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ORIGINAL ARTICLE

PERCEPTIONS OF THE FAMILY FACING DISCHARGE OF HOME CARE DEPENDENT PATIENTS

PERCEPÇÕES DA FAMÍLIA FRENTE À ALTA HOSPITALAR DE PACIENTES DEPENDENTE DE CUIDADOS DOMICILIARES

PERCEPCIONES DE LA FAMILIA FRENTE AL ALTA HOSPITALARIA DE PACIENTES DEPENDIENTES DE ASISTENCIA A DOMICILIO

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ABSTRACT

Objective: describing the perception of the family facing hospital discharge of patients who depend on home care. ***Method:*** a qualitative study conducted in the clinic of a university hospital. Four family members accompanying patients with total dependence on the verge of hospital discharge participated. The production of data was conducted in October and November 2011. For the analysis we used the principles of thematic interpretation. The research had the project approved by the Research Ethics Committee, CAAE nº 0193.0.243.000-11. ***Results:*** back home is a constant expectation of the family and of the care dependent family member, even in a situation of dependency; the family recognizes its difficulties and possibilities, gathering strength to care. ***Conclusion:*** the family prefers taking care of its family member at home, regardless the complexity in the demands of care needed, because it believes that this will have a better rehabilitation togheter with its family members. ***Descriptors:*** Nursing; Patient's Discharge; Homebound; Caregivers.

RESUMO

Objetivo: descrever a percepção da família frente à alta hospitalar de pacientes que dependem de cuidados domiciliares. ***Método***: estudo qualitativo realizado na clínica médica de um hospital universitário. Participaram quatro familiares que acompanhavam pacientes com dependência total em iminência de alta hospitalar. A produção dos dados foi realizada nos meses de outubro e novembro de 2011. Para a análise utilizou-se os princípios de interpretação temática. A pesquisa teve o projeto aprovado pelo Comitê de Ética em Pesquisa, CAAE nº 0193.0.243.000-11. ***Resultados***: voltar para casa é uma expectativa constante da família e do familiar dependente de cuidados e, mesmo na situação de dependência, a família reconhece suas dificuldades e possibilidades, reunindo forças para cuidar. ***Conclusão***: a família prefere cuidar de seu familiar em casa independente da complexidade das demandas de cuidados de que necessita, pois acredita que este terá uma melhor reabilitação junto ao núcleo familiar. ***Descritores***: Cuidados de Enfermagem; Alta do Paciente; Pacientes Domiciliares; Cuidadores.

RESUMEN

Objetivo: describir la percepción de la familia frente al alta hospitalaria de los pacientes que dependen de los cuidados en el hogar. ***Método:*** estudio cualitativo en la clínica de un hospital universitario. Participaron cuatro miembros de la familia acompañando a los pacientes con dependencia total al borde del alta hospitalaria. Los datos de producción se llevaron a cabo en octubre y noviembre de 2011. Para el análisis se utilizaron los principios de interpretación temática. La investigación tuvo el proyecto aprobado por el Comité de Ética de la Investigación, CAAE nº 0193.0.243.000-11. ***Resultados:*** volver a casa es una expectativa constante de la familia y de familiares dependientes de cuidado, incluso en una situación de dependencia, la familia reconoce las dificultades y posibilidades, reuniendo fuerzas para cuidar. ***Conclusión:*** la familia prefiere el cuidado de su familiar en el hogar, independientemente de la complejidad de las demandas de cuidado, ya que cree que esto tendrá una mejor rehabilitación con el núcleo familiar. ***Descriptores:*** Enfermería; Alta del Paciente; Salir de su Casa; Los Cuidadores.

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INTRODUCTION

The family is socially and culturally based and designed to support the development of the individual assuming the role of provider for different aspects and levels.[1] The family is constituted as a group of individuals bound by emotional attachment and sense of belonging. Events affecting a family member, somehow resonate in others, depending on the proximity and affinity.[2]

Faced with adverse situations such as illness, family fits the function to identify, facilitate and operationalize strategies that will help address the needs of sick family.[2] The presence and participation of the family element as capable of contributing to the recovery of the patient and minimize the impacts of a hospital is currently recognized.[3] In this context, the family can be considered a fundamental part of care by the staff and patient[2], especially in situations of dependency and inability of the family to meet their needs[4,5], constituting thus, in support and resource for the protection of its members.

Situations of dependence can be understood as those in which the person, for lack or loss of physical, mental or intellectual autonomy, resulting in different events, by itself, cannot perform activities that involve daily life.[4] The dependence leads to condition requiring a caregiver to meeting the demands of everyday life, such as food and medication, hygiene, locomotion, among others. Thus, the dependence can be translated as the indispensable need for help to perform the elementary tasks of life that can happen regardless of age, disease or event that has caused this situation.[4]

In the family, the care of people in the condition of addiction is primarily focusing on spouses, children, siblings, grandchildren and other family members with whom the patient has affinity.[5] The assumption of this new paper could result in a destabilization of family dynamics, requiring that the family find alternatives to reorganize itself allowing the inclusion of the patient in this family context.[6]

Preceding the care at home, the scene of illness usually includes a period of hospitalization which, although it may be extended, aims to discharge happen in the shortest possible time so that the patient has conditions for such.[7] Thus, before the clinical stabilization, discharge can occur on demand continuity homecare.[5,8] Returning home then comprises the assumption of a perspective that differs from hospital care, occurring "transition passage of cure to the process of care at home".[9:218]

During this period, due to the likelihood or imminence of the hospital, the family happens to be "prepared" by the nursing staff for this moment, which is usually attended by more effectively in the care of family activities to sick.[7] The family then sees facing a new reality that, although present as possible and even desired, seemed distant and unlikely.

The family when assuming this responsibility cannot be prepared to provide care to their family and feel unable to meet the needs of a bedridden and totally dependent care requiring knowledge and skills.[10] This feeling of inadequacy can be corroborated by the fact that, in most cases, guidelines are provided to close family members or at discharge and not throughout their hospitalization.[7]

In situations involving preparation for home care, the studies emphasize the importance of the guidelines to the family are carried out gradually and with the direct participation of those who will provide the care.[5,7] It is also important that there is anticipation of potential problems that may occur at home, as well as possible measures to solve them.[11]

Be prepared to discharge a patient dependent family care is essential in the reestablishment of family activities proceedings. Thus, the nurse, as coordinator of discharge planning, needs to direct its gaze[8] for the development of actions and practices of health education that does not focus only the sick and his illness, but is extended to the context and to the singularities of the family and also directed particularly to the members who will assume the role of caregiver(s). Such actions allow greater support and empowerment of families to care at home. In this context, it is noticed that the focus of the studies have been directed, on the one hand, the strategies of preparation for hospital discharge in different clinical situations[7,8,11] and, secondly, to the context of home care, both in refers to the care itself,[5,10] and home care[12] to family caregivers.[6] The family perspective just before hospital discharge seems to be a dimension that deserves further be explored by nursing, mainly constitute itself a transition period of coordinated care from hospital to home.[13]

It is hoped that this research contribute to the construction of knowledge that enables broaden the understanding of the perception of the family in the imminent discharge of dependent patients who will be cared for at

home. From this perspective, the study aims to:

- Describing the perception of the family in the hospital discharge for patients who depend on home care.

METHOD

This is a field study, of a qualitative, descriptive type conducted in a medical unit of a public hospital in the South of the country, where predominantly dependent hospitalized patients in this condition, regardless of age, is entitled to a companion full time.

Four relatives of care-dependent patients participated in the study. The selection of participants was intentionally visits the units to identify dependent patients who were discharged from hospital and expected they would need to continue receiving home care in that they are medically stable, but with serious neurological impairment or dependence. This information was obtained with nurses, residents and medical records of the patients.

To locate a patient, identified himself to the family accompanied him and, according to the defined inclusion criteria, he was invited to participate in the study. Inclusion criteria were: age; relationship of family bond with the patient by blood and/or emotional ties; participate in making family decisions and effectively participate in patient care, most present during the hospitalization period. The number of participants was defined by convenience and ended when the analysis of statements and answered the questions in order. The ethical issues related to research with human subjects were maintained in accordance with Resolution 196/96 of the National Health Council. Participants signed a consent form. The research protocol was approved by the Research Ethics Committee of the institution under paragraph CAAE 0193.0.243.000-11.

The relatives interviewed were female, aged 40 to 58 years, with an ex-wife, a wife, two daughters, one adopted. Three had incomplete primary education and incomplete secondary education. Two wielded the housewives, one was retired and other general services performed.

For the patients, two were male and two females, aged between 56 and 79 years old. The length of stay ranged 34-108 days. The clinical condition was vegetative state (a patient), and dependence (three patients).

Patient (P1) had a diagnosis of ischemic stroke, aspiration pneumonia by repetition and deep arterial obstructive disease in the left lower limb. It was bedridden, comatose, with muscular rigidity, musculoskeletal atrophy, voluntary movement, requiring alternating decubitus; had tracheostomy, requiring frequent mechanical aspiration; fed by gastrostomy; had urinary and bowel incontinence. Patient (P2), diagnosed with insulin dependent diabetes mellitus, hypertension, pulmonary mycosis, granulomatous disease; was conscious, not ambulating; remained lying or sitting in bed with cardiac arrhythmia and making use of oxygen by nasal continuous glasses; urinary elimination in urine and bowel collector device diaper; had wounds (diabetic foot) in both lower limbs. Patient (P3), with a diagnosis of chronic subdural hematoma, carries a permanent pacemaker; presented mental confusion, not ambulating; nasoenteric held probe; presented with right hemiparesis; had urinary and bowel incontinence. Patient (P4), diagnosed with aspiration pneumonia, pulmonary embolism, performed hip surgery to fix the fracture; dementia clarify; was bedridden, unable to walk, uncommunicative and periods of confusion; gastrostomy feeding; oxygen via nasal spectacles; with urinary and bowel incontinence.

Data were collected during the period October-November 2011, through an open interview, guided by the following questions: How is it for you and your family to know that Mr. (Mrs.) is about to discharge and that will remain dependent home care? As you and your family are organizing to take care of him at home?

Data were subjected to analysis technique thematic content 14 which provides for the ordering of data based on the mapping of information obtained during fieldwork, involving the transcription of recorded interviews, rereading and organization of the material; data classification performed after exhaustive and repeated readings of text, to identify specific categories; and the final analysis, which seeks to establish links between the data and the literature anchor, answering survey questions based on your goals.[14]

RESULTS AND DISCUSSION

Analysis of the interviews identified classes that describe the perceptions of the family in the hospital for patients who depend on home care. Thus, for convergence of meaning, conformed by three theoretical categories, so-called: back home: *a constant expectation; bringing together the strengths of the family and recognizing the difficulties.*

♦ Back home: a Constant expectation

Given the imminence of the hospital, it could be seen in the interviewees' statements, at that time, the family has the desire to return to the family home conviviality. The family believes that this fellowship will contribute to the recovery of the patient and can be organized to care for him at home:

> *Though he be using oxygen, for me is being very good to have discharge. I think so: in terms of recovery, will be faster he being at home, on our side, close to the family, friends and [...] For him, it's going to be a lot better! I think for his recovery will be great. (E2).*

Back home constitutes an expectation that is renewed every day, every sign that conditions have improved or family that do not worsen. Able to return home, initially, is the possibility of recovery of health of the person who is hospitalized and desire that family life can again be as before. This perspective is also found in a study that sought to describe how the family caregiver builds social representations of home care in terminally.[12] The possibility of having the help of health professionals and that the equipment and materials needed for continuity of care in home predisposes family to believe in the viability of this type of attention.[12]

Every family has the potential to care for themselves and each other. The way the family will stand before the need for care is related to the culture of the society and the family itself, the way care is designed and built along the family history, habits, customs, beliefs and relational ties built with the family dependent care.[2,9]

The perception that returning home is a viable decision will also be built in the daily admission, participation in care and constant observation of the reactions of the patient family. During this transition period the family looking to stay close and establish a form of communication with him, trying to decrease anxiety and providing, where possible, safety, relief and well-being.

> *She feels safe when the kids are around. You see a sparkle in her eyes. I can see and feel it. (E3).*
>
> *I think he's improving, in view of what he was. Until the girl said: 'Mom, Dad coming home will be better, happier'. You must see his happiness to be leaving. (E2).*

The possibility of securing the bond and maintain communication with the family, even before changes in neurological order, reinforces the importance of keeping the family close to him. Thus, the home is a space domain family, where personal objects and people are emotional reference, besides being a place where everyone can feel at ease and more freely.[12]

Associated with the desire to promote the comfort of the familiar, the hope of recovery is a feeling that strengthens the family before the illness. The hope is the possibility that discharge happen and, returning home, the family will present some kind of improvement in his clinical status, even in the face of evidence that indicate that the recovery may not be as they would like.

> *At home I hope she progresses. Of course she's going to be sequels, but all I hope is that she will walk a little, she can eat with her hand, who can warn you when you pee, poop, you know? That's what I hope, I really hope! (E4).*

Related to changing health conditions of family expectations seem to reflect the discourse of health professionals that highlight the benefits of home care and point out that, in situations of chronic diseases, the proximity of the family enables monitor the manifestations of the disease and the effectiveness.[15] This conception of therapy can also be evidenced in a study that supports the expansion of this type of health care, since home care may be possible in many environments, including the economically disadvantaged, and can effectively contribute to providing integrated and continuity of care.[16]

In this sense, the support of a specialized home care encourages families to feel able to meet the needs of the patient.[12] Thus, the hope and expectations regarding the return of the family home, encourage and strengthen the willingness to exceed the demands that may arise in this process. For the family, the hospital also is minimizing the discomfort and disruption of daily life[17] caused by hospitalization, as well as the solution to some difficulties experienced in trying to reconcile hospital care and everyday activities. Returning home proves a possibility of organizing the day to day activities of caring for dependent family.

> *I want her to go home. For me is being much sacrificed. At home, in the morning, do my meals, I make my food. Being here is everything running. Get it here, sometimes I go home and get that function. Home is best for me to organize. Up to take care of her better. At home, I have more ease. (E4).*

Although illness is a situation experienced by all family members[2], some engage more directly in decision-making and to take care of what other activities.[5,6] However, the desire to reorganize personal and family dynamics,

contributing to decision to take the patient to be cared at home, even in the condition of relying on complex care and equipment. In this sense, it is present in the literature that the family caregiver while in situations of physical dependence undergoes changes in various aspects, and family caregivers find themselves compelled often to change their daily activities to care for the sick, occurring sometimes subject to domestic activities, job abandonment, and leisure studies.[15]

♦ Bringing together the forces of family

Caring for a dependent family at home can be challenging for families that need developing strategies to bring the family back home. This movement requires flexibility and internal capacity to adapt to the family residence and organize the space to include the family respecting their needs.

> *I'm organizing at home. The place isn't big. I want to see if I can here, with them, a bed to take her. The rooms that I have everyone are busy and are very small. To deal with her in bed, common put-away, change, and get up, it's going to be very difficult. So, what am I going to do? I'll get my little room, I'm going to get some stuff you have and I'll put her bed where to stay near my room, so I have more access to care for her. (E4).*

The ability to be sensitive to the needs of the family and promote initiatives to meet them strengthens and encourages keeping them confident in family decision. Noting that manages to find alternatives, provide resources and reorganize the space of home, family, realizing able and competent to meet the needs of the family, feels encouraged to overcome the difficulties that arise.

The expectation of the presence and participation of other family members in the care process reinforces the idea that all somehow able to rearrange their lives to help in various ways during this period:

> *I said: one week for each, we'll have to stay a week each. Then the other my brother said: no! A weekend for each and during the week a person will take care will have a day person and another at night; because they cannot be alone, because my father is 86 years old and she's 79. You have to be a person with. (E3).*
>
> *My brother who works is who, so far, did everything. He always helped care for. Now [...] Of course, each child has to do its part, all work, all your life, but you have to have commitment to her, give quality of life and, for that, home is best. (E4).*

How will family planning care in the home explicit expectations, previous agreements, intentions and cooperation networks among family members. Despite this initial purpose, immersion in the daily care can often result in changes, adjustments or breaking of contracts which relate to crises and disruptions experienced by the family during the experience.[6] In crisis situations, such as triggered by the illness of a family, the need for support among family members is evident. When this happens, it can result in resentment and feelings of abandonment and sadness, which contributes to a chronic disease that causes addiction, is conceived as a phenomenon of social dimension.[12] In this sense, caring for a dependent family member requires flexibility and ability of reorganization of family members towards achievement of daily tasks and care in order to meet satisfactorily, your goal in relation to care.[4]

In that it forces the family are being identified, the individual strengths of each of its members are also emerging. The dynamics adopted to accompany the family during hospitalization reflects the strategies that the family meets to care in the hospital, but also, seems to signal to the way care is organized at home. You can see that some families take turns planning among its members to follow the family so that no one is overwhelmed. Others rely on the participation of people hired.

> *Home looks better to arrange and take care of her. We don't have any money available for all paying someone to be with her. You see: my son's College. Had weeks he left the College and came here, to the hospital. I stayed until a piece of the night with her. Then he came and went, but neither is it easy. (E4).*
>
> *His family is small, confined in two. But, whatever you need, they help, take care during the night. Every once in a while they take turns. Or we pay someone to pose, so I can go home and rest. (E2).*

Studies conducted with caregivers have identified that in certain families, the rule is to divide responsibilities; in others, is filial or marital obligation to take care of parents or spouse.[6] The way the family will lead the process of care and patient family who will participate in this, among other things, is influenced by the role of that person in the family and emotional ties.[5] Associate to affective ties, trust, understanding and shared among family members helps to support the primary caregiver and the care emerge materialize.

> *At first I was 20 days with her. I was on vacation. Alas, I'm back. My husband talked to me and said: ' at the moment your mother needs you, she's the one who needs*

you '. Then I came back and I was with her. (E3).

I understand him. I ask him: 'Do you hear me? Got any pain?' Right now I put the phone in his ear to talk with her daughter. And I said: 'when you want me to pick up the phone, you blink twice', then he blinked twice. That's how I understand it. (E1).

Some skills, such as sensitivity and empathy are traits that seem to be part of the caregiver personality, but take more expression in the act of caring[6], especially when associated with closeness, companionship and desire for reciprocity and cooperation among people. Thus, despite the instability and insecurity caused by the illness, hospitalization and the onset of symptoms of dependence, the family is gradually finding ways to reorganize and ensure continuity of care.

From this perspective, the skill and knowledge acquired during the hospitalization period for the development of some specialized procedures, such as cleaning, food administration probes or wound care, give confidence and autonomy for its execution. *As to bathing, grooming, dressing, then everything that I already have experience. (E2).*

Take care, bathe and stuff, food by the probe, yes for sure I can do; because in the time I've been here I have learned. Surely I'm not afraid to do [...] (E3).

The force arising from feelings of protection, commitment and concern for the welfare and care itself, are expressed by the study participants as factors that determine to follow during hospitalization, taking responsibility for the care and care at home, after hospital discharge.

For me, oddly enough, seems normal. I've got everything for him at home. I promised I wasn't going to leave him, no matter what. He was going to stay in my house and I would get along. (E1).

I'm taking and doing it from the heart, because if I were to take a lead, I tell you in all honesty, I wouldn't, because I think it's something I have to do, I feel compelled to take care of her. I've decided I'm going to take it and I'm going to take care of her. (E4).

A family's decision to accept the discharge of dependent family member for care at home, among the participants of this study rests on the conviction that they are able to meet the needs of the sick person. Although focused on the motivations of caregivers, studies show the compassion of the person cared for by the caregiver to alleviate their suffering, respect for the wishes of the patient, cohabitation that facilitates the provision of care, financial difficulties, a feeling of well- being and satisfaction by developing new skills and abilities and the obligation/duty, as factors in the home to care.[4-6]

From this perspective, considering that the illness of a family member affects the other two, knowing the resources and strengths of the family, as well as how this realizes the possibility of caring for a dependent family member at home during the period of hospitalization enables the nurse to direct actions that can reflect on and talk about the experience, ask questions and develop strategies that strengthen to care for your family.

♦ Recognizing difficulties

Although the study participants realize the discharge of the family dependent on home care as beneficial for everyone and believe that the family is capable of organizing itself to meet the needs, they recognize that the family may encounter difficulties. Among the difficulties mentioned identifies the possibility of physical fatigue on the part of the family who take primary responsibility for the care of the basic needs in everyday life.

I know it won't be easy. I was asking if two neighbors, who were accustomed to work like this, if you accept to help me take care of him. They said yes, an overnight, another during the day. Ai no weighs so much to me. Of course you have to pay, but they help [...] (E1).

Although the reality of care can only be clearly understood throughout the routine, the perception of responsibility and involvement required for the performance of activities refers the family to think in advance in strategies to cope with the demands that will arise. In this sense, the burden of family caregivers has been identified as one of the most important consequences of caring for a dependent in the household.[15] Among the factors contributing to this situation is the familiar gradual withdrawal of some members of the family care and the concentration of activities in a single person.[6] In such situations, the social support network of friends and neighbors and by hiring informal caregivers has been a resource used by the family to help in times of need.[12]

The complexity of some care to be provided, it is also pointed out as a difficulty for care at home, especially those who may pose a risk of complications for the patient family. The unreadiness may cause insecurity and anxiety for those who care:

> *Give shot I don't know how to do, you know? (E3).*
>
> *The only thing is vacuuming. I got to clean up. That I do. But vacuuming I feel insecure. I know how to do bathroom, but aspire [...] (E1).*
>
> *To deal with her in bed, fix, change, up [...] For me it will be very difficult [...] (E4).*

The conduction of care involving skill and expertise, as well as handling equipment is often not developed by their families during hospitalization, which provides greater fear of being performed at home without supervision. Although studies indicate that family caregivers learn to care mainly in the daily care[5] consensus is that when they are guided and taught during the hospitalization, care in the home is more peaceful and less complications.[18] The effective preparation mode for the discharge occurs when the nurse is committed to this purpose, clarifies the possible dependencies of the patient and the initial to be taken care by the family, taking with it a relationship of mutual cooperation.[5]

It is noteworthy that in addition to difficulties in relation to the wear of who provide direct care to family, another possible difficulty that the family could face refers to the discomforts and dissatisfactions of family members due to the changes of everyday life and family dynamics:

> *Back home I talked enough, explained, discussed, because in the beginning they didn't want. They thought it was going to be very difficult for me to take and taking care of Grandma. Thought thus: 'Bah, will totally change, will change everything here at home'. And I said: 'I know, I'm aware that'. (E4).*

The care of a dependent in the household family will inevitably compromise the organization and mode of functioning family. The expressions of acceptance or rejection between different members of the family unit present as a dimension of experience, depending on the beliefs, values and individual and cultural characteristics of each family.[19]

The changes needed may endanger the harmony and stability of the family system, even temporarily, requiring, by each member of the family, flexibility to adapt and cope installed crisis, the situation of concomitant illnesses, can be added the need for economic adjustments.[20] However, the recognition by the family of the difficulties that may face, can be in mobilizing resource of family strengths. It is noteworthy that in a literature review that evaluated the influence of the support network of families in caring for a family member with chronic disease process, it was shown that social support contributes to the family's adaptation to the new routine, the decreased burden of care, maintenance of domestic activities and financial management.[21]

Assist families in identifying their potential and alternatives to the perceived difficulties, too, is an important form of nursing care and preparation for discharge, but mainly points to the need for monitoring by the professional health care system over the period of transition after discharge, to ensure a proper care. Strategies as clear and revised information whenever necessary service and professional reference contact in situations of uncertainty and appropriate communication between patients, family caregivers at home and coordination professionals improve care, and facilitate recovery and prevent possible adverse effects.[13]

FINAL NOTES

Regarding the purpose of this study, regarding the perception of the family in the hospital for patients who depend on home care, the results allow us to affirm that, from the perspective of the participants, families, even before a clinical picture which, a priori seems averse, want the family to return home to be careful. The possibility of assisting the recovery and comfort to the sick person, plus the prospect of getting reorganize the everyday, encourages families to seek in the existing resources within the family, such as the availability of a member to take care and cooperation from other family forces for continuity of care after discharge.

The willingness and the interest manifested by the family to care highlight the importance and the need to invest in shares of nursing health education and preparation for discharge aiming for continuity of care in the home. Encouraging the development of specific skills to perform procedures is in one of the dimensions to be considered in the care of family. However, the possible impact arising from the change in family dynamics and difficulties in handling the situation in the relational context of the family also deserves special attention from nurses.

Facilitate family involvement as the lead partner and of caregiving and decision-making, respecting, understanding and helping to assimilate the experience that is being experienced is an important strategy that can develop skills and safety for care at home. Thus, within the limits of the analysis and the number of study participants, it is considered that these results corroborate the literature of family nursing that point to the importance

of implementing nursing interventions targeting the family unit during hospitalization. Help families identify their needs, limitations and potential for home care can facilitate the necessary adjustments to maintain, acquire or develop balance, helping to promote the health of all its members.

REFERENCES

1. Acosta AR, Vitale MA (org.) Família: redes, laços e políticas públicas. 4th ed. São Paulo: Cortez, 2008.

2. Wright, LM, Leahey M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. 5 ed. São Paulo: Rocca, 2012.

3. Almeida AS, Aragão, NRO, Moura E, Lima EC, Silva LASM. Sentimentos dos familiares em relação ao paciente internado na unidade de terapia intensiva. Rev Bras Enferm [Internet]. 2009 [cited 2013 Apr 08];62(6):844-9. Available from: http://www.scielo.br/pdf/reben/v62n6/a07v62n6.pdf.

4. Monteiro MCD. Vivência dos cuidadores familiares em internamento hospitalar – o início da dependência. [Dissertação]. Portugal: Instituto de Ciências Biomédicas de Abel Salazar da Universidade do Porto; 2010 [cited 2011 May 22]; Available from: http://repositorio-aberto.up.pt/bitstream/10216/26357/2/Maria%20Clara%20Duarte%20Monteiro.pdf.

5. Perlini NMOG, Faro ACM. Cuidar de pessoa incapacitada por acidente vascular cerebral no domicílio: o fazer do cuidador familiar. Rev Esc Enferm USP [Internet]. 2005 [cited 2013 Apr 08];39(2):154-63. Available from: http://www.scielo.br/pdf/reeusp/v39n2/05.pdf

6. Silveira TM, Caldas CP, Carneiro TF. Cuidando de idosos altamente dependentes na comunidade: um estudo sobre cuidadores familiares principais. Cad Saúde Pública [Internet]. 2006 [cited 2013 Apr 08];22(8):1629-38. Available from: http://www.scielo.br/scielo.php?pid=S0102-311X2006000800011&script=sci_arttext

7. Suzuki VF, Carmona EV, Lima MHM. Planejamento da alta hospitalar do paciente diabético: construção de uma proposta. Rev Esc Enferm USP [Internet]. 2011 [cited 2013 Apr 08];45(2):527-32. Available from: http://www.scielo.br/pdf/reeusp/v45n2/v45n2a31.pdf

8. Gazella M, Zago MMF. A alta hospitalar na avaliação de pacientes e cuidadores: uma revisão integrativa da literatura. Acta Paul Enferm [Internet]. 2008 [cited 2013 Apr 08];21(2):351-5. Available from: http://www.scielo.br/pdf/ape/v21n2/pt_a19v21n2.pdf

9. Rodrigues RAP, Marques S, Kusumota L, Santos EB, Fhon JRS, Fabrício-Wehbe SCC. Transition of care for the elderly after cerebrovascular accidents – from hospital to the home. Rev Latino-Am Enfermagem [Internet]. 2013 [cited 2013 Apr 08];21(Spec):216-24. Available from: http://www.scielo.br/pdf/rlae/v21nspe/27.pdf

10. Montezuma CA, Freitas MC, Monteiro ARMA. A família e o cuidado ao idoso dependente: estudo de caso. Rev Eletr Enf [Internet]. 2008 [cited 2011 May 22];15(2):395-404. Available from: http://www.revistas.ufg.br/index.php/fen/article/view/8041/5818

11. Pompeo DA, Pinto MH, Cesarino CB, Araujo RRDF, Poletti NAA. Atuação do enfermeiro na alta hospitalar: reflexões a partir dos relatos dos pacientes. Acta Paul Enferm [Internet]. 2007 [cited 2013 Apr 08];20(3):345-50. Available from: http://www.scielo.br/pdf/ape/v20n3/pt_a17v20n3.pdf

12. Oliveira SG, Quintana AM, Budó MLD, Kruse MHL, Beuter M. Internação domiciliar e internação hospitalar: semelhanças e diferenças no olhar do cuidador familiar. Texto Contexto Enferm [Internet]. 2012 [cited 2013 Apr 12];21(3):591-9. Available from: http://www.scielo.br/pdf/tce/v21n3/v21n3a14.pdf

13. Dossa A, Bokhour B, Hoenig H. Care transitions from the hospital to home for patients with mobility impairments: patient and family caregiver experiences. Rehabil Nurs [Internet]. 2012 [cited 2013 Apr 12];37(6):277-85. Available from: http://onlinelibrary.wiley.com/doi/10.1002/rnj.047/pdf

14. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 12 ed. São Paulo/Rio de Janeiro: Hucitec; 2010.

15. Cardoso L, Galera SAF, Vieira MV. O cuidador e a sobrecarga do cuidado à saúde de pacientes egressos de internação psiquiátrica. Acta paul enferm [Internet]. 2012 [cited 2013 Apr 12];25(4):517-523. Available from: http://www.scielo.br/pdf/ape/v25n4/06.pdf

16. Feuerwerker LCM, Merhy EE. A contribuição da atenção domiciliar para a configuração de redes substitutivas de saúde: desinstitucionalização e transformação de práticas. Rev Panam Salud Publica [Internet]. 2008 [cited 2013 Apr 12];24(3):180-8. Available from:

http://www.scielosp.org/pdf/rpsp/v24n3/a04v24n3.pdf

17. Freitas KS, Mussi FC, Menezes IG. Desconforto de familiares de pessoas internadas na UTI. Esc Anna Nery [Internet]. 2012 [cited 2013 Apr 12];16(4):704–11. Available from: http://www.scielo.br/pdf/ean/v16n4/09.pdf

18. Valadares GV, Paiva RS. Estudos sobre o cuidado à família do cliente hospitalizado: contribuições para enfermagem. Rev Rene [Internet]. 2010 [cited 2013 Apr 12];11(3):180-8. Available from: http://www.revistarene.ufc.br/revista/index.php/revista/article/view/409/pdf

19. Decesaro MN, Ferraz CA. Desvendando o senso do limite de familiares que convivem com pessoa dependente de cuidados físicos. Rev Eletr Enf [Internet]. 2009 [cited 2013 Apr 12];11(1):23-31. Available from: http://www.fen.ufg.br/fen_revista/v11/n1/pdf/v11n1a03.pdf

20. Schwonke CR, Silva JRS, Casalinho ALA, Santos MC, Vieira FP. Internação domiciliar: reflexões sobre a participação do cuidador/família/enfermeiro no cuidado. Ensaios e C [Internet]. 2008 [cited 2013 Apr 12];12(1):77-90. Available from: http://sare.anhanguera.com/index.php/rensc/article/view/285/284

21. Simon BS, Budó MLD, Garcia RP, Gomes TF, Oliveira SG,Silva MM. Social support network to the caregiving family of an individual with a chronic disease: integrative review. J Nurs UFPE on line [Internet]. 2013 [cited 2013 Apr 12];7(spe):4243-50. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/4181/pdf_2646

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