Sons and daughters with a parent hospitalized in an Intensive Care Unit

Filhos com pais hospitalizados em uma Unidade de Terapia Intensiva

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Abstract

The aim of this study, in the area of Hospital Psychology, was to comprehend the experience of sons and daughters whose mother or father was hospitalized in an Intensive Care Unit. Participants were 10 sons and daughters who responded to a socio-demographic questionnaire and a semi-structured interview, which were submitted to Content Analysis. The following were verified in the interviews: feelings of suffering and fear; concerns regarding the fact that the patient spends most of the time alone; lack of trust regarding the treatment offered by the healthcare team for the patient; lack of motivation to continue day by day routines; positive reappraisal such as personal, spiritual and professional growth, and satisfaction with the hospital team's care to the family. This data highlights the needs of these sons and daughters during their parent's hospitalization in an Intensive Care Unit and may support more effective care from the healthcare team for this population.

Uniterms: Coping strategies; Family; Intensive care unit; Psychology hospital.

Resumo

O objetivo deste estudo, na área da Psicologia Hospitalar, foi compreender a experiência de filhos que possuem a mãe ou o pai internado em uma Unidade de Terapia Intensiva. Participaram 10 filhos, de ambos os sexos, que responderam a uma Ficha Sociodemográfica e a uma Entrevista Semidirigida que foi submetida à Análise de Conteúdo. Nas entrevistas, constatou-se: sofrimento, medo e temor; preocupações quanto ao fato de o paciente ficar a maior parte do tempo sozinho, desconfiança quanto ao tratamento oferecido pela equipe de saúde ao paciente, perda da motivação de realizar suas rotinas, reestruturação positiva, tipo: crescimento pessoal, espiritual, profissional e satisfação em relação ao tratamento dispensado à família, pela equipe de saúde. Estes dados indicam as maiores necessidades dos filhos durante a internação de seus genitores na Unidade de Terapia Intensiva e podem subsidiar uma prática mais efetiva da equipe de saúde junto a essa população.

Unitermos: *Estratégias de enfrentamento; Família; Unidade de terapia intensiva; Psicologia hospitalar.*

Hospital psychology is one of psychology's professional practices. It promotes and develops several activities in different levels of treatment, health promotion and disease prevention. The Federal Psychology Council (FPC) in its 013/2007 Resolution says that hospitals, teaching institutions and research centers are the fields of work of these professionals, and their target public are patients, their relatives and/or the people responsible for them, community members, health staff and management staff. Campos (1995) stated that, when it comes to acting within the hospital, the aim is to contribute to the individual and social well-being, using information from other areas related to a hospital context, such as medicine, nursing, social service, nutrition etc. According to the *Conselho Federal de Psicologia* (2004), the agency that governs the psychologist's professional practice in Brazil, those who specialize in Hospital Psychology act in the secondary and tertiary levels of health care, working with: psychotherapy; psychotherapeutic groups; psycho prophylaxis groups; emergency care; wards; psychomotor issues; diagnostic assessment; psychodiagnostic assessment; consulting; inter-consulting; clinics and Intensive Care Units (ICU).

The Intensive Care Unit is a high complexity section with much technological apparatus, designed for patients with severe or potentially severe health conditions, with the chance of recovering and in need of continuous attention from a specialized interdisciplinary/multidisciplinary health team. However, patients who do not have the possibility of regression in their clinical status are also admitted, which highlights the need to distinguish between this model's curative proposal and palliative care. In the latter case, there is the philosophy of comprehensive care offered to relatives and patients in different stages of illness, aiming to care with comfort and dignity, in order to diminish the disease impact and manage the patients' and relatives' expectations. It is important to emphasize that when patients are in a final stage, the action is directed towards relief of the patients' and relatives' pain and suffering, given the proximity of death. ICU hospitalization may lead to a series of signs and symptoms of physical and emotional destabilization in patients and relatives. The separation process and, perhaps, the expectation of losing someone is a phenomenon that usually spreads throughout the whole family and the moments of worry and stress due to a relative's hospitalization in ICU may product symptoms and dysfunctions.

According to Angerami-Camon (2003), since this process causes emotional implications for the patient's family, the hospital psychologist must act offering emotional support to relatives so that they can find relief faced with the suffering brought on by the withdrawal of a relative. The process of becoming ill and hospitalized is a moment of crisis for the family, who do not always understand the procedures carried out by the health team, requiring care so they can face the hospitalization and its repercussions on the patients' and their own lives. Several studies have been developed aiming to verify how people with relatives in an ICU experience this situation.

The aim of Morgon and Guirardello (2004) was to validate the Relatives in ICU Needs Scale. Participants were 52 relatives of patients in the ICU of a University Hospital in *São Paulo*, most of them were women (71.1%) with a mean age of 41 years. Relatives were: sons/daughters (34.6%), followed by parents (27,0%), partners (21.1%) and others (17.3%). The most important needs for these families were: feeling that the hospital cares about the patient; being sure that the best treatment is being provided; sensing that there is a chance of recovery; knowing that medical treatment is underway and having their questions answered openly.

Moreno and Jorge (2005) interviewed eight mothers in the ICU of (Albert Sabin Children's Hospital) at *Fortaleza* (CE), Brazil, with the aim of understanding the expression of feelings and emotions of these mothers. The leading question used was: "How do you feel in an ICU watching and/or experiencing the care given to your ill child?". Interviews were analyzed using ideographic (individual comprehension of subjects' discourses) and nomothetic (understanding of the main assertions, obtained from the convergence of units of meaning) comprehensions, which is also called a situated phenomenon or existential phenomenology. The main reactions revealed by the mothers that emerged during the process of having their children in the ICU were: change of habits and behavior, frustration, anxiety, fear, guilt, pity, perplexity, sadness, loneliness, uncertainty, stress, and worry.

Paparrigopoulos et al. (2006) used the Center for Epidemiologic Studies Depression Scale and the Impact of Event Scale to assess the level of Depression and Posttraumatic Stress Disorder respectively in 32 relatives of patients in an ICU. It was verified that 97% of them presented depressive symptoms and 81% presented symptoms of Posttraumatic Stress. The authors concluded that such people had high levels of anxiety and distress that persevered during their relatives' hospitalization. Early identification of these cases by a psychologist and the creation of interventions may prevent the development of these disorders.

From analyzing these studies, it becomes evident that they focus on relatives' negative feelings, their needs during the patient's hospitalization and their level of depression and anxiety. No studies were found highlighting a specific type of kinship, except when it came to mothers with children in a Neonatal ICU (NICU). Furthermore, there is a lack of studies with emphasis on positive aspects resulting from the experience.

These reasons led to the interest in specifically investigating the experience of sons/daughters of patients. It is considered that there might be particularities in such experience, as parents represent protection for their children, no matter their age, and sometimes they are still the providers in the family. Such studies may offer theoretical support for hospital psychologist formation and for other health professionals, contributing to the development of programs to enable more timely and effective intervention planning. These programs must be developed with attention to Saunders' et al. (1995) concept of "total pain", which goes beyond merely physical pain, also considering social, emotional and spiritual dimensions. It is the pain that must be faced by the patient when coping with distress involving his/her identity and life objectives, as well as by the family when seeking the strength to deal with mourning and the future.

In this way, the aim of this study was to investigate what it means for a son/daughter to have his/her mother or father hospitalized in an ICU. It should be remember that, when considering a patient's recovery one must also take into account their family members, as they influence the treatment. This influence may be beneficial when well guided by a qualified healthcare professional or maleficent when poorly guided or not guided at all.

Method

Participants

Participants were ten sons/daughters of patients in an ICU of a private hospital in the city of *Recife*, state of *Pernambuco*. Three had their fathers hospitalized in this unit and seven had their mothers in the ICU. The mean age was 44 years, varying from 20 to 59 years.

Instruments

The instruments used were a socio-demographic questionnaire and a semi-structured interview. Andrade (2003) says that this type of interview consists of a conversation that can be guided by open questions, which allows the informant more freedom.

Data collection and analysis

Data collection occurred from March to July, 2010, after the project had been approved by the Research Ethics Committee from the *Universidade Católica de Pernambuco* under protocol nº 033/2009, and after the hospital management gave permission for the study to be carried out. The patients' relatives were approached while waiting for the visiting time to start. The aim of the study was explained and, if they agreed to participate, a time and place of their convenience was set. All of them preferred that it was in the hospital, before or after the visit to their parents.

Prior to beginning the interview, the Terms of Free Prior Informed Consent was presented to the participant, who read and signed it, after any necessary clarification. Next, the socio-demographic questionnaire was completed. The interviews took place in a room provided by the hospital for this purpose.

The interviews were submitted to Content Analysis (Minayo, 1999). At first, they were read and re-read focusing on the aims of the study and on what was recurrently mentioned by the participants. Five thematic categories emerged from this analysis: 1) Feelings most mobilized in the sons/daughters of patients in the ICU;

201

2) Main concerns and difficulties; 3) How this situation affected the routines of the relatives; 4) Positive aspects of the situation; 5) How the participants perceived the healthcare team's treatment of the patients and their families.

Inferences and interpretations from the interviews were made based on these categories or themes. It is important to highlight that the analysis considered the theoretical framework that guided the entire investigation. When presenting the results, the interviewees are identified as E1, E2 and so on, in order to maintain their anonymity.

Content Analysis of the interviews

The five thematic categories resulting from the content analysis of the interviews are discussed here.

Feelings most mobilized in the sons/daughters of patients in the ICU

According to Soares (2007), relatives have specific needs and present high rates of stress, mood disorders and anxiety during the period of hospitalization of their parents in the ICU. As Angerami-Camon (2003) states, the disease is a factor of maladjustment in the family group. Therefore, it is necessary for the hospital psychologist to care for these families. However, despite professionals indicating the need for a multidisciplinary/interdisciplinary intervention, in which psychologists should give relatives feedback on the patients' psychological conditions, such action does not occur very often. Psychologists' actions are seen as important, however, in a very subtle way, restrictions and prejudice emerge and this practice is not legitimized. In healthcare, action and participation are restricted to support and medical aid, reinforcing the fact that the psychologist is a professional of last resort for the users (Bock, 2003).

Lucchesi, Macedo and Marco (2008) highlight that the beginning of hospitalization is a moment of shock, denial and causes feelings of despair, which can be gradually substituted by a greater ability to cope and deal with the reality. There are many feelings involved in this process: moments of apprehension, despair, relief, fear, anger, and exhaustion, among others. Faced with this, the contribution of psychology for

healthcare, especially within a hospital context, is extremely important. As Mota, Martins and Véras (2006) state, psychologists have the role of understanding what is involved in the complain, in the symptoms and in the pathology, so they can have a broad view about what is happening with the patients, to help them through this difficult process, as well as to provide support for relatives to better understand this moment. As healthcare professionals, psychologists must observe and listen patiently to words and silences, since they are the ones, in the field of human therapeutics, who can offer the possibility for patients or relatives to confront their anguish and suffering when dealing with the disease and hospitalization, aiming to overcome moments of crisis. Psychology professionals can propose a discussion on the real conditions of humanization in the hospital, engaging in the role of caregiver with the aim to improve the care system.

In this study, it can be verified that the feeling most mobilized were: suffering, and fear. The following reports confirm this statement:

> It is complicated to tell you what I am feeling, you know? It is a lot of suffering. And, even though I can see her improving, I am still afraid... (E1).

> When they told me my mother was in the ICU, I got scared. I was like: the ICU? Because that is something that scares you, right? (E10).

It is worth highlighting an aspect presented by E10: the fear provoked by the ICU in some relatives. According to the literature, the ICU is socially seen in a negative way, there is a comprehension that patients in this unit present a severe clinical state with the possibility of death, which causes feelings of anguish in the relatives of patients, due to the fear of an imminent loss (Nunes, 2004). The lack of information on the routine of the ICU causes apprehension in the relatives regarding the health status of the patients, which causes them to become distressed. According to Di Biagi (2002) the psychologist must accompany these relatives, providing conditions for them to express their feelings, doubts, fantasies and false concepts on the disease or the ICU and allowing them to cope with the hospitalization and what may come from it.

During the period of the disease and ICU hospitalization, in addition to the feelings mobilized,

some concerns and difficulties are common. This theme is approached below.

Main concerns and difficulties

Intensive Care Unit hospitalization may cause emotional instability in the relatives of the patients, who become apprehensive and restless. When questioned about their main concerns and difficulties regarding their parent's hospitalization in the ICU, the responses given were as follows: *"We are afraid that our father might die.... That we come to visit him and he is dead. Have mercy! I would never believe that he had died"* (E6).

The fear of death overcomes other concerns for most of the sons/daughters; however some of them have concerns regarding the quality of life their parents might have if they survive. As one of the participants stated: *"My biggest fear is the sequels she might have, if she comes out of here. That she lives in a vegetative state. I think about that a lot. That is what concerns me"* (E2).

For Nieweglowski and Moré (2008), families with relatives in an ICU, in addition to being exposed to various stressors, constantly reflect about death. In this study, it was observed that the relatives were very succinct on that theme. This is similar to the findings of Urizzi and Corrêa (2007). These researchers said that their participants did not express in detail the experience related to the possibility of the death of their relatives, which is more concretely presented in the context of an ICU.

This configures the difficulty of speaking about death, even when considering this to be an inherent condition of the human being. Death is currently associated with pain and suffering, almost always happening in a hospital context in which there is an elongation of life, hence the importance of clarifying palliative caring procedures, with an emphasis on existential dimensions that influence physical pain. Caring for physical pain is not neglected, however, as the treatment is not focus on a cure, palliative care allows the necessary reflection to strengthen the coping mechanisms in a situation of threat to life.

As Kovács (1992) says, there is a myth responsible for one of this century's biggest fears: the belief that death is always accompanied by suffering. For this author,

an anticipatory mourning may occur in people when they become aware of certain diagnoses. According to Franco (2010), Londemann, in 1944, was the first one to talk about this kind of mourning, using the experience of wives of soldiers who were called to the battle field. Franco and Mazorra (2007) state that, what allows mourning to be elaborated is a re-signification, a transformation of the relationship with the lost object. Education concerning death may be a good path in the search for new caring perspectives for severely ill patients and their families. When considering the quality of death, palliative care focuses on providing a higher quality of life for as long as possible, which can diminish the suffering of the patients and relatives.

Other concerns indicated in the interviews were: the short period of time for visits and the care provided by the team: *"We are already used to being here with him and here we don't provide the care, there are others who do that, so we become concerned. And the visit is very quick, which is really bad. We want to spend more time, I feel like staying the night with him, but it is not allowed"* (E7).

As Nunes (2004) affirms, many relatives become concerned knowing their parents are alone, without someone to care for them, to hold or to talk with them. Molter (1979) comments that the need to see the patient several times or visit when desired may be a way for the family to rebuilt a broken bond and cope with the anguish caused by the lack of control when the patient is out of their sight.

For Urizzi and Corrêa (2007) the family wishes to stand by the patient; this can reveal that, many times, what matters is not only objective information regarding the patient's status and evolution, which is also relevant, but the family members predominantly want more: they wants to be protected, considered in their suffering and to have their needs provided for. Faced with this, the healthcare team must seriously consider actions aimed at the relatives (Angerami-Camon, 2003). To consider the family as a secondary element is not consistent with a philosophy of humanization. The hospital psychologist must support and make the relatives aware of aspects of the disease and the real need for hospitalization, as well as provide prognostic explanations so that they feel protected and safe (Angerami-Camon, 2003). However, the insertion and practice of a hospital psychologist is not always possible, with the main

203

difficulties being: hierarchy issues, difficulties with the medical language, the great demand for work considering with the small number of professionals, difficulties in talking with the medical team, lack of recognition by other professionals of the practice of the hospital psychologist. Despite the aforementioned difficulties, which are also mentioned by Vieira (2006). Tonetto and Gomes (2007) say that there is a rise in interest regarding psychologists working in hospitals and that Psychology, as a science, is ready to make its contribution efficiently and safely.

Other concerns indicated by the sons/daughters included a preoccupation regarding the care provided to their parents: *"We also think about the attention he is receiving inside, since we can't be there all the time. When he is on a ward, we can monitor the care, but not in the ICU"* (E9).

For Guimaro (2003) the anxiety of relatives is common due to maladjustment to treatment or distrust of the medical team. This is why there should be open communication between these family members, the psychologist and the technical team that accompanies the patient. According to Doca and Costa Junior (2011), psychological support in the hospital has been recommended in the literature as it might help with higher rates of treatment adherence and provide a decrease in anxiety. For Nunes (2004), the presence of the hospital psychologist is important because this can help patients to better understand their situation in a way that their emotional state is not disturbed, avoiding a worsening of the problem.

How this situation affected the routines of the relatives

According to Lucchesi et al. (2008), and to Romano (1999), the family can be understood as a system in which each member plays a role and allows the existence of a dynamic that has its own functioning. When one of the members becomes ill, especially when they are hospitalized in an ICU, an imbalance is introduced in this system, with a break in the routine. When questioned about changes in their routines after the hospitalization of their parents in the ICU, some of the responses were:

... I get anxious to come to the hospital and hear about her, that's why my house is a mess ... (E1).

I can say that all of this is like a tsunami. I am a very sociable person, you see? I used to go out with my friends, I am not married and don't have children, I used to go out a lot. But not now. I insist on coming here twice a day.... Everything has changed ... and now, she is like my baby. I am taking care of my baby, who depends on me for everything (E2).

I had many things to solve, but I couldn't do anything. My husband is taking care of that. Bills to pay, money to receive. He's got everything.... I feel like I am crystallized. I don't do anything at home, my daughter does it. I really stopped (E10).

Through the participants' statements, one can realize that they want to spend most of their time at the hospital. It is as if there was an inversion of roles, as they come to see their parents as babies and blame themselves when they cannot be together. The lack of motivation concerning daily activities, such as taking care of their homes, can also be verified. When they have a partner or children, they are the ones that become responsible for the house and daily activities, which highlight the change of roles in these family members.

In addition the participants mentioned that during the hospitalization of their relatives, their social lives finished and professional lives were compromised. A phrase used by one of them is very representative of these sons/daughters feelings: "I feel crystallized". It is as if time stopped while they are waiting for the recovery or death of their parent; while the situation is uncertain, they remain almost paralyzed, living with their parent's disease. They are also in a permanent state of alert due to the expectation of receiving news about the patient's status from the hospital. All of this is in accordance with the literature: Oliveira, Almeida, Araújo and Galvão (2005) state that hospitalization in an ICU causes a state of expectation and anguish, leading to interferences and implications in the rhythm of the social and professional lives of the relatives. This may contribute to them becoming more sensitive, demanding, depressed and/or distressed.

For Bousso and Angelo (2001), in this phase, the help given by other parents, friends and other families is essential. The families who are also dealing with similar situations sometimes even develop meaningful relationships in ICU waiting rooms. Relatives listen to

the same stories told by other families, sometimes facing different historical, cultural, ethical and religious contexts that may help them reflect on what they are going through and create new strategies to deal with this in a way that their routines are not so disturbed. In this moment, group work, guided by a psychology professional, could be useful and could allow the expression and exchange of feelings among the family members of the patients.

Positive aspects of the situation

Throughout this study, the fact that having a parent in an ICU unit causes concerns, suffering and distress in their sons/daughters could be verified. These aspects are already discussed in detail in the literature. However, in order to try and minimize the emotional load in such a situation, it is likely that some relatives try to restructure the event. They can do this by searching for positive elements of the situation. This is a less studied theme. When asked about this, some things the participants said were:

> I think this is making me a better daughter… I am praying more, trusting more in God, you know? My faith is strong (E1).

> We learn that we are nothing. We are nothing. Nothing, nothing, nothing. Whoever thinks they are something is very mistaken. I am learning a lot... . I have grown as a person and become more detached from material things (E6).

> It is like respect is more important in this moment... . I have always respected him, but today I think there is more respect, you know?... . It also makes us work on our patience, because he is gradually recovering and if you're not patient you can't handle it (E8).

> In my case, it helped me grow in the professional area, because I'm a nurse and seeing my father like that is making me become a more human professional when I take care of some patients (E9).

These statements highlight that this experience may have also been one of growth for the participants. What is shown is a rise in the experience of spirituality and almost mystical faith; some mentioned that they had become better sons/daughters; that they had become more human; that it was a moment to become more patient, and there was a chance of personal growth. According to Bousso and Angelo (2001) these

families do not wait passively while their relatives are in the ICU, they do not merely wait for death, but they search for ways and strategies during this situation. When this does not happen, it is relevant to offer other possible perspectives to these families, in order to help them live through the experience.

Pinho and Santos (2008) say that being ill under these conditions (ICU) can provide patients and relatives with a positive experience, as sometimes they start to appreciate small signs linked to the valorization of a religious life or personal growth that perhaps were not so important to them before. This can be observed in the statements, as they indicated the learning of new things, such as not getting too attached to material things, or personal and even professional growth. Regarding the affirmation that this experience made them into better sons/daughters. Kovács (1992) says that, in the context of disease and the ICU, guilt is very common, as well as reparation attempts by the relatives of the patients.

Concerning spiritual growth, Lima and Rosa (2008) claimed that, many times, suffering is transformed into a positive attitude faced with the fear of death and of the ICU, transcending the faith in God. There is trust, up to the very last moment, that their faith is what provides them with strength and hope. Believing in a religion is seen as salvation by the relatives, and religious practices bring peace of mind and hope that the situation will be reversed. The impact of spirituality and the religious experience have been evidenced in several studies, confirming their impact on patients' health and on relatives' hopes, strength and anxiety (Savoli, 2008).

Given the above, it is worth highlighting the importance of a psychologist who assesses and identifies the family member who shows more preserved positive internal resources, as this person can be a facilitator link in the relationship between the health team and the family.

There is also a need for more reflection regarding death and dying. Public policies have to recognize the importance of caring not only for life but for the quality of death too, supporting the requirements of terminally ill people and offering them a worthy and peaceful death. Palliative care proposes a new shared and responsible way of caring for life and death with patients and families. It emphasizes the art of caring in a respectful and calm

way, allowing exposure and reflection regarding the true possibilities for the disease and the treatment, so that decisions and choices can be made to guide the last moments of existence, giving more life to the time rather than more time to the life.

How the participants perceived the healthcare staff's treatment of the patients and their families

The treatment provided by the healthcare staff to the family is fundamental, especially regarding the relatives of critical patients. Anxiety, discomfort and uncertainty felt by relatives may be increased if such treatment is impaired. Regarding the healthcare staff the participants said:

> *They are great doctors…. They go beyond being doctors. They are kind and that helps any family…. The team is very good and explains the diagnosis very well* (E2).

> *Look, better than this, only if there is another hospital of this kind because they provide excellent treatment here. I believe this is a reference hospital* (E5).

> *I have no complaints so far, you see? To start with, the owner made himself available to see my father and asked us if there was anything missing, if there was anything wrong…. Everything here is really good; cleaning, refectory, staff. Everybody is polite* (E6).

> *They are more than professionals, because they don't see a patient, they see a person…. It is good to notice that the hospital has professionals and people who can see the human side and not the patient as just a number…. He's very full of emotion and it is good to have a human staff. They have that here* (E8).

The participants' satisfaction can be noticed in the above statements regarding the health staff's treatment towards them, especially because they could understand the explanations about patients' diagnosis. These findings are in accordance with some other studies: Wallau et al. (2006), when assessing care quality in an ICU, verified that visitors mentioned dissatisfaction concerning medical information, and Kirchhoff et al. (2002) verified the lack of communication between staff and family in their study, as well as a lack of more detailed explanations about the patient's health status, which made them suffer with uncertainty regarding the prognosis.

It is worth recalling that the data collection in the present study was carried out in a single hospital characterized as an ICU Hospital. It is possible that, as it has a structure especially dedicated to this type of treatment, it can offer better conditions for the satisfaction of the relatives of the patients. Although there is no intention to generalize the findings mentioned here, it can be said that they indicate the importance of humanization in all hospital contexts.

It should be highlighted that efficient communication between staff and family prevents conflicts, doubts and distress in the relatives, resulting in greater satisfaction and a positive perception of the care provided to the ICU patient. An integral palliative care proposal may lead to a significant change in healthcare, introducing complex issues about the end of life, which can be reflected in particular attention to patient and family suffering faced with such an ending. According to Soares (2007), the communication process is the cornerstone of family care. One of the most important tasks for an ICU professional is to provide relevant, clear and realistic information, as well as solidarity. This can also be evidenced in the statements of the participants, as they highlighted the humanity of the healthcare staff, saying that this is a characteristic that goes beyond medical services. They speak as if it was not common to find someone who valorizes the subjectivity of the patient.

Some studies confirm this, for example, when Morgon and Guirardello (2004) aimed to validate the Relatives in ICU Needs Scale, one of the most important needs cited was to feel that the hospital team cares about the patient. Bettinelli, Rosa and Erdmann (2007) interviewed relatives of patients in an ICU and perceived that, in addition to the lack of guidance, the availability and welcome were also lacking. Therefore, hospitals must attend to such issues.

Final Considerations

This study aimed to comprehend the experience of sons/daughters who have a parent hospitalized in an ICU. The prevalent feelings that emerged in the interviews were: suffering, worry, and fear, probably based on the interpretation that this unit is related to a situation of imminent loss. Such results show that the feelings

experienced by these sons/daughters are similar to ones felt by other relatives with family members hospitalized in an ICU, such as mothers and fathers etc.

Regarding the main concerns, the emphasis was the distress felt by participants due to the short time for visiting (three times a day for thirty minutes each). They wanted to remain with their parent for longer because they mistrusted the healthcare team's ability to care for them. Therefore, it is suggested that the team - and/or professionals, such as psychologists, direct their guidance towards the family, aiming to clarify actions and routines in the ICU, the reasons why the visiting time is so restricted and their commitment to the patient. This could provide the relatives with more peace of mind. It would be interesting to give them opportunities to express their fantasies and false concepts concerning the ICU, so the ideas they have about this space could be demystified.

Regarding the routine changes of these relatives, it was observed that the sons/daughters lost the motivation to engage in daily activities, and functions once exercised by them were delegated to other family members. Because of this situation, it is proposed that, when supporting patients' sons/daughters or other relatives, staff can give them the opportunity to speak about the experience. This intervention could be carried out in groups of families in which a psychologist would be the mediator, in order for them to jointly construct possibilities for a reversal of the aforementioned situation and gradually rediscover the motivation to engage in daily activities, as this can also serve as a coping strategy.

Another relevant issue observed was that patients reconstruct the fact that their parents are in the ICU in a positive way, they begin to value things that were not noticed before, such as personal, spiritual and professional growth. Therefore, this strategy of positive reevaluation is considered an important asset to be used by healthcare professionals to support sons/daughters and other relatives that are more fragile.

Finally, the importance of humanized treatment and healthcare professionals who see patients and their families as individuals, without forgetting about the disease, was demonstrated. It is important the healthcare professional does not relate death with merely bureaucratic and technical procedures, and is careful not to transform hospitalization and dying into institutional, lonely and impersonal acts.

The level of satisfaction of the sons/daughters with the treatment provided by the health staff is a result that contradicts the literature findings. It is worth mentioning that the hospital where this research was conducted is characterized as an ICU hospital, therefore, it can offer better conditions for the satisfaction of the patients and relatives. However, humanized care can also be found in other types of institutions.

In order for the ICU to be humanized, some simple procedures can be taken: the patients' recovery largely depends on the comprehension that someone cares about them. Staff attention increases patient comfort, identity and integrity. On the other hand, a lack of attention may have harmful effects on the health and recovery. Warmth, love and understanding attention are among the essential elements for any recovery, as well as the ability to assess the intervention limits of the healthcare staff. It is important to highlight that even when the team is humanized, effective integral care for the patient without a possibility of a cure is of extreme importance, as controlling the pain and other symptoms (psychological, social and spiritual) is a priority, with the aim being to achieve a better quality of life for the patients and their relatives.

Given the above, the creation of a space in which professionals can exchange experiences, difficulties and feelings aroused by working in an ICU is suggested. This practice could be the beginning of a meaningful process in the search for more humanized care.

It is considered that the humanization process already occurs in some Brazilian hospitals. Bergamini (2008) aimed to analyze this process in an ICU of the *Instituto do Coração do Distrito Federal* (Incor-DF, Heart Institute of the Federal District), from the perspectives of the healthcare team and the clients. It was noticed that, for the clients, technical competence, attention and care provided by ICU professionals helped them to overcome and accept the treatment, as they felt protected, gratified and safe with respect to their hospitalization. In the evaluation of the healthcare professionals, they considered themselves to provide integral and humanized care, due to the existence of proper working conditions. Simultaneously, they highlighted the use of communication, touch, support, and family participation as conditions to qualify the care.

207

The results also showed that humanized care, from the clients' perspective, is linked to the appropriate use of available technologies, valorization of material resources, technical-scientific competence and the quality of the relationships between professionals and clients in the ICU. However, technological instruments and institutional procedures cannot prevent relatives from deciding and knowing the patients' real conditions. The evidence shows that the Incor-DF ICU is concerned with the quality of care and the promotion of humanized assistance to their clients. In this way, it is possible to support relatives who become distressed when facing an unfamiliar situation and environment that they see as aggressive and traumatizing.

It is relevant to promote studies on this theme, so that humanized intervention programs for sons/daughters and other relatives of patients in the ICU can be implemented in the city of *Recife* (PE) and other cities. Furthermore, this study allows the work of the hospital psychologist to be recognized, creating a greater demand for them.

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