Original Article

Behavior characterization of informal caregivers of wounded patients in the hospital environment

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ABSTRACT

Wound care in the hospital environment continues at home after discharge and performed by the informal caregiver. The objective of this study was to characterize the behavior of the informal caregiver during the treatment of wounds in hospitalized patient. This is a prospective study with 39 caregivers of wounded patients in a university hospital in the Brazilian Midwest. We collected the data through direct non-participant observation and interview. We found that 94.9% of the caregivers remained in the ward during the dressing. Of these, 97.3% were close to the patient; 73% observed closely; 54.1% were familiar to the evolution of the wound; 59.5% were involved in the procedure and questioned about the dressing and/or used materials. Most caregivers of persons hospitalized with wounds are interested in and somehow participate of the dressing procedure. The nursing staff can take advantage of such moments to guide the caregivers and prepare them for homecare.

Descriptors: Medical-Surgical Nursing; Caregivers; Wounds and Injuries; Wound Healing; Occlusive Dressings.

INTRODUCTION

Informal caregivers contribute significantly to the continuity of professional care. A recent North American study of informal caregivers attending older adults showed that 44.1% of these are substantially involved in health care activities[(1)]. A Washington survey to characterize informal caregivers and their tasks found that 35% of these individuals reported performing dressings[(2)]. In Brazil, a qualitative study developed in Rio de Janeiro with caregivers of stroke victims identified that being a caregiver is not an expected task in the family's life; however, they recognize its importance in recovering the family member after hospital

discharge[3].

Persons with wound need specific care in relation to it, since wound healing is a dynamic process and involves complex cellular and molecular interactions[4-5]. Due to such complexity, the best practice is multidisciplinary and interdisciplinary patient care, including the informal caregiver as part of the wound care procedure[6].

An integrative review sought to identify informal caregivers participation specifically in wound care and evidenced an important gap in the literature due to the lack of studies where the informal caregiver is the main focus of publications[7].

Recently, it was evidenced that more than 80% of the patients discharged with a traumatic wound had the dressing at home and had high rates of complications such as necrosis and infection[8]. For that matter, the informal caregiver preparation for hospital discharge of wounded patients is an important tool to continue nursing care to reduce damages due to inadequate practices[9], since caregivers have needs and difficulties in providing homecare[10].

Becoming an informal caregiver for wounded patients is a challenging experience, surrounded by concern and uncertainties that culminate in insecure decision-making, which creates a great need for information for this caregiver[11]. Thus, knowing the characteristics of the informal caregivers can help determine which training strategies will be best applied to provide greater support for exercising their caregiver role[12].

Therefore, considering the lack of studies about informal caregiver of wounded patients and the importance of the continuity of home treatment in the healing process, the aim was to characterize the informal caregivers and their behavior during the treatment of inpatient wounds.

METHODS

This is a prospective study, carried out in a large university hospital, in a capital of the Brazilian Midwest. The hospital authorizes the stay of companions for patients under 18 years old, over 60 years, oncological, those with deficits in self-care, pregnant women and physically or mentally disabled. The units have no policy of receiving caregivers, they only deliver the hospital standards in writing to the caregiver at the time of hospitalization.

All the caregivers who, during the data collection period, met the following inclusion criteria participated in the study: being over 18 years old; being a caregiver accompanying the wounded individual hospitalized in the medical or surgical clinic of the hospital, regardless of the cause and predicted discharge, with the wound in the healing process; and being responsible for the dressing at home. We invited the individuals who met the inclusion criteria to participate in the study as well as the patients; they signed the Free and Clarified Consent Term (FCCT).

We collected the data from June to October 2015 with interviews and direct non-participant observation in two meetings; three nursing students of the last year, trained for the collection, collected the

data. Two meetings occurred to confirm that the observed behaviors would not suffer a variation of the events.

Initially, wounded patients were identified through consultations with the daily hospitalization maps and by the professionals who performed the dressing, then with visits in the bed to verify the fulfillment of the study inclusion criteria. After meeting the criteria, interview was conducted with a structured script at the first meeting. After the interview, the caregiver was observed at the time of the dressings, where the observer researcher stood next to the patient's bed and recorded through a two-part check-list: the first aimed to evaluate the caregiver's interest in perform the dressing; and the second sought to evaluate the involvement of the caregiver in the dressing procedure performed by the healthcare professional. The variables are presented in Table 1. This observation occurred a second time, two or three days after the first.

Chart 1: Variables evaluated in the two parts of the data collection instrument. Goiânia, GO, Brazil, 2015.

Purposes	Variables of observation
To evaluate the caregiver's interest in performing the dressing	Stay in the ward during the dressing;
	Proximity of the caregiver during the dressing;
	Attention to the procedure;
	Knowledge reports of the wound evolution.
To evaluate the caregiver involvement in the dressing procedure performed by the healthcare professional	Spontaneous and/or requested help made by the professional during the dressing;
	Questions asked by the caregivers to the healthcare professional about the dressing and/or materials used in the procedure.

The instruments for data collection were submitted to evaluations by two specialists and the pilot study in the field, from which the necessary adjustments were made to achieve the objectives.

The data were tabulated and analyzed using the Software Statistic Package for Social Sciences® for Windows (SPSS version 20.0) and presented in single frequencies or as median with minimum and maximum values.

We performed data collection after project approval by the Research Ethics Committee with Human Beings of the Federal University of Góias (CEP/UFG protocol no. 081/2014) in accordance with the Brazilian standards for human research.

RESULTS

Characterization of the study subjects

The study had 39 caregivers of patients hospitalized with wounds. Table 1 shows the sociodemographic characteristics of the caregivers and their patients.

The median time as a caregiver was 120 days ranging from four days to 24 years. All caregivers presented a degree of kinship with the person with a wound: 2.6% (1/39) were father or mother; 2.6% (1/39) were grandfather or grandmother; 2.6% (1/39) were father-in-law (a); 2.6% (1/39) were uncle (a); 2.6% (1/39) were brother-in-law or sister-in-law; 2.6% (1/39) were cousin (a); 2.6% (1/39) were grandson (a); 10.3%

(4/39) were sibling; 10.3% (4/39) were nephew; 25.6% (10/39) were husband or wife; and 35.9% (14/39) were son or daughter. Of these caregivers, 28.2% (11/39) did not alternate their caring activities.

Table 1: Sociodemographic characterization of caregivers of wounded patients. Goiânia, GO, Brazil, 2015.

Sociodemographic aspects	Caregivers %/ N (39)	Patients %/ N (39)
Sex		
Male	5.1% (2)	56.4% (22)
Female	94.9% (37)	43.6% (17)
Median age	43 years (±18 to 75 years)	62 years (±4 to 97 years)
Civil status		
Single	35.9% (14)	10.3% (4)
Stable union	59% (23)	51.3% (20)
Divorced	----	12.8% (5)
Widower	5.1% (2)	25.6% (10)
Occupation		
Student	7.7% (3)	Not assessed
Retired or Unemployed	23.1% (9)	
Household tasks	23.1% (9)	
Work	46.2% (18)	
Education		
Illiterate	5.1% (2)	Not assessed
Middle school	23.1% (9)	
Incomplete high school	56.4% (22)	
Incomplete higher education	15.4% (6)	

Of the patients, 41% (16/39) had acute wounds and 59% (23/39) had chronic wounds.

Of the 16 acute wounds, 6.3% (1/16) were due to pressure ulcer (PU); 12.5% (2/16) traumatic; 12.5% (2/16) vasculogenic; 18.8% (3/16) infectious; and 50% (8/16) had surgical cause.

Of the 23 chronic wounds, 4.3% (1/23) had surgical cause; 8.7% (2/23) due to PU; 13% (3/23) traumatic; 17.4% (4/23) infectious; 17.4% (4/23) neuropathic; and 39.1% (9/23) vasculogenic. The median duration of the chronic wound was five months (±2 to 168 months).

Caregiver participation in the care of hospitalized patients with wounds

Regarding the caregivers' stay in the ward during the dressing, 2.6% (1/39) remained there until the product application to the wound; 5.1% (2/39) of the caregivers were absent; and 92.3% (36/39) stayed throughout the dressing.

Of these 37 caregivers who remained in the ward during dressing, 2.7% (1/37) were distant from the patient and 97.3% (36/37) were close to the patient until the end of the dressing.

Regarding the careful observation of the procedure performed by the professional, 73% (27/37) of the caregivers observed closely, while 27% (10/37) developed parallel activities during the dressing, showing little attention to the procedure, as presented in Table 2.

During dressing, 54.1% (20/37) of the caregivers observed wound evolution through verbal reports, which were categorized into topics and presented in Table 3.

Table 2: Parallel activities developed by the caregiver while the healthcare professional performed the dressing. Goiânia, GO, Brazil, 2015.

Activities	%/ N (10)
Read documents	10 (1)
Left the ward, answered the cell phone and returned	10 (1)
Sat down away from the procedure	10 (1)
Observed the patients and/or what happened in the ward	20 (2)
Watched television at times	40 (4)
Talked to other professionals and/or patients in the ward	40 (4)
Handled cell phone	60 (6)

Table 3: Caregivers' verbal reports characterizing knowledge of wound evolution. Goiânia, GO, Brazil, 2015.

Reports	%/N (20)
Decreased edema and erythema	10 (2)
Ideal temperature for wound healing	5 (1)
Loss of sensitivity in the wound	5 (1)
Presence of myiasis in the wound	5 (1)
Increased wound extent	10 (2)
Location of the wound(s)	10 (2)
Volume and appearance of the bleeding	15 (3)
Pain in the wound area	25 (5)
Areas of tissue necrosis	25 (5)
Volume and aspect of the exudate in the wound	40 (8)
Changes in the wound bed aspect	55 (11)

Therefore, 59.5% (22/37) of the caregivers were somehow involved in performing the dressing. Of these 22 caregivers who assisted the healthcare professional at some point in the procedure, 27.3% (6/22) helped when asked and 72.7% (16/22) helped spontaneously. Table 4 shows the ways of helping.

Table 4: Caregiver's involvement in the accomplishment of the dressing by the healthcare professional. Goiânia, GO, Brazil, 2015.

How the caregiver got involved during the dressing	% / N (22)
Helped in removing the previous dressing	*4.5 (1)*
Put procedure gloves on to assist the professional	*4.5 (1)*
Showed to the professional cavity in the wound	*4.5 (1)*
Prepared the patient's bed for the dressing	*4.5 (1)*
Looked for materials for the dressing in the nursing station	9.1 (2)
Helped during the wound cleaning	18.2 (4)
Helped to cover the wound	27.3 (6)
Delivered materials to the professional to use in the dressing	*40.9 (9)*
Helped to position the patient	81.8 (18)

Regarding the questioning about the procedure and/or materials used in the dressing, 59.5% (22/37) of the caregivers did it for the healthcare professional. Table 5 shows the most questioned topics.

Table 5: Caregivers' doubts regarding the procedure and/or materials for the dressing. Goiânia, GO, Brazil, 2015.

Questions to the healthcare professional	% / N (22)
Analgesia before starting the dressing	*4.5 (1)*
Swab collection on the wound	*4.5 (1)*
How to do the dressing after debridement	*4.5 (1)*
How to deal with bullous wound	*4.5 (1)*
Doubts about the patient prognosis	*4.5 (1)*
Performing activities by the patient that may affect wound healing	*4.5 (1)*
Time required to perform the dressing	*4.5 (1)*
Maintenance of close or open dressing	9.1 (2)
Positioning and using of materials in the wound to increase patient comfort	9.1 (2)
Exchange of products used in dressing	9.1 (2)
Dressings after hospital discharge	27.2 (6)
Wound care products	*40.9 (9)*

DISCUSSION

Few studies characterize caregivers of wounded patients, since most studies assess the profile of older adults' caregivers, identifying that most caregivers are informal, predominantly women, with a family bond, which emphasized patience and lack of knowledge as the main difficulties in caring[11]. The median age of caregivers was 43 years. This age group was also predominant in other studies with caregivers[9,13-14], which may suggest greater responsibility and commitment toward the older adults. An international consensus recognizes the informal caregiver as part of the wound care team, and understanding their profile as well as their interest and willingness to care of wounds will assist the nurse in the caregiver training[6].

The treatment of wounds is complex and requires knowledge that must be transmitted by the nurse to the caregiver, so it is important to consider the level of education in planning the discharge, which preferably needs to be reviewed in advance in order to check the caregivers understanding. Identifying the informal caregivers profile reveals to nurses the characteristics of those who will be their allies in the treatment continuity[12] and other works can contribute to increase the knowledge on the subject.

All participating caregivers had a degree of kinship with the individual with a wound. This finding corroborates the results presented by a study carried out in the outpatient clinic of a public hospital in Rio Grande do Sul, which aimed to understand the influence of social networks on the therapeutic itinerary of persons with venous ulcer. From the data analysis, these authors elaborated three categories to present the results, one of them was "The family worries together", demonstrating that the family is the main source of assistance to the patient with venous ulcer[15]. Thus, it is evident that the family should be considered in the evaluation of the nurse and involved in their therapeutic plan, since the dressing at home can have an impact on the family life.

One study raised the feelings of the family caregiver and identified as positive aspects the perception of making an important contribution (57%), proximity to the family member (44%) and the acquisition of new life skills (24%), and as negative aspects, distance from work (14%), stress due to talking to healthcare professionals (23%) and concerns about conduct errors (19%). The same study raised the impact on the caregiver's mental health, indicating that 40% of them reported feeling sad, depressed or hopeless[2].

In order to avoid negative impacts on the well-being of the informal caregiver, the nurse needs to assess the care complexity as well as the caregivers' abilities to provide such care[16].

Dressing was one of the most challenging and difficult tasks for informal caregivers, most consider this due to fear of making incorrect decisions[2]. To minimize uncertainty, interventions must be undertaken in order to increase the knowledge and skills of these caregivers; the literature is still incipient in this subject.

The evaluation of the caregiver's behavior during the dressing showed that most of them remained with the patient and were involved in the procedure. The dressing exposes wound, odors and exudates, which may cause disgust to lay people attending the procedure; however, the permanence of caregivers at this moment may indicate an interest in learning and monitoring the wound evolution of the family member. This moment can be used to construct the teaching and learning relationship, since the learning of manual skills can happen through observation[17].

Considering general care, including dressing, 60% of caregivers reported knowing how to take care of the patient from explanations and follow-up in the hospital environment, and 40% reported that they did not know how to care for their family members. In addition, 46% felt no confidence to care of the family member and 6% were in doubt, thinking that they would have median knowledge, and little confidence to act as a caregiver after hospital discharge[9]. These results show and reinforce the importance of promoting patient and family preparation for hospital discharge and the care they will perform at home to provide early rehabilitation, reduction of complications, rehospitalization and iatrogenic deaths. Therefore, the permanence of these caregivers during the dressing can be used day-by-day as a moment of teaching and preparing the caregiver to continue care at home.

Some studies on informal caregiver training in different parts of the world have shown successful experiences. A tertiary-level pediatric hospital has recently shown in the United States that the establishment of an education protocol for tracheostomy wound care for parents of tracheostomized children has reduced operative wound complications from 31.6% to 17.9% reducing readmission due to this complication[18].

A rehabilitation hospital in Palestine evaluated an education program for caregivers of pressure ulcer patients and the study showed a significant increase in knowledge regarding prevention and treatment of pressure ulcers, showing that investment in informal caregiver education may result in improving the care and quality of life of wounded patients[19]. Another study determined the effect of an educational program on the knowledge of 32 caregivers of diabetic patients in Damanhur, Egypt. Educational intervention has increased the knowledge of informal caregivers, and the authors suggested that the use of educational posters and hands-on training can help prevent and control wound complications, such as limb amputation[20].

A video-based education program on ostomy care, a type of surgical wound, was developed and evaluated with 30 caregivers of inpatients in a tertiary care unit in India. The strategy showed a significant increase in the knowledge and skills of caregivers[21].

This study showed the involvement of family members, considering that 100% of the caregivers were

members of the family and that 54.1% were aware of wound evolution through the verbal reports of the modifications perceived throughout the treatment, evidencing the spontaneous engagement of the relative caregiver. In the scope of possible interventions with the family member, the possibility of monitoring the wounds by Smartphone arises, which also requires knowledge and training of the caregivers[22].

The caregivers involved actively in performing the dressing along with the healthcare professional, making it evident that such moments are opportune to train them. A recent study with caregivers of dependent persons and referenced by a research program in this area (Family Care) showed that caregivers pointed out the lack of knowledge, the need to learn instrumental skills, support and insufficient guidance as factors that interfere in the care and their quality of life[10], demonstrating the need to involve caregivers in care plans for wounded patients.

We found that most doubts of the caregivers were about how to perform the dressing after discharge and especially about the coverings and products. These doubts must be clarified by the nurses during the course of the assistance aimed at the prevention of complications after hospital discharge. A study with patients with traumatic wounds showed that after hospital discharge and outpatient return in 5 to 11 days, there were dehiscence of points in 13.80% of the participants, signs of infection in 14.95% and necrosis in 19.5% of the patients' wounds[8]. In this context, it is extremely important that the institution implements a training program for caregivers that will give continuity to the treatment of wounds at home, investments will reduce re-hospitalization costs, and will increase the quality of nursing care and patients' quality of life.

FINAL REMARKS

Informal caregivers of wounded patients are predominantly women, with family bonds, in mature age, with complete high school and alternate care with some professional activity.

For the first time, it was shown that caregivers of wounded patients are interested in the wound care in the hospital environment, carefully observing the procedure and following the evolution of the wound, which becomes a great potential for nursing interventions towards the possible deficit knowledge of caregivers.

Overall, few studies focus on the informal caregiver of wounded patients. This study contributes to the body of existing knowledge, as it characterized the caregivers' behavior of persons with wounds facing the dressing in the hospital environment. From the data of this study, other issues will be important in the elaboration of nursing interventions with the informal caregivers of wounded patients, such as: does the interested and participatory caregiver perform the appropriate care at home? What are the best teaching strategies for informal caregiver training in wound treatment? What knowledge and skills should the informal caregiver develop?

Nurses should involve caregivers in their care plans for wounded patients and take advantage of the dressing timing to guide the caregivers and prepare them for homecare, since in this environment the informal caregiver will be responsible for the procedure. This strategy may result in a more rapid evolution

of the wound and reduction of complications that interfere with the healing process.

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