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## HOME CARE AND HOSPITAL ASSISTANCE: SIMILARITIES AND DIFFERENCES FROM THE PERSPECTIVE OF THE FAMILY CAREGIVER<sup>1</sup>

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**ABSTRACT:** The aim of this study was to describe how the family caregiver builds social representations of home care in terminal cases, in relation to hospitalization. This qualitative study was performed with 11 family caregivers of terminally ill patients, enrolled in home care service of a university hospital in southern Brazil. Data collection was performed by means of narrative interviews, which were analyzed using content analysis from the perspective of social representations. Since home care is recent, caregivers relate it to hospitalization and thus are able to represent it well. It means easier access to technological resources, and also to the reference team of this service. In addition, home care represents more freedom and autonomy to the patient; however, for the caregiver, more deprivation and accountability. Hospitalization represents deprivation for the patient, and more freedom for the caregiver.

**DESCRIPTORS:** Home care services, hospital-base. Home nursing. Nursing. Hospitalization.

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## INTERNAÇÃO DOMICILIAR E INTERNAÇÃO HOSPITALAR: SEMELHANÇAS E DIFERENÇAS NO OLHAR DO CUIDADOR FAMILIAR

**RESUMO:** O objetivo deste estudo foi descrever como o cuidador familiar constrói as representações sociais da internação domiciliar na terminalidade, em relação à internação hospitalar. Tratou-se de um estudo qualitativo com 11 cuidadores familiares de doentes terminais, cadastrados no serviço de internação domiciliar de um hospital universitário do sul do Brasil. Para coleta de dados foram utilizadas entrevistas narrativas, analisadas por meio de análise de conteúdo com olhar nas representações sociais. Como a internação domiciliar é recente, os cuidadores a relacionam com a internação hospitalar, para poder assim representá-la. Ela significa acesso mais facilitado a recursos tecnológicos, e também à equipe de referência deste serviço. Além disso, a internação domiciliar representa mais liberdade e autonomia ao paciente, entretanto, para o cuidador, mais privação e responsabilização. A internação hospitalar representa privação para o paciente, e mais liberdade para o cuidador.

**DESCRIPTORIOS:** Serviços hospitalares de assistência domiciliar. Assistência domiciliar. Enfermagem. Hospitalização.

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## INTERNAMIENTO DOMICILIAR E INTERNAMIENTO HOSPITALAR: SIMILITUDES Y DIFERENCIAS DESDE LA VISIÓN DEL CUIDADOR FAMILIAR

**RESUMEN:** El objetivo de este estudio fue describir como el cuidador familiar construye las representaciones sociales del internamiento domiciliar en la fase terminal en comparación a la internación hospitalaria. Se trata de un estudio cualitativo con 11 cuidadores de enfermos terminales, registrados en un servicio de internamiento domiciliar de un hospital universitario del sur del Brasil. Para coleccionar los datos, fueron utilizadas entrevistas narrativas, analizadas por medio del Análisis de Contenido con énfasis en las Representaciones Sociales. Como el internamiento domiciliar es reciente, los cuidadores lo relacionan al internamiento hospitalario, para así, poder representarlo. Ello significa un acceso más facilitado para recursos tecnológicos, como también al equipo de referencia de este servicio. Más allá de eso, el internamiento domiciliar representa más libertad y autonomía al paciente, aunque, para el cuidador, significa más privación y responsabilidad. La internación hospitalaria representa privación para el paciente, y más libertad para el cuidador.

**DESCRIPTORES:** Servicios de atención a domicilio provisto por hospital. Atención domiciliar de salud. Enfermería. Hospitalización.

## INTRODUCTION

Home care emerges as a mode of care to meet the current needs of permanent care, both to terminal patients, and the chronically ill, thus avoiding hospitalizations that expose these individuals to the risk of infections, as well as the distance of their family environment. At the beginning of this century, the World Health Organization (WHO) pronounced itself about home care, justifying before the need of long-term care in chronic diseases, which have increased with respect to demographic and epidemiological transition in recent years.<sup>1</sup>

Home care can promote the stimulation and maintenance of patient autonomy, because home tasks can be performed within the patient's own time, with the encouragement, support and possibility of further development of the bond between the caregiver and the patient.<sup>2-4</sup> On the other hand, it also presents itself as a way to reduce expenses in the hospital scenario.<sup>5-6</sup>

Recent studies on home care emphasize the benefits provided to the patient, such as autonomy and freedom,<sup>2</sup> and how these services are organized to meet the demands,<sup>3</sup> to, somehow, lead to the consolidation of this type of care. Other studies bring the meanings it has for the family caregiver, such as deprivation, overburden<sup>7</sup> and changes in family dynamics.<sup>2,8</sup> It should be noted that these studies did not perform comparisons between hospital and home care, which may explain in a way that findings on the theme are more of benefits than the negative aspects for those involved, such as the caregiver and the patient, in the mode of care.

Thus, a study that identifies the Social Representations (SRs) on home care in terminal life, comparing it to hospital care is called for, given that these representations have been constructed as the players, the family caregivers, build their meanings the interpretations about the object of home care, comparing it with previous paradigms, such as hospitalization. It is further justified the specificity of home care in terminal life, for all the context that caring for a terminal patient involves, from the moment of the information that he or she is out of therapeutic possibilities for cure, as well as transfer of care that was once performed by the health team to the care that will be performed by a family member. Adding to this new family dynamic, which changes roles, it is noteworthy that Western society is still in the context of a culture of denial of death and valorization of technological advancements. The human being also lacks prepa-

ration to accept finitude, as well as to provide care in the process of death and dying at home.

The aim of this study is to describe how the family caregiver builds social representations of home care in terminal cases, in relation to hospitalization.

## METHODOLOGICAL THEORETICAL FRAMEWORK: SOCIAL REPRESENTATIONS

The SRs are built from realistic interpretations. They seek to recognize how groups build a stable and predictable world, from the differences, since there is, as a starting point, a diversity of individuals.<sup>9</sup> In this sense, the representations of an object are socially prepared and shared, contributing to the construction of a common reality, which enables communication.<sup>10</sup> They can also be defined as common sense theories. However, they are no more or less valid than the scientists' theories, because they are plausible and satisfy the intellect the same way as the latter, although they are formed with other methods and respond to different concerns.<sup>11</sup>

In order for the SR to be generated, i.e. from something unfamiliar to familiar, two processes are required: anchoring and objectification. Anchoring is a process that transforms something strange and disturbing, intriguing, into a particular system of categories, and compares it with a paradigm of a category considered appropriate. Anchoring is to classify and name something. In objectification, one links the idea of unfamiliarity to reality, becoming the true essence of reality. In other words, it would take something from memory and compare it with the object to be interpreted.<sup>9</sup>

## METHODS

This is a qualitative study developed with family caregivers, older than 18 years of age, of terminal cancer patients linked to the Home Care Service (*Serviço de Internação Domiciliar - SID*) of a university hospital in Southern Brazil. The data collection period was from January to June 2010. Eleven family caregivers were interviewed, four of which were men and seven women. Of these women, five were two daughters and two were wives. With regard to men, two were husbands, one was a brother and the other was a father.

We used sample saturation, with the understanding that saturation is achieved when the

introduction of new information on the analysis products no longer brings about changes in the results previously achieved.<sup>12</sup>

Data collection was performed using narrative interviews, which allowed the exposure of SRs through the reported personal experience. The narrative interview allowed rebuilding social events from the perspective of the informants. Thus, the informant was encouraged and urged to tell the story about some event.<sup>13</sup> All informants were encouraged to report their experiences related to the fact of caring for a terminally ill patient at home.

For the performance of the narrative interview guiding principles were established in order to give a direction in the conversation, such as: hospitalization and home care, similarities, differences, and organization.

The visit to the terminal patient's home, to do the interview with the family caregiver for data collection was scheduled in advance by telephone. The interviews were conducted individually with the family caregiver, at the patient's home. Only in two situations, in which two members of the family named themselves caregivers, the interview took place in pairs. The interviews were recorded and transcribed into a document and, from this document, we proceeded to analyze the data.

For the data analysis phase, we used the content analysis, which is defined by the explanation of the meaning contained in a document or the way in which it can be transformed in order to provide a meaning. We carried out an initial preparation of the material, in which the transcribed interviews constituted the *corpus* of the study. Next, pre-analysis was started, by means of brief readings, which sought to overcome the obvious trying to reveal the implicit, contradictory, that which was silenced, hidden between the words. This first reading allowed seeing what was not said. After several of these readings and re-readings, data impregnation was achieved. From here onwards, categorization began, through separation of the subjects, by relevance or repetition, and eventual regroupings, thus transforming the raw data into polished or organized data. Moreover, we also took into account the contradictions, which allowed originating the categories, as well as possible subcategories.<sup>12</sup>

In accordance with ethical principles and abiding by Resolution 196/96,<sup>14</sup> which guide human research, the Term of Consent was read and delivered to each participant. The identity of the study participants was preserved by assigning

codes to identify the statements, thus keeping their anonymity. The letters that make up these codes are FC family caregiver, followed by numbers and also with the addition of F (female) or M (male), to identify the lines. For example: FC1-M, FC2-F, FC3-F, FC4-M and, so on.

The project performance was later submitted to the approval of the Ethics Committee of UFSM with the Certificate of Presentation for Ethical Appreciation (CAAE) number 23081.014219/2009-85.

## RESULTS AND DISCUSSION

From the content analysis, two categories were constructed: hospitalization: potentialities, strengths and weaknesses; and home care and hospitalization: similarities and differences.

### Hospitalization: potentialities, strengths and weaknesses

Home care, in some cases, seems to be regarded as a form of facilitated access to certain resources, usually difficult to obtain free of charge. One such resource is oxygen necessary to maintain the lives of some terminally ill patients. This could be seen in the statement by the caregivers: *he was hospitalized four days in bed, only with O<sub>2</sub>. However, after O<sub>2</sub> was removed, he went home and could not do without it. Then I rented O<sub>2</sub> for some two or three days. I went to the hospital to get the prescription for it and met a nurse. She asked me about him, and I said, 'Oh he's at home with oxygen.' But are you renting it? [asked the nurse] and I say: 'I am'. Then she said: 'But talk to his doctor and talk to home care ' I talked to the doctor and talked to one of the nurses [SID]. Look, this was [one day], [the other] the concentrate was already here in the house. So, I got lucky, 'cause people say it is very difficult, [...] because they generally have to file a lawsuit. The rent is four hundred and fifty [reais] [...] I was lucky to get it from the hospital. This home care was, look, bah! Just in getting that concentrate there, which is expensive to rent, I could easily (FC4-F).*

The SR that home care is a way to get access to equipment in an easier way may be related to the fact that often the availability of certain technologies is restricted to the hospital. Since home care is something relatively new, that is, unfamiliar, family caregivers tend to associate it with familiar things such as access to oxygen, which can easily be obtained in the hospital.

This construction process of the SRs is related to the anchoring of strange ideas, reducing them

to common categories and images, i.e., family, comparing an object to home care, to a paradigm of a category that is thought to be appropriate, in the case, the resources offered within the hospital setting.<sup>9</sup> In fact, home care is one of the most specific modalities of health care, involving the continuous presence of professionals at home and use of equipment and materials. It is a way to make the service operational, just like it uses home visit as a strategy to achieve this activity.<sup>5</sup> Accordingly, professionals, in addition to providing caregivers the widest possible range of information and advice about care and about the possibilities of evolution on the patient's clinical condition, they have the attribute to provide the basic equipment to maintain assistance at home.<sup>15</sup>

Another convenience that home care enables is the accessibility to medications and diapers, thus relieving the family from buying them: *he has all the medication, has oxygen, [...] they brought a package of diapers. This week we bought some Sustagem; yesterday when they [professionals from SID] came, they brought some more. This all helps and if you leave the home care system [...] it makes it more difficult (FC9-F).*

We can see that the conveniences of home care seem to provide some safety to caregivers, as they have access to the materials present within hospital environment. Without home care it might become more difficult to obtain these resources, implying the need for acquiring them. In face of this, home care also includes medications, diapers, supplies in this provision of materials and technological resources.<sup>16</sup>

Home care also facilitates emergency services, because there is the possibility of the team to dislocate to the patient's home, or the patient having access to hospital services more quickly, avoiding certain bureaucracies, since the patient already has SID team as reference, as per the lines: *he is already presenting a swelling on the side there, so instead of dislocating to PA [emergency ward], the staff comes here and already sees what it is about (FC6-M); they said there were any problem with her, she would go through the emergency ward; she would go straight in because she is already part of home care [...] then she would not go through those stretcher nuisances. She would have a right place to go; this is very important. Because going through all that emergency process that is so bad that only someone who has experienced it knows how bad it is (FC7-M).*

The possibility of receiving the team at home in an emergency situation, or having a reference team in the hospital setting, seems to reassure fam-

ily caregivers, since it facilitates access and quick service in this situation. In this regard, the elimination of the transportation of the patient, often with the own family vehicle as well as reducing the long wait in an emergency service, due to ease of access to the health care team, because it is reference to the patient, produce, in a certain way, this SR of easiness in emergency and urgency service.

This building happens as much by the anchoring, association of familiar and unfamiliar situations, and by objectivation,<sup>9</sup> in which the individual relates to new situations, such as home care, with something from their memory, already lived or experienced. The experience of transporting the patient and the long waits for service in emergency wards are part of the life of people with chronic diseases and in situation of terminal diseases, as well as their families. Another study<sup>16</sup> revealed that one of the facilities of home care is to reduce patient referrals to hospital and coping with the delay of emergency services of hospitals.

On the other hand, perhaps because of the fact that SID belongs to the hospital, the reference to the resources and other services offered in this environment, as a possible hospitalization, is easier for the patient. This can provide the family caregiver a way to get specialized service, preventing the entry through the emergency ward, which would result in a reassessment of the patient. Presumably, furthermore, that this image of home care is built by the fact that this modality of care is recent and therefore leads family caregivers to perceive it as a continuation of the hospital. Therefore, it is believed that the family caregiver, clinging to facilities that provide home care, would feel less threatened against the possible feelings of caring for a loved one in a position of end of life at home, without the support of hospital resources.

The organization of home care, as the guidelines to caregivers, the records of the events and the monitoring of vital signs, seem to facilitate their preparation to perform the actions for the patient: *I went there in the administration of home care, and they explained everything well; gave me a folder. Each visit they do, they record what her blood pressure is. This is very important because if there is someone here, someone to check her blood pressure, I go to the folder and say: Her pressure is right here [...]. This control is important, it would not do any good for them to come here and go away not leaving anything (FC7-M).*

The organization of home care seems to provide family caregivers better instrumentation for the observation of the patient, compared to

this new experience of home care. Just like the records of the signs and symptoms manifested by patients allow nurses and health professionals to keep closer monitoring of what actually happened to the patient, since this, in a situation of home care, is somewhat far from the “eyes” of the health professionals.

This organization is approaching with the palliative care unit of another study in which the family caregiver receives guidance on how to record the care performed to provide subsidies to the health team at the time of the visit.<sup>17</sup> The notebook or chart that is kept at the patient’s home is also used in a home care service in Minas Gerais, with the purpose of following the patient’s treatment progress.

This mode of organization is also related with the hospital environment favoring further that the SRs of home care are constructed from the care provided in a hospitalization. Thus, this anchoring that transforms something strange into familiar occurs when a particular object or idea, in this case, home care, is compared to the paradigm of a category, which may be the hospital, causing it to acquire characteristics of this category, adjusting so it will be classified in it.<sup>9</sup>

Home care is also seen as confirmation that there is nothing left to do for the patient, since he or she is going home. This could be confirmed by the speech of the caregiver: *when I went there at home care, I spoke with the girl, but [she] never said: ‘go because there is nothing else to be done here [hospital].’ I tried not to put this [into my head], because her own mother asked me, but I have a booklet there, [and said]: no, this here is because of the hospital system, which sometimes has no bed [...]. Because it is not that’s it, go home, and they are coming here [...]. What remained unanswered is how they ran out of ammunition, through the function of home care (FC7-M).*

In this representation of home care, it is implied that the hospital environment is an atmosphere of healing, due to the healing treatments offered, and the home environment, a space that can provide control of signs/symptoms and follow-up, meaning therefore that the patient is outside healing possibilities and, therefore, in terminal situation.

This perspective of home care tends to produce a fragile relationship, because it shows that the home environment should not be a place, in the eyes of the family caregiver, favorable for the patient, since it lacks the hard technology and resources that the hospital environment ensures,

being inevitably explicit that the patient actually is beyond treatment. In addition, home care would imply a merely substitute, for the home environment would occupy the space of the hospital environment, and the caregiver, possibly the place of nursing. Implicitly, it would be understood that the family caregiver does not see the team as a facilitator for the process of terminality. It is understood that this perspective does not depend only on the home care team, but also on the staff who assisted the patient during the healing treatment.

### Home care and hospitalization: similarities and differences

Many family caregivers, first of all pointed out the advantages of home care, including among them the representation that care at home means more freedom for the patient, and that the patient feels more comfortable, as per the lines: *he cannot stand the hospital any more. He wants to come home, he wants to be in his room, watching TV (FC6-M); ‘I’m a hundred times better here in my home than in the hospital’ [...]. And the visitors come here, the acquaintances, he sits in the chair he wants, he has his place to eat. There he had to take a bath every day, here we do as he was already accustomed for the last five years. He decided he would take a shower one day in another day out because he is not naughty to get dirty’ (FC9-F).*

In view of the speech of the caregivers, it is noticed that home care seems to provide some comfort, freedom, because it is the patient’s own space, and also with the rules and regulations unique to each family member. This perspective differs from the hospital, which has its own organization and rules, which direct the actions of everyone involved in this space, whether they are health professionals, patients, family caregivers or visitors. This implies that, within the home space, family and patients seem to have more autonomy to decide on their schedules and type of food, time for hygiene, the possibility of leaving home. Now, in the hospital, this autonomy is diminished because the organization of the institution imposes times for eating, hygiene and visits.

Thus, the actions of care at home, reference space of the patient, may develop as per needs and peculiarities of the patient and family.<sup>18</sup> In other words, they can be planned according to the demands and habits of each patient. In this line of thought, home care makes the subjects to be perceived as unique in their culture, life histories and subjectivities. Home care is done by taking into ac-

count the preferences and tastes of the patient.<sup>19</sup> In another study, it was observed that most caregivers, though referring hospital care as satisfactory, prefer the home environment, because this offers them comfort, freedom and more family support.<sup>20</sup>

The house, for some caregivers, represents the support from other people, with the possibility of rotation between them, in addition to avoiding displacement for visits and staying in a different environment, such as the hospital, as per the speech of the family caregiver: *and the fact that the father is not hospitalized is much better. Because we have more people here. We are located quite far; any time we wanted to admit him out at there (at the hospital), it would be much harder. The person gets stuck there, and until you get there, you've got to an appointment and everything. And here at home you do not. It's different. We take shifts; there are two people. One comes and the other goes; no one skips a meal because of it. It is much easier. Admitted, it is a lot harder (FC10-F).*

Again, one sees that the rules and regulations of the hospital can isolate the patient from his or her comfortable environment, i.e., their home, as well as their relatives. Just as, in some situations, family members manage to make shifts among themselves to provide care, not implying to abstain completely from their daily functions.

These statements are in line with a study performed with family caregivers, where it was revealed that going to the hospital is difficult, restricting the amount and rotation of visitors. This is because the dislocation in public transportation for long distances is costly, and requires a long time, which does not always allow assiduity on the part of the family caregiver during hospitalization.<sup>15</sup> In addition to this factor, we highlight the importance of social support in the home care.<sup>4</sup>

On the other hand, we realized that many arguments of the SID's health team are repeated by caregivers, leaving somewhat between the lines some uncertainty in relation to care provided at home, and a desire for hospitalization, which represents more security in view of the supply of technology and more resources for the patients. However, family caregivers demonstrates that they realize the benefits that home care provides to the patient: *at home it is one thing at the hospital, it is something else. While at home we do not have all the technology they have to run and do, at home we do not see all that we see in the hospital [...] in the hospital, she was there, but she was anxious to come home. They get tired of staying in the hospital [...] at home, if she is sleepy she goes and lies down. At the hospital,*

*one enters, one leaves. [She] is a little better because of this, that's what they [SID team] themselves said. [...] she felt an improvement. But we do not know if the improvement is because she is at home. And that hospital environment affects people, although they are treated for their well being (FC7-M).*

It is noted that the arguments of the home care team are repeated by the family caregiver in a very positive way, emphasizing that the patient at home, in addition to presenting an improvement in relation to his or her health condition, feels more at ease, which in a certain way, can suspend the thought that the patient is going home because there is nothing left to do in the hospital. On the other hand, even though the hospital environment harms the patient, this space still represents a location to do good, i.e. to heal. On the other hand, home care seems to raise doubts about whether the improvement in the patient actually is due to their being at home.

The hospital is an artificial place where humans are at risk of losing their characteristics.<sup>21</sup> Complementing this idea, it is emphasized that the hospital environment disembodies the individual, since the bodies become deprived of what gives them a given identity and that inserts them in history.<sup>22</sup> In fact, the hospital environment occupies a place of accumulation and development of knowledge, in which one can have access to technology and a quick service, but it is also an environment where many times, one loses the individuality, because customs and habits are not respected and routines are imposed. Thus, the hospitalization process is painful in many respects to those who are hospitalized. The separation from family and friends often results in a feeling of abandonment and sadness.<sup>15</sup>

Another perspective also refers to the caregiver feeling alone in home care, which creates uncertainty in the family member who will assume the role of caregiver. Thus, the family caregiver reports have required the patient to stay a little longer in the hospital until she was feeling better: *I was not able, how could I, if there [in hospital] in three nurses, plus me, helping. Here I was alone, and to turn her in bed had to be done straight [block movement], has to be three people to turn. So that's why I asked [to stay a little longer in the hospital] (FC2-M).*

In this speech, once more, it is noted that, because the hospital setting provides equipment and human resources, it becomes easier to care for the patient. Thus, the hospital may represent more support, while at home the representation

for the caregiver would be that of overburden and lonely responsibility.

Being a hospital a place with equipment, supplies, human resources, of course, it provides a greater technical support than in the home space. On the other hand, it is recognized that the intention of home care is to reduce costs with hospitalization.<sup>6</sup>

Another modification to the caregiver's role in these two areas, i.e., household and hospital, as per the speech of a caregiver, refers to the responsibility for the patient. At home, the family caregiver is responsible for patient care and for situations that can happen. Now, in the hospital, the doctor is accountable: *in the hospital you have a doctor and at home do your care [...] if during the bath he has an arrest, and I'm alone, then, you revive him or you do not know what you do. So you become so anxious, so insecure... it is not even like in the hospital. At the hospital, if at the time the patient is being care for, something happens, the doctor comes, call another doctor, call the nurse, they provide you with support [...]. There in the hospital I think is not so much. It's because there, [the family] go fetch the doctor. And at home they turn to me (FC4-F).*

In view of that, the hospital represents a greater support and assistance, because the responsibility is transferred to the health professionals of this institution in case of death of the patient, thereby reducing the guilt and responsibility of the family caregiver. Now home means more responsibility for the caregiver by the patient and possible feelings of guilt, if the patient eventually dies, as there are fingers pointing at me by other family members. Finally, the independence that home care provides presents some facets. For the patients, more freedom in their actions and possibility of participation in therapy decisions. For the caregivers, greater accountability, bringing anxiety, when they do not feel as prepared for the care of a terminal patient at home.

Some family caregivers emphasized their views about the negative aspects in the hospital setting, such as the short time of the visit, the risks of acquiring other diseases, the discomfort of being with other patients in the same room, the patient isolation, among others: *at the hospital one is moaning, the other is reading. You hardly get a room that has only one person. You get a room with four or five people. Not to mention all the risks that you run by being hospitalized, hospital infection (FC6-M).*

Therefore, it is clear that some family caregivers see the hospital as a place of loneliness and

distress for the patient, besides the risk of exposure to infections. The prolonged hospitalization causes major change in the patients' lifestyle, taking them away from their social network and personal belongings, besides the risk of hospital infection.<sup>23</sup>

In the hospital, there also emerged some discomfort with the issue of routine feeding. However, the family caregiver's questions produced the change, since the patient was not accepting the type of feed: *at home we eat what we want and there [in hospital] we don't. Those mixtures that come ready [...]. She [nutritionist] said: 'but he needs it because he has to gain weight.' Then I [...] said: 'look, I know your work is that, but we know he will not be cured, then it will not matter if he gains one kilo or two. Give him Jell-O, regular yogurt that he wants' [...]. And every once in a while we bring a sardine for him to eat with a little water bun, which I know won't kill him, I know it can't kill (FC9-F).*

It is observed that in the hospital environment it becomes more difficult the exercise of autonomy, both for patient and the family, requiring several discussions with health professionals so that their arguments are valued. Despite the hospital rules and regulations, the relatives always seek a way around them, to provide a little more comfort to the patient, since they are not in their own space.

The difficulty of the patient and family to exercise their autonomy in the hospital environment is also found in another study, which indicates that this aspect is one of greatest challenges, since the hospital routine with its rules and regulations hinders the realization of this bioethical principle.<sup>24</sup> In addition, hospitalization suppresses the personal characteristics of the patient and the family to shape them to hospital environment, stripping them of their characteristics.<sup>19</sup>

## FINAL CONSIDERATIONS

The public programs and policies about home care highlight the benefits that it provides to patients because they are at home, near their family, being cared for by one or more family members, as well as the possibility to organize schedules in relation to food, medication, hygiene, leisure, among others. This narrative was strongly observed in the statements made by family caregivers, especially at the beginning of the interviews. They believe that home care represents, for the patient, more freedom, more comfort, more quality of life and more social interaction. However, along the speeches,

it was realized that, for the caregiver, home care represents more responsibility, more deprivation, more overburden, resulting from, quite often, from lack of social support. It is emphasized that the representation of hospitalization is built exactly on the contrary, because, although it understands the benefit that this space provides bringing healing or recovery, the family caregiver points out that, for the patient, the hospital is presented in an unfavorable way because it disembodies, isolates them from their context and submits them to hospital routines. However, hospitalization for the caregivers, allows more freedom because they can combine visits to the patient in the hospital with their routine activities, not feeling so responsible for the care, as in the case of home care.

Still, home setting is seen as possibility of care, in the eyes of family caregivers, provides easier access to material and human resources, such as the health team, and control of signs/symptoms and monitoring. However, it was associated to the meaning that the patient is out of healing possibilities, and thus in a terminal situation. Now, for hospitalization, the representation is an atmosphere of healing, due to the healing treatments offered.

Understanding how family caregivers build their SRs around home care may promote more effective communication among those involved in the care process, and help nurses and health care teams develop and conduct effective practices to the patient and family in this type of care. Given this, the nursing and health care staff need to be aware and understand the anxiety and distress of home caregivers due to referral of patients to home care. In many situations, health professionals do not explain the reasons for a decision for this type of care, and, thus, raise doubts and concerns among the relatives.

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