



Revista da Escola de Enfermagem da USP

ISSN: 0080-6234

reeusp@usp.br

Universidade de São Paulo

Brasil

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O sentido de vida do familiar do paciente crítico

Revista da Escola de Enfermagem da USP, vol. 42, núm. 3, septiembre, 2008, pp. 547-553

Universidade de São Paulo

São Paulo, Brasil

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The life meaning of the parents of the critical patient*

O SENTIDO DE VIDA DO FAMILIAR DO PACIENTE CRÍTICO

EL SENTIDO DE LA VIDA FAMILIAR DEL PACIENTE GRAVE

Adriana Braitt Lima¹, Darci de Oliveira Santa Rosa²

ABSTRACT

This study emerged from the reflection of my nursing professional experiences. The objectives were to understand the life meaning of critical patients' relatives, in view of the Tragic Triad: guilt, suffering, and death; to identify the contents of these individuals' life meanings, based on Existential Analysis. The methodological trajectory implied the qualitative approach and content analysis. The understanding of the meanings was guided by the Triadic Configuration, from which the following categories emerged: existential emptiness, suffering, guilt, death, meaning of life and ICU care. For the critical patients' relatives, finding the meaning of life in view of the Tragic Triad means perceiving the tragic optimism, such as the possibility of answering life questions in a positive and responsible way, by means of spiritual forces, as of their inner God, though the purpose of creating or performing something, or through the love dedicated to their sick loved one.

KEY WORDS

Nursing.
Intensive Care Units.
Family relations.
Professional-family relations.
Existentialism.

RESUMO

Este estudo emergiu da reflexão acerca de vivências, como profissional de enfermagem. Teve como objetivos compreender o sentido de vida do familiar do paciente crítico, diante da Tríade Trágica: culpa, sofrimento e morte; e identificar os conteúdos de sentido de vida destes, fundamentada na Análise Existencial. Na trajetória metodológica, a abordagem foi qualitativa, e a análise de conteúdo. A compreensão dos significados foi guiada pela Configuração Triádica, de onde surgiram as categorias: Vazio existencial, Sofrimento, Culpa, Morte, Sentido de vida e Assistência na UTI. Para o familiar do paciente crítico, encontrar o sentido de vida frente à Tríade Trágica é perceber o otimismo trágico, como possibilidade de responder às questões da vida de modo positivo e responsável, através de forças espirituais, como do seu Deus interior, do objetivo de criar ou realizar algo ou do amor dedicado ao seu enfermo.

DESCRIPTORES

Enfermagem.
Unidades de Terapia Intensiva.
Relações familiares.
Relações profissional-família.
Existencialismo.

RESUMEN

Este estudio surgió de la reflexión acerca de las vivencias tenidas como profesional de enfermería. Tuvo como objetivos: comprender el sentido de la vida del familiar del paciente crítico, frente a la Triada Trágica: culpa, sufrimiento y muerte; e identificar los contenidos del sentido de la vida, fundamentado en el Análisis Existencial. En la trayectoria metodológica el abordaje fue el cualitativo y el análisis de contenido. La comprensión de los significados fue guiada por la Configuración Triádica de donde surgieron las categorías: Vacío existencial, Sufrimiento, Culpa, Muerte, Sentido de la vida y Asistencia en la UCI. Para el familiar del paciente crítico, encontrar el sentido de la vida frente a la Triada Trágica es percibir el optimismo trágico, como posibilidad de responder a las cuestiones de la vida de modo positivo y responsable, a través de fuerzas espirituales, como de su Dios interior, del objetivo de crear o realizar algo o del amor dedicado a su enfermo.

DESCRIPTORES

Enfermería.
Unidades de Terapia Intensiva.
Relaciones familiares.
Relaciones profesional-familia.
Existencialismo.

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INTRODUCING THE THEME

This paper originated from the master's degree thesis *The meaning of life for the critical patients' relative*. Its motivation was my experience with people at the general intensive care unit (G-ICU). Based on the fact that the critical patients' family members express emotions, values and diversified cultures, the purpose of this study was to understand them as biopsychospiritual beings, according to Frankl's existential analysis⁽¹⁾.

The interest in studying the theme further emerged out of the reflexive analysis about the academic background and experiences that marked the authors' education, especially regarding the meaning of life. They realized that this search, along with the phenomena of suffering and death, are present in the routine of nurses, patients and family.

The Tragic Triad of suffering, guilt and possibility of death is at the core of the ICU setting, in the conflicts experienced by these patients' families. Thus, the guiding question was: What is the meaning of life for relatives of critical patients in an ICU? The objectives were to understand the meaning of life for relatives of critical patients in the ICU when it comes to the Tragic Triad: guilt, suffering and death; and to identify the meaning of life contents for the relatives of the critical patient at the ICU.

By understanding this experience, the daily practical knowledge may be implemented in order to help nurses assist the family at the ICU waiting room and contribute to nursing education, since nursing students are not ready for the relations with patients and their families regarding questions about the dying process in the healthcare setting⁽²⁾.

Another aspect to be considered is the small number of articles focusing on the meaning of life, especially that of critical patients' family members. This study intends to add information to the issue and bring about reflections, reevaluating such nursing practice with these people and encourage further studies on the theme.

CONTEXTUALIZING THE THEME

Intensive Care Units (ICU) are services that gather, among their practitioners, doctors, nurses, nursing assistants and technicians, all of them trained and organized to provide assistance to the clinical and surgical patient in a critical situation. The objective in these units is to diminish mortality through intensive care, continuous and full individual observation, according to the patients' needs⁽³⁾.

The ICU has become the most stressful, aggressive and traumatizing place in the hospital since it holds critical

patients likely to die in the same space⁽⁴⁾. In this context, the positive points are the technological advances and an array of techniques, medication, equipment and procedures for the recovery or cure of the critical patients. The negative point is the lengthening of life for those who will not recover⁽⁵⁾.

The presence of a relative at the ICU means security for the sick person and fraternal care. Being always present, the family suffers since they are not sure of how long their relative will exist. Grief, expressed through uncertainty, emerges in all the relatives' levels of life, with different intensities that leave marks when looking ahead and visualizing the possibility of death⁽⁶⁾.

It is not enough to allow the relatives to visit the ICU. It is necessary to look after them so as to empower the nursing work. Looking after the relatives means understanding their emotions, gestures and speeches, their concepts and limitations⁽⁷⁾.

The relatives of critical patients' are tirelessly searching for messages such as a *tear that rolls over the patient's face after hearing their own nickname* or signals that reveal life or death without suffering, such as color and sporadic eye opening of patients in coma and feet temperature. Also, vital signs like blood pressure⁽⁸⁾. These pieces of information become meaningful for these relatives, frequently revealing the denial of the dying process.

The time of dying has a meaning, no matter how clear the gravity status has been made. For the relatives, being there is to recognize the human limits. The patients approaching death will die, regardless of all the love that people feel for them. What nurses can do is to prevent this suffering from being experienced in solitude and abandon, and attempt to turn this process into a solidarity and humanized moment⁽⁹⁾.

FRANKL'S EXISTENTIAL ANALYSIS

The *Existential Analysis* or *Logotherapy* used by Viktor Frankl originated from the Greek word *logos*, that means meaning⁽¹⁰⁾. It is a study-based therapy and relies on the search for the meanings of the human existence. According to it, men are free, responsible and aware of their responsibilities. They search for a meaning for life and have an unconscious God within.

The bases of Existential Analysis are grounded on responsibility and unconditional freedom. The latter is the expression of what is extremely human in each person, who experiences the anguish of life in their everyday routine. This freedom is present in consciousness of coping with the ghosts of death and suffering⁽¹¹⁾.

In the existential analysis, life has a meaning that starts when people are brought to this world. Each individual

should find it out⁽¹¹⁾. A meaning for life is reached whenever a significant content is found. Also, whenever values are achieved. These values, the experience of the Tragic Triad, are shown whenever the individuals positively fill the void around them⁽¹²⁾. The individual void is characterized by existential frustration with *feelings of loss regarding the meaning of existence and content of life*⁽¹³⁾.

People become filled with faith and hope in their lives when they believe in a meaning. However, it is in the feeling of intense anguish that faith appears. It is the hope for the future and it causes the meaning of life and faith in God to emerge. Such God lives in the individuals' intimacy and is a power that emerges when all the others disappear. The *noetic* dimension is characterized. This dimension reveals a feeling that emerges like a supporting beacon of light and that *seemed to be hidden deep within each person*⁽¹¹⁾.

The word *noetic* comes from Greek *nous*. It means mind and spirit. Such *spiritual in men constitutes their personality*⁽¹⁴⁾. In this perspective, the human being is made up of three dimensions: physiological, psychological and *noetic*, which constitute body, mind and soul, respectively. The individual becomes an indivisible being, a whole with all the parts⁽¹⁾. Spiritual is specifically understood here as a human dimension. It is not the only one, since a man is a unity and a whole⁽¹⁾.

In this whole, suffering may be overcome by the intensity of hope that may emerge in the condition experienced by humans. Hope and values are held together and are joined to faith in the future and the mood that is turned into *spiritual nourishment*⁽¹⁵⁾.

METHOD

The choice of a qualitative methodology took into account the possibility of describing behaviors, facts or elements that help the nurse in situations of suffering, guilt and death. Laws to create generalizations were not established. By contrast, there was the association of principles of understanding the existence universe of the ICU patient, with the experience of non-quantifiable phenomena.

The institution where the study was carried out is located in the city of Salvador. It is a general private hospital that serves as a hospitalization unit, emergency room, clinic analysis laboratory, and performs image diagnostic exams, among others.

The choice of the critical patient's relative was in compliance with the following criteria: being fully informed by the doctor of the diagnostic and prognostic; having a relative at the ICU classified as acute or critical; being the relative who lives with the patient; being the most present relative during hospitalization; agreeing to participate in the study, after explanations; being willing to sign the consent form⁽¹⁶⁾.

In order to develop this study, the legal and ethical criteria were observed to guarantee integrity, respect for the inter-

viewed people and authorization from the Ethics Committee of the institution to perform this research, according to resolution 196/96 that covers the Guidelines for Research with Human Beings in Brazil (CM - 007/01). The theme, the type of research, the presence of a consent form and respect for the individual were taken into consideration⁽¹⁶⁾.

The objective of qualitative data is to fully understand the phenomenon, relying on the relevance of subjective factors obtained through semi-structured interviews with a recorder. The interviews were transcribed and analyzed. The cassettes were stored by the researchers in a safe place, where they will remain for five years. After that, they will be either returned to the interviewed people or destroyed. Ten interviews were held and six were selected, according to the content criteria that were shown to be sufficient for the study. To maintain anonymity, the interviewed people received fictitious names of precious stones.

Understanding the individuals requires an existentialist and humanist background^(15,17). Thus, the critical patients' relatives, at the core of their existence and through their singularities, find themselves in a world-reality – the ICU – experiencing threshold situations with the life phenomena. They express guilt, suffering, possibility of death, bringing out existential conflicts regarding themselves (interior) and the reality (exterior).

The following are approximation questions asked to critical patients' relatives: do you know what is happening to your relative at the ICU? How was your life before the hospitalization of your relative? And the guiding question: How is your life right now? To conclude the interview: do you have something else to say?

The background to understand the testimonials was performed through content analysis. Its techniques consist of approaching subjective contents, searching for evidences objectively, *the features and powers regarding stimuli experienced by the subjects*⁽¹⁸⁾.

After data collection, analysis, categorization and understanding of the meanings were performed. The categorization method was used to describe the speeches, formulating *some sort of meaningful drawers or events that allow for the classification of significant elements in the message*⁽¹⁸⁾. This categorization method was used to understand the meaning of life in the perspective of the critical patients' relatives⁽¹⁷⁾.

Out of the descriptive and reflexive analysis of contents, the following empirical categories emerged: *The existential void, suffering, guilt, death, the meaning of life and the care toward the critical relative*. They were constructed with the classification of the register units in context units and, in turn, in empirical subcategories.

The existential void: unveiling the relatives' concrete situation.

The critical patients' relatives unveil the situation of suffering and the void that emerges out of a situation with a relative at the ICU.

A friend of his came [...]. I said: *do you want to take a look?* He said: *I don't have the guts to.* Then, he didn't enter but I did, because I'm a mother and I want to see. But it's a time [...]. My God, I don't know [...] so anguished when I, I come closer to my son and I can't do anything for him. He [...] (Pearl).

During the visit, Pearl feels the void when she realizes that she cannot communicate with her son at the ICU. This restriction is marked by anguish and sadness in realizing the limits that are imposed by the use of wires and devices.

I went there the other day. Then, he was moving his foot. He moved his hand when he opened his eyes. I ended up saying: Oh! Doctor! My son has pulled through, he is moving. He said: *No, sedation is low. I'll make it higher.* But on this day the body was shaking. I stayed [...]; I didn't stay because I couldn't make it (Pearl).

For Pearl, verifying her relative's gravity was one of the most difficult moments in life. The hope of finding a significant sign of improvement and the loss of hope were shattered after the *no* uttered by the doctor. She argues that during the visit, seeing him in that condition and hearing the doctor's answer caused her to feel anguish, frustration and sadness. It should be pointed out that *suffering is somehow part of life, just like destiny and death. Affliction and death are part of existence as a whole*⁽¹⁰⁾.

The void also occupies a non-dimensioned condition before the possibility of death.

I'm in a void, a large void inside me as though I had a maze here [...]. I'm lost deep inside of my feelings, of my heart. And I can't find the way out because he was my way, he was my life [...]. I don't know what I am now [...] (cries) (Amethyst).

For Amethyst, it is a difficult situation to enter the ICU and see her relative suffering. When present, she realizes the lack of reactions by the relative due to sedation or coma. With this concrete situation, she feels the void left by the absence of meaning for life, causing a feeling of solitude and loss of identity.

The concrete situation experienced by Pearl reveals the existential void caused by the anguish after seeing her relative at the ICU. For Amethyst, the void is unveiled when the abyss between them is considered, with the loss of the meaning of life.

The suffering: unveiling the relatives' gravity and the unconscious God

Suffering makes the unconscious God emerge in the critical patient's relative at the moment in which all the medical healing possibilities are gone.

I wait every day for a miracle [...] because only God heals [...]. But healing happens through medicine and God. I saw when he had it for the second time. I thought that, God willing, He'll cure him (Pearl)

Despite suffering, Pearl acknowledges believing in a miracle from God to cure her relative and bring him back to the family. This power is expressed as the energy and the beacon of light that come from within, after suffering with the health problems and the relative's hospitalization at the ICU.

This God isn't a magic god, in the spiritual sense, but an energy that appears at the moment all the others disappeared. It appears as soothing, soothing light that seemed to be hidden in the deepest places. This is the noetic dimension [...]. It is incorruptible and lucid, although illness and suffering are infinite⁽¹¹⁾

Guilt: being guided by responsibility

Guilt and responsibility emerge out of consciousness when there is a concrete situation.

Of course I won't feel guilty for what happened. It isn't on my mind. He came. This was his objective. Unfortunately, it was fate what happened, but it derails our routine, right? I get a little lost. I got off-track. Then, it's too sad (Crystal).

Crystal reports the actions performed by her relative before hospitalization and examines her consciousness being guided by the *responsibility* for being at the ICU. She reveals her presence at the side of the critical relative, the feeling of guilt regarding whatever led him to the ICU. She also expresses feelings of loss of meaning of life that this condition brings to her.

Pushed by guilt, Crystal understands the meaning of responsibility for being with someone and discovers in this situation a possibility of meaning.

Responsibility is everything that people are *pulled to and escape from*. The wisdom of the language indicates that there are contradictory powers in men that prevent them from taking responsibilities [...]. It is terrible to know that you are responsible for someone all the time. Each decision, important or not, is a decision [...]. It is decision *for all eternity*...⁽¹⁹⁾.

Death: unveiling moments of reflection

The relative ponders about the acceptance of suffering experienced by the critical patient and expresses that the objective of living with the possibility of death is to raise children and study. Such attitude will provide strength to face the concrete situation.

I live with the purpose of looking after my children, studying and doing law school. That was his wish. Sometimes, I thought to myself that I wanted to pass away first, [...]. I'd rather pass away. I don't want to lose him. I don't want to lose my mom. I have always said to myself that I'd rather pass away first than them (Jade).

With the suffering that the possibility of death brings, Jade establishes as meanings: to continue to live, to study and to look after the children. This power emerged from

the moment of reflection about life and the meaning that death brought in order to take responsibility for existence.

Meaning of life: unveiling the eternal file

The relatives express possibilities of meaning when reflecting about the past. They are constituted by *values*, considered by the existential analysis as pathways to find the meaning of life⁽²⁰⁾.

The experience values occur when *experimenting something – such as kindness, truth and beauty – experimenting nature or culture, or even, experimenting other human beings in their unique originality – loving them*⁽¹⁰⁾.

He said: *My mom! I've bought the tickets. We'll travel to Rio Grande do Sul. Don't say no [...]* I got so glad when he gave me such joy. He didn't know I was crazy for Rio Grande do Sul. We spent some days in Gramado, in July. Now he's like that (cries) (Pearl).

Pearl reports experiences with happiness and joint contemplation that she enjoyed with her relative on a trip. This was a situation cherished by her and the critical relative, such as happiness, beauty and plenitude. Here, the joint activities are apprehended and attribute meanings of co-existential concreteness.

The creative values are moments filled with job-related activities and bringing up children. Happiness that attributes meaning to everyday life is considered. These values are characterized by the discovery of a meaning of life. That is when human beings *feel capable of providing the world with something*⁽¹⁵⁾. The most significant factor, when performing creative values, is how it occurs.

We've always worked together [...]. We own an ice cream parlor [...]. If he went for supplies, I would go with him. If he had to deliver ice cream, I would go with him. If he bought flour, I would hold the sack to help him carry it [...]. Always close (Amethyst)

Amethyst recalls the contents that were the most significant in the past, pointing out the cooperation when working with the relative.

The attitude values are apprehended in suffering situations endured with courage, which they are proud of⁽¹⁰⁾.

He gave me the apartment [...]. *This insurance, you'll only give to my son when he becomes a man, in college, when he is good [...]*. He organized a meeting and said: *Oh, don't leave me! [...]*. Last time, he didn't say anything, but this time he knew the situation. When he got worse, he always had something to say [...]. He knew it! (Pearl).

Pearl remembers her son's attitude when, realizing his situation and the likelihood of death, he organized his things for her and for his son. This was an attitude value that demonstrated the power to perform positive tasks and encouraged the taking of responsibility, considering that life is finite.

When dealing with their eternal files, Pearl and Amethyst understand the context of ICU assistance and find out the meaning of life, which is revealed through experiencing value, creativity and attitude.

Assistance to the critical patients' relatives: unveiling the ICU as a health care space.

When dealing with their eternal files, the critical patients' relatives understand the context of ICU assistance, in their dimensions of behavior and those shown by professionals.

The ICU is seen as a health care space with positive and negative aspects.

Then, the positive part of ICU [...], he has all the required assistance. Everybody is there to assist anytime. It doesn't apply to the room, not even to the semi-ICU. Now, nurses and assistants are there all the time. I can't complain about anyone. The absence of the relative [...] But you can't stay there (Sapphire).

Sapphire evaluates positively the assistance provided by the nursing professional in the ICU to the critical patient. She points out the availability of these professionals when serving their patient full-time. She argues that the assistance provided in other units is inferior. For her, family presence is important and has limits. The ICU is a place of isolation, since the critical patients' gravity and this condition is a requisite for treatment. However, feelings of abandon and rupture of affective bonds are observed more intensively in Sapphire's speech.

The apprehension of the attitudes of the nursing professionals is regarded as positive in the ICU setting.

They [...] did that with love. They cared. In relation to that, I'm OK because my son has always been treated well, has never been mistreated. (Pearl).

Pearl expresses calmness when considering the assistance provided by the nursing team and justifies the practice as possible and lovely, despite the context. She reveals that some professionals liked the patient.

The ICU is a place of isolation for treatment, where the professionals are affectionate and dedicated. In this context, there is more intensity in the feeling of affective bond rupture, awareness of the positive and negative aspects of caring, in which the relative cannot remain all the time, although there are doubts regarding the benefits of their constant presence in the place. However, separation causes suffering, with feelings of solitude and abandon.

CONCLUDING REMARKS

The critical patients' relatives express the existential void when they are aware of the concrete situation and the possibility of death. The feelings are sadness, frustration, pessimism, disorientation, anguish and lack of a reason to live.

In order to understand the triad, it is necessary to define each critical patient's relative as an individual constituted by unit and totality in three dimensions: body, soul and spirit. The bodily dimension happens when there are somatic limitations related to the condition. The psychic dimension, the soul, happens in relation to what occurs in the mind, experiencing the condition, and it is exteriorized through emotions. The patient feels all this process, body and soul. The spiritual dimension is revealed when the relatives turn to themselves and suffer in a personal, specific way, which makes them transcend to a better understanding. In their tridimensionality, the critical patients' relatives find meanings, transforming negative aspects into positive ones, through the search for possibilities of growing inside.

Suffering is then transformed into positive attitude in face of the fear of death and ICU, transcended through faith in God, in energy when there is no hope for cure; awareness, until the last minute, of faith providing strength and hope. The latter is the final meaning; the creed in the relative's salvation and religious practices, peace and hope to revert the situation.

The critical patients' relatives are responsible for the ill person. This responsibility is demanded by consciousness and the limits in their attitudes. The feeling of guilt enables reflections about what could have been done during the activities with the relative; unkept promises; dedication and authentic love as a power to face suffering.

Being aware of the possibility of death, the relative suffers and lets his mind bloom with plenty of other people's death memories, comparisons between the suffering endured; understanding about the theme; the establishment of new objectives; the revelation of dilemmas not perceived before, although there was some sort of search for quality of life and attitudes of the critical relative facing death.

The reflection about the transitory nature of life leads the relatives to search other reasons that will empower their lives, namely children, studies, and work. Among other things, it shows the intention of acting with responsibility and the expression of experience, creation and attitude values.

It is possible to find a meaning with the presence of the tragic triad when there is an irreversible situation. However, these content meanings emerge out of the eternal file experienced when a relative is ill. By recalling previous experiences with the relative, it is possible to find out meanings for life, plenitude, and accomplishments through experiences of creation, attitude and reminiscences of shared moments, the relative's qualities, intentional and authentic love for the relative, taking into account the power that gives one a reason to live.

For the critical patients' relatives, finding the meaning of life within the magic triad is to realize the tragic optimism as a possibility to answer the questions of life positively and consciously, through spiritual powers, the inner God, actions and attitudes, from where the meaning of life may be configured.

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