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REFLECTIVE ANALYSIS ARTICLE

REFLECTIVE APPROACH ON THE ROLE OF INFORMAL CAREGIVERS IN THE CONTEXT OF CONTINUITY OF CARE HOME

ABORDAGEM REFLEXIVA SOBRE O PAPEL DO CUIDADOR INFORMAL NA CONTINUIDADE DOS CUIDADOS EM CONTEXTO DOMICILIÁRIO

ENFOQUE REFLEXIVO SOBRE EL PAPEL DE LOS CUIDADORES INFORMALES EN EL CONTEXTO DE LA CONTINUIDAD DE LA ATENCIÓN DOMICILIARIA

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ABSTRACT

***Objective*:** reflecting on the role and importance of informal caregivers in the context of continuity of care home. ***Method*:** it consists of a review with reflective approach to continuity of care provided by informal caregivers at home, made through literature by various authors in the study area and also based on the author's experience as a nurse in a team integrated continuum of care home context. ***Results*:** as a result of their research and reflection on the role of informal caregivers in the community, it was found that is a partner in home care in context, with specific requirements relating to the functions and needs by all those who implement health policies greater recognition and support. ***Conclusion*:** the promotion of well-being of caregivers and crisis prevention, deserves the part of professionals in the areas of health and social care, including community health nurses, a particular attention, since these depend on the patients under their care, as well as his stay in the community. Among other things, it becomes essential to enable informal caregivers to perform the skills that are inherent to the role it assumes, caring person with addiction. ***Descriptors*:** caregivers; patients at home; community health nursing.

RESUMO

***Objetivo*:** refletir sobre o papel e importância do cuidador informal na continuidade dos cuidados em contexto domiciliário. ***Método*:** consiste numa revisão com abordagem reflexiva sobre a continuidade dos cuidados assegurada pelos cuidadores informais no domicílio, efectuada através de pesquisa bibliográfica de vários autores na área em estudo e também baseada na experiência profissional da autora, enquanto enfermeira numa equipa de cuidados continuados integrados de âmbito domiciliário. ***Resultados*:** fruto da pesquisa e respectiva reflexão acerca do papel do cuidador informal na comunidade, constatou-se que é um parceiro no cuidar em contexto domiciliário, apresentando necessidades específicas inerentes às funções que desempenha e que carece por parte de todos os que implementam as políticas de saúde um maior reconhecimento e apoio. ***Conclusão*:** a promoção do bem-estar dos cuidadores e a prevenção de crises, merece pela parte dos profissionais das áreas da saúde e social, nomeadamente pelos enfermeiros de saúde comunitária, uma atenção particular, pois deles dependem os utentes a seu cargo, bem como a sua permanência na comunidade. Entre outros aspetos, torna-se fundamental capacitar os cuidadores informais para o desempenho das competências que estão inerentes ao papel que assume, de cuidar a pessoa com dependência. ***Descritores*:** cuidadores; pacientes domiciliares; enfermagem em saúde comunitária.

RESUMEN

***Objetivo*:** al reflexionar sobre el papel y la importancia de los cuidadores informales en el contexto de la continuidad de la atención domiciliaria. ***Método*:** se trata de una revisión con enfoque reflexivo a la continuidad de la atención prestada por los cuidadores informales en el hogar, realizadas a través de la literatura por diversos autores en el área de estudio y también se basa en la experiencia del autor como enfermera en un continuo del equipo de atención integral entorno de origen. ***Resultados*:** como resultado de su investigación y reflexión sobre el papel de los cuidadores informales en la comunidad, se encontró que es un socio en la atención domiciliaria en su contexto, con los requisitos específicos relativos a las funciones y necesidades de todos los que poner en práctica las políticas de salud un mayor reconocimiento y apoyo. ***Conclusión*:** la promoción del bienestar de los cuidadores y la prevención de crisis, merece por parte de los profesionales en las áreas de la atención sanitaria y social, incluyendo las enfermeras de salud de la comunidad, una atención particular, ya que éstas dependen de los pacientes bajo su cuidado, así como su estancia en la comunidad. Entre otras cosas, se convierte en esencial para permitir a los cuidadores informales para llevar a cabo las competencias que le son inherentes a la función que asume, el cuidado de las personas con adicción. ***Descriptores*:** cuidadores; pacientes en el hogar; enfermería en salud comunitaria.

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INTRODUCTION

We watch, actually, the aging of the Portuguese population, where the number of people with chronic incapacitating and dependent illness within the family, predominantly dependent of a third person, has increased. The last census of the passed Portuguese population in 2011, accented this reality evidencing itself that 19% of the population are 65 or more years, and the country presents an index of aging of 129, what face to the young is expressed a predominance of the aged population, that is, more exist 29 aged for each 100 people of the zero to 14 years old. This population aging constitutes a challenge for the society in the measure where, underlying it, finds aspects of loss of autonomy and dependence that cause deep necessities of social political reorganization.

In this direction it seems to meet reform of the primary cares of health, passed in the last years in our country, detaching itself the Equipas de Integrated Continued Cares that constitute a domiciliary reply for all the people who, independently of the age, find in a dependence situation, and that they need continued cares of health and social support, of preventive nature, rehabilitative or palliative.

The domicile as the place of election for the installment of cares to the dependent people causes an accountability of the families/informal caregivers for its installment, only possible by means of the acquisition of specific abilities to the care to be played.

For such, becomes indispensable the support on the part of professionals of the social and health areas, in the qualification and aid of that who take care of at a delicate moment of their lives, because any that should be the illness it's always a generating of crisis situation, causer of stress that it, in such a way, produces effect in those who possess it as in those who had assumed the task to take care of.

Having in account that the permanence of the dependent person in the domicile proceeds from the empowerment of the informal caregivers, becomes indispensable the precocious creation of an efficient joint between formal caregivers and informal, that in their complementarities, concur in such a way for the satisfaction of the necessities of who is well-taken care of, as of who takes care of.

OBJECTIVE

- To reflect about the role and importance of the informal caregiver in the continuity of the cares in domiciliary context.

METHOD

The present study consists of a reflexive approach on the continuity of the cares assured by the informal caregivers in the domicile, effectuated through bibliographical research of some authors in the area in study and also based in the professional experience of the author, while nurse in one equip of integrated continued cares of domiciliary scope.

It is started by approaching the thematic of the informal caregiver, defining concepts and abilities, followed by the presentation of his necessities that emerge from the task of taking care and, finally, a reference to the politics of health in its role of taking care of that who takes care of.

RESULTS AND DISCUSSION

Next will be presented the results that had standed out from the realized research, and consequent reflection concerning the role of the informal caregiver in the continuity of the cares in domiciliary context.

• To be an Informal Caregiver

Informal Caregiver is understood by everyone who provides care of the dependent people, and that is not rewarded economically by providing aid, and you may have family ties, friendship, neighborhood or other, with the person cared for. Inside of these rendering of cares, two types can be differentiated, in accordance with the care that gives: primary or main caregivers and secondary caregivers. It is considered main caregiver, the one who performs more than half of the job involved in the care process.

To the informal caregiver is the responsibility to take care of, that affirms Collière "to take care of, to give cares, to look at, is first of all, a LIFE act, in a mean of that it represents an infinite variety and activities that aims to keep, to support the LIFE and to allow it to continue multiplying".

The necessity to be taken care is transversal all human being throughout their vital cycle presents a bigger expression in the group of the children and the aged ones, due to the necessity those present of aid in the accomplishment of their daily activities of life. To take care is armed thus with a dynamics between the person that takes care

of and that one that is well-taken care of, developing a process to take care of, that is, the form as the care occurs, that wants personalized and individualized.

Relatively to the profile of the informal caregiver is verified the defended by Martins, Ribeiro and Garret when affirming that

> *Although the alterations in the functions and familiar structures registered in the last few decades, continue to be, in the majority of the cases, relatives direct from the feminine sex that mostly support these sick people, thus playing the paper of informal caregivers.*[5:132]

This predominance of the women associated to the informal care causes in many cases a physical and emotional overload, a time that currently the women are active in the labor world, as the men, contrarily to what happened in the past. For, moreover, it is verified still many of the tasks related with the domestic organization and education of the children, also are to their position, becoming them thus more vulnerable to situations of fatigue and stress.

Whenever appears a state of illness, as much the sick person as the family come across with the obligatoriness of reorganizing, nominated in what is said in respect to the definition of the relations, obligations and capacities, therefore as affirms Martins, Ribeiro and Garret "any illness, is always a crisis situation, a stressor event, that produces effect in the sick person and the family".

Thus, when the caregiver comes across with the incapacity in answering to the inherent requirements to the process of taking care of, he stays before a situation of stress that will have repercussions in the caregiver and in that who is well-taken care of. In accordance to Devi and Almazán, the informal caregiver recognizes as factors of stress, the following ones:

♦ Direct cares, continuous, intense and necessity of constant monitoring;

♦ Absence of knowledge or information to play the cares;

♦ Overload of work;

♦ Familiar conflicts related to the absence of help and nonrecognition of ones effort;

♦ Difficulty in adapting the requirements of taking care of to the available resources.

It is common to listen to the part of the informal caregivers that find themselves in a solitary task, where the presence of friends and relatives becomes each time lesser when the measure that taking care of becomes continued in the time. Thus being, in order to give adequate reply to this situation of crisis, it ants to the level of the installment of cares the sick person, wants to the adaptation of the life of the cuidador to this new function, emerges as necessity the acquisition and development of abilities that contribute for a positive experience of the act to take care of.

Nursing of communitarian health in this way is convoked to intervene next to this target group that is the informal caregivers, valuing them and empowering them in a relation of partnership in taking care of people with dependence.

• Necessities of the Informal Caregiver in the Taking Care Process

When we talk about necessities, we cannot ignore the factor subjectivity, in the measure where each person has different desires and pretensions, attributing one individual meaning to what it is valued.

According to Lage "the process of taking care is habitually a complex and demanding process, involving a potentially responsible set of situations and experiences for alterations in the health and well-being of the lender of cares, nominated in terms of his mental health." Hence we can never forget that the caregiver as a person who is, has needs that must be met in a holistic perspective, to achieve their well-being.

The informal caregiver encounters, then on, necessities of what are detached, according to Quaresma, the following ones:

♦ Financial situation, due to the functions with the cared person;

♦ Techniques of help which allow a major autonomy of the depended person, making easy the help of the caregiver;

♦ Protection, assistance and social support;

♦ Communitarian supports, making easy the Access to information and available services;

♦ Availability of time;

♦ To have companion, live and to be supported to the psychosocial level;

♦ Formation which allows a more adequate help to the person who is taken care;

In practice, we depair very often with caregivers who over time are forgetting themselves, neglecting their needs, focus on the person cared for, your full attention and dedication. This leads to situations of exhaustion, accompanied by low self-esteem and depression, verifying social isolation, with disgust in realizing inclusive leisure or care about body image.

According to Moreira, in a study he developed with caregivers of people who are in the end of life, is detected that existed difficulty by the part of the informal

caregivers to ask for help to the health professionals, feeling as essential that these assess their needs. Often, this lack of support experienced by caregivers to help them meet their felt needs, can lead to rejection of the dependent person at home, looking for careers institutionalize it as an answer to their difficulties. Neglect the necessities/difficulties of the informal caregivers is synonym to compromise the quality of the given cares, in accordance with the defended one by Gonçalves, Alvarez and Santos that associate the lack of formation and qualification of the caregiver to the occurrence of serious problems, such as: intromission in the dynamics of the family; assistance not systemize; dependent behavior and maltreatment to the well-taken care of person.

The informal caregiver, today more than ever, must be properly valued and supported by formal home care services, because it depends on the continuity of the dependent person at home, which is the place of excellence, where possible, to provide care.

In 1st International Conference on Health Promotion, is highlighted the importance of health professionals in empowering people to learn throughout their lives, preparing them for all stages of their development and to fight against chronic and disabling diseases

• To Take Care of Whom Takes Care: Utopy or Reality?

The World-wide Organization of Health, in the Politics of Health for All in the XXI Century (goal 15) underlines the necessity to give a "much more strong emphasis in the primary cares. (…) that provides to a number limited of families an ample fan of counseling on style of life, familiar support and cares in domicile". This familiar support becomes indispensable, when it is intended to promote the health and well-being of the informal caregivers (in its majority familiar of the well-taken care of person), being necessary to integrate some social sectors, to answer of holistic form to the necessities of the caregivers, a time that the only reply of the sector of the health discloses insufficient manifestly, face to the necessities for these presented.

Also the National Plan of Health 2004-2010, when presenting the Strategies To get More Health For All - Boarding centered in the family and the cycle of life, mentioning itself specifically to the Active Aging, defends that one of the "Settings to privilege, in this phase of the life cycle, includes: the family, enabling it to the installment of informal cares" .

This necessity of formation together to the family comes strengthened in the National Program for the Health of the Aged People, defining, among others, the following recommendation for the action:

> *To inform the aged population and families about: a) correct use of the necessary resources to the health; b) approach of the dependence situations most frequent, nominated by motor deficits, sensorial, cognitive, ambient and sociofamiliar; c) approach of the dementia situations, nominated the illness of Alzheimer, as well as on the prevention of depression and pathological fight; d) boarding of the incontinence; e) promotion and recovery of the verbal health; f) prevention of the adverse effect of the self-medication and polimedication; g) installment of domiciliary cares the sick aged people or with dependence.*

This emphasis given to the formative component of the family-caregiver does not have to be faced as a mere and reducing formative process, a time that what it is intended is an educative intervention, in the direction to enable the caregivers to the process to take care of. In such a way, the professionals must take care of to some components of dyad person informal dependent-caregiver, a pointedly: cognitive; affective; psychomotor and spiritual of both, not forgetting the environment where they are inserted.

The nurses, being the professionals of health who next are of the informal caregivers, decurrently of its installment of cares in the domicile, are many times the first resource when necessities in the process appear to take care of.

In this scope we detach as one of the abilities attributed to the nurse specialist in communitarian nursing, nominated, that this contributes for the process of qualification of groups and communities, in the measure where "Participates, in partnership with other institutions of the community and the social net and of health, in projects of communitarian intervention directed the groups with bigger vulnerability".

In the current organization of the primary cares of health, we have between the some functional units that compose each grouping of health centers, the unit of cares in the community that presents as one of the with priority activities of its wallet of services "Projects of domiciliary intervention with dependent individuals and families/cuidadores, in the scope of the RNCCI, as they are: (…) Informal education for the health of the users, familiar and

caregivers" .16: 15440 This constitutes thus, one of the activities that must be developed by the nurses who exert functions in the units of cares in the community, contributing for the justification of the development of the project presented.

In this direction, also meets, as one of the specific objectives of the National Net of Integrated Continuous Care, "the support to familiar or rendering the informal ones, in the respective qualification and the installment of the cares". It is related still, specifically Equip de Integrated Continued Cares, that being to multidiscipline, must assure services among others: "Education for the health to the sick people, familiar and caregivers".

As much the primary cares of health as the differentiated cares of health, need to look at the informal in optics of partners in taking care of, valuing them and following its work in the domicile, its sources relational and formative. Thus, the promotion of wealth of caregivers and crisis prevention deserves the part of health professionals special attention because users depend on them and their dependents, and his stay in the community. Among other things, it becomes essential to provide information and training for family / informal caregivers, enabling them to plan the care for dependent people's home in context, since "the nurse has the responsibility for the education of human beings who are under their care ".

In this way, be-in the certainty that still much has to be developed to the level of the services of communitarian support (health, social…) so that this if becomes a reality, accessible to all the ones that heroically assume nowadays the role of informal cuidador, although the some difficulties (economical, social, labor, familiar…) with that they are come across throughout the process to take care of.

CONCLUSION

Having in account the current demographic reality, where is the increase of the longevity and the accented aging of the populations, becomes emergent to look at for the informal caregivers as communitarian partners in taking care of, which have of recognized and being valued by the work that develops in the support to the people with dependence. In this direction, it is basic to identify its necessities of holistic form, so that it is promoted and assured its well-being throughout all the process to take care of.

The nurses and more specifically the specialists in communitarian nursing must contribute for the qualification of the informal caregivers, through the optimization of existing abilities as well as while facilitators in the acquisition of new, in accordance with his area of action and influence. To take care of that they take care of constitutes plus a challenge for the health politics, that they must hug it with persistence and devotion, for good of that they are well-taken care of, thus making possible its permanence in the domicile, that, whenever possible, is the place of excellence for the installment of the cares, opposing the trend of the institutionalization of the cares.

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