Objective: to know the main care activities performed at home by family members accompanying bedridden clients.

Methodology: this was a qualitative study carried out with seven family members who care for completely bedridden clients at home. The research was developed in an area connected to a Family Health Basic Unit and it was approved by the Research Ethics Committee of Centro Universitario Serra dos Órgaos, under the Memorandum 68-11. The open interview with a semi-structured script was used, containing three questions, recorded through a MP3 voice recorder device. The period for data collection was about two months, from the end of October to the end of November 2011. After the collection, the transcription of interviews was performed and the analysis was held through the categories which emerged.

Results: among the care activities performed by family members at home, one highlights the body hygiene, nutritional and pharmacological aspects, mobilization, and creation of a playful environment for the client. The factors that hinder such care activities involve heavy workloads, financial resources, and access to health services. Among the facilitating factors one highlights the family inclusion in the dynamics of care.

Conclusion: one considers that the care activities listed are not minor ones and they deserve specialized care by several health professionals, something which minimizes the potential risks for (re)hospitalization of bedridden clients.

Descriptors: home nursing; health services accessibility; family.
INTRODUCTION

Many are the settings where the interaction between healthy people and sick people occur. They include hospitals, outpatient units, community environments, among others, and this study focuses on the home space.

The home space presents

... peculiar ways of conceiving life, health, and disease; expressing thoughts and feeling, values and beliefs; relating; attributing meaning to the events of daily life.\(^1\)\(^2\)\(^4\)

In this sense, home presents individual characteristics related to the people who live there, which range from habits, customs and life routines to economic, social, religious, cultural factors, and the way of thinking through the health-disease process.

Contextualizing the disease process in this space, one understands that the habits and routines of people involved in the care to a sick client change. This refer to the need for construing a theoretical field and developing new ways of health care in the home domain.\(^2\)

To understand home as a favorable place to care actions is an ambitious mission whose first thought is triggered in the hospital environment itself, in the moment of discharge, where the client and her/his family members face changes that can be somewhat radical interfering in a greater or lesser degree with their daily life activities.

The understanding on how to care for at home space causes restlessness, lack of confidence, and anxiety to family members, especially to the person in charge of the client, here name caregiver, who assumes or should assume the routine of care activities of the person who experiences the disease process.

Starting from this, the family caregiver is considered the person who assumes the responsibility of performing care actions at the home space, even if she/he doesn’t have the knowledge on how to care in a structured way. Be it due to availability, obligation, solidarity, affection, and/or gratitude, the family caregiver becomes responsible for the other.\(^3\)

The distresses experienced by the family caregiver are even stronger when the client becomes completely dependent with regard to the daily routines of self-care and/or presents any kinds of external device, such as catheters, probes, ostomy pouches, wound dressings, among others.

At this moment, the family caregiver expresses her/his way of caring, in which her/his knowledge on health and disease are reflected, permeated by values and beliefs which are structured day by day, many times in an empirical basis.

The home space, approached here as a setting of care, is where the doubts and restlessness experienced by those involved with the dynamics of care need to be conducted by multiprofessional health care teams, be it with regard to the home attention based on the structuring of public health models or even within the context of home hospitalization, which is increasingly adopted in the private sector.

Moving our look to the public health, one realizes that home visits to bedridden clients who have a family member as her/his main caregiver

... should conceive family in its social space, approaching the client within her/his socioeconomic and cultural context in a comprehensive and individualized manner.\(^4\)\(^1\)\(^3\)

The Family Health Strategy (FHS) allows the population unable to come to the health services access to health care, and nowadays home assistance shows a prevalence.\(^5\)

The socioeconomic profile, the clients’ morbidity, and the offer of service by the FHS clarify and claim again the importance of home assistance, where a multiprofessional team, above all a nursing team, develops care and guidance actions which can be effective to the family.

Another perspective of the care to people at home is supported by the programs of home hospitalization, which, through an interprofessional approach, aim to guide and fulfill the needs of clients in a comprehensive way, with the participation of a nurse, speech-language pathologist, physical therapist, physician, psychologist, nutritionist, and social assistant, among others.

The characterization of home hospitalization is considered

... a set of activities provided at home to the clinically stable people who need care actions which can be carried out at home, since they are assisted by a team with this specific purpose. The development of this assistance modality stresses the relevance of the family context and the family caregiver to the care provided to the client.\(^6\)\(^3\)\(^0\)\(^5\)

Having these definitions as a basis, one understands that the family members who care for bedridden people at home sometimes face actual care situations which, directly or
indirectly, demand assistance to minimize health risks, and it can be done through the connection to the health programs that provide home assistance.

Since the experience with the care lines (client’s follow-up carried out by the students and their professors throughout the health care system, passing by the primary, secondary, and tertiary units) developed during the undergraduate nursing course, there was a motivation to extend the discussions on the home setting, which is considered to have a potential to be used by many health care areas peculiar with regard to care, as it integrates the following protagonists: bedridden client and family member.

Home care is a complex process, in order to develop it in an adequate manner the active participation and support of the family members, the neighborhood, the community and society, in a relation combined to other elements and resources that complete the assistance, such as hospital and rehabilitation, forming a care line.7

Starting from this understanding, the study becomes relevant as the home setting is considered a favorable place to play the care scenes since the movement established by the interaction between the bodies which are present in the care actions, represented here by the caregivers, clients, and health care professionals.

This living dynamics, where art and care are embodied in the home setting, present the following study object: the factors which interfere with the care activities provided by family members to bedridden clients in the home environment.

To deal with this study object, the following aims were defined: to know the main care activities performed at home by family members who assist bedridden clients and to describe the factors which turn easier or more difficult the home care provided by family members to bedridden clients.

**METHOD**

The method used in this research was a qualitative one, which is able to answer very particular questions, since it is concerned with a level of reality that can’t be quantified in the individual and collective domains; it deals with the universe of meanings, which corresponds to a deeper space of relationships, processes, and phenomena.8

In this method the researchers try to “make sense or interpret phenomena in terms of significance”, it is not the study on the phenomenon itself that matters to these researchers, but the significance such a phenomenon assumes for those who experience it.9:509

The setting where this research was carried out is an area connected to a Family Health Basic Unit (FHBU), located in the mountainous region of the state of Rio de Janeiro, which receives Nursing, Medicine, and Dentistry undergraduate students.

For the processing of the survey, the authorization by the head of the setting was asked through the signing of a research request letter. After fulfillment of this ethical requirement, the study was submitted to the Research Ethics Committee of Centro Universitario Serra dos Orgaos (UNIFESO), where it obtained a positive opinion, according to the Memorandum 668-11.

After the project’s approval, a sample of 18 families which met the following inclusion criteria was selected: being located at the connected area and being enrolled in the FHBU, as well as having bedridden clients completely dependent for daily living activities.

Once the survey on the number of families was complete, seven participants who met the following criteria were included: being a family caregiver of bedridden at home, regardless of gender, being aged over 18 years, and agreeing to participate in the study.

Every entry in the field was preceded by a survey with the community health agents (CHA) on the family members who care for bedridden clients at home.

In this regard, it is understood that the entry of the qualitative researcher in the field must

[...] be facilitated through the knowledge of residents or those who maintain strong bonds with the subjects under study.8:951

The researcher-participant contact through home visits was preceded by the delivery of two copies of a Free and Informed Consent Term, one remained with the respondent and the other with the main author of the study. The confidentiality of information and maintenance of anonymity of respondents was guaranteed through the use of the word “CAREGIVER”, followed by an ordinal number representing the order in which the interviews were held.

After the consent of participants, an open interview was carried out using a semi-structured questionnaire, having three questions, followed by the recording with the aid of a MP3 voice recorder device.
Data collection instruments or semi-structured interviews consist of a systematic script addressing the proposed theme in a more direct manner, based on previously written questions.8

The first question dealt with the family caregiver-bedridden client relationship, for the production of primary care provided at home, while the second and third questions addressed, respectively, the main factors that facilitate and hinder the performance of these care activities by family members.

The period for data collection was about two months, from the end of October to the end of November 2011. After data collection, the transcription of interviews was carried out, maintaining the utmost fidelity with regard to what was said, and the analysis was carried out with convergence of answers, that were organized and categorized in accordance to the similarity of its content to that predicted by Laurence Bardin.10

### RESULTS AND DISCUSSION

Regarding the care activities performed at home by family caregivers to bedridden clients, five major categories emerged from the interview’s data, arranged as follows.

- **Category I: The bedridden client and the essential care activities performed by the family caregiver**

  Home space is a place where scenes of care can happen, for this to effectively happen there is a need for the meeting between the bedridden client and the family member in charge of the caring dynamics.

  Thus, the development of home care activities becomes relevant, since there is a need to provide the family context with a new meaning, where the caregiver provides care to the sick person, here contextualized in a total dependence level.6

  These totally dependent clients require care actions defined as essential for the maintenance of organic activities, which range from maintaining body hygiene to nutritional needs. This is evidenced by the respondents’ answers listed below:

  - [...] bathe [...] and I have also cut her hair [...] (Caregiver 5).
  - [...] I bathe [...] and [...] change diapers [...] (Caregiver 6).
  - [...] I bathe [...] I cut his hair, cut his fingernails [...] and [...] I change diapers [...] (Caregiver 7).

  Through these responses, one sees the need to introduce the concept of care, since understanding the interaction between a body and another body, that is, the body who cares for (caregiver) and the body which is cared for (bedridden client), sometimes, permeates the act of zeal and affection.

  - [...] care means attention, caution, cautiousness, dedication, affection, commitment, and responsibility, to serve, offer to the other, in the shape of a service, the result of her/his talents, training, and choices.11,17

  This acquires a greater significance when one glimpses care actions, such as the experience of bathing, feeding, and cleaning the client’s body, which can be taught by nurses to fully lay persons who assume themselves to be caregivers.

  In these care experiences, the caregiver aims to assist the client with regard to all her/his needs, trying to meet, besides physical well-being, the nutritional and pharmacological demands, and understanding that they are important to the bedridden person’s life.

  Nutrition is important for maintaining the physiological parameters, usually the disorders caused by nutritional deficiency, overeating, or poorly balanced meals are major causes of illness and death.12

  Contextualizing this information within this study, one realizes a significant concern of family caregivers with helping or providing direct care actions that address the nutritional needs. This can be seen in the following testimonies:

  - [...] I give food [...] (Caregiver 1).
  - [...] I give her breakfast for, [...] adequate lunch, afternoon snack, dinner [...] and [...] I give her medicine [...] each 8 hours [...] (Caregiver 2).
  - [...] water, food, [...] I give it all in hand [...] (Caregiver 3).
  - [...] I offer all the food he needs [...] and [...] all the medicines [...] (Caregiver 4).
  - [...] feed her [...] and sometimes I give the medicine [...] (Caregiver 5).
  - I give her lunch [...] (Caregiver 6).
  - [...] I give food [...] (Caregiver 7).

  The other aspect involved in this category, with the convergence of responses, is related to the practice of administering medication in...
their own home space by the person in charge of the care activities.

This person accommodates activities, such as rearranging schedules, preparing a different kind of food, administering medicines, and adopting a new routine of exercise and comfort activities, which includes mobilization and transport of the bedridden client.3

This leads us to move to the next category, that specifically concerns the body’s biomechanics and the tegumental maintenance of the bedridden client.

♦ Category II: Mobilization and tegumental maintenance of the bedridden client

Assuming the role of caregiver, the person, who is usually lay, develops actions at home, intuitively or based on beliefs and culture, in which she/he seeks to promote health and maintain the bedridden client’s functional ability that still remains, something which shows an attention with regard to the prevention of harms, in order to avoid hospitalizations and confinement in asylum.

One of the care actions indicated in the literature concerns the clients with mobilization problems, the caregiver often observed it when providing assistance in cases of chronic degenerative diseases.13

In this study it was not different, the mobilization was reported by the respondents who scored questions related to passive exercises, maintenance of the bedridden client’s body positioning, moving from bed to chair, among others. This may be evidenced through the following speeches:

Then I support it on a pillow to balance out a bit. […] if [she/he] wants to have sun, I lay on the chair […] and […] see whether there’s some hurt […] (Caregiver 1). […] If it is sunny, I put her outside […] (Caregiver 2).

[…] to turn him […] changing his position, to prevent any hurt […] and […] I have to apply a hydrating […] (Caregiver 4).

[…] I exercised her myself, because she just stayed in bed […] (Caregiver 5).

[…] when [she/he] changes position in bed, I restore the position […] (Caregiver 6).

The other care action clarified in secondary responses to the bedridden client’s transport and mobilization by the caregiver concerns the maintenance of physical status, represented by skin integrity.

It is already known that moist and irritated skin turns vulnerable to rupture under pressure. In this sense, the frequent changes in position are necessary to relieve and redistribute pressure on the client’s skin and avoid injuries to the tissue.12

This is an invitation to think through such a responsibility of the health professional, especially the nurse, with regard to providing the caregiver with guidelines involving skin care and the redefinition of changes in the lying position and the constant bedridden client’s mobilization at home.

The last category, regarding the care actions performed by family caregivers at home space, involved different strategies that favor the client’s integration to the world in a safe way.

♦ Category III: Alternative care actions provided by the family caregiver to the bedridden client

The bedridden client at home experience a “prison without bars”, where many times she/he has no contact with external reality and looks forward so that time pass by fast, in order to see the care routines happening and an interpersonal relationship being established.14

Starting from this problem, caregivers mentioned other strategies of care that include this client to the shapes and colors of the world, with their expressions and meanings.

[…] I put her in front of the television to watch a little bit […] (Caregiver 2).

[…] phone, everything has to be taken in hand […] (Caregiver 3).

Making her happy is like this, when she's walking and playing […] (Caregiver 5).

Through these speeches, one understands the need for a playful environment that demonstrates the care’s sensitivity and creativity,

[…] expressed through actions such as turning on the radio, watching television, offering books and magazines. The playful element is manifested not only by the activity itself, but by the way, the attitude of the person who performs the action.6,306

Thus, it is understood that caregivers, who know and live with the bedridden clients in a daily basis, provide a unique care. Through their experience in home care, one realizes in the respondents’ reports extended care practices. Where talking, active listening, provision of a playful environment, and offering of leisure options are strategies adopted to relieve suffering and afford the patient a feeling of comfort and well-being.

Regarding factors that hinder the care practices by the family caregiver at home, the analytical categories presented below were created.

Caring for bedridden clients home in space...
Category IV: Tasks overload and change in the caregiver’s life habits

Often the responsibility for the bedridden client’s care lies on a single family member, although the decision to care for was not a choice of her/him.

Once assuming her/himself as the family caregiver, the person starts to develop many new activities, which are added to those already present in her/his daily life. This tasks overload allows the emergence of physical fatigue, emotional stress, and, in extreme cases, psychiatric disorders. There’s no doubt that these factors can deprive the family caregiver from leisure activities and work outside home, causing a disruption in her/his social life.

This becomes evident through the speeches of respondents that follow:

[...] I have no one to take turns with me [...] I did not go to church [...] and [...] I get stressed [...] (Caregiver 1).

[...] I stay alone, with nobody there [...] because I also need to live! And there are some days when you get stressed [...] (Caregiver 3).

[...] I'm having difficulties because I'm alone [...] I can't do anything else [...] (Caregiver 4).

[...] It is extremely difficult for me to go out with my husband [...] and I'm feeling very tired [...] (Caregiver 7).

Starting from this, the life changes or changes in duties or role of each individual in the family are potential generators of insecurity and disagreement. In this sense, one highlights the importance of other persons’ participation for the provision of care. This support would offer the caregiver the opportunity of self-care, and it would take away the possibility of maltreatment to the bedridden client related to physical and emotional distress due to the task of caring for. 11

Moreover, family caregivers also expose another difficulty which is closely related to the maintenance of daily care associated to the provision of materials that provide the bedridden client with well-being and access to the health care services.

These reports lead us to discuss the next category, which considers the economic factors as a difficulty for performing care practices offered to the bedridden client at home, along with the barriers to access the health care services, especially at the home space.

Category V: Economic factors and the access to the health care services

Similarly, the family caregiver and the bedridden client present various needs that are directly influenced by economic factors in a greater or lesser degree.

Regarding the special care required by these clients, most often the material resources are provided by the family itself. 15

Considering this, it is usually found that the family caregiver is penalized by the familial state,

[...] when it gives her/him the responsibility of caring for, without any concern of knowing the family resources to face it. 7,16

A financial constraint is expected, which sometimes leads the person in charge of home care to depend on others with regard to the material resources.

This dependence is related to members of the family itself, people of the community, nongovernmental organizations, and even the government itself, especially with health inputs provided by home care programs.

This money difficulty to provide basic care to the bedridden client at home can be evidenced through the responses that follow, when respondents refer to the lack of income:

[...] because I have no income (as a job) [...] (Caregiver 3).

[...] neither the gauze, which is something cheaper, I could afford [...] (Caregiver 4).

[...] the diaper, there're so many things to purchase [...] (Caregiver 7).

We must remember that the health services are currently experiencing the effects of the global financial crisis, the public services very often lack material and human resources to meet the Brazilian population’s needs.

At the current time of state’s financial crisis, it becomes important to adequately use the economic resources available. To spend less and better should be one of the goals to be pursued by the health care sector. The reasons most commonly evoked to explain the increase in health spending are the aging populations, the increased availability of physicians and health services and technological progress. These factors are, undoubtedly, very important, but they are not enough to explain the increased spending in health. 16-128

Starting from this, the burden of health care services become very clear, and, especially, this lack of health care professionals is directly reflected in the actions directed towards home care.

With this, family members are increasingly assuming leading roles of care, even if, sometimes, their concepts and practices are
empirical. In this sense, the activities assigned to the family caregiver emphasize her/his function as a link between the patient/family and the health team.4

It should be remembered that the act of caring for does not characterize the caregiver as a health care professional, so she/he should not carry out technical processes designed to professional individuals.10

This claim leads us to consider ideas that deserve further insights when we describe the factors related to health care services that hinder home care. One of these factors concerns the care practices carried out by health care professionals which, in some cases, constitute a paradox with regard to the foundations proposed by the Brazilian Unique Health System (SUS).

It is understood that the public service is currently saturated with activities due to the increasing demand from the population, but it is recognized that bedridden people at home who are cared for by lay family members deserve more attention and zeal with regard to the instrumentalization of how caring for, why caring for, and even when caring for, something which establishes the boundary between empirical knowledge and scientific knowledge derived from professional training in health care.

Starting from this thought, one can see in the discourses of family caregivers the size of the challenge, that requires attention from the government spheres and from those professionals who are on the edge of the service; it is evidenced through two speeches:

[…] I told her (the physician) that I needed a visit. When she comes it takes two, three minutes and she goes away […] (Caregiver 1). […]

[…] he is a patient who depends on physical therapy and we haven’t got it so far […] without help, without an explanation, without someone (health professional) to guide, we have more difficulties […] (Caregiver 4).

It is understood that one of the most important ways to help people is providing them with information. People who have adequate tools are better prepared to handle the situation in which they are involved.11

This applies perfectly to the home caregivers, who have many doubts when facing the care dynamics with the new situation which presents itself at home (the bedridden client’s body), as well as the ways to overcome the challenges inherent to the health care system and to the lack of material resources.

Thus, one highlights the responsibility of health care professionals in the use of technical and scientific knowledge to accomplish their duty, that is, the (re)signification of the activities developed by the family caregiver, as well as their continuous training to carry out the care activities that, in most cases, are performed in a lonely basis, without any aid from the health care services.

Regarding the factors which facilitate the care provided by the family members to bedridden clients at home, the sixth and last category of this study was created.

Category VI: Integration of the family to the provision of care actions to the bedridden client

The inclusion of family members can be seen as a strategic and effective way to assist in the development of the care activity at home.6

Health and vulnerability are then the two elements that turn the structure of the family dynamic as a system of care, which requires the participation of each member, not only to build it, but also to consolidate it and maintain its force.2,106

This claim is proved through the following speeches of respondents:

[…] everybody has a special affection for her, they help me […] (Caregiver 2). […] when my brother comes home, we go out to walk with her […] (Caregiver 5). […] the help from family, which is always there […] (Caregiver 6).

Based on this, when there is a closer emotional bond and affection in the family, the support is felt and, therefore, its members can help each other. Thus, the more communication and cohesion the members of a family have, the more likely they are to ease the task of the person who plays the role of caregiver.17-170

Thus, the integration of family members to home care provided to the bedridden patient can be developed through their own experiences, possibilities, and needs, which are arranged having personal and affective involvement as a basis.

Becoming daily and collective, the construction of home care promotes solidarity and ethics among the family group, the family caregiver and bedridden client, and it turns the act of caring for a unique experience.

CONCLUSION

The home care provided by family members to bedridden clients demonstrates practices encompassing body hygiene, attention to
nutritional status, administration of medicines, mobilization directed towards the tegumental maintenance of the bedridden person, besides the creation of a playful environment with leisure options.

However, one considers that these care activities aren’t minor ones, and they deserve attention with regard to guidelines and/or even the performance of specialized care actions by many health care professionals, minimizing, this way, potential risks for (re)hospitalization of bedridden people.

It’s necessary to remember, also, that the care carried out at the home space is a special one, as, besides involving feelings with the peculiar characteristics of the family and home space, they involve institutions and social policies.

Among the factors which turn care in the home space more difficult, pointed out by family members, the study revealed that, in addition to the ineffective health care policies regarding the fulfillment of bedridden clients’ needs at home, we have the economic factors that turn impossible, in a greater or lesser degree, the supply of material health care resources, as well as the tasks overload, leading to changes in the life habits of the caregiver.

The only factor that turned easier the work of the main caregiver with regard to the care actions provided to the bedridden client at the home space was the integration of the various family members in the new life dynamics established after the beginning of the disease process in one of their own.

One understands that new studies should be carried out to extend the discussion on the home space, home care, and their protagonists, above all intervention experiences by health care professionals, especially nurses, which are successful with regard to the quality of life of the bedridden clients and the people in charge of providing them with care.

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