, which often is transmitted to the succeeding generations.⁵

Families are becoming increasingly smaller, but with a significant number of elderly people, so, they'll face the problems associated to aging. Families are made up of members bound by unique stories and experiences, and particular emotional ties which unite them. With these inherent characteristics, many families believe it's their own responsibility to care for the health of the one who gets sick in their bosom.⁶

All duties required in this process of caring bring up a negative impact to the family environment, because it's known to all its members that the care for dependents elderly people demand attention, time, and effort. Caring for a dependent elderly person on a daily basis generates distress, anguish, and disruption and, in an attempt to minimize this problem, the family caregiver chooses to hire someone who helps her/him. However, sometimes the caregivers who perform this function don't have the skills that this job requires; they aren't nursing professionals, but perform procedures which are specific to this category. It's known that, with aging, significant changes occur in the body of the elderly people, thus, it's required from the person providing the care some knowledge with regard to these issues. Thus, the risks to the elderly person increase and she/he becomes more vulnerable to iatrogenesis.⁷

The question guiding the research was: "What are the issues generating illness of the family caregiver indicated in the literature?"

However, we understand that the family's presence, in many cases, is of paramount importance for the improvement of the elderly patient's condition. Given the above, the aims of this study were: to identify generators of illness of a family caregiver and discuss strategies to support a family caregiver.

The rationale and relevance of this study lies on the fact that with the rapid and growing number of elderly people, the care for the elderly ones will increasingly become a fact for families. However, prevention has always been the focus and, accordingly, to know the factors causing diseases and harms to the one who cares for becomes extremely relevant and deeply essential, especially for nursing, which has a holistic look.

The care provider has dual responsibility, self-care and care for the dependent individual; given the increased losses and impairments observed in the biological structure of the elderly person, she/he will need to be compensated, requiring sacrifices beyond the caregiver's physical and emotional

limits. We also understand that these care providers need support and recognition for their work, and that researches on this individual's quality of life are needed, as well as guidance that turn, somehow, the care practice less sorrowful.⁸

The elderly people need embracement strategies which use the public health policies available. The relevance of developing nursing care for the quality of life of the elderly person faced with the family caregiver allows reflections on the importance of knowing the strategies to embrace the elderly people and their impact on the family environment. The nursing practice proposed for guidance and care of elderly people's family members and caregivers has relevant scientific grounding, allowing a continuous getting together between patient and family/caregivers.

Moreover, we can't ignore the huge importance of designing and implementing strategies which involve a process of continuous adaptation of the elderly person to this reality of illness and that, thus, bring up significant changes in their families. In the academic field of Nursing, this theme has a significant importance, because the academic collection needs a deepening feasible in the Brazilian reality and, in this respect, its relevance is singular for Nursing research.

It is noteworthy that the main problems related to the elderly person are unique and their relevance with regard to the illness of a family caregiver must be studied, understood, and worked on as a necessary challenge to Nursing, with regard to the strategies to embrace this clientele aimed at its quality of life, something which, undoubtedly, demonstrates the social relevance of this study. Besides, this research will subsidize issues relevant to the academic knowledge concerning the nursing care offered to this clientele.

METHOD

Integrative review study, with data collection period from September to December 2011, with selection of references through fluctuating reading. The search was done in the following databases of the Virtual Health Library (VHL): Latin American and Caribbean Health Sciences (LILACS) and Scientific Electronic Library Online (SciELO).

The choice of these bases is due to their relevant representativeness in health sciences in terms of updated publications which provide evidence for the development of knowledge.

The descriptors used were: elderly, caregivers, nursing.

The inclusion criteria were: adherence to the proposed aim and theme; papers published in Portuguese; full papers which addressed the theme strategies to support the family caregiver's health maintenance, preventing her/his illness; and papers published and indexed in these databases within the last five years (2007-2011).

The exclusion criteria were: published papers which were repeated; papers which didn't address the theme concerned; papers which weren't published in full version and whose approach doesn't contribute to Nursing knowledge.

The data collection instrument used to organize the content obtained in references comprises the following items: year, database, methodology, factors related to illness, and suggested strategies.

We performed a fluctuating reading of the references of 18 papers, selected by means of descriptive statistics, being 16 (89%) from the database LILACS and 2 (11%) from the database SciELO, which presented adherence to the study, and all met the established criteria. Thus, the analysis is grounded on 18 papers.

In the process for selecting the references was noticeable that there was a significant increase in the number of publications on the theme, therefore, one calls attention to a more accurate analysis of the data.

RESULTS

For analysis of the references, the content obtained was organized with regard to year, database, methodology, factors related to illness and suggested strategies.

Out of the 18 selected papers, 2 are from 2011 (11%); 6 are from 2010 (33%); 6 are from 2009 (33%); 3 are from 2008 (17%); and 1 paper (6%) is from 2007.

In the LILACS database we found 16 papers (89%) presenting adherence to the study and all of them met the established criteria. In SciELO we found 2 references (11%).

Aiming to analyze the methodology, the papers were selected and grouped with regard to: qualitative studies (50%); quantitative studies (39%); and qualiquantitative (6%). The others were ruled by references of literature review and reflection (5%). Regarding the type of design, we have: cross-sectional (28%); descriptive (33%); and exploratory (6%).

Regarding the factors related to illness, 5 papers (28%) highlighted overload with the

tasks of caring for, the presence of one or more diseases when dealing on a daily basis with the management of an elderly person's behavioral disorders, bathing, clothing, and hygiene. Moreover, the task of caring for a dependent elderly person is emphasized, without rest and with the accumulation of several roles by the caregiver aged over 50 years.

Another factor related to illness was the issue of not receiving help from other family members in the tasks of caring for the elderly person, leading to an overload of tasks reported in 2 papers (11%).

The physical and psychological distress caused by the act of caring for and the repetition of tasks derived from behavioral symptoms (neuropsychiatric ones) of an elderly patient was stressed in the references in 3 papers (17%). It's noteworthy that the caregiver lives with the patient, this function is performed by a woman, and she spends many hours a week caring for the patient.

The progression of the elderly patient's disease hampers the possibility that the family caregiver develops social activities. This fact affects the relationship with family and it brings up a burden to the caregiver's health when there're feelings of loneliness and isolation, found in 4 papers (22%).

A relevant keynote was ruled by the actions not well aimed at the family's development and functioning. The lack of attention and direct monitoring to family members by the health team was highlighted in three papers (17%). Furthermore, there's the decrease or absence of cognitive abilities in the dependent elderly person with Alzheimer's disease, which leads to an integral provision of care added to the lack of support in 2 papers (11%).

The lack of information to understand and cope with the disease and the support needed in the assistance to a dependent elderly person was considered indispensable to the caregiver in 2 papers (11%).

Regarding the suggested strategies to support the family caregiver, we have interventions aimed at specific characteristics of caregivers which can contribute to the achievement of an improved quality of life for elderly people, besides the planning of interventions aimed at both of them. A partnership between professionals and family caregivers can minimize the difficulties experienced, that was the keynote in 2 papers (11%).

Instruments were also suggested to assess the family support network, with genogram

and eco-map, and they may help understanding the family structure, as well as the design of a good family relationship, it's important for the provision of care, so that not only one family member become overloaded with the elderly person's care. All family members, not only those who care, should participate in support groups which explain diseases, seeking to understand how to deal with the changes arising from the disease, that was the keynote in 3 papers (17%).

It was suggested a literature search for scientific support in the adoption of tools for the development of abilities to carry out family approach. Thus, it's possible to propose aid interventions in partnership with families, in order to improve the quality of family life. The deepening of discourses on the subjectivity of caring for in cases of demential syndrome, especially Alzheimer's disease, was also highlighted in 3 papers (17%).

Another aspect was the change with regard to the aims of consultations and actions of care and guidance and to professionals specialized in the field of gerontogeriatrics. This way, it's possible to know the profile of caregivers, the redesign of programs aimed at treating the families, the rebuilding of care technologies appropriate to different situations, which were the keynote in 3 papers (17%).

Planning in terms of intervention was taken into account by inserting the caregiver in an assistance plan to ensure her/him a better quality of life. Therefore, there's a need for articulating in the practice of local networks of social support through health services for maintaining social inclusion of family caregivers. Institutions should determine the number of elderly people being cared for by each person and, according to the functional capacity of the elderly person, offer specific training in order to strengthen this relationship of care; that was highlighted in 5 papers (28%).

In terms of service availability, stood out special attention of services and health professionals to caregivers in a multidimensional manner. Attitude, posture, empathy, and understanding foster a better communication between the professional and the user, improving treatment and embracement by identifying patients and caregivers at greater risk to develop strategies which reduce this impact. Thus, there's a greater commitment of health professionals with regard to support, guidance and explanation, and compliance with legal requirements, with the implementation of

support associations and reference centers, something which stands out in 4 papers (22%).

Knowledge on the disease, so that care procedures are performed in a specific way, was noticeable in 2 papers (11%). One highlights the understanding with regard to the condition and progress of the disease through the teaching of new forms of behavior and knowledge to keep playing the role of caregiver, persevering in their own needs. The importance of caregiver's awareness about her/his needs stands out in 1 paper (6%).

DISCUSSION

The disease or disease process in the elderly person brings about the burden on its functional structure, which will lead to the need for continuous monitoring, by family caregivers or those paid for this purpose. The family is still the primary source of support for home care in various cultures.

When the elderly person who enjoyed total independence begins to experience the condition of dependence due to a disabling disease, the probability of hospitalization in the most critical cases is high, taking into account the fragility of the aged body. Returning to family life after clinical stabilization, there may be a need for assistance to perform activities of daily living (ADLs), on a full or partial basis, which may occur for a short period or indefinitely.⁵

The caregivers have been increasingly requested and they have gained, in recent times, a high reputation with regard to the current situation experienced through the country's aging.

In most situations concerning the need for care of a dependent elderly person, who takes on this responsibility is a family member who not always have knowledge or training to perform the procedure concerned. As the care activity is complex and demanding in its structure, the one who provides care must have the knowledge and skills needed, so that management is facilitated and carried out correctly, preventing this individual to be exposed to vulnerability in the future.⁹

It's an arduous task for the family to provide care to the elderly person at home, because, often, who plays this role is someone performing various other activities; this accumulation of functions in the long term will bring up a huge amount of negative impact on the family caregiver's health. Furthermore, besides willingness to carry out multiple activities, she/he will need guidance and monitoring do so with quality and safety. Thus, there's a need for a planned

professional assistance, which is in line with the needs of each family.¹⁰

In Brazil, despite the creation of public policies to treat the geriatric population, there isn't one of them aimed at disabilities resulting from usual diseases of individuals with advanced age. Being family, as a rule, the enforcer of care procedures, a qualified support to these individuals is needed. This support can come from primary care, through the Family Health Strategy.¹¹

Although the theme of work done by the family caregiver has been widely discussed, there isn't a significant approach on the caregiver's relationship with the health professional, and the latter has an absolutely undeniable importance so that care is provided without burden, both for those who care and those who are cared for. When there's an imbalance in the relationship between these individuals, the results won't be satisfactory from the point of view of prevention of illnesses. Often, the family hasn't an adequate support to provide care and, also, it experiences many difficulties when assisting the elderly person in its own facilities.¹¹

The deficiencies found in the public sector have contributed to turn the family into the main support center to care for the elderly at home. Reducing the cost of hospital and institutional care and, in most cases, the lack of financial resources to hire qualified people to provide care, have been making the family member the only option available to the dependent elderly person.¹²

The care for the elderly person can be provided by a family member, a professional, or a health institution. The caregivers were classified as formal or informal. Formal is the hired professional and informal are relatives or those who have some bond of friendship or offer themselves voluntarily.¹³

Regarding informal care, this comes from the family members. However, for this, the family needs to restructure itself. There must be a division of tasks to assist in the provision of care.

The family caregivers complain about numerous issues, ranging from the physical to the psychological aspect, due to the accumulation of activities; some of these individuals are older than 40 years and they already have a chronic disease, something which enhances the risk of worsening diseases in this caregiver, if there's no division of tasks. Depending on the pathology affecting the elderly person, there's a need to make changes in the physical environment, in order

to meet their needs. There're cases where the caregiver needs to move closer to the elderly, since all these changes can raise a family segregation. Support for the family caregiver from the other family members has as its main aim to reduce the negative aspects caused by care tasks and contribute to improve the health of those providing care, since, in most cases, they're individuals with impaired health, something which makes them more vulnerable.¹⁴

Issues related to aging have deserved attention from authorities all around the world. The elderly population is growing fast every year. Often, with the aging process, some major disability is perceived in these individuals, especially in the oldest ones, something which will lead to the need for continuous monitoring by caregivers, relatives, or people paid to perform this function. So, these subjects providing care actions will require support and preparation to assume these responsibilities in a safer manner with regard to all.

Aiming to improve the care provided to the elderly people, the Brazilian Portaria Interministerial 5,153 was signed, on April 7 1999, establishing the National Program of Elderly People's Caregivers. It was drawn up by representatives of the State Department of Social Welfare, from the Social Security Ministry, and the Department of Health Policies, from the Health Ministry. It aims at the improvement of home caregivers, be they relatives or not, contributing to the reduction of the percentage of institutionalized elderly people. Article 3 of this legislation states that: "There shall be established specific protocols with universities and non-governmental entities, with well-known competence, aimed at training human resources in the different modalities of caregivers: home (family and non-family) and institutional".¹⁵

The existence of a caregiver often prevents the dependent elderly person from being institutionalized, besides, it contributes to the implementation of various welfare programs; thus, the guidance and monitoring of this individual is extremely relevant.¹⁶

It's highlighted by the same author that many initiatives related to what was proposed by the National Program of Elderly People's Caregivers don't meet the established aims, there's a diversity of actions with this purpose, generating discontent on the part of Regional Nursing Councils, which believe that the misunderstanding of caregivers' assignments may get them to perform tasks unique to a professional nursing. Another

point stressed by the author is the lack of follow-up to these caregivers. Thus, issues related to legal activities assigned to them need to be discussed at a national level.

The nurse who works with a person with Alzheimer's dementia needs to assist not only these clientele with regard to its needs, but she/he also have to pay attention to the family/caregiver. At certain times, we should be closer to family/caregiver than to the patient her/himself. Such responsibility is assigned to the family/caregiver and the nurse should be the professional who guides a health care model compatible with the reality of this clientele.¹⁷

There's a predominant characteristic in cognitive impairment, which causes progressive dependency, and the caregivers dealing with it notice the deficits presented, as well as the need for an accurate nursing care, according to the singularity posed by the support needs, as described by identifying the care procedures specific to the elderly person with Alzheimer's disease.¹⁷

Furthermore, it's understood that the caregiver should be included in the care plan of a patient with Alzheimer's disease, among other illnesses, since she/he may show changes in various aspects of her/his health. And one should provide an integral care to the caregiver, the health team will ensure not only a better quality of life to her/him, but also to the patient she/he cares for.¹⁸

CONCLUSION

Considering the results found, through the research with the aim of identifying generators of the family caregiver's illness and discussing strategies to support her/him, we can consider that the public and private sectors need to turn their attention to the caregiver's health. The methodology to achieve this aim proved to be adequate because it analyzed the main highlights from the productions on this theme, indicating relevant evidence for further research in the field of Nursing.

The limitations related to the lack of discussions and researches aimed at issues of illness and strategies to support family caregivers, with regard to access to the health services. The studies highlighted in this paper involved issues of overload resulting from the care for elderly people, social isolation, lack of information, and difficulties to manage family problems. There was little discussion about access to public policies aimed at the caregiver.

Therefore, we indicate relevant considerations raised by this study: the perception of nursing professionals and families and/or caregivers with regard to the elderly people's illnesses and the detection of problems; the planning which aims to achieve equilibrium; the problems leading to conflicts found may be mitigated by guidance consistent with the problems presented; the elderly person's vulnerability should be understood by family members and/or caregivers as something real in need of effective participation for the continuity of care; the importance of ongoing training of nursing professionals with regard to singularities of nursing care procedures; as well as a continuing support network for family members and/or caregivers.

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Sources of funding: No

Conflict of interest: No

Date of first submission: 2012/02/09

Last received: 2012/08/22

Accepted: 2012/08/23

Publishing: 2012/09/01

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