Cogitare Enferm. 2016 Oct/dec; 21(4): 01-09

Original article

NEEDS FOR AT-HOME NURSING CARE AFTER DISCHARGE FROM HOSPITAL IN THE SUS CONTEXT

Ana Carolina de Oliveira Jeronymo Neves[1], Edna Aparecida Barbosa de Castro[2], Sibely Rabaça Dias da Costa[3]

ABSTRACT: This article presents an analysis on the needs for at-home nursing care and care through the Unified Health System, after the discharge, of adults and dependent elderly. Research undertaken in two phases, between October 2012 and July 2013. The first, exploratory research involved 217 patients hospitalized to assess the capacity for self-care and care demands after discharge according to Orem's theory. The second phase, based on the Grounded Theory, was developed at six homes of people with self-care deficit through semistructured interview. It was evidenced that the patients and caregivers evidenced difficulties in attending to their needs, highlighting the burden, lack of professional support and difficulties to respond to the demand for material and equipment. In conclusion, the effective implementation of Home Care is fundamental for care integrality.
DESCRIPTORS: Home nursing; Nursing care; Self-care; Health policy.

NECESSIDADES DE CUIDADOS DOMICILIARES DE ENFERMAGEM APÓS A ALTA HOSPITALAR NO CONTEXTO DO SUS

RESUMO: O artigo apresenta uma análise sobre as necessidades de cuidados domiciliares de enfermagem e o atendimento pelo Sistema Único de Saúde, após a alta, de adultos e idosos dependentes. Resulta de pesquisa realizada em duas etapas, entre outubro de 2012 e julho de 2013. A primeira, exploratória, com 217 pacientes internados para avaliar a capacidade de autocuidado, e demandas de cuidados após a alta, segundo constructo teórico de Orem. A segunda, com aporte da Teoria Fundamentada nos Dados, realizada em seis domicílios de pessoas com déficit de autocuidado, por meio de entrevista semiestruturada. Evidenciou-se dificuldades vivenciadas pelos pacientes e cuidadores no atendimento de suas necessidades, destacando-se a sobrecarga, a falta de apoio profissional e as dificuldades em atender a demanda por insumos e equipamentos. Conclui-se que a implantação efetiva da Atenção Domiciliar é imprescindível para a integralidade do cuidado.
DESCRITORES: Assistência domiciliar; Cuidados de enfermagem; Autocuidado; Política de saúde.

NECESIDADES DE CUIDADOS DOMICILIARIOS DE ENFERMERÍA TRAS EL ALTA HOSPITALARIO EN EL CONTEXTO DEL SUS

RESUMEN: El artículo presenta un análisis sobre las necesidades de cuidados domiciliarios de enfermería y la atención por el Sistema Único de Salud, tras el alta, de adultos y ancianos dependientes. Resulta de investigación desarrollada en dos etapas, entre octubre del 2012 y julio del 2013. La primera, exploratoria, con 217 pacientes internados para evaluar la capacidad de autocuidado, y demandas de cuidados tras el alta, según el constructo teórico de Orem. La segunda con base en la Teoría Fundamentada en los Datos, desarrollada en seis domicilios de personas con déficit de autocuidado, mediante entrevista semiestructurada. Fueron evidenciadas dificultades vividas por los pacientes y cuidadores en la atención a sus necesidades, destacándose la sobrecarga, la falta de apoyo profesional y las dificultades en atender a la demanda por insumos y equipos. Se concluye que la implantación efectiva de la Atención Domiciliaria es fundamental para la integralidad del cuidado.
DESCRIPTORES: Atención domiciliaria de salud; Atención de enfermería; Autocuidado; Política de salud.

[1]RN. Master's student in Nursing. Universidade Federal de Juiz de Fora. Juiz de Fora, MG, Brazil.
[2]RN. Ph.D. in Collective Health. Nursing Professor, Universidade Federal de Juiz de Fora. Juiz de Fora, MG, Brazil.
[3]RN. M.Sc. in Nursing. Nurse, Hemocentro Regional de Juiz de Fora. Juiz de Fora, MG, Brazil.

Corresponding author:
Ana Carolina de Oliveira Jeronymo Neves
Universidade Federal do Rio de Janeiro
R. Oswaldo Perlingeiro, lote 12 - 25770-390 - Petrópolis, RJ, Brasil
E-mail: anacarol.jeronymo@gmail.com

Received: 14/07/2016
Finalized: 25/10/2016

INTRODUCTION

This article presents a study on the at-home nursing care needs of adults and elderly after discharge from hospital, considering the partly or wholly compensatory self-care ability, according to Dorothea Orem's self-care theory.

The motivation for the research resulted from the authors' participation in the study and research group on self-care and the education process in health and nursing at Universidade Federal de Juiz de Fora (GAPESE/UFJF). The authors' experiences in the Extension Project "Nursing consultation for self-care after discharge from hospital" and in the Professional Training Program "Nursing monitoring for self-care after discharge from hospital" are highlighted, undertake at the University Hospital (HU) of UFJF.

In addition, the authors participated in the multicenter research "Health care at home: effects and movements in the supply and demand in the Unified Health System (SUS) in the State of Minas Gerais", coordinated by the study and research group on nursing teaching and practice at Universidade Federal de Minas Gerais (NUPEPE/UFMG). These experiences permitted both a theoretical and practical approach of the theme and the identification of a gap in scientific production on nursing care required at home in accordance with the National Home Care Policy, reasserted in Decree 963, from May 27th 2013[1].

Home Care (HC), considered as the "most integral" and continuous form of care, is perceived as an effort to change the SUS, constructed in accordance with the substitutive care logic, targeting other types of objects and care forms[2-3].

Home care involves the "family's home", a dynamic environment, where the nurse assumes the delivery of care, the organization of the work process, the elaboration and management of the care plan, together with the other team members[4].

At home, the care that is demanded from nursing comprises technologically less dense activities, which require support-education, light-hard activities and technologically more dense activities[5].

Based on the Resolution of the Federal Nursing Council (COFEN) 358, the nurses' work is strengthened when it is based on the Nursing Care Systemization (NCS), permitting the acknowledgement of what is truly necessary for the caregiver and for the "being cared for", increasing the problem-solving ability of the required care[6-7].

Care, as the epistemological core of nursing, systemized in the exchange of knowledge with other sciences, is the study object of Dorothea Orem's nursing systems theory, who defends the classification of the client in three subtypes. Patients classified as wholly dependent are totally unable of developing their self-care activities; partly dependent patients accomplish certain activities, while the others are performed by nurses and/or their caregivers; and patients classified as independent need support, including health advice[5]. Therefore, self-care is the activity the individuals practice to their benefit in order to maintain their life, health and well-being[5].

According to Carpenito-Moyet, in line with Orem, the Self-Care Deficit Syndrome is understood as the state in which the individual experiences an impaired motor function or cognitive function, causing a decreased ability to perform the activities of daily living (ADLs), which are basic care actions, such as eating and walking. In addition, it also involves a reduction in the development of instrumental activities of daily living (IADLs), including the capacity to do the shopping and the housework[8]. Hence, this nursing diagnosis contributes to nursing's understanding of the care process in HC involving patients who are dependent for self-care.

Therefore, the goal is to understand the nursing care needs and the way they are attended to at home after discharge in the context of the SUS, based on Orem's self-care theory. The analysis aims to emphasize how the individuals with self-care deficit solve their needs for nursing care at home, highlighting the current context of HC.

METHOD

Qualitative research, using the Grounded Theory (GT) as a methodological framework. The objective was to develop a substantive theory on the research phenomenon, deriving from systematically collected and analyzed data. As proposed in this approach, the concept of "theoretical sampling" was used, in which the sampling is complete when the theories are saturated and developed[9].

To reach the objectives, the study was developed in two phases. One was exploratory, for which the data were collected at the clinical nursing wards of a teaching hospital in Minas Gerais. This phase was intended to identify the users' profile, aiming to capture participants with demands for nursing care at home. Individuals over 18 years of age were included, which lived in the city where the research was undertaken and who were hospitalized for clinical treatment. Two forms were used. One served to organize the database and was intended to register the hospitalizations and collect data in the patient histories. The other served to assess the self-care capacity and was applied during the nursing visit, with a Likert scale design and based on the reference frameworks by Orem[5] and Carpenito-Moyet[8]. The second form was applied to 217 patients between October 2012 and April 2013. The data collected in this phase were organized in a portfolio and submitted to analysis using statistical tools in Microsoft Excel.

In the second phase, the research was undertaken through home visits (HVs), including as participants the patients classified in the previous phase as partially or totally dependent. The patients were focused at the moment of the data collection and had a caregiver who was willing to participate, signing the consent form.

Among the 217 patients assessed, 93 were potential participants in the second phase, being 71 partially and 22 totally dependent for self-care. The empirical data collection in the second phase was closed off after visiting six participants, four of whom were classified as wholly and two as partly compensatory, with demands for HC services. Three of them were elderly (two male and one female) and three were adults (two female and one male).

The data were collected during HV by means of interviews, using a semistructured script, with an average length of two hours. Each interview was recorded and fully transcribed, using pseudonyms to guarantee the participants' anonymity. Before the next interview, the previous interviews were pre-analyzed and the data were systematically coded with the help of a text editor for qualitative data, OpenLogos (version 2.0)[10]. The participants were contacted by telephone to schedule the interviews. This phase of the data collection happened between May and July 2013.

The data analysis followed the three coding types proposed by Strauss & Corbin. In the open coding, the interviews were examined in detail to extract the codes, which were grouped to constitute categories; in addition, the concepts were identified. As the analysis advanced, axial coding was carried out, when the categories were related with their subcategories. In the final phase, the selective coding took place, with a view to identifying the central category, validating its relation with the other categories and mutual relations among the latter[9].

This research complied with the ethical aspects defined in Resolution 466 from December 12th 2012[11]. Before the start of the data collection, approval was obtained from the Ethics Committee for Research involving Human Beings at HU/UFJF, under opinion 229.712.

RESULTS

Based on the data collected in the exploratory phase, it was verified that most hospitalizations were due to neuropathies, 40 (18.43%), followed by gastrointestinal diseases, 33 (15.21%), lung diseases, 25 (11,52%), infectious-parasitic diseases, 24 (11.06%), cardiac diseases, 23 (10.60%), nephropathies, 19 (8.76%) and cancer, 18 (8.29%).

As verified, the level of dependence for self-care was closely related with the sex and age range, according to data described in Tables 1 and 2.

Table 1 – Distribution of patients hospitalized at the clinical nursing wards according to assessment of self-care capacity, sex and age range. Juiz de Fora, MG, Brazil, 2013

Level of dependence	Adult (<60 years)		Subtotal	Elderly (>=60 years)		Subtotal	Total
	Female	Male		Female	Male		
Independent	30 (50.85%)	56 (70.89)	86 (62.32%)	15 (42.86%)	23 (52.27%)	38 (48.10%)	124 (57.14%)
Partly compensatory	22 (37.29%)	17 (21.52%)	39 (28.26%)	16 (45.71%)	16 (36.36%)	32 (40.51%)	71 (32.72%)
Wholly compensatory	7 (11.86%)	6 (7.59%)	13 (9.42%)	4 (11.43%)	5 (11.37%)	9 (11.39%)	22 (10.14%)
Total	**59**	**79**	**138**	**39**	**44**	**79**	**217**

Table 2 - Distribution of patients hospitalized at the clinical nursing wards, assessed according to self-care capacity and sex. Juiz de Fora, MG, Brazil, 2013

Level of dependence	Female	Male	Total
	Adult/Elderly	Adult/Elderly	
Independent	45 (47.87%)	79 (63.23%)	124 (57.14%)
Partly compensatory	38 (40.43%)	33 (26.83%)	71 (32.72%)
Wholly compensatory	11 (11.70%)	11 (8.94%)	22 (10.14%)
Total	**94 (43.32%)**	**123 (53.68%)**	**217**

The analysis process of the empirical data guided by the Grounded Theory resulted in 25 codes, distributed in three categories with their respective subcategories, as represented in Picture 1.

Picture 1 – Categories and subcategories. Juiz de Fora, MG, Brazil, 2013

Patient-family binomial in the home context: experiences, appearance, perceptions and feelings
"Family home" in home care: appearances, personalities and feelings
Home care: facilities and difficulties
Central Category – The SUS in home care: supply versus demand for instrumental care
Human resources and service provision at home
Service network: the needs for home care and the (un)availability in the SUS
The patient and his/her family caregiver in situation of dependence for home care and its relation with the different conditions
Diagnoses, conditions and hospitalizations: a new look for life
Self-care deficit versus family caregivers
Dependence for care and its implications in daily life

In the category "Patient-family binomial in the home context: experiences, appearances, perceptions and feelings", religiosity/spirituality was recurrent in the reports.

The only thing I have to say is just thank you, I really thank God, because being alive and still being here, thanks God, without worse things in my life. Because in fact everything is temporary. And I believe that soon, if God wants, I may walk again. (Celeste)

In addition, the lack of financial resources was mentioned as an obstacle in home care.

We are managing because we are asking help. Like the wheelchairs we asked. Diaper, she already got that. We are sharing the supplement between the siblings, but it's difficult, because we are salary workers, so our money is not enough. (Luana)

In the central category called "The SUS in home care: supply versus demand for instrumental care", the participants highlighted feelings of disregard of the health services towards the patients and/or their caregivers, as mentioned below.

I think like, that the work done with my father there was good, but at the moment of the discharge it was as if they were disposing my father to our care. From now one it's you and nobody else. (Ricardo)

During the interviews, the participants listed home care needs and the difficulties to attend to them.

She is using a wheelchair, she is using diapers. (Luana)

Ah, it has been a year that he's got gastrostomy, more or less. (Mariana)

And, then he got this problem that he needs to, that he has to use oxygen 24 hours because of the lack of air. (Luana)

We have tried to get the diaper through the SUS, but it's that much bureaucracy that we gave up to tell you the truth. They are, they are in command, that's the truth. Then she goes there and they start, they demand different papers again. (Luana)

In the third category "The patient and his family caregiver in situation of dependence for self-care, and its relations with the different conditions", the family caregiver's physical and mental burden is highlighted, as mentioned below.

Because there's my mother too who has reached an age when she causes a lot of work. Like, senile, she says things that sometimes hurt us. She does not do it, I do everything, you know? Sometimes I can't bear it, because I've got stomach problems, sometimes I can't even bear it, but I'm there doing to. (Mariana)

The patients also highlight feelings of fear and sadness because they are still incapable of accomplishing "simple" activities of daily living.

But I think that, walking really, I won't manage. And I'm not revolted because of that either. I have to accept what God is giving me. (Roberta)

DISCUSSION

In the exploratory phase, the profile and self-care capacity of the patients in the initial research scenario was analyzed, showing that most hospitalizations referred to male patients, 123 (56.68%). This finding is in line with Brazilian studies to analyze the profile of hospitalizations[12-13].

As for the self-care capacity, 127 (57.14%) patients were classified as independent for self-care in both sexes and age ranges. Nevertheless, the male patients presented a higher degree of independence, 79 (64.23%), when compared to the female patients. Thus, in line with a study developed in 2013, this research found a difference in the level of dependence related to gender[14].

Of all elderly, it was verified that 41 (51.9%) presented some degree of dependence. Among the adult patients, a lower percentage was observed, 52 (37.68%). These data are in accordance with a Brazilian study that found a direct relation between age and level of dependence[14].

As regards the causes of hospitalization, the highest percentage of hospitalizations was related to: neuropathies, followed by gastrointestinal diseases; lung and infectious-parasitic diseases.

According to this study, a research undertaken in the Zona da Mata of Minas Gerais highlighted a higher incidence rate for lung diseases, followed by gastrointestinal diseases and neuropathies[14].

In line with more recent DATASUS data, published in 2008, 13.76% of the patients are hospitalized due to cardiac diseases with neurological consequences, followed by gastrointestinal diseases (9.80%), lung diseases (9.11%), genito-urinary diseases (7.56%), cancer (6.91%), infectious-parasitic diseases (5.81%) and finally mental disorders (3.34%)[15].

Patient-family binomial in the home context: experiences, appearance, perceptions and feelings

This category represents the existing relation between patient and caregiver in the home context, highlighting aspects experienced in each daily reality of the "family home".

In that home context, the Divinity is emphasized as the main source of support for their lives, depositing hopes of overcoming the high care burden in that Being.

The need to offer a more comprehensive and beneficial treatment through the understanding of the complexity and importance of the spiritual caregiver role was evidenced in a study undertaken in the United States[16].

As observed, the support for self-care by sustaining religiosity/spirituality contributes to treatment compliance, shorter treatment and decision making[17].

As difficulties the family needs to overcome, the lack of financial resources is underlined, leading to the search for alternatives to deliver the care delegated by the SUS.

In accordance with findings from other studies, in the daily reality of the families attended in HC, economic and social difficulties are identified, such as unemployment and high treatment costs[18-19].

The role of the State is to expand the access to HC, delivering high-quality services, so that the full responsibility for the patient is not transferred to the caregivers, neither in the execution of care nor in the transfer of expenses[1]. The large amounts the family members themselves spend on HC services can threaten the family economy and the patient's wellbeing.

The SUS in Home Care: supply versus demand for instrumental care

In this category, the nursing care needs are analyzed, a theme that stands out in the current context of public policies related to HC.

According to the research participants' report, it was verified that the nurses do not systematically offer therapeutic education for the discharge. When they mention that they received orientations, independently of the professional category, the participants emphasized the lack of quality and continued without understanding what and how to do it, in order to relieve their insecurities and, mainly, to solve their health needs.

In that sense, we consider that the discharge needs to be planned since the admission to avoid an information burden upon departure[13].

The orientations need to be provided systematically and linked to the health care network (HCN), for the sake of integrality. Nevertheless, we know that the HCN is still a process under construction, with important gaps related to fragmented practices[20].

In the search for diagnoses and treatments, represented by movements of coming and going, the patients and their caregivers mention that they feel "lost", "swallowed by the system", that is, disoriented in the search to solve their problems. This situation points towards a possible increase in the demand for self-care, superior to the existing HC teams' capacity, that is, an unbalanced relation between supply and demand[2].

Based on the participants' recurring and intense reports, we understand the importance of supplying at-home nursing care, sometimes delegated to the patient and the family, but without a productive and systematic assessment of what they are able to accomplish.

In a recent study on the home care needs, it was shown that: 73.7% of the patients used an enteral diet, 24.6% tracheotomy, 22.8% needed oxygen therapy, 17.5% were on airway aspiration, 8.7% capillary glucose monitoring and 5.2% peritoneal dialysis[21].

The patient and his/her family caregiver in situation of dependence for self-care and its relations with the different conditions

In the study, we identified the care experiences in the sphere of ADLs and IADLs, accomplished by the patients and their caregivers. These experiences are surrounded by feelings characteristic of the

disease process and of the dependence level.

In the home care context, patients and their relatives experience intense feelings, not only due to the proximity of death, but also to the awareness of a life-threatening disease[22].

The family member's illness changes the family's routine, increases the responsibilities and difficulties, changes the way of seeing and living life. For the caregivers, this change is more intense. They become overburdened, with a turmoil of feelings, but at the same time feel guilty, try to show the sick relative and society that they are strong, that they are able to do what is best for their loved one.

In view of this process of illness and dependence, the caregivers highlight the physical and mental burden related to the increased demand for time and the care expenses[23].

In that category, the relation between the disease evolution and the level of dependence is also emphasized, in which the loss of autonomy and the functional commitment, including the accomplishment of ADLs, modify the individuals' daily life, producing feelings of frustration, sadness and impotence[24].

As the patient and his/her family experience this new situation of dependence and disability, the physical and functional structure of the "family home" is readjusted and needs to be adapted, sometimes abruptly.

General theory of the study: "Needs for at-home nursing care after the discharge in the context of the SUS"

Through the method used in this study, the final result is a theory deriving from the data, summarized in the following diagram.

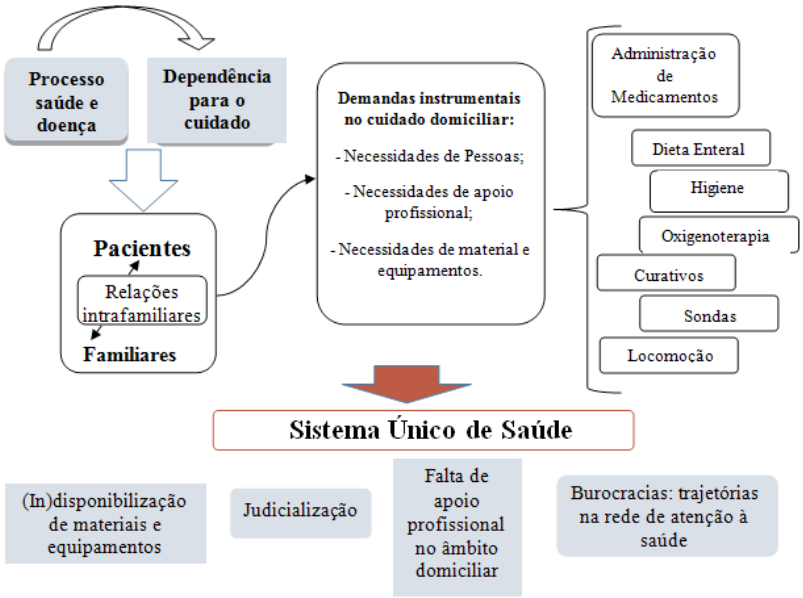

Diagram 1 – General theory of the study: "Needs for at-home nursing care after the discharge in the context of the SUS". Juiz de Fora, MG, Brazil, 2013

The in-depth analysis permitted the understanding that, in the course of the illness process deriving from chronic-degenerative conditions, the participants developed a level of dependence classified as partially or totally dependent on home care. The care provision gains complexity as it involves the patient-family binomial, in a given social, economic and political context.

The emergence of the disease, which compromises the capacity for self-care, evidences the conflicts and troubled intrafamily relationships. In the attempt to respond to the demands for home care, deriving from the level of dependence, the SUS users, together with the family caregivers, initiate a process of "coming and going". In this "coming and going", accompanied by intense suffering, they

invest, try, persist until they "manage", or not, to get their needs attended to through instrumental and therapeutic care, represented by the following in this study: oxygen therapy, body hygiene, nutrition, dressings, locomotion, medication and tubes. To solve this care, the family members face bureaucracies and what they call "failures" in the SUS, evidenced by the lack of professional support in home care and the unavailability of material and equipment. To obtain these, some users make use of a legal mandate.

CONCLUSION

The research awakens Brazilian nursing to a new health care scenario, signaling the need for education and training to work in HC. The difficulties appointed in the search for care in the SUS are related to needs in the activity sphere, demanding actions in the fields of care management, assistance, training and research.

In view of the size of the research hospital and its particularities in the SUS, the results may not express the reality of other locations. Therefore, the need is highlighted to undertaken other studies on this theme, deepening the searches in other geographic regions.

In conclusion, it is relevant to expand the implementation process of HC, as triggered by the current Program *Melhor em Casa* (Better at Home), with a view to overcoming the "hassles and ordeals" of frail users and family members, immersed in a universe of continuous home care needs.

REFERENCES

1. Brasil. Portaria n. 963, de 27 de maio de 2013. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União, n. 101, Brasília, 28 mai. 2013. Seção 1:30.

2. Andrade AM, Brito MJM, Silva KL, Von Randow RM, Montenegro LC. Singularidades do trabalho na Atenção Domiciliar: imprimindo uma nova lógica em saúde. R. pesq.: cuid. fundam. online. [Internet] 2013;5(1) [acesso em 12 fev 2016]. Disponível: http://dx.doi.org/10.9789/2175-5361.2013v5n1p3383.

3. Silva KL, de Sena RR, Seixas CT, Feuerwerker LCM, Merhy EE. Atenção domiciliar como mudança do modelo tecnoassistencial. Rev. Saúde Pública. [Internet] 2010;44(1) [acesso em 27 fev 2016]. Disponível: http://dx.doi.org/10.1590/S0034-89102010000100018.

4. Silva KL, de Sena RR, Silva PM, Braga PP, de Souza CG. Serviços de atenção domiciliar na saúde suplementar e a inserção da enfermagem em Belo Horizonte/MG. Acta paul. enferm. [Internet] 2012;25(3) [acesso em 1 dez 2015]. Disponível: http://dx.doi.org/10.1590/S0103-21002012000300014.

5. Orem DE. Nursing: concepts of practice. New York: McGraw-Hill; 1985.

6. Pinto EA, da Silva DDA, dos Santos RM, Trezza MCSF. Necessidades de cuidados expressas pela família que possui um acamado no domicílio. Enferm Foco. [Internet] 2012;3(4) [acesso em 6 fev 2016]. Disponível: http://revista.portalcofen.gov.br/index.php/enfermagem/article/view/383.

7. Conselho Federal de Enfermagem (COFEN). Resolução n. 358, de 15 de outubro de 2009. Dispõe sobre a Sistematização da Assistência de Enfermagem e a implementação do Processo de Enfermagem em ambientes, públicos ou privados, em que ocorre o cuidado profissional de Enfermagem, e dá outras providências. Rio de Janeiro: COFEN; 2009.

8. Carpenito-Moyet LJ. Diagnósticos de Enfermagem: Aplicação à Prática Clínica. 13ª ed. Porto Alegre: Artmed; 2012.

9. Strauss A, Corbin J. Pesquisa Qualitativa: técnicas e procedimentos para o desenvolvimento de teoria fundamentada. 2ª ed. Porto Alegre: Artmed; 2008.

10. Camargo Junior, KR. Apresentando Logos: um gerenciador de dados textuais. Cad. Saúde Pública. [Internet] 2000;16(1) [acesso em 05 dez 2015]. Disponível: http://www.researchgate.net/publication/282651258_Apresentando_Logos_Um_gerenciador_de_dados_textuais.

11. Ministério da Saúde (BR). Conselho Nacional de Saúde. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Resolução n. 466, de 12 de dezembro de 2012. Brasília; 2012.

12. Nogueira LS, de Sousa RMC, Padilha KG, Koike KM. Características clínicas e gravidade de pacientes internados em UTIs públicas e privadas. Texto Contexto Enferm. [Internet] 2012;21(1) [acesso em 2 fev 2016]. Disponível: http://dx.doi.org/10.1590/S0104-07072012000100007.

13. Souza ICP, Silva AG, Quirino ACS, Neves MS, Moreira LR. Perfil de pacientes dependentes hospitalizados e cuidadores familiares: conhecimento e preparo para as práticas do cuidado domiciliar. REME, Rev. Min. Enferm. [Internet] 2014;18(1) [acesso em 2 fev 2016]. Disponível: http://www.dx.doi.org/10.5935/1415-2762.20140013.

14. da Costa SRD, de Castro EAB, Acioli S. Capacidade de autocuidado de adultos e idosos hospitalizados: implicações para o autocuidado de enfermagem. REME, Rev. Min. Enferm. [Internet] 2013;17(1) [acesso em 25 nov 2015]. Disponível: http://dx.doi.org/10.5935/1415-2762.20130016.

15. Ministério da Saúde (BR). Informações de saúde. Departamento de Informática do SUS-DATASUS. [Internet] 2016 [acesso em 15 mar 2016]. Disponível: http://tabnet.datasus.gov.br/cgi/tabcgi.exe?idb2008/d13.def.

16. Lillis BS. Understanding the complex role of a hospice spiritual counselor. Am J Hosp Palliat Care. [Internet] 2014;31(4) [acesso em 11 fev 2016]. Disponível: http://dx.doi.org/10.1177/1049909113494746.

17. Santo CCE, Gomes AMT, de Oliveira DC, Marques SC. Adesão ao tratamento antirretroviral e a espiritualidade de pessoas com HIV/AIDS: estudo de representações sociais. Rev. enferm. UERJ. [Internet] 2013;21(4) [acesso em 02 mar 2016]. Disponível: http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/10005/7801.

18. Freitas IBA, Meneghel SN, Selli L. A construção do cuidado pela equipe de saúde e o cuidador em um programa de atenção domiciliar ao acamado em Porto Alegre (RS, Brasil). Ciênc. saúde coletiva. [Internet] 2011;16(1) [acesso em 17 nov 2015]. Disponível: http://dx.doi.org/10.1590/S1413-81232011000100032.

19. Janus AL, Ermisch J. Who pays for home care? A study of nationally representative data on disabled older Americans. BMC Health Serv Res. [Internet] 2015;(15) [acesso em 11 fev 2016]. Disponível: http://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-015-0978-x.

20. Brito MJM, Andrade AM, Caçador BS, Freitas LFC, Penna CMM. Atenção domiciliar na estruturação da rede de atenção à saúde: trilhando os caminhos da integralidade. Esc. Anna Nery. [Internet] 2013;17(4) [acesso em 05 dez 2015]. Disponível: http://dx.doi.org/10.5935/1414-8145.20130002.

21. Brondani CM, Ramos LH, Beuter M, Lampert MA, Seiffert MA, Bruinsma JL. Caracterização de pacientes dependentes de tecnologias de um serviço de internação domiciliar. Rev. Enferm. UFSM. [Internet] 2013;3(n. esp) [acesso em 30 jan 2016]. Disponível: http://dx.doi.org/10.5902/2179769211063.

22. Rodriguez MIF. Internação domiciliar: avaliações imperativas implicadas na função de cuidar. Psic. Rev. [Internet] 2013;22(2) [acesso em 20 jan 2016]. Disponível: http://revistas.pucsp.br/index.php/psicorevista/article/view/17989.

23. da Costa SRD, de Castro EAB. Autocuidado do cuidador familiar de adultos ou idosos dependentes após a alta hospitalar. Rev. bras. enferm. [Internet] 2014;67(6) [acesso em 14 nov 2015]. Disponível: http://dx.doi.org/10.1590/0034-7167.2014670617.

24. Faber V, Rosanelli CP, Loro MM, Kolankiewicz ACB, Piovesan S, Leite MT. Percepção de doentes crônicos acerca do cuidado prestado por familiares. Cienc Cuid Saude. [Internet] 2012;11(3) [acesso em 09 fev 2016]. Disponível: http://dx.doi.org/10.4025/cienccuidsaude.v11i3.14990.