

Family caregiver's needs in caring for the dependent person: an integrative literature review

Necessidades do cuidador familiar no cuidado à pessoa dependente: uma revisão integrativa da literatura

Necesidades del cuidador familiar en relación al cuidado de la persona dependiente: una revisión integradora de la literatura

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Abstract

Background: Population ageing and dependency increase require a growing need of home-based care to be provided by family members.

Objectives: To determine what are the main needs expressed by family caregivers in caring for the dependent person by performing a literature review.

Methodology: Search in both national and international electronic databases, using specific search engines. A total of 516 scientific studies were initially obtained. After an analysis according to inclusion criteria, a total of 21 papers were selected.

Results: The obtained scientific evidence highlights certain needs, which were divided according to the Transitions Theory: community and societal resources, knowledge and preparation, personal meaning, beliefs and attitudes, and socioeconomic status.

Conclusion: We can conclude that the correct diagnosis of family caregivers' needs is essential for an effective planning of nursing interventions, which can be translated into health gains both for the caregiver and the patient.

Keywords: family caregivers; needs assessment; family; frail elderly.

Resumo

Contexto: O envelhecimento e o aumento da dependência da população implicam a necessidade crescente de cuidados no domicílio a serem prestados por familiares.

Objetivos: Determinar quais as principais necessidades manifestadas pelo cuidador familiar no cuidado à pessoa dependente, através de uma revisão da literatura.

Metodologia: Recorreu-se à pesquisa em bases de dados eletrónicas, nacionais e internacionais, com o recurso a motores de busca específicos, tendo sido obtido inicialmente um total de 516 produções científicas que, após a análise segundo os critérios de inclusão, ficou resumido a um conjunto de 21 artigos.

Resultados: Da análise da evidência científica obtida, esta orienta para um conjunto de necessidades, as quais agrupamos à luz da Teoria das Transições: recursos comunitários e sociais, conhecimentos e preparação, significado pessoal, crenças e atitudes e condição socioeconómica.

Conclusão: Podemos concluir que o correto diagnóstico das necessidades dos cuidadores familiares é determinante para o planeamento eficaz das intervenções de enfermagem, o que pode traduzir-se em ganhos para a saúde, tanto do cuidador, como da pessoa que é cuidada.

Palavras-chave: cuidadores familiares; determinação de necessidades de cuidados de saúde; membros da família; idoso dependente.

Resumen

Contexto: El envejecimiento y el aumento de la dependencia de la población implican una creciente necesidad de que los familiares presten cuidados en el hogar.

Objetivos: Determinar cuáles son las principales necesidades manifestadas por los cuidadores familiares en relación al cuidado de la persona dependiente, a través de una revisión de la literatura.

Metodología: Se realizó una búsqueda en bases de datos electrónicas, nacionales e internacionales, y se usaron motores de búsqueda específicos. Inicialmente se obtuvo un total de 516 trabajos científicos que, después del análisis de acuerdo con los criterios de inclusión, se resumió en 21 artículos científicos.

Resultados: El análisis de la evidencia científica obtenida conduce hacia un conjunto de necesidades, que agrupamos de acuerdo con la Teoría de la Transición: recursos comunitarios y sociales, conocimiento y habilidades, significado personal, creencias y actitudes, y nivel socioeconómico.

Conclusión: Un diagnóstico correcto de las necesidades de los cuidadores es crucial para la planificación efectiva de las intervenciones de enfermería, lo cual puede resultar en beneficios para la salud, tanto para el cuidador como para la persona cuidada.

Palabras clave: los cuidadores familiares; evaluación de necesidades; familia; anciano frágil.

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Introduction

Population ageing is a current reality, with serious consequences on society. According to the 2011 census of Statistics Portugal (2012), people are living longer due to advances in health care, which lead to an increase in the average life expectancy, but also due to an increase in the incidence of chronic and/or incapacitating diseases. This highlights the widening top of the age pyramid and, associated with this, its narrowing base, as a result of the decrease in the birth rate (Carrilho & Patrício, 2008). The decline, which is common to the ageing process, and the increase in chronic diseases lead to a loss of autonomy and increased dependence on third parties for the satisfaction of the most basic daily needs and maintenance of quality of life (Sequeira, 2010).

The provision of such care can be extremely exhausting and often entails an increase of stress and overload among caregivers. On the other hand, they face a set of constant challenges, for which they need to be organized and properly prepared so that they can experience a healthier transition to this new role. Therefore, it becomes important for caregivers to work closely with health professionals, including nurses, so as to meet their needs, maintain the appropriate level of health and well-being and, similarly, ensure the continuity of care provided to the dependent person.

A facilitator of this continuity is the long-term care network, which can be an important support for these caregivers, when it cooperates with the different health care services. In Portugal, long-term care is composed of a formal support and an informal support network (Martins, 2008). The role of the family member who provides care or family caregiver is of extreme importance in the informal support network, because it is intended to ensure the continuity of care of the dependent relative. Thus, informal care is unpaid care which is provided in part or as a whole to the dependent person by people belonging, in general, to the family network (Sarmiento, Pinto, & Monteiro, 2010). Informal care can be provided by friends, neighbours, or others, but it is often the family that is responsible for organization or assistance and care provision.

The family plays, from the earliest times, an important role for the person, for which it is considered a primary social system, within which

the person is cared for and physically, personally and emotionally developed (Sarmiento et al., 2010). In this context, for a long time now, the family plays a vital role in providing assistance and support to disabled or dependent members due to sickness or old age. It is the primary group of support and plays a key role in long-term care (Sequeira, 2010). When the family is faced with the need to take care of one of its members who is dependent in daily activities, which is often the case, care-related tasks are not evenly distributed by all family members. Care provision is an arduous, complex and dynamic process, which is characterized by constant changes over time, both on the needs and feelings of those who provide and receive care (Sarmiento et al., 2010). Caring for a dependent person can be a physically and emotionally exhausting and demanding work, which is time and energy-consuming. The role of informal caregivers is mostly undertaken by family members, so they are defined as family caregivers or family members who provide care and are responsible for the prevention or treatment of illness or disability and care organization (International Council of Nurses, 2011). Family caregivers are often women, single, housewives or unemployed, who live with the dependent person.

At the beginning of these new roles, there is a transition to the new role of family caregiver which, in addition to being a complex process, involves many variables that influence each other and, consequently, have different predictive values, depending on the variables involved, such as the caregiver, the dependent person, the context and the care provision setting (Sequeira, 2010). As a transition, and to better understand this process and how it affects family caregivers, it would be an added-value to use a middle-range theory, more specifically, Meleis' Transitions Theory.

According to this theory, the transition is characterized by different dynamic stages, milestones, and turning points and can be defined through processes and/or terminal outcomes (Meleis, 2010). It is a passage from one life stage or state to another so as to achieve the adequate adaptation to the new role and/or situation. It is, therefore, a multiple concept embracing the elements of process, time span, and perception (Chick & Meleis, 2010). Based on this assumption, there are factors that can be facilitators or inhibitors of an effective transition, such as knowledge and skills, personal meaning, beliefs and attitudes,

socioeconomic status, and available community and societal resources. Thus, the responses of caregivers to this process, their involvement, confidence and coping strategies are process indicators, which are expected to be adequate so that outcome indicators (mastery and integration of the new role) are as efficient and healthy as possible. According to the Transitions Theory, family caregivers experience a situational transition (Schumacher & Meleis, 2010). This type of transition includes unexpected situations which occur throughout the life cycle and require a redefinition of their roles and/or integration of new roles.

Transition is present in different areas, including health care. Within this scope, nurses are health care professionals who, due to their activity and close proximity to people, often deal with various processes of transition in different contexts and are often the primary caregivers of people undergoing transitions. In this way, they attend to the changes and demands resulting from the relatives' needs concerning the activity of care provision and the fulfilment of the caregiver's role. In this area, they are the health care professionals who prepare them for this new stage, promoting and encouraging the acquisition of new knowledge and learning of skills and abilities related to their situation so as to facilitate the process and a better adaptation (Meleis, 2010).

During this transition and taking into account a set of variables inherent in the provision of care, including their personal and societal resources, skills, knowledge and availability, family caregivers express a set of needs which should be a focus of concern and intervention by the nurses. These professionals should, then, guide their interventions to properly meet these needs, thus obtaining the desired gains for caregivers' health and well-being.

In short, not only is it important to establish partnerships between formal and informal caregivers, but also plan situated interventions to facilitate and improve the quality of care.

Care provision and the consequences from this activity have been studied by several researchers due to their individual, familiar and societal effects. Thus, in a study conducted by Sequeira (2010), the author highlights that caregivers are faced with difficulties related to relational problems, social constraints, reactions to care provision, and family support. Cruz, Loureiro, Silva, and Fernandes (2010), in a review of

the experiences of informal caregivers of dependent elderly, highlight the difficulties expressed by these caregivers, in particular: care demand, lack of both formal and informal responses, financial problems, and social constraints. When these difficulties are not met, they may result in adverse consequences for the caregivers, such as anxiety, stress, and/or burnout, the family and society.

This literature review aimed to identify and categorize the main needs expressed by family caregivers based on the scientific knowledge produced.

To synthesize the current evidence on the topic, the following research question was raised: What are the family caregiver's main needs in the transition to caring for the dependent person which are evidenced in the literature?

Methodological Procedures of the Integrative Review

Based on the previous research question and the knowledge to be synthesized, a literature review was performed according to the following descriptors: Caregiver, Family Caregivers, Needs, Dependent. Boolean operators *and* and *or* were used to combine the different descriptors.

The studies were classified according to their level of evidence and based on the classification proposed by Lewin, Singleton, and Jacobs (2008).

The literature search was carried out between April and June 2011. Studies published between January 2000 and June 2011, using English as the language of choice, were selected. For this purpose, the search was performed in national and international electronic health databases, using specific search engines, namely: EBSCO [Cinahl, Medline, Medclatina, ERIC, Psychology and Behavioral Sciences Collection, Cochrane Central Register of Controlled Trials, Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews, Health Technology Assessments, and Cochrane Methodology Register) and B-on (Annual Reviews, Current Contents (ISI), Elsevier–Science Direct (Freedom Collection), Nature, PubMed, RCAAAP, SpringerLink (Springer/Kluwer), Taylor & Francis, Web of Science (ISI) and Wiley Online Library (Wiley). The Academic Search Complete database was searched twice, using both search engines.

Scientific studies which addressed family caregivers aged over 18 years, who cared for dependent people on self-care at home, with reference to their needs, and in a long-term care situation were included. Studies which focused on formal caregivers, family caregivers aged less than 18 years and with care being provided at institutions and/or other themes were excluded.

Initially, there was a survey of the main needs expressed in the scientific literature through, first, reading the title, followed by reading the abstract and, finally, at a later stage of paper selection, reading the

full text. The needs highlighted by the various authors were grouped into categories, which were drawn up according to the Transitions Theory.

Results and Interpretation

Of the 516 studies initially obtained and considering the previously defined inclusion and exclusion criteria, a set of 21 articles were selected (Table 1) and carefully analysed to obtain the main needs expressed by each caregiver.

Table 1
Articles meeting inclusion criteria

Reference	Type of Study	Level of Evidence
Casado, B. L. (2008). Sense of Need for Financial Support and Respite Services among Informal Caregivers of Older Americans. <i>Journal of Human Behavior in the Social Environment</i> , Vol. 18 (3), 269-287.	Quantitative	IV
Carretero, S., Garcés, J., & Ródenas, F. (2006). Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders. <i>International Journal Of Geriatric Psychiatry</i> , 22, 738-749.	Quantitative	II
Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A Broader View of Family Caregiving: Effects of Caregiving and Caregiver Conditions on Depressive Symptoms, Health, Work, and Social Isolation. <i>Journal of Gerontology: Social Sciences</i> , 64B(6), 788-798.	Quantitative	II
Salin, S., Kaunonen, M., & Astedt-Kurki, P. (2009). Informal Carers Of Older Family Members: How They Manage And What Support They Receive From Respite Care. <i>Journal of Clinical Nursing</i> (18), 492-501.	Quantitative	IV
Woolfe, P., M. Mcmillan, M., & Conway, J. (2007). The Needs of Caregivers of People with COPD: A Study. <i>Australian Journal of Primary Health</i> , 13(1), 28-35.	Quantitative	IV
Francis, L. E., Bowman, K. F., Kypriotakis, G., & Rose, J. H. (2011). Relationships and emotional wellbeing among African American and White advanced cancer caregivers. <i>Patient Education and Counseling</i> .	Quantitative	II
Ryn, M. v., Sanders, S., Kahn, K., Houtven, C. v., Griffin, J. M., Martin, M., & Rowland, J. (2011). Objective, burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? <i>Psycho-Oncology</i> , 20, 44-52.	Quantitative	IV
Nichols, L. O., Martindale-Adams, J., Greene, W. A., Burns, R., Graney, M. J., & Lummus, A. (2009). Dementia Caregivers' Most Pressing Concerns. <i>Clinical Gerontologist</i> , 32, 1-14.	Quantitative	IV
Sinclair, A. J., Armes, D. G., Randhawa, G., & Bayer, A. J. (2010). Caring for older adults with diabetes mellitus: characteristics of carers and their prime roles and responsibilities. <i>DIABETIC Medicine</i> , 27, 1055-1059.	Quantitative	IV
Ganea, L. W., Iosifb, A. M., Flynn-Wilson, L., Venturino, M., Hagerman, R. J., & Scritan, A. L. (2010). Assessment of patient and caregiver needs in fragile X-associated tremor/ataxia syndrome by utilizing Q-sort methodology. <i>Aging & Mental Health</i> , 14 (8), 1000-1007.	Quantitative	IV
Jullamate, P., Azeredo, Z. d., Pául, C., & Subgranon, R. (2006). Thai Stroke Patient Caregivers: Who They Are and What They Need. <i>Cerebrovasc Diseases</i> , 21, 128-133.	Qualitative	V
Mavundla, T. R., Toth, F., & Mphelane, M. L. (2009). Caregiver experience in mental illness: A perspective from a rural community in South Africa. <i>International Journal of Mental Health Nursing</i> , 18, 357-367.	Qualitative	V
Davey, C., R. Wiles, R., Asburn, A., & Murphy, C. (2004). Falling in Parkinson's disease: the impact on informal caregivers. <i>Disability And Rehabilitation</i> , 26 (23), 1360-1366.	Qualitative	V

Molassiotis, A., Wilson, B., Blair, S., Howe, T., & Cavet, J. (2009). Living with multiple myeloma: experiences of patients and their informal caregivers. <i>Support Care Cancer</i> , 19, 101-111.	Qualitative	IV
Chan, W., Ng, C., Mok, C., Wong, F., Pang, S., & Chiu, H. (2010). Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study. <i>East Asian Arch Psychiatry</i> , 20 (4), 163-168.	Qualitative	V
Cruz, D. C. M., Loureiro, H. A. M., Silva, M. A. N. C. G. M. M., & Fernandes, M. M. (2010). As vivências do cuidador informal do idoso dependente. <i>Revista de Enfermagem Referência</i> , 3(2), 127-136.	Systematic Literature Review	I
Innes, A., Morgan, D., & Kostineuk, J. (2011). Dementia care in rural and remote settings: A systematic review of informal/family caregiving. [Artigo de Revisão]. <i>Maturitas</i> , 68, 34-46.	Systematic Literature Review	I
Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. [Artigo de Revisão]. <i>Psycho-Oncology</i> , 19, 1013-1025.	Systematic Literature Review	I
Washington, K. T., Meadows, S. E., Elliott, S. G., & Sequeira, R. J. (2011). Information needs of informal caregivers of older adults with chronic health conditions. [Artigo de Revisão]. <i>Patient Education and Counseling</i> , 83, 37-44.	Systematic Literature Review	I
Blake, H. (2008). Caregiver Stress in Traumatic Brain Injury. <i>International Journal of Therapy and Rehabilitation</i> , 15 (6).	Literature Review	V
Jorgensen, D., Arksey, H., Parsons, M., & Jacobs, S. (2009). Caregiver Assessment of Support Need, Reaction to Care, and Assessment of Depression. <i>Home Health Care Services Quarterly</i> , 28, 130-150.	Mixed Research	IV

This review is composed of 10 quantitative studies, 5 qualitative studies, 4 systematic literature reviews, 1 literature review and 1 mixed research. Based on the level of evidence, 5 studies fall in level V, 9 in level IV, 3 in level III and 4 in the higher evidence level, level I. Taking into account the transition inherent to the integration of the role of family caregiver, the identification of the main needs expressed by them related to the performance of this activity and its correct diagnosis may be, in a sense, a turning point in the whole process of transition. In this way, needs may be considered inhibitors and/or facilitators, partly due to the way they are experienced, diagnosed and satisfied/met. With a set of properly planned, coordinated and effective nursing interventions, these needs are expected to be met so that, in the end, a set of indicators of positive outcomes, particularly mastery and fluid integrative identity, are obtained. If the need is an inhibitor of which the nurse is aware of and in which he/she intervenes, it can be met with the correct interventions. Thus, caregivers continue in their healthy situational transition with the acquisition of the required skills.

This study highlights the most commonly mentioned need in scientific literature so as to provide a possible orientation for a nursing practice with more quality and efficiency, and care plans that are individualized, contextualized and directed to caregivers. In this way, caregivers' well-being is promoted and the care

provided to the dependent person is improved. Family caregivers are extremely important partners to ensure the vital continuity of care for the dependent person, so nurses should pay special attention to ensure the effective maintenance of this partnership. As highlighted in the analysis of this literature review, the main family caregivers' needs are diversified. Thus, and taking into account the assumption of a new role and the changes that take place, we believe it is important to group them, based on the Transitions Theory, as facilitators or inhibitors of the Transition (community and societal resources, knowledge and skills, personal meaning, beliefs and attitudes, and, finally, socioeconomic status) of the new role of providing care and its continuity, which, which will be addressed below.

Community and Societal Resources

The need for family and social support is one of the most highlighted needs by different authors, by which the support to meet this need may be considered a facilitator throughout the whole process.

The family is crucial throughout the transition to the role of family caregiver, because it plays an important role in the whole process. Good family relationships, both between family members, and between caregiver and dependent person, is one of the most evidenced aspects in the studies included in this review, as it promotes the establishment of a

network of appropriate and necessary support within the family (Francis, Bowman, Kypriotakis, & Rose, 2011; Mavundla, Toth, & Mphelane, 2009; Molassiotis, Wilson, Blair, Howe, & Cavet, 2009; Stenberg, Ruland, & Miaskowski, 2010; Blake, 2008; Jorgensen, Arksey, Parsons, & Jacobs, 2009).

According to Francis et al. (2011), it is essential to intervene and provide effective strategies that enable the development, maintenance and strengthening of these relationships due to their importance in the whole process.

Stenberg, Ruland, and Miaskowski (2010), in a systematic review on the effects of caring for a patient with cancer, mention that one of the positive aspects of caring is the time that families spend together and the quality of these moments.

Social support is also frequently mentioned as a means to avoid social isolation (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Mavundla et al., 2009; Molassiotis et al., 2009; Chan, Mok, Wong, Pang, & Chiu, 2010; Cruz, Loureiro, Silva, & Fernandes, 2010; Blake, 2008; Jorgensen et al., 2009), thus facilitating the access to the resources available in the community and society and the inherent assistance of support groups.

The caregiver's lack of personal time is considered an inhibitor due to insufficient resources to allow breaks in care provision so that the caregiver has time for his/her leisure or socialization needs. Several authors emphasize the importance of support groups (Sinclair, Armes, Randhawa, & Bayer, 2010; Ganea et al., 2010; Mavundla et al., 2009; Chan et al., 2010; Jorgensen et al., 2009), or the need for interventions and/or services that allow for a break and rest in the activity of caring (Casado, 2008; Carretero, Garcés, & Ródenas, 2006; Salin, Kaunone, & Astedt-Kurki, 2009; Woolfe, McMillan, & Conway, 2007; Cruz et al., 2010). These are all considered facilitators and essential for the maintenance of a good level of health of the caregiver.

The needs identified at the level of the community and societal resources, when duly met, help strengthen interpersonal relationships, both within the family and the community, promoting the development of individual strategies that increase self-esteem and strengthen personal identity, thus allowing for a better integration of the caregiver's role.

Acquisition of knowledge and preparation

Providing the caregivers of dependent people with the knowledge and skills they need is important for them to better care for their relatives and for themselves, being a facilitator of a healthy performance of the functions.

The support of nurses, as health professionals capable of conveying the required information for the performance of the new role, as well as the learning and acquisition of skills, are highlighted by different researchers (Salin et al., 2009; Sinclair et al., 2010; Davey, Wiles, Asburn, & Murphy, 2004; Molassiotis et al., 2009; Chan et al., 2010; Jorgensen et al., 2009).

In addition to this, the access to health care services is also highlighted (Chan et al., 2010; Innes, Morgan, & Kostineuk, 2011). Due to a whole range of difficulties and adversities (bureaucracies, architectural barriers, reduced human resources, lack of protocols and coordinated work between services, among others), they can become inhibitors of the process of fulfilling the role of caregivers, if they are not properly resolved.

In relation to the knowledge to be acquired by the caregiver, these must be specific and allow for the acquisition of certain instrumental skills which are useful in care provision. They can also be conveyed with the aim of improving already acquired skills through the learning of some basic procedures and techniques which are important to some specific care provided to the dependent person (Ryn et al., 2011; Ganea et al., 2010; Davey et al., 2004; Cruz et al., 2010).

Some authors emphasize the importance of these instrumental skills in care provision, namely Ryn et al. (2011) who stresses the importance of training to provide care, and Ganea et al. (2010) and Cruz et al. (2010) who emphasize a skill set that caregivers need to acquire in the area of self-care to meet every activity of daily living.

Knowledge is, for the family caregivers, one of the most important needs, because if this need is met they begin to better perceive the whole situation and, consequently, their new role and relevance. In this context, it is important that nurses understand the complexity of conveying information to the caregiver and its consequent integration as knowledge so as to allow for an effective perception, thus preventing it from being considered an inhibitor (Nichols, Martindale-Adams, Greene, & Burns, 2009; Ganea

et al., 2010; Jullamate, Azeredo, Paúl, & Subgranon, 2006; Molassiotis et al., 2009; Chan et al., 2010). Thus, nurses should be properly aware of the caregiver's personal and social resources to be able to adjust and optimize their interventions. The information should be conveyed in a clear manner, in a calm environment, especially when it concerns the disease that affects the family member, its evolution, prognosis, and the available resources, as highlighted by Chan et al. (2010) and Ganea et al. (2010).

Stenberg et al. (2010) show that the need for information differs according to the stage of the disease but underline its importance not only because of the data available on the disease, but also on the prognosis/evolution and the treatment options, assigning a sense of control and security to the family caregiver. Washington, Meadows, and Elliot (2011) conducted a systematic review in the specific field of information, highlighting the need for general information on disease aetiology, diagnosis, and prognosis, and on the available support and assistance, but also for specific information, namely on a clear and individualized education and information, and separately from the patient. Nichols et al. (2009), in a study on the main concerns expressed by caregivers of people with dementia, highlights that the caregivers' information needs vary according to the presence of depression and the severity of the dementia of the person receiving care.

Personal Meaning, Beliefs and Attitudes

The role of family caregiver is extremely stressful, leading to an increase in emotional burnout. From this point of view, the importance of emotional support and its role in the whole process of transition and in the healthy integration of this role is made clear (Robinson et al., 2009; Woolfe et al., 2007; Ganea et al., 2010; Molassiotis et al., 2009; Cruz et al., 2010; Stenberg et al., 2010). Several other authors have also highlighted the importance of the acquisition of effective coping strategies (Ryn et al., 2011; Molassiotis et al., 2009; Chan et al., 2010; Blake, 2008; Jorgensen et al., 2009), as it may be an important facilitator in the provision of care and in the transposition of the resulting difficulties, when this need is equivalent to effective interventions.

According to Molassiotis et al. (2009), the family is an important resource for the caregiver, not only due to interpersonal relationships, but also due to psycho-

emotional support that it offers. This aspect is also highlighted by Chan et al. (2010) who shows that the lack of emotional support and assistance from family members, as well as the lack of recognition of their role as caregivers can hinder the transition process.

Several authors, such as Cruz et al. (2010), Stenberg et al. (2010) and Blake (2008), also underline the need for emotional support, which is important to better manage the different types of emotional reactions such as anxiety, fear and uncertainty. This aspect is due to the fact that the more common coping strategies used by the caregivers usually focus on emotions, stressing, however, the importance of problem-solving strategies, such as the learning of ways to cope with stress, feelings, fears and loneliness so as to reduce the caregiver's stress (Salin et al., 2009; Woolfe et al., 2007; Blake, 2008). Other authors, in particular Ryn et al. (2011), Jorgensen et al. (2009), Molassiotis et al. (2009) and Cruz et al. (2010), highlight the importance of the acquisition and promotion of coping strategies that are effective in problem solving and focus on the problems rather than on emotions.

Woolfe et al. (2007) highlights the psychological and emotional support needs of family caregivers as facilitators, highlighting the learning of ways to cope with stress in an effective and healthy way.

The role of the family caregiver is also recognized in this area, highlighting the reasons leading to the assumption of this role, as well as the importance to the dependent person (Chan et al., 2010; Jorgensen et al., 2009).

In a study carried out within the scope of the informal care to people with mental illness, Mavundla et al. (2009) demonstrated that, in addition to the already mentioned importance of family involvement, social support is also important to avoid the isolation which family caregivers and their families undergo in many situations, mainly due to the social stigma inherent to this type of pathology, the previously defined societal beliefs and the lack of knowledge in this area.

Socioeconomic Status

In relation to this status, several authors have mentioned the financial burden and the costs of informal care to the dependent person, which are considered inhibitors, thus highlighting the need for economic support (Casado, 2008; Woolfe et al., 2007; Ryn et al., 2011; Sinclair et al., 2010; Mavundla

et al., 2009; Cruz et al., 2010; Stenberg et al., 2010; Jorgensen et al., 2009).

In addition, some authors mention the need for family caregivers' flexibility in terms of working hours to be able to reconcile the care provided to the dependent person with their jobs and source of income that they need to maintain (Robinson et al., 2009; Ryn et al., 2011; Jorgensen et al., 2009).

This literature review has some limitations. Thus, by using the search term "family caregiver", some studies may have been excluded which addressed this issue or even the issue of when the informal care is provided by a person outside the family as the term that is usually used in the literature is informal caregiver.

On the other hand, the classification of the needs identified by family caregivers in the different studies using the Transitions Theory may have hindered their categorization as some may be included in different categories or individualized in specific categories.

Taking into account the scientific studies and the interest of this theme in the Portuguese context, it would be important to perform the same type of analysis, using the same search terms but in the Portuguese reality.

Conclusion

The recognition of family caregivers' needs is of extreme importance, taking into account that it is the first step for the situational diagnosis and subsequent planning of nursing interventions. An effective data collection allows for a correct diagnosis of these needs and, if it is associated with a useful intervention, it may assist the entire transition process. The lack of intervention may result in an unhealthy transition and, thus, result in damages to the health of both the family caregiver and, consequently, the dependent relative. During the analysis of the various studies, different types of needs were identified in a variety of settings. Based on these needs, the following categories were created: community and social resources, acquisition of knowledge and skills, personal meaning, beliefs and attitudes and, finally, socioeconomic status. Although the scientific studies included in this literature review have been carried out in different areas and taking into account their singularity, the identified needs are, to a certain extent, common to all studies. Thus, without minimizing the individuality of this process, one can

say that the transition inherent to the integration of the role of family caregiver is, in general, universal, because its needs are equivalent to the needs of this type of transitions.

One of the most highlighted aspects in this review refers to the importance of the family, as well as the social support to the family caregivers in the whole process of transition. With a good family relationship, the network of informal support is really improved and strengthened, which allows meeting one of the most expressed needs. Another clear need is the need for psycho-emotional support, as well as the acquisition of effective coping strategies which, by effectively promoting problem solving, allow for a better integration of the family caregiver into this new role. Several studies also emphasize the support of health care professionals, namely nurses, in the learning of instrumental skills for a better care provision from the family caregiver. Finally, the family caregivers' need for information in different areas (both related to the disease and the care provision) is common to all studies in this literature review.

We recommend that, taking into account that a significant share of the studies in this review were carried out in different contexts, a similar study should be carried out in the Portuguese context, possibly in specific areas, such as needs of caregivers of stroke patients, disabled people or people with Alzheimer's or Parkinson's disease, so as to better perceive the needs expressed by these family caregivers.

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