PERCEPTIONS AND NEEDS OF RELATIVES OF CARDIAC INTENSIVE CARE UNIT PATIENTS

ABSTRACT

Objective: to know the perceptions and needs of family members of patients admitted to a cardiac intensive care unit. Methods: Descriptive research with qualitative approach developed with 10 family members of patients admitted to the cardiac intensive care unit of a university hospital in Rio Grande do Sul. The study was approved by the Research Ethics Committee on 11 October, 2011, under Opinion nº 23081.013113/2011-89. Data collection took place between November 2011 and April 2012 through semi-structured interviews, which were analyzed according to Bardin’s content analysis. Results: The findings were distributed in two categories and highlighted the mixed feelings aroused by the experience of a unique moment of helplessness and belief. In addition, the study revealed as main needs: the importance of hosting the family, adjusting visiting hours, improving communication with the health team and providing accurate information to the relatives. Conclusion: The multidisciplinary team needs to consider the patient-family binomial in their activities in the context of cardiac intensive care units, seeking to develop strategies that may enable the humanization of care and optimization of the recovery of patients.

Keywords: Nursing Care; Family Nursing; Humanization of Assistance; Cardiology Service, Hospital.
RESUMEN

Objetivo: conocer la percepción y las necesidades de familiares de pacientes internados en una unidad de cuidados intensivos cardiológicos. 

Métodos: investigación descriptiva de enfoque cualitativo realizada con 10 familiares de pacientes internados en la unidad de cuidados intensivos cardiológicos de un hospital universitario de Rio Grande do Sul. Aprobada por el Comité de Ética de la institución el 11 de octubre de 2011 bajo dictamen nº23081.013113/2011-89. La recogida de datos se llevó a cabo entre noviembre de 2011 y abril de 2012, por medio de entrevistas semiestructuradas analizadas según el análisis de contenido de Bardin. Resultados: los hallazgos se agruparon en dos categorías, destacándose los sentimientos ambiguos, la vivencia de un momento singular de desamparo y de creencia. Además, se evidencian, como principales necesidades: considerar la importancia de la acogida de los familiares, adecuar los horarios de visita, mejorar la comunicación con el equipo de salud y proporcionar información precisa a los familiares. 

Conclusión: el equipo multiprofesional debe considerar el binomio paciente-familiar en sus actividades en el contexto de la unidad de cuidados intensivos cardiológicos e implementar estrategias de acogida que permitan humanizar la atención y optimar la recuperación de los pacientes.

Palabras clave: Atención de Enfermería; Enfermería de la Familia; Humanización de la Atención; Servicio de Cardiología en Hospital.

INTRODUCTION

The heart is seen by most people from a mystical perspective, giving it the role of center of life, feelings, passions and moral principles. In this sense, any disease that may affect this organ is seen by society in general as an immediate threat to life, undermining not only the physiological functions of individuals, but also their emotional side. In Brazil, according to the World Health Organization (WHO), cardiovascular diseases are responsible for 16.7 million deaths per year, with projections for the year 2020 that make them to continue as the main cause of mortality and disability.

When a hospitalization due to severe cardiac disease happens, the patient and the family may experience feelings such as fear, insecurity, distress, and so forth. Usually these patients are referred to cardiac intensive care unit (CICU), a differentiated sector with high-tech equipment and specialized care. Besides the scientific specialized training of team skills are needed for streamline the care for critical patients. This unit is, therefore, able to provide care to cardiac patients with cardiac disease.

Because the CICU is fully equipped with all the necessary materials for detection and treatment of heart disease complications, this place brings as a consequence stimuli that can be sources of stress patients, such as loss of privacy, need for continuous monitoring, bed restriction, among others. Furthermore, hospitalization may be associated with the possibility of death, especially in severe cases or when the cardiac surgery is necessary. We believe that these sources of stress negatively affect not only the patient but also the family, who is experiencing such a unique moment.

Hospitalization for reasons of serious and unexpected illness can cause imbalance in the family structure. Families need to participate in patient care, they have expectations and concerns that must be addressed and all health workers should be available to deal with their needs. This becomes even more relevant in cases of hospitalization in intensive care units. The nurse in intensive units is often the professional assigned to meet the needs of relatives of patients in ICUs. Nursing professionals must be prepared to work with the patient-family binomial in order to minimize the effects and inconveniences resulting from hospitalization.

Knowing the important role that the family plays in the health recovery of patients and in their reintegration to their activities, we believe that it is fundamental to involve them in the process of hospitalization of their family member, as this is a moment of uncertainty about their health. Therefore, it is necessary to know the issues related to the meaning of the hospitalization in cardiac intensive care unit and its implications in the everyday life of families so as to promote intervention strategies.

Given the above, we developed the study with the following question: what are the perceptions and needs of family members of patients hospitalized in cardiac intensive care units? And from this, the objective of study was defined as knowing the perceptions and needs of family members of patients hospitalized in cardiac intensive care units.

METHOD

This research is descriptive with a qualitative approach and was developed in a cardiac intensive care unit of a university hospital in the state of Rio Grande do Sul. The individuals included in the study were 10 relatives of patients who were admitted to the CICU, and the sample was chosen at random, following the inclusion criteria: aged 18 or older; be present at the moment of visits in the period of interviews; and be willing to participate in the research.

The invitation to participate in the survey was done individually to each family member that was waiting in the waiting room. Only one person refused to participate. After the invitation, participants signed the Informed Consent (IC), and the interview was scheduled and conducted in a private room, giving priority to the welfare and privacy of individuals.
Data collection took place between the months of November, 2011, and April, 2012, in three visiting hours to the patients in the CICU (10:30h to 11:00h, 16:00h to 16:30h, 20:00h to 20:30h). Semi-structured interviews were recorded and then transcribed. The interviews followed a script containing questions pertaining to the purpose of the study, in which they discussed the family’s living relationship with the patient before admission, what they understand by cardiac intensive care unit, the experiences with the family member hospitalized in the CICU and what that represents for them, how the family experienced the process of hospitalization and what changes took place, the feelings aroused, the identification of professionals working in the cardiac intensive care unit and suggestions for service.

For validation of the data collection instrument and training of researchers, interviews tests were carried out. Nurses and inexperienced undergraduate research students were instructed and accompanied the researchers during these first interviews. Three interview tests were conducted in the first half of November, and the content of these collections was used for data analysis. Data were collected until the saturation. Saturation happened when new element ceased to emerge in the data analysis, with no further contribution to achieve the objective of the study.

Because this is a research involving human beings, all requirements of Resolution 196/96 were respected. Thus, this study was developed after approval under Opinion number 23081.013113/2011-89 by the Ethics and Research Committee. In order to preserve the anonymity of the family members, interviews were identified by the letter “I” representing the word interview, followed by Arabic numerals, not following the sequence in which the samples were taken.7

After the interviews, the information collected was analyzed according to content analysis proposed by Bardin, which consists of three stages: pre-analysis, exploration of material and processing of results. The first stage was the pre-analysis, when material is organized to be analyzed, making it operational, that is, ideas are systematized through a quick reading. Contact with the documents of the data collection was established, the establishment of the corpus with the delimitation of what was analyzed and the formulation of hypotheses and goals, as well as identification of indicators through text clippings in documents to be analyzed.

The second stage was the material exploration, consisting in the definition of categories and identification of the units of record. This resulted in the creation of context units in the documents. Finally, treatment of the results took place. In this stage, data was interpreted, with condensation and highlight of information for analysis, culminating in inferential interpretations, a moment when intuition and reflective and critical analysis are used.8

RESULTS AND DISCUSSION

Ten individuals participated in the study, of which four were male and six female. The age of respondents ranged from 26 to 67 years. The kinship with the hospitalized patient was to the first and second degrees. Among these family members, four were children, four spouses, one was brother and one was brother-in-law. From the 10 interviewees, seven were married and three were singles.

Regarding the level of education, we observed that most of the respondents had completed secondary education (40%), followed by those who had completed primary education (35%) and, to a lesser extent, by university graduates (25%). This indicator shows the need to adapt the guidance provided to the patient’s family. The level of education is important for the degree of understanding of the information received, which may even affect the patient’s recovery. Professions were varied among respondents.6

The length of stay of patients in cardiac intensive care unit ranged from one to eight days, and the main diagnosis was acute myocardial infarction (AMI). According to data provided by the Ministry of Health in Brazil, AMI is responsible for over 25% of all deaths, with 65% increase in the number of admissions from 1998 to 2005 (119,000 to 196,000). Thus, the expenses of the public network with treatment increased 195% between 1998 and 2005 (149 to 449 million) and the number of deaths increased by 10% between 1998 and 2003 (76 to 83 thousand deaths per year).3

The content analysis of the interviews led to the construction of two categories: perceptions, feelings and main needs experienced by family members; and communication between the health team and the family members.

Perceptions, feelings and main needs experienced by family members

The admission to the cardiac intensive care unit (CICU) is considered a difficult moment because a heart disease most often triggers emotional distress linked to fear. Families, in addition to witnessing the changes caused by the disease of their relatives, still face a strange environment, unknown so far, with unknown people and diversified and often incomprehensible procedures. The presence of machines generates expectations with consequent state of anxiety, fear, grief and sorrow, which may remain throughout the whole time of hospitalization.2,10

Negative feelings that permeate the statements of the respondents are exemplified in the following line: I felt bad, anxious. [...] this never happened to me, when I think it’s happening to my mother [...] it is hard to think that. (I4) Despite these feelings, some family members understand the hospitalization in the CICU as something positive because they feel security and
confidence in both the treatment and the health team. Even being an environment with prevalence of sophisticated technological resources, the family members see it as a place where their relative is well cared and receives 24-hour of assistance, as in the following speech: there is always someone there with him [...] I see that he is getting better every day a bit more, and I think it’s because he is here at CICU. (I1)

The findings converge with the data from another study, which found a considerable number of family members who said they felt well about the situation, in the sense that they understand that their hospitalized relative is being cared, and feel safe with the treatment the patient was receiving.11

The painful situation of hospitalization of a family member in intensive care includes facing the possibility of death. In order to have a positive reaction to the moment lived, many relatives verbalize their feelings as a coping mechanism, engaging in the care of their loved one. Those who understand the meaning of the existential process that they are living start to take the illness of their family member, adopting attitudes and strategic ways to address this situation, believing in life and keeping hopeful. Thus, the presence of the family is vital to the patient.2,12

Faith and hope were positive feelings present in the statements of some respondents. We inferred that in such cases, family members have in religion the comfort and “explanation” for the situation they are experiencing, perceiving, with so much patience and persistence to overcome the difficulty of having their family hospitalized in a CICU. We can identify, in the following statement, the use of religion as a coping mechanism: [...] I have a religion [...] everything that happens to us has a reason [...] my feeling is that I will overcome this [...]. (I3). The spirituality is a human characteristic that, among other things, enables individuals to find meaning and purpose to their life.19

Hope is a feeling of support for the family who experiences the disease process. Health team professional must try to stress in in their speech the importance of hope and point to the family and the patient the positives aspects already achieved. Showing the progress and the steps towards the top until complete healing can give emotional support to the family and the patient.2,12

Family members experiencing such a unique moment often find in faith the support they need to face the obstacle experienced. Thus, faith can be a foundation to stand such difficult situation. Hope permeates the mixed feelings they experience, and it is extremely important for maintaining confidence in the treatment, in the team and in the improvement of their loved one.

It became clear in the study that the subjects have similar fears, insecurities and needs, regardless of their level of education or social status. Thus, it is clear that the relationship between family members and subjective aspects does not depend directly on the level of education.

The presence of the family, as a constitutive element of family care, comprises actions, interactions and interpretations through which the family shows solidarity towards their members. There are situations, along the individual and group trajectory in which this presence becomes essential, as for example, at the time of hospitalization.2

The presence of a spouse close the patient is very striking, because the spouse represents security, a provision great emotional support.13 An example of this situation is explained in the following line: [...] I lost my companion [due to hospitalization]. We were always together! But I have to find strength to overcome this! (I1)

The study showed that children are also present in the CICU. Four out of 10 participants were direct descendants. Good relationship between family members, daily living, fear of losing their family member, the feeling of helplessness in face of care, and hope for recovery, these are all factors that lead to more frequent visits of children and other family members. This fact is exemplified by the statement: But now I just think of him, because he [father] is my all. [...] I have to enjoy him to the fullest, if I could I be with him all the time, he is my idol (I9).

Visiting hours represent an important time for the family. They are highly anticipated. This time is the opportunity to see the loved one, pass him love and security, among others feelings. For patients, this moment is also of fundamental importance because they come close to their loved ones, those who know and want to see their improvement.

The study showed that many families understand the cardiac intensive care unit as a differentiated sector and they feel reassured because their loved one is there, with full assistance throughout the day. However, many complain about the little time that they are allowed to stay in the sector during the visits, because very often the little time available still needs to be shared with all family members and friends who come to visit the hospitalized patient. The following statement explains the situation: [...] I think the really bad visiting hours, even for us who live outside, I think the time is too short. [...] (I4)

From the study it can be understood that many families understand the cardiac intensive care unit as a different sector and are reassured by your loved being there, where there is assistance throughout the day. However, many complain about the little time that may remain in the sector during the visits, because several times the little time still needs to be shared with all family and friends who came to visit the hospitalized patient. The following statement explains the situation: [...] I think visiting hours are really bad, even for us who live far from the city, I think the time is too short [...] (I4).

Family members are able to provide emotional support to the patient in the CICU, facilitating their recovery. However, according to institutional standards, the possibility to stay there
is reduced, because visits should be brief and specific. Visitors feel helpless to step into that unknown environment where the sophistication and the amount of equipment cause astonishment and constraint. All this causes much anxiety and stress to families and patients. The possibility of more flexible visiting hours to families in the cardiac intensive care units should be re-considered, as we perceive dissatisfaction in relation to the short visiting time period and the scheduled times which often do not match the schedules available to family members.

Adult persons, when sick, need to have close to them someone in whom they have confidence and with whom they feel comfortable to express their needs. Therefore, the permanence of family members close to them is advisable. Thus, the presence of relatives requested by patients seem to express the need for emotional security, support they seek among family members and/or friends.

Therefore, it is the family that supports the various moments of the life of the patient. The hospitalization in the CICU deprives the person from living or staying for prolonged time in contact with the family, mainly due to the routines imposed by the institution. This situation can be seen the following expression: I think it’s a bad thing that the person cannot have a companion, we wanted to stay with her, what if something happens and we are there.

Presence of accompanying persons in special situations, in the case of children and elderly, has permeated the discussions about the humanization in the hospital environment. This presence is provided by the Law nº 8069 of July 13, 1990, which ensures the parents or guardians their right to stay with their kids in cases of hospitalized children or adolescents, and Law nº 10.741 of October 1, 2003, which allows the presence of companions in the case of hospitalized elderly, or in observation. Some studies reveal the difficulties encountered by the teams to accept companions, highlighting, among the reasons, the belief that the presence of relatives is more stressful for critically ill patients.

The resistance to allow companions in closed units such as the CICU is understandable. The risk of cross infection is increased and, most likely, companions can also come to overwhelm the team with their demands. However, the institutions could propose studies to evaluate the risks and benefits for patients if they had the right to companions in full-time. If full-time companions were allowed, it would be necessary to plan educational strategies not only for the family but for the whole team, aiming at better conviviality. In order to allow the permanence of family members close to patients, the need of the institution to promote the comfort of companions should be considered, providing them basic acceptable conditions to sleep and rest, allowing them to develop supportive their role in the intensive care unit.

The family’s priority is the care of the sick person. Family members leave their own lives in the background. During this period, the family needs to reorganize itself in order to overcome the difficulties that arise in affective, social and economic aspects. The following report shows the organization needed for the family to be present during the visiting hours every day: We are a small family, so we organize ourselves, the times that we have to come.

We noticed that family members take on different social roles while a loved one is hospitalized. They need to reconcile their personal life and their work with the visiting hours, which often do not coincide. Thus, many must rely on the cooperation of their employers, to be released and to be able to be present during the visits. The following statements clarify the changes that relatives had to do in their routines so that they could visit their hospitalized family member.

My life has changed a lot, because I work as travel bus driver and we have to change the timetables. I work with people, I cannot travel when I am tired.

Everything changes. [...] The lunch time also changes, you have to do everything in a rush because the visit is at 11h. Everything has changed. After he came back home, someone need always to be with him. I had quit work.

In some cases, it was noticeable that the hospitalization of a family member not only changes the routine of those who go to visit the person, but also the daily life of the whole family. It is quite complicated, I have three children and they are desperate waiting for me.

By understanding the feelings involved and the perceptions exposed by the family members, planning and developing strategies for hosting them becomes imperative. This is needed for a more humanized and personalized assistance. The interaction with family members-visitors makes it possible that they receive guidance on the assistance and treatment goals, including them in the measures for recovery of the patient.

Thus, we see the importance of the health team, particularly the nursing team. They must know the real needs of these family members in order to make the comprehensive care to patients feasible. Thus, family members need to be involved in the admission process, with attention and care also directed to them, emphasizing the importance of communication in the relationship between workers, patients and family members.

The communication between the health team and family members

Among the various professionals working in cardiac intensive care units, nursing professional stand out. They are responsible for several intensive care procedures and constant moni-
toring of patients admitted there. Because this is an environment where severe diseases are present, it can be seen that most of the nursing workers end up looking after the physical condition of the patient at the expense of the emotional state of patients and their families.

In this context, the coexistence of a mechanized work and the humanized care can be jeopardized, resulting in increasing dehumanization. Overvaluation of technology is notable, preventing professionals to become more sensitive, critical and humanized as to the patient’s situation.16

Based on this appreciation, we understand the establishment of the link with patients and with their family as something essential. Interaction with families has to take place from the very time of admission, allow space for dialogue and answering questions. The establishment of this link should happen in a responsible and healthy manner, and this issue should be worked with the team in order to prevent further suffering.17

The analysis of data revealed that the participants could not identify the professionals who work in the CICU. Particularly, the little contact with nurses called attention. The first contact I had was now, because in the morning I came out of time and they did not let me up, it was after 11 hours. But I spoke only with the doctor. There was no nurse.14

A previous study with nurses found that the non-involvement with patients and relatives is a defense mechanism adopted by the team in order to avoid bonds that will later make them suffer because of the patient’s situation.18

Another hindrance to the identification of professionals is the use of private clothes evaluated in the cardiac intensive unit sector. All health and sanitation workers use the same uniforms, making it difficult to distinguish between them. The difference between the positions is possible only through personal presentation or by the use of badges with the discrimination of functions performed.

It is clear that when the professionals identify themselves, family members feel more satisfied with the service and feel safe with the treatment provided to their hospitalized family member. The simple act of identifying oneself represents a welcoming attitude for the family to feel at ease to address their doubts or ask things. This is exposed in the following statement: Some, who identify themselves, the doctor, the nurse, the nursing technician, the secretary out here [in the reception], they treat us very well!1)

We highlight, then, the importance of establishing a relationship of trust between health workers and patients/families because, when there is no complicity between them, the therapeutic approach can be difficult. Patients/families need to feel safe, comfortable and supported by the health team, because this way they keep their autonomy/citizenship and opportunity for expression.2

The assistance will only be humanized when workers understand this scenario and the process experienced by these families and recognize their actual condition and needs. In this perspective, the nurse must prepare the team for receiving the family in the unit, establishing clear communication, speaking calmly but consistently, providing comfort, and give instructions on the operation of the unit and of the professionals working in it.19

The need of the family to have updated, honest and understandable information was also identified in the study. Unfortunately, however, these issues are often ignored or overlooked by the team. We can attribute these flaws to factors such as time, lack of knowledge and lack of understanding of the real needs of these family members. For the respondents: [...] Employees, both in the CICU and the ICU had to be more accessible to the family, because it is painful to have a relative here [...] they could have better [...] manners (I2).

The difficulty of communication between the triad, health team-patient-family, is related, among several factors, to the different views of those involved or the short time of interaction between people.19

Professionals responsible for providing information to family members should be cautious about the terminology used in this guidance; they should understand the social differences and pass the guidelines in individual basis. By doing so, they will be recognizing individuals as unique and incomparable and misunderstandings of information passed on to the family will not happen.6

Usually, a noticeable fact is that families, and not the health team, have the initiative of starting dialogues. The professionals who stood out in the statements were the doctors. They are the ones who, at the end of the visits, talk to the families about the patient’s evolution, acting in accordance with the sector’s routine. This situation is illustrated below: When I ask, they [CICU workers] respond, and when we go out in the morning, the doctor comes to talk to us, to explain [...] (I3); the doctor was the only one who talked to us (I5).

Besides the importance of receiving information, companions show the need to communicate their observations to the health team, as well as to address doubts and keep the family informed about the situation of the patient. It is important that professionals practice attentive listening, valuing the complaints of patients/families, identifying their needs and respecting the differences.2,12 Thus, we corroborate the idea that working their discomfort is the first step towards the ability of CICU professionals to respond to the psycho, social and spiritual demands of patients and families.20,21

Given the importance of communication between the health team and family members, ways to facilitate such contact must be planned. We suggest creating a space where families could express their doubts and feelings and make sugges-
tions for the improvement of services, and, thus, be welcomed by professionals.

**FINAL CONSIDERATIONS**

With the study, we could see that hospitalization in intensive care units, especially in cardiac intensive care units, is a unique and difficult moment not only for patients but also for their families. Many are the feelings aroused in the family when they experience the hospitalization of a family member in the ICU. The study showed that this is a time when the family feels helpless because little information about the health status of the patient is given to them, and the information provided is often inconsistent. Thus, the fear and anxiety are feelings aroused by the unknown environment.

Thus, it is essential that the health team be enabled to provide care not only for patients, but for their families. This binomial patient/family should not be separated, but included in the assistance under a humanized perspective, allowing integration with the healthcare team. We believe that one way to create links is the identification of the professionals present in the sector, so that in this way the family starts to recognize who are the caregivers of that unit and to whom they could seek in cases of doubts or information.

We understand that the nursing staff is often overwhelmed and ends up valuing the mechanical work to the detriment of humanized care. Thus, nurses keep far from visitors, what was evident in the report of the individuals when they said that they cannot make clear distinction between the professionals working in the sector. This reality is not only bad for the creation of bond between the nursing staff and the families, but for the profession itself, which ends up not being recognized.

Based on the perception of respondents, there is a need to develop a proposal for hosting families of patients hospitalized in CICUs. This would contribute to the needs identified by the participants and suggestions for improvement of the service. Thus, the hosting is no longer a place or a location, but an ethical stance, which implies sharing of knowledge, needs, possibilities, anguish, or the involvement of the multidisciplinary team assigned to hearing and taking care of the problems of the individuals involved in the hospitalization. We emphasize also the importance of including health workers and institutional support in the hosting process, to create opportunities to continuing education. Also, adjusting visiting hours to some families that have difficulties to reach the hospital at certain times could be considered.

As for the possibility of allowing companions in intensive care units, this proposal should be evaluated, provided this does not interfere negatively in the care provided to patients. Also, issues related to infection control and physical availability of sites must be evaluated.

Noteworthy is the role of nurses as key professionals in the insertion of families in the setting of intensive care, as these professionals are usually responsible for the management of the unit. However, these professionals have not been easily identified. Furthermore, family members need to have a space to share feelings, experiences and doubts. This initiative should be an inherent part of the professional activity of nurses. If the strategies recommended here are applied, this could promote stronger bonds and strategies to support families could be feasible.

As limitations of the study, the restriction of the research to family members as participants can be mentioned. Further aspects that could be investigated are the perception of workers on the presence of family members; the existence of strategies for approximation; the identification and preparation of professionals for visiting hours; the presence of family members as companions in cardiac intensive care units; and the relationship between families and health teams. Thus, the realization of studies to broaden the understanding of the needs of family members of patients admitted to ICUs is recommended.

Therefore, it is emphasized that nursing professionals should be able to provide immediate support to families, becoming able to detect potential problems and implement the necessary measures in order to provide them with assistance to cope with the situation. There is a compelling need for these professionals to be present, supporting families to deal with problems, helping them by providing appropriate information and developing a professional attitude and sincere personal listening, welcoming them in their moments of crisis, emphasizing the autonomy and respecting the view of the individuals.

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