Exploring the family caregiving phenomenon in nursing documentation | OJNI

by

[Manuel Fernando Oliveira RN, MPhilSc, PhD-student](#),

Maria Joana Campos RN, MNSc, PhD-student,

José Miguel Padilha RN, MNSc, PhD-student,

Filipe Pereira RN, MNSc, PhD and

Paulino Sousa RN, MNSc, PhD

CITATION

Abstract

Background: Today, an increasing number of family members assume a great responsibility for taking care of a dependent person at home. Nurses must prepare the family caregiver for this transition—to be a caregiver, by providing the best solution for each case. Taking care of a dependent person is not an easy task; it involves cognitive and instrumental skills to perform this role.

Aim: We intend to study the types and frequencies of nursing diagnosis related to the family caregiver, documented in the Nursing Information System (NIS) in use, in a District Hospital in Portugal.

Method: The data were extracted from the Nursing Information System to a new database, and, after codification, we analyzed the nursing diagnosis related to the family caregiver. ICNP ® (International Classification for Nursing Practice) was used as referential terminology in data analysis.

Findings: The analysis shows that more than 40% of patients admitted with nursing diagnosis are related to the family caregiver, even in readmissions cases. These nursing diagnoses are centered on the prevention of patient's complications, such as pressure ulcer, replacement in self-care activities, i.e., feeding, optimization of the family caregiver role, and in the promotion of the therapeutic regimen management. The major skills that we found in diagnosis related to the family caregiver were associated with knowledge acquisition.

Conclusion: We conclude that, in many readmissions cases, family caregivers continue to have many weaknesses, specifically related to their level of knowledge and skills learning. This finding opens a window of opportunity to develop solutions that will help these families take care of a dependent person at home, including web-based solutions that can be a tool to promote the continuity of care.

Keywords: *nursing information systems, continuity of care, family caregiver, nursing diagnosis, ICNP ®*

Introduction

Being a family caregiver is a challenge. The responsibility of caring for a dependent person at home involves the adoption of behaviors and actions that may be indicative of proficiency, particularly when the dependency is the result of an acute event or sudden illness. The preparation of family caregivers must begin in the hospital and should only be concluded when the family caregiver demonstrates cognitive and instrumental skills to provide care and a "fluid integrative identity" (Meleis, Sawyer, Im, Messias & Schumacher, 2000).

Many people are faced with the situation of beginning a new role as caregiver to a dependent person. They are, therefore, faced with an event of transition, in which "*anticipatory preparation facilitates the transition experience*" (Meleis et al., 2000, p. 22). So, some questions arise: how do nurses prepare the family caregiver in the hospital? Which areas are explored with the person who will take care of a dependent person at home?

The study reported here is part of a research project already underway, focusing on the problems of preparing the family caregiver for caretaking performance. But, by looking at this vast and complex process, it is necessary to limit the research, as well as the scope of the theme. We will seek, then, to define and direct our attention, to the resources available to family caregivers that can help them take care of dependent persons at home. A feature—web-based solutions for family caregivers—based on information technologies may be a resource for finding organized information, asking questions, and contacting other health care providers. With that in mind, the objective of the project is to create, implement, and test this solution.

We will direct our attention to the nursing diagnosis related to the family caregiver, documented in the NIS in use. By analyzing this information, we can develop some ideas about the content that should be included on the web-based feature.

Purpose

The goal of this study is to understand which aspect nurses need to include in the preparation of the family caregiver. We have established some questions that will guide us in this research:

- What are the most common medical reasons for hospitalization?

- What nursing diagnosis, related to the family caregiver, is documented?

By knowing this reality, nurses can identify and plan their nursing interventions to correspond to the family caregiver's needs, with the aim of achieving continuity of care during the hospitalization, and at home. This data can help us understand the nature of "information needs" experienced by family caregivers.

Background

The majority of care is provided by family and friends, so-called informal carers (Nolan, Keady & Grant, 1995). However, the competence of caregivers or how well they can take care of a dependent person is rarely identified in a systematic manner.

According to Brereton (1997, p.432),

"*Such consideration appears not to have been given to the needs of family carers, who are poorly prepared to 'take on' the caregiving role, particularly in terms of making an informed choice and having their willingness and ability to care assessed.*"

These conclusions were also later mentioned by Brereton and Nolan (2002) when they analyzed the previous studies of Banks (1999), Henwood (1998), Opie (1994), and Taraborrelli (1993).

Discroll (2000) analyzed the perception of information received by family caregivers during the hospitalization of the dependent person. In a sample of 40 family caregivers, she concluded that caregivers weren't given information related to "activities the patient can do" (77.5%); "activities the patient should avoid," as well as "food the patient can eat" (70%); "when to return to hospital if experiencing problems post-discharge" (75%); and "potential complications to watch for" (80%). In general, they received very little information from health care professionals concerning the patient's care at home.

In a study conducted in Portugal (Petronilho, 2007), family caregivers demonstrated a marked lack of knowledge in the areas of the musculoskeletal, integumentary, and respiratory system processes, as well as in the prevention of pressure ulcers and footdrop. These family caregivers also mentioned the need to search for additional information in other sources such as the Internet, other professionals or other people with experience in caring for dependents. This conclusion was also referenced in a study developed by Graham, Ivey, and Neuhauser (2009).

Mackenzie et al. (2007) concluded that the main problems reported by caregivers before discharge were "handling with elimination," not related to incontinence, but concerning problems of mobility/access to toilets and the use of commodes at home; "handling communication difficulties;" and "dealing with fluctuating moods." Family caregivers also anticipated problems in assisting with daily living activities and some were worried about how this would restrict their social lives. The authors also found that 4 to 6 weeks after discharge, the problems remained, although with different priorities: changes in mood and behavior of the dependent person became the first priority.

Some home care is complex and demanding, requiring training and learning new skills. Nurses tend to be a kind of "caregiver," preparing clients for impending transitions and facilitating the process of learning new skills related to clients' health and illness experiences (Meleis et al., 2000).

Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) describe family caregiving skill as the ability to engage effectively and smoothly in nine core caregiving processes. It's effective when it reaches the best outcomes of care, such as prevention of complications or optimal therapeutic regimen management and it's smooth when it flows with the seeming effortlessness of actions honed through experience and practice. They also identified and categorized 63 indicators of caregiving skill into one of nine caregiving processes: monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system.

There are patients discharged after an acute episode of illness, who do not acquire the power to live the transition that they will experience. The same applies to family members who will assume the role of caretaker of a dependent person. Consequences can result from this lack of preparation, such as, how many patients are readmitted to the hospital shortly after the initial hospitalization? And, in addition to the inconvenience and costs of subsequent hospitalizations, there are consequences concerning the quality of life of patients and caregivers.

Some family caregivers reported that at times they did not receive adequate training from health professionals and that a lot of the information provided was generic, not responding effectively to the particular needs of each one (Graham, Ivey & Neuhauser, 2009).

Method

Below is a description of the methodological decisions for the purpose of this thesis, in order to achieve the overall and specific aims.

Study Design and Sample

The nursing data collection was accomplished by appealing to the analysis of the nursing records documented in the NIS. The results presented are derived from a quantitative, descriptive, and exploratory study. A retrospective collection of nursing data was made.

It used a convenience sample of hospitalized patients admitted in a Medicine ward. In this case, we chose all patients admitted from January 1, 2008 to December 31, 2008, in an Oporto Hospital.

Data Collection

In addition to socio-demographic data (age, sex) for patients (N=816), we have collected data on hospital admissions (N=907) regarding the duration and reason for hospitalization, and also on the nursing data, in particular the nursing diagnosis related to the family caregiver. These nursing diagnoses are available in the NIS, based on the ICNP ® , version 2.

The nursing data were extracted into an MS Access® database, stored, and recoded automatically in order to protect the identity of every patient, and to make it impossible to link the data to the patient. The collected data have been processed in the software "IBM SPSS Statistics 18″ for analysis of descriptive statistics.

Ethical considerations

Authorization was requested to grant access to the nursing data of the patients. Afterward, all the necessary procedures were taken to maintain the anonymity and confidentiality of the data.

Findings and Discussion

We proceed to the analysis of the nursing data of all admissions (816 patients / 907 admissions). This sample corresponds to 816 patients that were admitted in impatient settings, concluding then that some patients, (n=76) had one or more readmissions during this period. These 76 patients had the average readmission rate of 1.2 hospitalizations (ranging from 1 to 4 hospitalizations) in 2008.

In terms of patients profiled that participated in this study, 418 (51%) were male, and 398 (49%) were female, with an average age of 70.68 years (SD=16.13, Med=75, ranging from 61 to 82 years of age), with an average length of stay (medicine) of 11.80 days (SD=11.30, Med=8, ranging from 1 to 97 days). The most frequent medical reasons for hospitalization in patients without readmissions were: infections (38.1%), acute diseases (31.3%), exacerbation of chronic diseases (18.4%), oncological diseases (6.9%), and other diseases (5.4%).

When comparing patients with readmissions, we found less acute diseases (19.8%) and oncological diseases (5.5%), but more infections (44.0%) and exacerbation of chronic diseases (25.3%). These kinds of medical problems may be associated with family caregiving skills (Petronilho, 2007).

In Table 1, we list the frequency of nursing diagnosis related to the family caregiver in the first admission and in the readmissions cases.

We

Table 1. Frequency of Nursing Diagnosis related to the family caregiver

Hospitalizations	Cases TOTAL	Hospitalizations without nursing diagnosis related to the family caregiver	Hospitalizations with nursing diagnosis related to the family caregiver
1st admission	816	464 (56.9%)	352 (43.1%)
Readmissions	91	54 (59.3%)	37 (40.7%)
TOTAL	907	518 (57.1%)	389 (42.9%)

observe in 389 (42.9%) hospitalizations, nursing diagnosis related to the family caregiver. When comparing the nursing data between the first admission and the readmissions, we found nursing diagnosis in 43.1% of the patients in the first hospitalization, and 40.7% in the readmissions cases. This appears to indicate there are less needs identified by nurses of the family caregivers. But, on the other hand, this shows that some needs of the family caregivers, which must be solved during that hospitalization, still remain.

Petronilho (2007), in his study, affirmed that one month after discharge, family caregivers continued to express many difficulties. So, it's permissible to infer that in the readmissions of the dependent person, the family caregivers continue to express some needs.

We can say that discharge planning involves a complex process of patient assessment, development of an appropriate plan, provision of education to the patient and caregivers, and follow-up and evaluation (Bauer, Fitzgerald, Haesler & Manfrin, 2009; Chenoweth & Luck, 2003; Chow, Wong & Poon, 2007; Shepperd, Parkes, McClaran & Phillips, 2010). We believe that many readmissions can be avoided if nurses assume their fundamental role: to prepare the family caregiver to take care of the dependent person at home.

The nature of the nursing diagnoses related to the family caregiver documented in the NIS can be grouped into four main dimensions: *"Prevention of complications,"* attendance in *"Self-care deficit," "Family caregiver role strain"* and *"Managing the dependent person's therapeutic regimen,"* as shown in Table 2.

We found 2137 records of nursing diagnosis related to the family caregiver: 991 (46.4%) of them are focused on prevention of

Table 2. Dimensions of Nursing Diagnosis related to the family caregiver

DIMENSIONS	TOTAL		1st admission		Readmissions	
	N	(%)	N	(%)	N	(%)
Prevention of complications						
Pressure Ulcer	521	(24.4%)	482	(24.3%)	39	(24.8%)
Infection	168	(7.9%)	145	(7.3%)	23	(14.6%)
Falls	118	(5.5%)	112	(5.7%)	6	(3.8%)
Constipation	113	(5.3%)	105	(5.3%)	8	(5.1%)
Impaired tissue integrity (Maceration)	71	(3.3%)	65	(3.3%)	6	(3.8%)
Self-care deficit						
Feeding	211	(9.9%)	197	(9.9%)	14	(8.9%)
Toileting	182	(8.5%)	170	(8.6%)	12	(7.6%)
Bathing / hygiene	170	(8.0%)	160	(8.1%)	10	(6.4%)
Dressing / grooming	162	(7.6%)	149	(7.5%)	13	(8.3%)
Transfer ability	156	(7.3%)	148	(7.5%)	8	(5.1%)
Walking	14	(0.7%)	14	(0.7%)	0	(0.0%)
Family caregiver role						
Caregiver role strain	161	(7.5%)	147	(7.4%)	14	(8.9%)
Therapeutic regimen management						
Ineffective therapeutic regimen management	73	(3.4%)	71	(3.6%)	2	(1.3%)
Others						
Others	17	(0.8%)	15	(0.8%)	2	(1.3%)
TOTAL	2137	(100.0%)	1980	(100.0%)	157	(100.0%)

complications, in particular, on pressure ulcer (24.4%); 895 (42%) are related to the self-care deficit; 161 (7.5%) are focused on the family caregiver role and 73 (3.4%) are related to the therapeutic regimen management. When comparing the two groups, in the group with readmissions, we observe a higher percentage in some aspects; in particular, infection (14.6%) and caregiver role strain (8.9%).

Hinojosa and Rittman (2007) describe, in their study, the information needs of family caregivers, which show significant differences between the information needed and received in many of the dimensions used in this study. Some studies suggest that we must give attention to the social support of the family caregivers, as a way of reducing readmissions, once some of them have symptoms of stress (Shyu, Chen & Lee, 2004).

Table 3 shows the nursing diagnosis related to the cognitive and instrumental skills of the family caregiver. In the cognitive skills, we can find abilities like *"Family Caregiver's knowledge to turn the patient"* or *"Family Caregiver's knowledge to feed the patient,"* and in the instrumental skills *"Family Caregiver's skill learning to prevent pressure ulcers"* or *"Family Caregiver's skill learning to feed the patient."*

Table 3. Skills of the family caregiver

SKILLS	TOTAL N (%)	1st admission N (%)	Readmissions N (%)
Family caregiver deficient knowledge	1510 (76.6%)	1397 (76.4%)	113 (79.0%)
Family caregiver deficient skills learning	461 (23.4%)	431 (23.6%)	30 (21.0%)
TOTAL	1971 (100.0%)	1828 (100.0%)	143 (100.0%)

We can observe that, from the 2137 nursing diagnoses related to family caregiver, 1971 (92.2%) records are associated with deficient knowledge and deficient skills learning. Of these, 1510 (76.6%) are related to knowledge, stronger in patients with readmissions (79.0%). Again, we can infer that many problems remain in readmissions, i.e., we must continue to invest in solving problems that arise in the hospitals and also at home.

We can assume that the problems that form the subject of an attempt to resolve the first hospitalization, are still in the readmissions cases, and do not reflect the positive gains in knowledge and skills learning of the caregivers (Petronilho, 2007). But, the content of the knowledge needed for illness care at home has been described extensively, and knowledge alone does not guarantee skillful caregiving. Rather, families must put knowledge into practice; it is through this practice that caregiving skill can be observed (Schumacher, Stewart, Archbold, Dodd & Dibble, 2000).

Higher readmission rates were observed in patients with more activities of daily living limitations, or lower levels of consciousness and in patients with the need for mouth care, wound care, replacement of tubes, or other invasive nursing care (Chuang, Wu, Ma, Chen & Wu, 2005).

Evidence suggests that one of the most significant factors influencing the success of discharge planning for frail, older patients is the role of the family (Bauer et al., 2009). The care provided by family caregivers can improve the patient's recovery from acute illness, and decrease the likelihood of readmission (Grimmer, Moss & Falco, 2004). The readmission can be used as an indicator of quality of care (Halfon et al., 2006; Rumball-Smith & Hider, 2009).

There seems to be a consensus that a nursing informatics system can contribute in a decisive manner to the continuity of care. For Pereira (2005), the information processed by the NIS should gather the needed attributes to guarantee that the continuity of care becomes a reality. In this context, we argue that the portal should have a close connection/linkage to the NIS to provide, at-home, personalized information to the caregiver depending on the nursing diagnosis assessed at the discharge.

But, we must do even more; we should provide as many resources as possible to family caregivers in order to minimize the episodes of readmissions. As stated earlier, a web-based solutions program to support family caregivers may be one such resource. Several studies show the importance of these solutions by contributing to the satisfaction or increasing the competence of the family caregiver (Fenton et al., 2007; Gaikwad & Warren, 2009), or by reducing the number of readmissions of the ill person (Chetney, 2008; McManus, 2004).

Conclusion

After careful analysis of the nursing diagnosis documented by nurses, we have concluded that there is still much that needs to be done to properly prepare family caregivers. There are some areas identified by nurses, e.g., helping family caregivers prevent complications or dealing with the self-care deficit of the dependent person, that we see as an opportunity to the development of the profession, thus contributing to improving the quality of life of patients and family caregivers.

It is noted that in the episodes of readmission, the deficits of knowledge and skills learning are similar to those observed in the 1st readmission, which justifies the relevance of developing solutions that will help family caregivers take care of dependent persons at home.

Providing family caregivers with access to clinically useful information can be one key to avoiding readmissions. At time of discharge, we must feel confident that caregivers have the information and skills necessary to take care of the dependent person at home. To achieve this, the web-based solutions for family caregivers can provide a resource to reduce the complications of the dependent persons.

As reported by Bath (2008), in addition to competing for the improvement of quality of life of customers, these web-based solutions are an important aid to reducing the economic costs, or the readmission of patients, and may also play an important role in early detection of symptoms associated with disease.

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Associate Professor at Oporto Nursing School, Portugal

Escola Superior de Enfermagem do Porto

Rua António Bernardino de Almeida 4200-070, Porto, Portugal

Fax and phone number: 351225096337 / 351225073500

URL: http://portal.esenf.pt

E-mail address: fernando@esenf.pt

Maria Joana Campos RN, MNSc, PhD-student

Associate Professor at Oporto Nursing School, Portugal

José Miguel Padilha RN, MNSc, PhD-student

Associate Professor at Oporto Nursing School, Portugal

Filipe Pereira RN, MNSc, PhD

Professor at Oporto Nursing School, Portugal

Paulino Sousa RN, MNSc, PhD,

Professor and Post-graduation of Nursing Information Systems Coordinator at Oporto Nursing School, Portugal

Director of the ICN-Accredited Centre for Information Systems Research and Development of the Oporto Nursing School

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