



## Messages from relatives of patients in coma: hope as common element\*

*Mensagens dos familiares de pacientes em estado de coma: a esperança como elemento comum*

*Mensajes de los familiares de pacientes en estado de coma: la esperanza como elemento común*

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### ABSTRACT

**Objective:** Identifying common meanings in messages from relatives of patients in coma who had been admitted into intensive care units. **Methods:** Descriptive study, qualitatively analyzing 30 messages from families of critical state patients. **Results:** Seven categories emerged: search for spiritual support to overcome difficulties; the necessity of expressing one's feelings; the wish for the patients to return to family life; patients should not worry about external events; family is concerned with reporting the visits, reaffirming that the patient is not alone; concerns about the patient's recovery; memories about daily life and news from home. **Conclusions:** Feelings and concerns emerged, along with a universal feeling: hope. This was a part of all categories; hope not only about a cure, but also in adaptation. **Describers:** Intensive care unit; Hospitalized patients; Family; Coma

### RESUMO

**Objetivo:** Identificar significados comuns nas mensagens dos familiares de pacientes em estado de coma internados em UTI. **Métodos:** Estudo descritivo com abordagem qualitativa de análise de conteúdo de 30 mensagens de familiares de pacientes em estado crítico. **Resultados:** Emergiram sete categorias: a busca de apoio espiritual para superar as dificuldades; a necessidade de expressão dos sentimentos; o desejo que os pacientes retornem ao convívio familiar; não se preocupem com os acontecimentos externos; preocupação dos familiares em relatarem as visitas reafirmando que o paciente não está sozinho; preocupação na recuperação dos mesmos; lembranças da vida cotidiana e notícias de casa. **Conclusões:** Sentimentos e preocupações emergiram, além de algo universal: a esperança. Esta permeou praticamente todas as categorias; esperança não só na cura, como também na adaptação. **Descritores:** Unidades de terapia intensiva; Pacientes internados; Família; Coma

### RESUMEN

**Objetivo:** Identificar los significados comunes en los mensajes de los familiares de pacientes en estado de coma internados en una Unidad de Cuidados Intensivos (UCI). **Métodos:** Se trata de un estudio descriptivo con abordaje cualitativo de análisis de contenido de 30 mensajes de familiares de pacientes en estado crítico. **Resultados:** Emergieron siete categorías: la búsqueda de apoyo espiritual para superar las dificultades; la necesidad de expresión de los sentimientos; el deseo de que los pacientes retornen a la convivencia familiar; no se preocupen con los acontecimientos externos; preocupación de los familiares para relatar las visitas reafirmando que el paciente no está solo; preocupación en la recuperación de los mismos; recuerdos de la vida cotidiana y noticias de casa. **Conclusiones:** Emergieron sentimientos y preocupaciones, además de algo universal: la esperanza. Ella permeó prácticamente todas las categorías; esperanza no sólo en la cura, sino también en la adaptación. **Descriptores:** Unidades de terapia intensiva; Pacientes internos; Familia; Coma

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## INTRODUCTION

Technology in Intensive Care Units (ICUs) has increased even more the complexity of the clinical status, also increasing the incidence of lowered of consciousness levels by drug effects therapeutic procedures and also, the disease itself. "The incorporation of computer science technology has allowed the full development and modernization of several types of monitoring equipment, covering all the physiological systems in the human body, from mechanical ventilators incorporating several models of full or partial respiratory assistance to infusion pumps with a more precise control of drug delivery and its diluents"<sup>(1)</sup>.

There is no doubt that ICU treatment is a high-technology area of Medicine. Even in cases that are apparently hopeless, lives may be saved by using modern technology. However, although this context is successful, ICU treatment has failed in other aspects. Patients seem to suffer from other problems, caused by insufficient communication, alterations in their sleeping patterns and lack of empathy with the team. Several intensive care activities may seem to happen between the team and the machines, subjects and objects<sup>(2)</sup>. We evolve as nurses and healthcare professionals according to the technique, but, since technique does not mean ethics, we can not keep our dignity in small things such as: forgetting to smile, forgetting to look into the eyes of our patients and colleagues eyes, forgetting to shake hands or caressing, pulling out a chair, sitting and listening<sup>(3)</sup>.

Nobody challenges the importance of the existence of technology, because it is not good or bad in itself; it all depends on how it is used. The ICU needs and must use technological resources that become more advanced each day, but professionals should not forget that machines will never substitute the human essence<sup>(4)</sup>.

People outside the healthcare area hold several beliefs and fantasies about ICUs. For those who do not know the hospital environment, the ICU is considered as a critical place where "people go to die"; "when they are about to die" or "when it is severe". Stereotypes like these could be undone with adequate definitions, as well as communication and efficient interaction with the families of patients admitted into ICUs<sup>(5)</sup>.

The nurse could be indicated to establish communication with the family about the ICU routine, its devices, procedures, as well as offering emotional and spiritual support. However, this type of care, considering both the patient and the family, is certainly one of the most difficult to be implemented. The complex daily routine involving the ICU environment induces the Nursing team to forget touching and talking

to the patient in front of them<sup>(6)</sup>.

A study<sup>(7)</sup> performed with nurses about families of ICU patients identified a significant perception. All speeches referred to the difficulty that the nurses had in dealing with families, revealing several dimensions of this experience. Some notice the feelings of grief of the family and learn to deal with them. Others relate this difficulty to the working organization, to the Intensive Care specificity, to their own personal or the healthcare team limitations and also to how the families express their feelings.

"The hospitalization of a family member in an ICU generally occurs in a severe and unexpected way, leaving a short time for family adjustments. This stressful situation may cause the family to feel disoriented, abandoned and with difficulties to mobilize, bringing up different types of needs"<sup>(8)</sup>.

The family tends to experience fear, anxiety and insecurity. These feelings emerge from difficult situations following hospitalization, such as the possibility of the patient's death, the search for information about the health status of the patient and the working dynamics of the intensive care unit, with its technology and specific professional knowledge<sup>(7,9)</sup>.

On the other hand, nurses realize that, in certain situations, the family feels safe in leaving their relative in this well-equipped environment, which comes from the idea that the patient will be well cared for when under Intensive Care. As such, the nurse realizes that family experiences ambiguous feelings about ICU: a strange place which frightens but offers security in caring for the patient with a severe condition, always wishing for the person to leave the ICU as soon as possible<sup>(7)</sup>.

In the study<sup>(10)</sup> aiming to verify the influence of music and an oral message on the vital signs and facial expressions of the patients in physiological or induced coma; and relating the existence of a patient response with the Glasgow Coma Scale or Ramsay Sedation Scale, regarding musical and verbal stimulation. The families of ICU patients had the opportunity to record a message (verbal stimulus), with the goal of being exposed to their loved ones.

It is believed that, by repeating the patient's name and recording a message by a close family member and with their own voice, the patient's attention will focus on the stimulation more easily<sup>(11)</sup>, since there is a high tendency of "paying attention" to things which have a certain cognitive and emotional value.

## OBJECTIVE

The objective of this study was, therefore, identifying common meanings in the family of the coma patient hospitalized in an ICU.

## METHODS

### Type of study

It is a descriptive, cross-section, exploratory and field study, with a qualitative approach, since the focus is complex and needs subjective interpretation, being the speech the basic element of investigation.

### Place of study

The study took place in two Intensive Care Units (Trauma and clinic) in a school hospital in the city of São Paulo (Brazil).

### Sample

The sample of the study was constituted by 30 messages from relatives of patients in coma, hospitalized in Intensive Care Units.

### Procedures for data collection

The analysis of the messages recorded in the aforementioned study<sup>(10)</sup> was considered adequate to better understand the necessities and expectations of the family members of patients hospitalized in Intensive Care Units.

For the verbal stimulation, the family was invited to participate in the research by recording message with their own voices, and choosing a song according to the patient's preference, which was recorded in the same CD.

During the visitation times, the researcher approached the family members when they were close to the hospital bed. She quickly introduced the research and their possibility of participating or not. If the family member accepted or showed some interest, they were guided to a meeting after the visit at the meeting room of the hospital. The author was especially careful not to disturb them at the only moment of the day when they could be close to their loved one, so she avoided long explanations at that moment. Several times, before approaching the family, she observed their attempts to communicate with the patient. When that happened, their participation on the research was almost certain<sup>(10)</sup>.

The family members were oriented about the criteria for the elaboration of the messages in groups of two or three people at the meeting room. Paper and pens were supplied so they could write down a few notes about what would be said and recorded. Besides, the family members were oriented on how to use the digital voice recorder and that, at the moment of the recording, they should be alone, away even from the researcher, to feel more comfortable<sup>(10)</sup>.

The oral message was used had two basic objectives: exposing the patients to language stimulation and focusing their attention. Some standardization criteria was used for its production: the message should be

elaborated by a family member who is significant to the patient, since person beside the patient at that moment was not always close to the patient; recordings with a maximum length of 3 minutes; saying, both in the beginning and at the end of the message, who is speaking; saying the name of the patient at least three times during the message; situating the patient spatially: where the patient was and what was happening to him/her; saying a tender and optimistic message; saying something about the patient's family routine.

Regarding the elaboration of the message, which should be made by a close family member, there was not a precise way of evaluating this, but the person was always asked how both are related, and whether this relative would like an opinion from another family member regarding the participation in the research.

After the approval by the Review Board of the Institution (Process #1079/04), the collection was made from March to September 2005, along with the family members who accepted recording the messages and who filled in the Term of Consent to the research described.

### Data treatment

The speeches of the family members were completely transcribed, respecting their usual way of speaking. The data were analyzed according to the Content Analysis methodology<sup>(12)</sup> which proposes a set of technical analyses of the verbal communication in order to obtain pointers (qualitative or not), which allow the description of the content of the messages of the interviewees. This method is made up of three stages (previous analysis, material exploration and treatment of results, interference and interpretation), and the criteria for the categorization of data may be semantic or thematic when all themes with the same meaning are grouped.

## RESULTS

The speeches of the family members resulted in seven categories, highlighting the search for spiritual support to overcome difficulties; the necessity of expressing one's feelings; the wish for the patients to return to family life; patients should not worry about external events; They even reveal the concern of the family in telling about the visits. reassuring the patient that he/she is not alone in their process of recovery, as well as in remembering moments of their daily lives and bringing news from home.

### Category I – Search for spiritual support to overcome difficulties.

In this category, it is evident that regardless of religion

or the bond with some of them, the family members seek some sort of spiritual support in this moment of uncertainty and insecurity. There is a strong religiosity in the messages; words such as “God”, “Jesus” and “prayer” were present in almost all the speeches. Besides, this attachment to spirituality is most frequently related to the necessity of not losing hope, proposals of change, promises and waiting for a miracle.

*“Our brothers in Christ have prayed a lot of you. You are a beloved person in the Christian community. Our kids are shaken but they have responded well, since we educated them in the ways of the church, in God’s grace, God has comforted our kids and they are reacting well” (Wife of patient IV)*

*“Although I do not go to the church, I have faith in God and that you will leave this place strong and walking and you will live a long long long time...” (Daughter of patient XVI)*

*“Everybody is praying, talking to and asking God to make this miracle so you can come back home, to our life (...)” (Son of patient XI)*

*“(...) F has made the Sebastião’s pledge, she had her hair cut and father also made a promise to walk all the way to Aparecida, and W also made one, we have to fulfill this now, with your strength you will stand, will recover and you will go along, too” (Brother of patient XXIV)*

### **Category II – The need of expressing one’s feelings.**

This category highlights the necessity of the family in expressing their feelings of love, sorrow, caring and dedication to the patients, as well as regret and guilt for past acts.

*“I need to say I love you so much.” (Sister of patient V)*

*“We miss you a lot at home.” (Wife of patient VIII)*

*“I just want you back, kiss you, hug you, say how much I love you, I have always loved you, always have, love and always will love you until the end of my days.” (Daughter of patient XIII)*

*“I want to apologize for our fights, I have fought a lot but I need you a lot, I need your presence.” (Daughter of patient XVI)*

*“Mommy A, receive all my love, my tenderness and my gratitude for the greatest opportunity you gave me in this existence and also for supporting me in all areas of my life.” (Daughter of patient XXIII)*

### **Category III – The wish for the patients to return to family life.**

This category highlights the wish for things to come back to the way they used to be, for loved ones to go back to family life, and for this “nightmare” to end soon.

*“Mommy, we are eager for you to come back soon so we can have fun, travel and go to fantastic places.” (Son of patient XV)*

*“We are getting ready for your return to our home, full of life,*

*joy and health.” (Son of patient XV)*

*“Come back home, please.” (Daughter of patient XVI)*

*“Everyday people ask about you, you have to come back.” (Brother of patient XXIV)*

### **Category IV – Patients should not worry about external events .**

This category shows the concern of the family towards the patient’s well-being, telling them not to worry about activities they left undone nor with people who depend on them, and to focus solely on their recovery.

*“There is nothing to worry about. I am eating and working. There is nothing to worry about.” (Daughter of patient IX)*

*“There is nothing to worry about, we are very well at home, I am getting along well with dad, (...)” (Daughter of patient IX)*

*“Mom, get well soon, don’t be anxious, don’t get tense, don’t be excited, try to be calm and do all that has to be done. The important is that you stay alive, that you get out of this, mom, that you get out of this alive.” (Daughter of patient XIII)*

*“Be calm, wake up relaxed, calm, and don’t be nervous or agitated.” (Wife of patient XXVI)*

### **Category V – Concerns about the patient’s recovery.**

In this category, it is evident the family concerns with the recovery and reestablishment of the patients’ health, with affection, regardless of being useful. It is worth highlighting that when family members talk about recovering of their loved ones, they do not refer only to the improvement of their clinical conditions, but also to the fact that patients can go back to being and living as they did before the hospitalization (not the thin or swollen, but walking and talking, for example), in a different condition than the state in which the patient was at the moment the message was recorded.

*“Every day, all the time, each second we are cheering for you recovery.” (Daughter of patient III)*

*“We love you a lot and we hope in God you get well soon and come back home well, walking and with all your senses working, because we believe in the Lord and we know He will help you recover you soon, just as you were before.” (Wife of patient IV)*

*“T, P and M are helping me a lot, we are cheering for you, Jesus will help us and you will be good.” (Wife of patient VIII)*

### **Category VI – Family is concerned about reporting the visits, reaffirming that the patient is not alone.**

In this category, it is evident how important the hospital visits are to the family. They describe them praising the presence of the family as a factor of security for the patient. Besides, there is a demonstration on how



loved the patient is and how the patient is important and beloved by their family.

*"Mrs. M wants to visit you, sister L. has come already, T., sister D., right?! There are so many people wanting to visit you, but in the ICU, only two persons can come in. So, there has to be time because I don't give my turn to anybody." (Daughter of patient II)*

*Me and C. come to visit you everyday. The visits are in the afternoon, from four to five, ok?" (Son of patient XI)*

*"Mommy would come today but she couldn't, but tomorrow she will be here again, dear." (Father of patient XXV)*

*"(...) you are not alone, you are with us, we are all with you." (Wife of patient XXVI)*

### Category VII – Memories about daily life and news from home.

This category expresses the family's necessity of reporting news from home and some changes, memories of special moments and also activities which were once the responsibility of the patients, and now were taken over by another person.

*"So, mom, don't worry, at home everything is all right." (Son of patient XI)*

*"My dog R is in São Roque. We took him to São Roque because he is very big and did not fit in the apartment, But then we brought B, the kitten, remember cat F? B is there at the apartment." (Mother of patient I)*

*"As for the bike shop, we are taking care of everything, I does what he knows, he sells parts, takes note of the orders." (Sister of patient V)*

*"When you can come to Vinhedo, we will play with the kids, with L. E and F. They are fine, they all want you together with us playing there at the backyard, in that big grass field, jumping rope, playing in the swing..." (Wife of patient VIII)*

## DISCUSSION

In studies<sup>(9,13-14)</sup> which also approach the seeking of spiritual support by family members to overcome difficulties related to the condition of a loved one, some similar results showed up: the matter of spirituality, regardless of the person's religion, is a marked aspect for patients and family during hospitalization at an ICU. In the reports, the beliefs and faith in God are highlighted as entities directly tied to the hospitalization process and clinical discharge. Besides, religion shows as a source of support for the family to understand the event.

Spirituality shows itself as a source of support for the family to understand the clinical state of a family member and the suffering that is inherent to this condition. That exalted being is, after all, the only supporting point; it can be easily transferred to family

members who also undergo such an experience, and, under another perspective, not less painful<sup>(15)</sup>.

The presence of God is directly related to the issues of cure and gratitude. The family member seems to give over to God the responsibility and decision about life or death of the patient<sup>(9)</sup>.

Sometimes this warm pursuit for spirituality may seem with the third stage of an incurable disease mentioned by Klüber-Ross<sup>(16)</sup>: the bargain. Most bargains are done with God and usually kept in secret or revealed in special situations; they are attempts to postpone major suffering and they include promises and changes of behavior if the grace is obtained.

In this moment of intense suffering, it is evident the necessity of family members of facing some feelings and the elaboration of messages seemed like another opportunity of them to express themselves to the patients - Feelings that are not always mentioned in situations of full health.

Mainly, in the verbalization of messages, the words of love and absence came out involved in intense emotion and tears. It was exciting, through this strategy of recording, to observe children who had difficulties in expressing their love for their parents, children apologizing and promising things, spouses pledging eternal love... attempts of recovering experiences which were not enjoyed correctly or adequately.

In general, the patients' conditions were too severe, and, in some of the messages, this type of request had a strong tone of desperation and abandonment. Some family members repeated "come back soon" countless times along the message.

Chronological time measured by clock ticks is the same to every one of us; each person has 24 hours a day. But the perception of this time measured, by heart beats, may be very different. When expecting something important, time seems to last an eternity... torturing and slow, very different from what it would be if we were doing something we like<sup>(17)</sup>.

Time for these family members may seem a factor of anguish due to the uncertain of the ending.

The messages also highlighted concerns of the family members in reporting who visits and/or has visited the patients, that several people call and ask about their health, and, especially, that the patient is not alone, being closely assisted by the family members. For patients in a critical state, these statements are essential, since all they perceive (sounds, voices, faces, smells, touches) come from strange people in an unknown environment, most times.

Memories from daily life and news from home, also mentioned by family members, may seem important in this moment as the acceptance of the continuity of life: reorganizing the financial, relational and psycho-emotional structures, memories of good moments,

learning and changes of habits acquired through suffering, motivation to react, the value of small things...

It is interesting to notice that in a quantitative study<sup>(18)</sup> about the necessities of family members of patients hospitalized in ICUs, the authors identified different perceptions in the family members. An adaptation of the Critical Care Family Needs Inventory was used for the collection of data in this study. The sample was made up of 39 family members. The results show that the major necessities of family members are: being sure the patient is receiving the best treatment (89.7%), knowing real facts about the progress of the patient (84.6%), talking to the doctor everyday (79.5%) and having a toilet and a telephone near the waiting room (56.4%).

Several factors may have influenced this difference between the results found in this study and the one previously described<sup>(18)</sup>, such as the approach of the study (qualitative or quantitative), the use of instruments and the procedures of data collection. In this article, the primary purpose was to have the family recording messages to their loved ones, and therefore, the objectives are different in this aspect.

In fact, the studies are complementary and bring up a very important theme in nursing healthcare: assistance to families of patients hospitalized in ICUs. The perception of the necessity of the families may result in the implementation of new policies, such as more flexible visit schedules and more adequate accommodations to

companions, besides promoting more proximity between the nurse staff and the patients and their family<sup>(18)</sup>. Our challenge is to be able to face the family care, as well as their presence with these patients, as an essential part of Nursing.

## CONCLUSIONS

During the hospitalization process of a loved family member in an Intensive Care Unit, the family experiences countless feelings; as common sense, we could highlight fear, anxiety and insecurity. However, other feelings and concerns showed up, along with something that is universal: hope. Considering the categories, hope was present in almost all of them; hope not only in cure but also in adaptation.

In fact, family may undergo a disturbing period of changes, transformations, growth and intense search for internal and external strength to overcome the difficulties, and they seem to find them. The value of happy moments and learning with suffering brings other perspectives besides the continuity of existence.

Identifying these feelings can improve and individualize the nursing assistance. Maybe, when we see the family members not only as people who suffer but also who feel countless emotions and learn during this process, we can take the first steps to help them overcome this experience.

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