THE EXPERIENCE OF THE PERSONS WITH CRITICAL CONDITION HOSPITALIZED IN AN INTENSIVE CARE UNIT

A EXPERIÊNCIA VIVIDA DA PESSOA EM SITUAÇÃO CRÍTICA INTERNADA EM UMA UNIDADE DE CUIDADOS INTENSIVOS

LA EXPERIENCIA DE LAS PERSONAS EN ESTADO CRÍTICO HOSPITALIZADAS EN UNA UNIDAD DE CUIDADOS INTENSIVOS

Cidália Maria da Cruz Silva Patacas de Castro¹, Maria Antónia Rebelo Botelho²

ABSTRACT

Objective: to assess the experience of persons with critical condition during hospitalization in an intensive care unit. Method: study within the qualitative paradigm using a phenomenological descriptive approach. The phenomenological approach allowed accessing the reports about the experience of twelve participants who agreed to be interviewed. Results: the essential structure that reflects the nature of the experience of persons with critical condition during hospitalization in an intensive care unit consists of three components: feeling trapped - the loss of control over the body; between life and death; and the need for security. Conclusion: it is an experience of suffering, felt in a unique and singular manner. Waking up in the intensive care unit was scary and hopeless. The existence is compromised; life and death are a constant. These persons need to feel secure, valuing the immediate care provided by the nurses. The family represents a safe haven.

Descriptors: Intensive care Unit; Nursing; Experience; Qualitative Research; Phenomenology.

RESUMO

Objetivo: explorar a experiência vivida da pessoa em situação crítica durante a internação em uma unidade de cuidados intensivos. Método: o estudo inseriu-se no paradigma qualitativo, em uma abordagem fenomenológica descritiva. A abordagem fenomenológica permitiu o acesso à narrativa da experiência vivida por doze participantes que aceitaram ser entrevistados. Resultados: a estrutura essencial que reflete a natureza da experiência vivida pela pessoa em situação crítica durante a internação em uma unidade de cuidados intensivos é constituída por três componentes: sentir-se preso - a perda de controle sobre o seu corpo; entre a vida e a morte; e a necessidade de segurança. Conclusão: trata-se de uma experiência de sofrimento, vivida de forma única e singular. Foi assustador e desesperante acordar na unidade de cuidados intensivos. A existência está comprometida; a vida e a morte são uma constante. Esta pessoa necessita sentir-se segura, valorizando o atendimento imediato do enfermeiro. A família representa um porto de abrigo.

Descritores: Unidade de Terapia Intensiva; Enfermagem; Experiência Vivida; Investigação Qualitativa; Fenomenologia.

RESUMEN

Objetivo: explorar la experiencia de la persona en estado crítico durante la hospitalización en unidad de cuidados intensivos. Método: el estudio se inserta en el paradigma cualitativo, con un enfoque fenomenológico descriptivo. El enfoque fenomenológico permitió el acceso a la narración de la experiencia de doce participantes que aceptaron ser entrevistados. Resultados: la estructura esencial que refleja la naturaleza de la experiencia de las personas en estado crítico durante la hospitalización en unidad de cuidados intensivos consiste en tres componentes: sentirse atrapado - la pérdida de control sobre el cuerpo; entre la vida y la muerte; y la necesidad de seguridad. Conclusión: se trata de una experiencia de sufrimiento, vivida de una manera única y singular. Fue asustador y desesperante despertarse en la unidad de cuidados intensivos. La existencia se encuentra comprometida; la vida y la muerte son una constante. Estas personas necesitan sentirse seguras, valorando el cuidado inmediato de los enfermeros. La familia representa un refugio seguro.

Descritores: Unidad de Cuidados Intensivos; Enfermería; Experiencia; Investigación Cualitativa; Fenomenología.
INTRODUCTION

Diseases emerge in the persons’ lives in a sudden and unexpected manner, endangering their lives due to the fragility and vulnerability of the body and the existence. For us, a disease is, if not the most common, the most evident expression of human vulnerability, making itself felt in the body, especially by feeling pain and changing the identity, putting at risk the existence in a general way.2,18

The persons with critical condition (PCC) is the one whose life is threatened by failure or imminence of failure of one or more vital functions, and whose survival depends on advanced means of surveillance, monitoring, and therapy.4

Intensive care units (ICU) are: places qualified to assume full responsibility for patients with organs dysfunctions, enduring, preventing, and reversing failures with vital implications.5,6

When PCCs are admitted to an ICU, they are invaded by technological equipment and multiple painful interventions, all the emphasis being centered on biological and technological aspects, with the primary aim of saving lives. For PCCs, the experience of being hospitalized in an ICU is a situation that generates impact, causing feelings of instability and insecurity due to the experience of imminent risk. According to Meleis,4 the individuals experience processes that imply transitions caused by the impact generated on their lives, their peers, and family members.

The health-disease transitional process, in which PCCs are involved, represents a state of fragility and vulnerability that covers their existence with a more concrete individuality and uniqueness. They experience their existence at the limit. We can infer that these persons experience a limit situation within the context in which struggling, suffering, and death are a constant, and are frequently invaded by anguish and despair. The limit situation emerges as something that destroys the bases that the persons had, experiencing the existence at its limit.7 Life ceases to be planned and adversity is faced by living each moment. As pointed out by Rebolo and Botelho5,38 the limit situation—which is a singular experience—is worth by what is inside and not by the facts or objective determinations, due to which it can be elucidated by the perspective of the inside, i.e. by those who experience it. The clarification of these transitional processes—from the perspective of those who experience it—reveals itself as an important contribution to the understanding of the phenomena inherent to nursing, thus substantiating the relevance of the present study, whose goal was:

- To explore the experience of PCCs during the hospitalization in an ICU.

METHOD

This is a qualitative study, with a phenomenological descriptive design. We used Husserl’s transcendental phenomenology and Amadeo Giorgi’s descriptive approach,2 with the purpose of accessing the experience of PCCs.

The data were collected through in-depth unstructured interviews carried out between October 2012 and December 2013. The procedure took place after the approval of the Board of Directors of the hospital in which the participants had been hospitalized and the respective Ethics Committee.

The study was conducted with twelve participants. They were intentionally selected in accordance with the following inclusion criteria: having been admitted to an ICU; aged 18 years or more; having understood the purpose of the study; having verbal communication skills that would allow them to describe the phenomenon; agreeing to participate in the study; and feeling that they were at the right moment to talk about their experiences. The participants were aged between 27 and 77 years. Nine were female and three male. The length of stay at the ICU ranged from five to twenty-nine days.

We used the descriptive phenomenology guidelines, or phenomenology of essences, for the analysis of the participants’ reports, integrating theoretical-methodological guidelines of the phenomenological method proposed by Amadeo Giorgi.1,2 This author proposed a phenomenological research method suggesting a four-step process for data analysis. The first step corresponded to the reading of all the participants’ reports about their experiences relating to the phenomenon, in order to achieve the general sense of the phenomenon. The second step was carried out after understanding the general meaning. It consisted of re-reading the texts several times, with the goal of determining the units of meaning. At the end of this step, we obtained the division and definition of the units of meaning. These units retained the participants’ language of common sense, i.e., their experiences understood as they had been transmitted. In this way, the language of common sense was not transformed into the scientific language of
common sense, as occurred in the following step. The units of meaning that emerged from the participants’ reports illustrated the descriptions of the data obtained and their meanings for further construction of the essential structure of the phenomenon.9

The third step consisted of transforming the participants’ language of common sense into scientific language, with emphasis on the phenomenon under study. These transformations basically took place through a reflective and imaginative variation process. The language expressed by the participants was transformed into expressions that had the purpose of clarifying and explaining the meaning of the descriptions given by them. The fourth and last step presented the synthesis of the units of meaning—their key constituents—transformed into a general descriptive structure consistent with the general phenomenon under study, i.e., the participants’ experiences relating to the hospitalization in the ICU.

RESULTS

The analysis of the reports produced an essential structure that reflected the nature of the experiences that the PCCs had during the hospitalization in an ICU. This is a health-disease transitional process marked by total despair, distress, and disbelief in the future.

This structure consisted of three components: (1) feeling trapped, i.e., the loss of control over the own body; (2) between life and death; and (3) the need for security, all of them being interconnected. Each component consisted of four interrelated elements.

### Feeling trapped - the loss of control over one’s own body

Diseases appear as an unfamiliar mode of being in the world. It is the body’s own disease, the body lived, the I-body division. The huge shock experienced when the persons wake up in an environment that does not look familiar, threatened by the number of devices, surrounded by professionals who are strangers, with immobilized upper limbs, unable to move, without knowing what happened to them, and no power to take decisions on themselves and their bodies make the patients feel trapped without control over their bodies. It is a scary and revoltiting situation of extreme violence. The persons are terrified and disoriented towards their existence.

> I only remember when I woke up there, intubated, mechanically ventilated, receiving saline solution, surrounded by machines, that mechanical ventilator made me terrified, because what I had always been more afraid of was shortness of breath. Those machines all around me were frightening, it’s scary opening your eyes and see everything there, and what if something fails? Constança E3.

Her world collapsed. That was not her reality. She felt completely helpless and unprotected, as if she was living a nightmare. This threat to her survival was disturbing her existence. PCCs feel that the bodies are not theirs; they are not their usual bodies that allow them to be-in-the world. It is a foreign and instrumentalized body that was invaded by technology, dependent on the others and the equipment for meeting the most basic human needs. It is the power of technology over the submission of the physical body.

> [...] I was really bad; I had no control over my body; I couldn't move; I had no strength; they made everything for me, I couldn't even breathe by myself; I couldn’t speak, it was very sad; I looked like a plant in that bed, always waiting for someone to come and make something for me. João E10

The patients are completely dependent on the professionals to have their most elementary basic human needs met. They expose their bodies to others, a body broken by critical diseases. It is a situation of extreme violence and dependence on the maintenance of life.

PCCs are in a context of extreme impotence, feeling their lives suspended in time and the suffering being settled in the body. They feel different; their routines have

<table>
<thead>
<tr>
<th>Components of the structure</th>
<th>Key constituents</th>
</tr>
</thead>
</table>
| Feeling trapped: loss of control over the own body | - Huge shock  
- Suffering by having the body invaded by technology  
- The body exposed to the other  
- Threatened identity |
| Between life and death | - Fear caused by announced presence of death  
- Distress caused by the night  
- Transformed perception of time  
- Surrounded by noise and alarms |
| Need for security | - Constant presence of professionals  
- The family seen as safe haven  
- Information provided about the situation  
- Hope and inner strength |

**Figure 1.** Essential structure resulting from the analysis of the reports.
been interrupted. They no longer recognize their bodies, which are surrounded by diseases, vulnerable and fragile, devoid of their uniqueness. It is a strange way of being-in-the-world.

Due to the pain and suffering caused by multiple technical procedures directed to their bodies, the PCCs become more and more aware of their fragility and dependence and try to give meaning to their existence. It is a body torn by pain in a world that is strange and demanding, these persons experience their limits. The desperation caused by suffering makes sometimes these persons desire death as a release.

I remember there was a time when I wanted to pull the whole thing out, because I wanted to die; I was already tired of so much suffering, and then they made me sleep. Rui E8

Altered verbal communication was considered by the participants as one of the most negative aspects during the period in which they were orotracheally intubated. They wanted to know from the professionals what was going on and were not understood. They made efforts to speak and did not hear sounds. They felt lost and without resources to be understood. In addition, they needed to know how their families were. The family members were their fellows, their world; however, they did not manage to do that and felt helpless, sad, subject to certain isolation, motivated by the fact of not being able to communicate effectively.

When I had the tube in my throat to breathe, I wanted to talk to the professionals, and tried to speak, but I wouldn't listen to myself, it was very complicated, it's very weird, a person wants to, but can't hear any sound, [...]. It was distressing, I wanted to talk, I wanted to know what was going on and nobody heard me. Teresa E5

The dependence caused by diseases, in which the persons feel completely helpless with respect to the control of their lives, needing others’ help to meet their most elementary human needs, and exposing their bodies to others is seen as something embarrassing. The condition of vulnerability and fragility tends to appear. Intimacy is invaded by unraveling the body, surrendering to the professionals’ eyes and care. In this way, PCCs feel that their personal identity and physical and mental integrity are threatened.

I remember that it was very bad when I had to be washed; it was as if my body was being completely invaded by strangers, and I couldn’t say anything, because the malaise was huge, and we were there completely helpless in the hands of strangers, who do their best to help us, but it’s disturbing; we aren’t ourselves any more, and we become completely dependent on the professionals. Marta E11

PCCs feel fragile, exposed, and unprotected against the world around them. The body can be experienced as a foreign body, in absolute silence, fragmented and reduced in its identity, autonomy, and ability to experience the world in its entirety. Without references and with total absence of bonds, they feel their perimeter of security and their lives being threatened.

I felt like that a lot, with no identity; I can’t explain it well. We were there, I know it was me, my physical body and my identity, my family, my people, nothing of that exists there, we lose our names, our identities, that's it, it’s a strange thing. Cristina E6

💙 Between life and death

Life and death are intertwined expressing the human condition. The human being is mortal and experiences the confrontation with the unpredictable death. The seriousness of PCCs make them feel as if they were in a limbo, feeling their lives suspended, crystallized, between life and death, with a deep emptiness around them. Their bodies lose the vital functions and they predict the degradation of their bodies and their personal identity, death is announced.

I reached a point at which I had to ask myself if I was going to get out of there alive. Constança E3

In this confrontation with the announced presence of death, PCCs appeal to the other in order to preserve their own existence. In this way, the children emerge as central in their life projects, in the maintenance of their existence.

The night is usually associated with silence, peace, the peace following the bustle of the day. It is the time to restore the sleep, a basic human need essential to the well-being and quality of life. However, the night is the twilight due to its gray tone. It carries certain melancholy that promotes reflection.

For PCCs, the night is experienced under a whirlwind of feelings, in which questioning about their existence is a constant. Peace is disrupted by a false silence that carries the uncertainty and fear that death lurks stealthily while they sleep. It is a non-familiar form of being-in-the-world.

The night was scary, when the lights were off and there were just the equipment lights. I couldn’t get to sleep; I saw the nurses going from one side to the other, but I couldn’t fall asleep, and I wondered, when...
is the night going to end? Then, all those alarms sounded and I immediately thought that something wasn’t right, that was terrible. Teresa E5.

It was during this period that the participants felt the need to call the professionals, even if it was just to feel that they were connected to the world; they were afraid of dying alone. This dependency on the others to stay alive was very stressed in the reports of the participants.

The dawn was announced by opening the blinds and turning on the lights, bringing order to the chaos that the night had caused. This moment was felt by the PCC as having survived one more night. Another day was coming and the bustle was in the ICU again; now they could rest. During the hospitalization, the perception of time changes and the PCC lose the sense of time, days, and nights; their time is different.

I didn’t know the time, the day, the hours, how long I had been there; I didn’t know what was happening to me; I just wanted to go away. Cristina E6

This loss of sense of time may be associated with the lack of contact with natural light, given that artificial light in the ICU is a constant. In addition, the fact of staying in bed almost without moving makes the time pass more slowly. This empty and suspended time, which results from the health-disease transitional process that these persons experience, prevents them from carrying out their projects and give continuity to their existence, that is, being-in-the world.

PCCs live in a state of constant alert, surrounded by a highly technological environment in which the fear that something fails and puts the existence at risk is persistent. It is not just their situation that troubles them, but also the situation of the other patients, transferring to themselves the experience of others. It is like a mirror that reflects others’ situations.

- The need for security

The need for security is a constant for PCCs in view of the fragility and vulnerability caused by the situation. The threat to their survival is present, and they need to appeal to the others to preserve their existence. These persons feel that the professionals are there to meet their needs and promote their well-being, to appease this body-consciousness-world division.

The people have always been flawless to me, always nice and trying to help me in what was possible. I remember those people walking by my side every time I called them, and I am aware that I called them many times, they talked to me. Catarina E9.

These persons feel that this continuous presence is critical to help them overcome this transitional process. Every human being needs to feel supported in various stages of life, especially in a situation of critical disease, in which the person feels more needy, fragile, and insecure. Away from their family members, home, and ‘things’, without emotional references, they feel alone and unprotected. The families are their safe haven, their support, their connection to the outside world, and their affective references in this time of great human vulnerability and frailty. The presence of their family members makes them forget the disease and fear; it makes them fell secure.

PCCs feel that their existence is threatened. They need to know what is going on with them and about their clinical situation. However, the participants of the present study affirmed that the information provided to explain their situation had been almost non-existent, either by unawareness on the part of the team about the true clinical situation or by omission. The participants felt invisible to the eyes of the professionals who talked about themselves, but not about their patients.

When PCCs experience a situation that ends up unveiling their fragility, they develop a reflective process, from which feelings of struggle and courage associated with the will to live emerge. At some point, they believe that it is possible to deal with this situation and overcome it. They develop strategies based on hope and faith.

PCCs are aware that they have lived a period with a very serious disease, even a limit situation, ‘their life hung by a thread’, and that there had really been a ‘divine being’ who helped them, since the care provided by the professionals had not been enough. These persons feel that they were given a new chance to live; it was like a rebirth, allowing them to internalize a new outlook on life.

DISCUSSION

Due to sophisticated equipment and the severity of the condition of the persons admitted, an ICU provides one of the most aggressive, austere, and frightening hospitalization environments. This fact has been pointed out by a significant number of studies.10,11,12,13 For the participants of the present study, waking up in the ICU, surrounded by machines and wires, was a huge and frightening shock, an affliction. They
felt completely desperate and disoriented regarding their existence. These experiences have been confirmed by other studies, in which the participants had affirmed that when they became aware of the admittance to the ICU, they imagined that their clinical condition was more serious, associating their situation with death and serious diseases.

The hospitalization at and ICU can generate behavioral and psychological modifications when the patients realize that they are in a strange environment, surrounded by unknown devices and with doubts about their disease. This situation can trigger feelings such as fear, anxiety, insecurity, and depression, which is in line with the feelings experienced by the participants of the present study.

For the participants, this state of vulnerability caused by the situation, requiring sophisticated equipment and professionals for the maintenance of their existence and having their bodies instrumentalized did not allow them to be in the world. It was the suffering of a physical body invaded by technology. It was a monitored body, with graphs and technical devices displaying them in a number of observable images. In a highly technological environment, such an ICU, the eyes, even those of their family members, are focused on the machines, not on the PCCs. It is the field of technology in the submission of the physical body. This pain and suffering settled in the body, leaving the persons with no uniqueness, only with a focus on a body as an object, was mentioned by the participants with respect to the multiple invasive procedures and techniques to which they had been submitted. This finding is in line with results reported in other studies.

The presence of orotracheal tubes was also referenced by the participants as something that limited verbal communication. They felt frustrated and powerless for not being understood, and eventually they would give up. This result corroborates those of other studies.

In the face of the vulnerability, the distance between life and death becomes very tenuous. Death was announced when these persons felt the deterioration of their vital functions. They noticed that their existence was threatened. Death was always present and feelings of fear and distress emerged. The fear in the presence of the announced death is a constant in the experience of the PCCs hospitalized at an ICU, a fact corroborated by various studies.

This threat felt by the presence of death was exacerbated during the night. This fact was experienced by sleep disorders accompanied by a period of reflection and questioning about life and the eminence of death. The participants felt lonely and insecure. Sleep disorders are common in ICUs and have a negative influence on the patients, either psychologically or in behavioral aspects.

During the period of hospitalization in an ICU, PCCs’ perception of time is transformed. This issue of temporality is complex, because it represents the loss of the reference of the day and night, and lighting aspects. When PCCs lose their references, they can feel that they are losing control over their own lives.

Due to the state of great fragility that PCCs experience during hospitalization in an ICU, the demand for security is a constant. This security is sought in the continuous presence of the professionals, in the families as safe haven, in the information provided by professionals about their clinical situation, and in their hope and inner strength.

For the participants of the present study, this relationship with the care provided by the nursing team was important for the recovery process of this critical disease situation. There are many studies that have affirmed that participants felt safe and supported by the professional teams, including nursing. Another study claimed that, although the presence of the health team had been uninterrupted, it did not prevent feelings of loneliness; it was as if the patients were among a crowd of strangers.

Visiting time turns out to be fundamental moments of the day for PCCs. It is a time really desired; however, it goes by very fast even though the nurses are not very rigid in terms of visitation schedules, since they usually provide more extended periods. There is consensus that the presence of the family members is a source of security.

PCCs hospitalized at ICUs are not allowed to be visited by children. The health teams use some strategies trying to reduce this absence, such as putting children’s pictures or drawings in strategic places; however, this procedure does not resolve the problem. The absence of children is experienced in a distressing manner. The patients do not know whether the will see and embrace them again. At the same time that the absence of the children induces suffering, it is a source of energy that makes them believe that they have to overcome this situation. Frank cites Nietzsche stating that: who has a reason to live can bear almost anything.

In a study conducted by Rebelo, one of the participants had stated that, in the
moments when she felt dying, the children appeared as her anchor of life, reassuming in the relationship with them a new centrality in her project of life due to the certainty that her survival was meaningful.

The need for security expressed by PCCs also results from the need to feel informed in regards to their medical condition. The duty of nurses in terms of providing information is included in the Code of Ethics of the Statute of Nurses Association, article 84, Duty to Inform, respect for the right to self-determination of clients about healthcare. The participants mentioned that, during the period of hospitalization at the ICU, they felt lack of information about their clinical situation. To some participants, this information had been provided by their family members. This lack of information experienced by PCCs aggravates their vulnerability.

The time of great human fragility that PCCs experience, in which they look for meanings in their lives, accentuates the search for the ‘divine’ in order to keep the faith, hope, and inner strength alive. For the participants of the present study, this hope increased during the hospitalization, giving them strength to continue fighting in the direction of recovery, in order to maintain their existence.

CONCLUSION

The professional nursing practice involves patients’ experiences of life. The phenomenological method is proper for the investigation of phenomena that are relevant to nursing, providing new ways to describe the nature of consciousness in the world.

There was uniqueness in the experience of each participant. However, when we analyzed these experiences, we observed that there were experiential moments that were common to all the participants. Unraveling this transversality helps us elucidate the phenomenon.

The essential structure resulting from the analysis of the participants’ reports, which reflected the nature of the PCCs’ experience during the hospitalization in an ICU, was regarded as a health-disease transitional process marked by total despair, distress, and disbelief in the future.

The hospitalization in an ICU is a sudden and abrupt event due to a health-disease transitional process, in which the body-consciousness-world division occurs. Waking up in the ICU was a huge shock in an austere environment dominated by technology, in which the bodies of the PCCs become to be seen as instrumentalized bodies, in a situation of total dependence that makes them feel their existence threatened. The body is something that acquires new meanings with respect to the limits of existence, as well as the way to exist and be related to the world.

PCCs feel that they are between life and death, and the line that separates these two aspects is very tenuous. The fear in the presence of announced death is a constant, in which life is suspended, quietly emptying the existence, changing the meaning and direction of the existence of being-in-the-world.

The night is experienced in a distressing manner. It is silence, twilight, the time to interrupt the calmness and fear that death may arrive surreptitiously during sleep. PCCs think about life and question their existence.

PCCs are surrounded by noise and alarms that, although fundamental to the maintenance of their existence, constantly remind them of their fragility, and the fear that something may fail haunts their fragile body. They live in a state of constant alert about themselves and the others, transferring to themselves, as if through a mirror, others’ experiences: the disease or the loss of capabilities that the other exhibits before me increases my awareness of my own fragility.

Health professionals have an important role. They value immediate care provided, in particular nurses. The families of PCCs are their safe haven. The family members give PCCs strength and light the way forward. PCCs miss their children, their smell, embracing them, feeling them. They do not know whether they will see them again. Their children are they life buoy, their inspiration, for whom they struggle to overcome this situation characterized by extreme vulnerability.

PCCs seek inner strength and believe that it is possible to overcome the situation and survive. Hope gradually gains space: The fragility assumed generates—or even is— an authentic power, a spiritual force.

For the participants of the present study, the hospitalization at an ICU was a very painful experience, a limit situation, in which the confrontation with the finitude and the awareness of representing a being-for-death was a constant. They felt that the experience changed them and caused appreciation and enjoyment of the little things that had been unnoticed before and had another dimension now, increasing their sensitivity to the everyday life moments and those around them, contributing to give value and meaning.
to their lives, helping them make some decisions.

ACKNOWLEDGEMENTS

To Escola Superior de Enfermagem de Lisboa, Portugal, for the financial support provided to publish the present study.

REFERENCES

The experience of the persons with critical...